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# The Permanente Journal

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## Original Research & Contributions

*Special Report*

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**Where Time Stands Still**
photograph
by Sapna Reddy, MD

A spring morning in the Redwood National Forest along the Del Norte Coast of CA. As the morning fog dissipates under the warmth of the rising sun, the soft light showcases the fresh spring bloom of the rhododendrons.

Dr Reddy is a Radiologist at the Walnut Creek Medical Center in CA and is pursuing a dual career as a landscape/nature photographer. More of her work can be seen at www.sapnareddy.com, on page 55 and in other issues of *The Permanente Journal.*

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4 **Fundamental Use of Surgical Energy (FUSE): An Essential Educational Program for Operating Room Safety.** Stephanie B Jones, MD; Malcolm G Munro, MD, FACOG, FRCS(c); Liane S Feldman, MD, FACS, FRCS; Thomas N Robinson, MD, MS, FACS; L Michael Brunt, MD, FACS; Steven D Schwaitzberg, MD, FACS; Daniel B Jones, MD, MS, FACS; Pascal R Fuchshuber, MD, FACS

The lack of fundamental understanding of energy device function, design, and application contributes to avoidable injury and harm at a rate of approximately 1 to 2 per 1000 patients in the US. Most injuries are associated with the use of energy-based surgical devices. The Society of American Gastrointestinal and Endoscopic Surgeons developed the Fundamental Use of Surgical Energy (FUSE) program, which fills a void in the curriculum and competency assessment for surgeons and other procedural specialists.

10 CME **Morbidity in Pregnant Women Associated with Unverified Penicillin Allergies, Antibiotic Use, and Group B Streptococcus Infections.** Shilpa H Desai, MD; Michael S Kaplan, MD; Qiaoling Chen, MS; Eric M Macy, MD, MS

In Kaiser Permanente Southern California, there were 170,379 women who had 201,316 pregnancies between 1/1/2009-12/31/2014. Women with a penicillin allergy, with or without group b streptococcus infections, had significantly higher cesarean section rates, days in the hospital after delivery, and higher rates of adverse drug reactions associated with all antibiotic use. Penicillin allergy testing of pregnant women with a history of penicillin allergy may help reduce these unwanted outcomes.

16 **Understanding Preferences for Osteoporosis Information to Develop an Osteoporosis Patient Education Brochure.** Stephanie W Edmonds, RN, MPH, PhD(c); Samantha L Solimeo, PhD, MPH; Vu-Thuy Nguyen, MS, PhD(c); Nicole C Wright, PhD, MPH; Douglas W Roblin, PhD; Kenneth G Saag, MSc, MD; Peter Cram, MBA, MD

To develop an educational brochure on bone health for adults aged 50 years and older the authors used a mixed-method, semistructured interview methodology. The authors enrolled 64 participants (most were women, white, and college-educated, with an average age of 66.1 years). Participants restated the basic content of the brochure and preferred Brochure A's use of photographs. This process can guide others in developing health educational brochures.

24 **Understanding Faculty and Trainee Needs Related to Scholarly Activity in a Large, Nonuniversity Graduate Medical Education Program.** Davida Becker, PhD, MS; Hanna Garth, PhD, MPH; Rachel Hollander; Felice Klein, RN, MN; Marc Klau, MD, MBA

Faculty and trainees in primary care and specialties have differing research-related needs that graduate medical education programs should consider when designing curricula to support scholarly activity. Developing research skills of primary care faculty, who reported the lowest skill level, is a priority to support trainees' scholarly activity. Research barriers that differed across groups included other work roles taking priority; desire for work-life balance; and lack of managerial support, research equipment, administrative support, and funding.

32 **The Evolution of the Medical School Deanship: From Patriarch to CEO to System Dean.** Danny A Schieffler, PhD; Philip M Farrell, MD, PhD; Marc J Kahn, MD, MBA; Richard A Culbertson, PhD

An alternative path to the Dean/CEO model has developed—the System Dean, who functions as a team player within a broader health system that determines the mission for the medical school and the related clinical enterprise. In this paper, the authors discuss the evolution of the medical school dean with respect to scope of authority and role within the health care system.

39 **Transcendental Meditation and Reduced Trauma Symptoms in Female Inmates: A Randomized Controlled Study.** Sanford Nidich, EdD; Angela Seng; Blaze Compton, MA; Tom O'Connor, PhD; John W Salerno, PhD; Randi Nidich, EdD

Compared with the general population, trauma experiences are higher among incarcerated women. Twenty-two inmates at the Coffee Creek Correctional Facility in Wilsonville, OR, with at least 4 months left of incarceration were enrolled in this randomized controlled pilot study. Significant reductions were found on total trauma, intrusive thoughts, and hyperarousal. These results indicate the feasibility of a Transcendental Meditation (TM) program in a female prison population and that TM may be an effective tool for decreasing trauma symptoms.

## SOUL OF THE HEALER

CME

CME credits are available online at www.tpjcme.org. The mail-in CME form can be found on page 128.

**44 Pediatric Hip Fractures in California: Results from a Community-Based Hip Fracture Registry.** Heather A Prentice, PhD; Elizabeth W Paxton, MA; Jessica J Hunt, MA; Christopher D Grimsrud, MD; Jennifer M Weiss, MD

In our series of 39 patients using registry data (2009-2012), hip fractures in patients younger than age 21 years were more common in boys and Hispanic people. Intertrochanteric fractures (Delbet Type IV) were the most frequently observed type in our community-based hip fracture registry. Short-term complications were infrequent.

**48 Participation in Activities Associated With Quality of Life for Long-Term Survivors of Rectal Cancer.**
Carmit McMullen, PhD; Liyan Liu, MD, MS; Joanna E Bulkley, PhD; Mark C Hornbrook, PhD; Christopher Wendel, MS; Marcia Grant, RN, PhD, FAAN; Andrea Altschuler, PhD; Larissa KF Temple, MD, MSc, FACS; Robert S Krouse, MD, FACS; Lisa Herrinton, PhD

Cancer patients' participation in social, recreational, and civic activities is strongly associated with quality of life (QOL). In an observational study with longitudinal and cross-sectional components, 567 rectal cancer survivors completed a mailed questionnaire. Overall response rate was 61%. The type of operation, receipt of radiation therapy, and bowel function were significantly associated with participation in activities (the strongest predictor of QOL). The authors recommend revising QOL instruments, and interventions addressing preferred activities and adoption of new, fulfilling activities.

**56** CME **End-Stage Renal Disease Outcomes among the Kaiser Permanente Southern California Creatinine Safety Program (Creatinine SureNet): Opportunities to Reflect and Improve.** John J Sim, MD; Michael Batech, DrPH; Kim N Danforth, ScD; Mark P Rutkowski, MD; Steven J Jacobsen, MD, PhD; Michael H Kanter, MD

In this longitudinal cohort study (2/2010-12/2015) of 12,394 Kaiser Permanente Southern California individuals (in the creatinine safety program), 83 (0.7%) reached End-Stage Renal Disease (ESRD). A higher incidence was found of ESRD among individuals captured into this program than if the Chronic Kidney Disease Epidemiology Collaboration equation were used. The findings demonstrate the importance of a creatinine safety program in an integrated health system.

**64 Physicians' Perceptions of Volunteer Service at Safety-Net Clinics.**
Laura McGeehan, PhD; Michael A Takehara, MD; Ellen Daroszewski, PhD, APRN

Physicians belonging to the Southern California Permanente Medical Group conveyed uniformly positive perceptions of their volunteer service, and most were motivated by humanitarian or prosocial desires. Volunteering also provided a protective "escape hatch" from the pressures of the physicians' regular jobs. Physicians cited few challenges to volunteering. The most common personal barrier was a lack of time. The most common professional barriers were organizational and supply issues at the clinic, along with the patients' social, transportation, and financial challenges.

**73** CME **Implementation and Evaluation of the Safety Net Specialty Care Program in the Denver Metropolitan Area.**
Meredith P Fort, PhD, MPH; Lynnette M Namba, MPH; Sarah Dutcher, MIA; Tracy Copeland; Neysa Bermingham; Chris Fellenz, MD; Deborah Lantz, RN; John J Reusch, MD, FACC; Elizabeth A Bayliss, MD, MSPH

This program offers safety-net clinicians the option to electronically consult with specialists. Uninsured patients may be seen by specialists in office visits for a defined set of services. From 5/2013 to 12/2014, safety-net clinicians at 23 clinics made 602 e-consults to specialists, and 81 patients received face-to-face specialist visits. Of 204 primary care clinicians, 103 made e-consults; 65 specialists participated in the program.

**82** CME **Reducing Unnecessary Postoperative Complete Blood Count Testing in the Pediatric Intensive Care Unit.**
Maya Dewan, MD, MPH; Jorge Galvez, MD; Tracey Polsky, MD, PhD; Genna Kreher, MPH; Blair Kraus, RN, MSN; Luis Ahumada, MS; John McCloskey, MD; Heather Wolfe, MD

The authors identified a cohort of patients for whom routine postoperative complete blood count (CBC) testing is unnecessary. They saw sustained decreases below their 50% goal. There were no hemoglobin results below 8 mg/dL, or surgery-related blood transfusions in this cohort within 7 days of surgery. Estimated hospital charges related to routine postoperative CBCs decreased by 87% during 6 postintervention months.

**86 Comprehensive Description of Comorbidity for Autism Spectrum Disorder in a General Population.**
David Cawthorpe, PhD

Direct physician billing data for the city of Calgary, Alberta, Canada, for the treatment of any presenting concern in the Calgary Health Zone (n = 763,449) from 1994 to 2009 were extracted. Annual rates of autism spectrum disorder (ASD) increased 3.9-fold for males and 1.4-fold for females. Males with ASD had overall higher odds ratios (ORs) in 11 main ICD-9 classes, and females with ASD had higher ORs in 12 main ICD-9 classes. Patients with ASD have significant comorbidity of physical disorders.

**91 Collaborative Management of Neurocognitive Disorders in Primary Care: Explorations of an Attempt at Culture Change.** Lewis Mehl-Madrona, MD, PhD, MPhil; Barbara Mainguy, MA

Two group programs were implemented offering exercise, diet, cognitive enhancement, and socialization for patients with minor neurocognitive disorder (MiND): one at a hospital and one at a skilled nursing facility. Thirty-two different patients attended the groups for at least six sessions. Participants enthusiastically reported positive change on qualitative interviews and showed improvement in cognition, balance, and self-esteem. Family medicine residents and practicing physicians both shifted toward lifestyle medicine and significantly changed their views on the efficacy of treatments

*Special Report*
**100 The Grateful Aging Program: A Naturalistic Model of Transformation and Healing into the Second Half of Life.**
Marilyn Schlitz, PhD

This article applies an empirically derived naturalistic model of transformation to aging. Nine steps are identified: 1) answer the call to transformation, 2) cultivate curiosity, 3) formalize a practice, 4) set intention, 5) pay attention to the gifts of aging, 6) build habits, 7) find guidance, 8) move to acceptance, and 9) transform self and society. Educational programs are described, and are designed to expand awareness of healthy, mindful, and meaningful aging; to promote individual and social well-being; and to facilitate a supportive atmosphere for personal enrichment and shared learning.

## REVIEW ARTICLES

**106 Use of Improving Palliative Care in the ICU (Intensive Care Unit) Guidelines for a Palliative Care Initiative in an ICU.**
Eluned Mun, MS, MSN, DNP, APRN-Rx, AGNP-BC, CCRN; Craig Nakatsuka, MD; Lillian Umbarger, MD; Ruth Ruta, MSN, RN; Tracy McCarty, RN; Cynthia Machado, RN; Clementina Ceria-Ulep, PhD, RN

A systematic method was developed to create a new program compatible with the authors' specific intensive care unit (ICU) environment and patient population. A literature review revealed an extensive array of reports and numerous clinical practice guidelines, assessed for information and strategies appropriate for their unit. Recommendations provided by the Center to Advance Palliative Care from its Improving Palliative Care in the ICU project were used to successfully implement a new palliative care initiative in their ICU.

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## CASE REPORTS

**112 Consideration of Personal Adverse Childhood Experiences during Implementation of Trauma-Informed Care Curriculum in Graduate Health Programs.**
Joshua Strait; Tiffany Bolman, MAT

Scientific findings of adverse childhood experiences (ACEs) and their lifelong graded relationship with leading causes of death are well established. Many health care practitioners, however, have yet to implement ACEs screening in clinical practice. Furthermore, ACEs screening and trauma-informed care (TIC) are not part of standard graduate-level training. Among 967 graduate students from 9 health professions programs, who voluntarily completed an ACE questionnaire, there was statistical significance in familiarity with clinical and scientific findings of the ACE Study and familiarity with TIC.

## EDITORIAL

**122 Mind-Body Training for At-Risk Populations: Preventive Medicine at its Best.**
Charles Elder, MD, MPH, FACP

This article is a companion to, and offers editorial commentary in support of, “Transcendental meditation and reduced trauma symptoms in female inmates: A randomized controlled pilot study,” in this Winter 2017 issue, and “Reduced trauma symptoms and perceived stress in male prison inmates through the Transcendental Meditation program: A randomized controlled trial,” in the Fall 2016 issue of *The Permanente Journal.*

## NARRATIVE MEDICINE

**124 On The Shoulders of Giants.**
Tom Paluch, MD

A mentor is defined in *Webster’s Dictionary* as a trusted counselor or guide. Irwin was, and ever will be, my dearest and most influential mentor. He is the man who taught me how to operate, what it meant to be a surgeon, and, most importantly, how it *felt* to be a surgeon; for without the feeling, a surgeon is a mere technician: a manipulator of human flesh. With feeling, a surgeon can find transcendence, a special, powerful intimacy with another human being in this most unique of human relations.

**126 Practicing Healing—Cleaning the Back of an Elderly Tibetan Woman.**
James Lake, MD

While the author volunteered at a Tibetan hospital, he encountered an elderly woman who has become an icon of Tibetan stoicism in the face of suffering. He felt deeply humbled by the realization that he had participated in a sacred space with a patient—and he felt awake. He found himself contemplating how many “exchanges” of spirit he had missed during the weeks in Tibet, how many encounters between one sentient being and another might have taken place had he paid closer attention and taken more time to be present with an open heart while doing the hard work of healing.

# ONLINE

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Review by David D Clarke, MD

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# Fundamental Use of Surgical Energy (FUSE): An Essential Educational Program for Operating Room Safety

**Stephanie B Jones, MD; Malcolm G Munro, MD, FACOG, FRCS(c); Liane S Feldman, MD, FACS, FRCS; Thomas N Robinson, MD, MS, FACS; L Michael Brunt, MD, FACS; Steven D Schwaitzberg, MD, FACS; Daniel B Jones, MD, MS, FACS; Pascal R Fuchshuber, MD, FACS**

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## ABSTRACT

Operating room (OR) safety has become a major concern in patient safety since the 1990s. Improvement of team communication and behavior is a popular target for safety programming at the institutional level. Despite these efforts, essential safety gaps remain in the OR and procedure rooms. A prime example is the use of energy-based devices in ORs and procedural areas. The lack of fundamental understanding of energy device function, design, and application contributes to avoidable injury and harm at a rate of approximately 1 to 2 per 1000 patients in the US. Hundreds of OR fires occur each year in the US, some causing severe injury and even death. Most of these fires are associated with the use of energy-based surgical devices.

In response to this safety issue, the Society of American Gastrointestinal and Endoscopic Surgeons (SAGES) developed the Fundamental Use of Surgical Energy (FUSE) program. This program includes a standardized curriculum targeted to surgeons, other physicians, and allied health care professionals and a psychometrically designed and validated certification test. A successful FUSE certification documents acquisition of the basic knowledge needed to safely use energy-based devices in the OR. By design FUSE fills a void in the curriculum and competency assessment for surgeons and other procedural specialists in the use of energy-based devices in patients.

## INTRODUCTION

Adverse events caused by the use of energy-based devices in surgical operating rooms (ORs) are a daily occurrence. Millions of patient interventions occur every year in ORs and procedure suites throughout the US. Many of these invasive procedures carry a substantial risk for the patient and OR team and can lead to potentially serious complications. A large body of evidence exists on human factors underlying those risks. Many safety programs recently have been developed to address risks generated by a lack of human interaction, the increasingly challenging patient disease burden, and inadequate communications within the OR team. Heightened public awareness about safety in the OR has led to the adoption of a variety of performance-improvement programs and tools, including checklists and team training.[1] Hospitals have implemented extensive training programs, and physicians and staff are required to learn the skills needed to improve clinical outcomes and optimize patient safety.

Despite these efforts, a large gap in OR safety education and training remains on the topic of safe application of energy-based devices. From the first electrosurgical instrument invented more than 100 years ago to the most modern computer-driven device, serious harm and death of patients can result from their inappropriate use because of a lack of basic understanding of design, function, and application. Hundreds of OR fires, patient harm resulting from interference with implantable cardiac devices, and latent, life-threatening intraabdominal injuries could be avoided if this gap were addressed.[2-13]

### Historical Perspective

For millennia the only available energy device for physicians was cautery. Cautery is the direct application of heat to tissue and has been used to attain hemostasis and destroy tumors since 3000 BC.[14] Approximately 100 years ago the first surgical instruments based on radiofrequency (RF) electrical energy were developed for surgical practice. The best known and one of the earliest devices successfully deployed for clinical use was developed by William T Bovie, who combined a "high-voltage" RF generator for fulguration with a lower-voltage generator designed to create a waveform that could be used to transect tissue.[15] By the end of the last century, isolated RF circuits and microprocessor-enhanced instrumentation were introduced, which have dramatically improved both safety and functionality for processes such as tissue transection and the sutureless sealing of relatively large blood vessels. Surgical and technologic innovations have generated an ever-increasing demand for, and number of, energy-based surgical devices from multiple vendors with a wide range of price and cost points.

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This large and diverse armamentarium of energy-based devices has also drastically increased the susceptibility of surgeons and other proceduralists to inadvertently cause harm to patients. The incidence of injuries related to energy-based devices during laparoscopic procedures is estimated at 1 to 2 per 1000 patients, which translates into thousands of avoidable patient injuries every year in the US alone.[4] Unrecognized bowel and major vascular injuries—mostly because of thermal energy—constitute many of these events, with serious consequent morbidity and mortality.[4,16-19]

In the 1970s, several cases of electrocution in the OR were published related to accidents with electrosurgical equipment.[20,21] Although dramatic and mortal injuries from electrocution are exceedingly rare in modern ORs, intestinal thermal injuries and fires caused by energy-based devices are not uncommon. In 2010, a well-known US senator succumbed to an unrecognized intestinal injury that occurred during a routine laparoscopic cholecystectomy.[22] The same year a young woman undergoing excision of a benign skin lesion on the face sustained second-degree burns from an OR fire, apparently scarring her for life.[23]

According to a recent study, laparoscopic bowel injuries occur at an overall rate of 0.85%, nearly 1 in 100 cases, of which one-third are unrecognized at the time they occur.[24] Overall mortality is 3.13% and jumps to 8% for unrecognized injuries. One-third of these injuries is directly related to the use of surgical energy-based devices.[24] Today's OR monitors and tables, anesthesia machines, and other electrical equipment are manufactured according to strict safety standards. These technical advances have not been able to close a major knowledge gap regarding the potential risks of energy-based devices in and out of the OR among the primary users: surgeons, gastroenterologists, and interventional radiologists. We must recognize that almost all the aforementioned accidents and injuries were completely preventable.

### Initial Response

Since the 1990s, health care professionals and surgical societies both in the US and internationally began responding to these safety issues. Specific complications associated with electrosurgical devices and the risks involved in their use were described. A first attempt was made to develop practical educational and engineering solutions to the described complications.[25-29] These early studies included a survey conducted under the auspices of the American College of Surgeons to assess the complication rate associated with the use of electrosurgical devices.[30] Notably, the survey showed that most surgeons were unfamiliar with the optimal use of electrosurgical instruments and that they used inappropriately high power settings.[30] The Consortium on Electrosurgical Safety During Laparoscopy, convened in 1997, published recommendations that emphasized the acute need for training and education during residency and beyond,[31] and the Association of periOperative Registered Nurses published its recommended practices for electrosurgery in 2005.[32] Unfortunately, these important and timely initiatives had little impact on surgical practice at the time.

**… technical advances have not been able to close a major knowledge gap regarding the potential risks of energy-based devices in and out of the OR among the primary users: surgeons, gastroenterologists, and interventional radiologists.**

Fundamental knowledge about the correct use and inherent risks of energy-based devices in surgical practice as well as in radiologic and gastrointestinal interventions is still not systematically taught. In contrast to anesthesia and nursing textbooks, educational material that teaches surgeons about the risks and proper use of energy-based devices is lacking or inadequate. There is no specific requirement for surgeons to train on energy-based devices or to obtain certification that validates their knowledge of device-related safety issues.

## NEEDS ASSESSMENT

In 2011 the Society of American Gastrointestinal and Endoscopic Surgeons (SAGES) developed and ran a postgraduate continuing medical education course on energy-based surgical devices. This comprehensive lecture and hands-on course was the first didactic effort designed to teach surgeons and other health care professionals the fundamentals of the use of energy-based devices in the OR and gastrointestinal endoscopy suite. An 11-item, multiple-choice, pre- and posttest encompassing critical knowledge points was administered to course participants and SAGES leadership.[33]

The survey results were sobering. The median number of correct answers was 6.5 of 11 (59%) for the SAGES leadership group. These SAGES leaders did not know how to correctly handle a fire on the patient (31%), could not identify the electrosurgical device least likely to interfere with a pacemaker (31%), did not know that thermal injury could extend beyond the jaws of a bipolar instrument (13%), and thought a dispersive electrode should be cut to fit a child (10%).[33,34] Results among course participants and surgical trainees were similar to each other.[33,34] This finding demonstrated that surgical "experts" do not necessarily have greater knowledge of energy-based surgical devices compared with nonexpert surgeons or even junior trainees. These results highlight the need to educate trainees and surgeons in the knowledge and understanding of safe and appropriate use of energy-based surgical devices.

## TRAINING PROGRAM FOR ENERGY-BASED SURGICAL DEVICES

The SAGES leadership was in a unique position to recognize that a rigorous and standardized training program on energy-based devices was needed as a greater number of potentially harmful devices were introduced into routine clinical practice. The timing of this initiative could not have been more appropriate for three reasons:

1. rapid innovation in the OR and procedure suite
2. rising national awareness of OR fires
3. transformation of the relationship between industry and physicians.

*Rapid innovation in the OR and procedure suite:* Today's ORs and procedure suites are sophisticated computer-driven control centers of highly complex "point-of-care" delivery. Electronic medical records, anesthetic workstations, high-definition monitors, recording equipment, and a multitude of complex energy-based surgical devices can quickly overwhelm an OR team that is

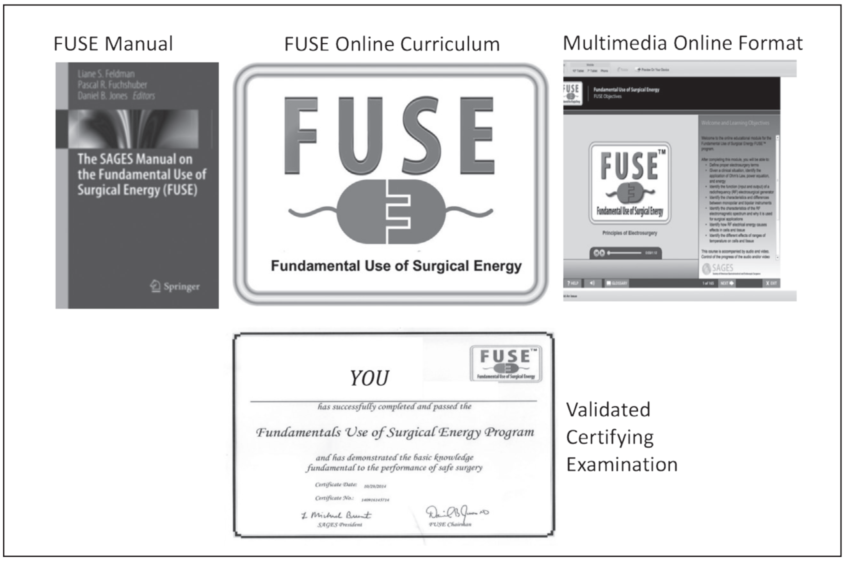

Figure 1. Fundamental Use of Surgical Energy (FUSE) educational program components: Manual, online curriculum, multimedia online format, and certifying examination.[a]

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[a] The educational program was developed through multidisciplinary cooperation.

SAGES = Society of American Gastrointestinal and Endoscopic Surgeons.

potentially unfamiliar with the basic function and designs of these instruments.

*Rising national awareness of OR fires:* Hundreds of preventable OR fires occur every year in the US. The ingredients of this potential disaster are present every time an operation or procedure is undertaken in a patient: the presence of fuel and an oxidizer with a spark from an energy-based device. Despite the distribution of educational materials in multiple formats highlighting the dangers of OR fires, they still occur. The US Food and Drug Administration has made prevention of OR fires one of its most important patient safety goals, but there still is no common national educational program to teach fire prevention in either the OR or the procedure suite.

*Transformation of the relationship between industry and physicians:* Despite many changes in health care, such as industrial relationships and the implementation of regulations and barriers, the introduction of new surgical devices into the OR remains an informal process mostly governed by industry representatives. The required knowledge regarding the use of new devices is still disseminated through industry-sponsored courses or the private interaction between the industry representative and the physicians. No standards are set to determine whether a surgeon is ready and able to use the new device safely. The Physician Payments Sunshine Act, Section 6002 of The Patient Protection and Affordable Care Act of 2010[35] and other regulations have placed appropriate barriers between physicians and industry influence. However, without ready access to industry representatives, it is difficult for surgeons and nurses to learn how to use new devices. Fundamental Use of Surgical Energy (FUSE) is beginning to address important questions raised by this shift away from industry-centered instruction:

- Where will the training to master new energy-based surgical devices come from?
- How should appropriate training and certification be structured?
- Should there be a standard approach for how energy-based devices are introduced to those responsible for using and operating the equipment?
- Who will create these standards?
- Who will create a curriculum covering the function and safety profiles of new equipment?
- How will we mandate and pay for fire safety training?

It has become clear to all involved that perhaps the best solution is a national, multidisciplinary educational program, independent of industry that includes a validated assessment. Only in this way can we address the baseline knowledge gap as well as prepare for the introduction of new devices in a way that maximizes efficacy, efficiency, and, most importantly, patient safety.

## FUNDAMENTAL USE OF SURGICAL ENERGY EDUCATIONAL PROGRAM

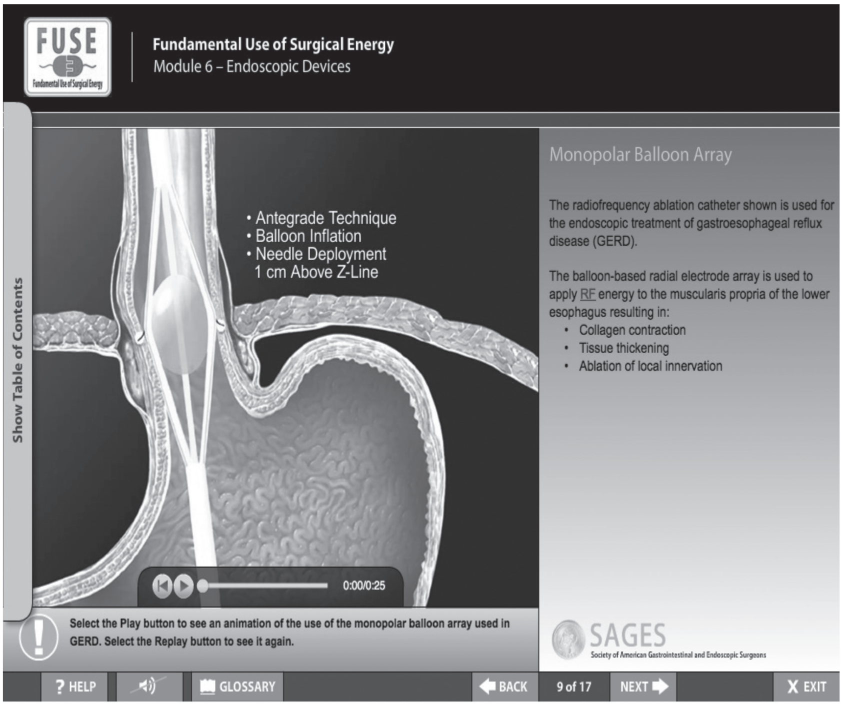
The FUSE educational program was created by SAGES in partnership with the Association of periOperative Registered Nurses, the American Association of Gynecologic Laparoscopists, and the American Urologic Association. Members of the FUSE team include a variety of general and subspecialty surgeons, nurses, anesthesiologists, gynecologists, and engineers.

The FUSE program has three main components (Figure 1): 1) A standardized educational curriculum that is online-based and free of charge (Figure 2); 2)

**Ten Sections of the Fundamental Use of Surgical Energy Online Curriculum[1]**

1. Fundamentals of electrosurgery
2. Mechanisms and prevention of adverse events with electrosurgery
3. Monopolar devices
4. Bipolar devices
5. Radiofrequency for soft-tissue ablation
6. Endoscopic devices
7. Ultrasonic energy devices
8. Microwave energy systems
9. Energy-based devices in pediatric surgery
10. Integration of energy systems with other devices.

[1] Surgical fundamentals online didactics [Internet]. Los Angeles, CA: Society of American Gastrointestinal and Endoscopic Surgeons; 2002-2016 [cited Aug 11]. Available from: www.fusedidactic.org.



Monopolar Balloon Array

The radiofrequency ablation catheter shown is used for the endoscopic treatment of gastroesophageal reflux disease (GERD).

The balloon-based radial electrode array is used to apply RF energy to the muscularis propria of the lower esophagus resulting in:

- Collagen contraction
- Tissue thickening
- Ablation of local innervation

Select the Play button to see an animation of the use of the monopolar balloon array used in GERD. Select the Replay button to see it again.

Figure 2. Example from Fundamental Use of Surgical Energy (FUSE) online curriculum: Module 6 – Endoscopic Devices.

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continuing medical education credits or continuing education units that can be obtained as part of the online curriculum for a small fee; and 3) a high-stakes certification examination that meets rigorous psychometric and accreditation standards. This voluntary, validated, and proctored examination is administered at one of the many test centers across the nation. Successful completion of this test provides verification that the participant has the basic knowledge necessary to safely use energy-based devices in the OR and/or procedure room. If the participant fails the test, it can be retaken without additional charge. *The SAGES Manual on the Fundamental Use of Surgical Energy (FUSE)*, a handbook published in 2012, is an additional offline resource.[36]

**Table 1. Example of educational objectives from sections 1 & 2 used to develop online curriculum and the certification examination**

| Section | Objective |
|---|---|
| 1 | Fundamentals of electrosurgery |
| 1.1 | Define proper electrosurgery terms |
| 1.2 | Given a clinical situation, identify the application of the Ohm law, power equation, and energy |
| 1.3 | Identify the function (input and output) of an electrosurgical (RF) generator |
| 1.4 | Identify the characteristics of monopolar and bipolar instruments and the differences between them |
| 1.5 | Identify the characteristics of the RF electromagnetic spectrum and why it is used for surgical applications |
| 1.6 | Identify how RF electrical energy causes effects in cells and tissue |
| 1.7 | Identify the different effects of ranges of temperature on cells and tissue |
| 2 | Mechanisms and prevention of adverse events with electrosurgery |
| 2.1 | Identify general patient protection measures for setup and settings for the electrosurgical unit |
| 2.2 | Identify various mechanisms whereby electrosurgical injuries may occur |
| 2.3 | Identify circumstances, mechanisms, and prevention of dispersive electrode-related injury |

RF = radiofrequency.

The FUSE online curriculum[37] includes ten sections that teach the basic principles underlying energy-based surgical devices and the application of those principles to safe and effective use of the devices (see Sidebar: Ten Sections of the Fundamental Use of Surgical Energy Online Curriculum). For example, Section 1, Fundamentals of Electrosurgery, starts with the basic physics concepts, nomenclature, and the difference between "cut" and "coag" (coagulation), monopolar vs bipolar RF instrumentation, and active vs dispersive electrodes. The different tissue effects—desiccation, coagulation, and fulguration—achieved by the physical effects of temperature and alternating current on cells and tissue are explained, laying the groundwork for a discussion of specific energy applications. Section 2 describes a crucial safety issue, current diversion in the form of direct and capacitive coupling and insulation failure, as well as prevention and response to OR fires. A similar format emphasizing core principles and safe application is used in the subsequent device sections: monopolar RF, bipolar RF, ultrasonic energy, RF ablation, microwave, and devices designed for use in the alimentary tract. Special considerations for use of energy-based devices in pediatric patients and in patients with other medical devices, most notably cardiac implantable electronic devices, are addressed as well. The FUSE manual also contains supplemental hands-on chapters describing in detail how to set up "live" demonstration and teaching stations.[36]

The FUSE curriculum includes an optional structured interactive benchtop simulation component that is available on demand from SAGES. This goal-directed, hands-on training session has been shown to improve learning and retention of key knowledge points in surgical trainees three months after the session.[38] It also includes a novel virtual reality-based simulation station.[39]

The FUSE curriculum was designed to provide surgeons with the knowledge they need to pass the FUSE certifying examination. The curriculum and examination underwent a development process specifically designed to meet the stringent design and validation requirements for professional certification.[40] Psychometricians conducted an iterative process with 15 FUSE content experts, defining the competencies to be taught and tested. A total of 72 learning objectives were identified for the entire curriculum, 2 to 20 per section. Table 1 lists the objectives from Sections 1 and 2. Leaders from SAGES, the Association of periOperative Registered Nurses, and the American Association of Gynecologic Laparoscopists were used to rank each objective, which in turn helped determine the number of test items for each objective on the written examination. Draft versions of the examination underwent further iterative scrutiny by the FUSE committee, and beta testing was completed in April 2014. The FUSE certification test is now available to all health care professionals at 30 national and international FUSE test centers. More than 400 practicing surgeons and residents are certified.

Until standard mandatory surgical education curricula address the teaching of safe use of energy devices, FUSE remains one of the most comprehensive voluntary options for surgical training program administrators to add this essential component of surgical teaching to their curriculum. The FUSE program office at SAGES[a] welcomes any request to establish FUSE testing centers at individual hospitals and teaching institutions and will guide you through the process.

## CONCLUSION

The FUSE program was developed to provide a standardized educational tool for all physicians and staff who interface in the OR and procedural and interventional suites to bridge a knowledge gap in best-practice use of energy devices. It encompasses the safe and appropriate use of the most common energy devices employed in the operative and endoscopic field, as well as their contribution to OR fire risk and impact on implantable electronic devices. FUSE is the first educational tool of its kind that addresses patient and OR team safety for energy devices.

Ongoing development will ensure that the FUSE program will continue to evolve and fill the curricular, regulatory, safety, and competency assessment needs that exist for the use of energy devices by surgeons, endoscopists, anesthesiologists, and nurses worldwide. ❖

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### Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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### References

1. Banki F, Ochoa K, Carrillo ME, et al. A surgical team with focus on staff education in a community hospital improves outcomes, costs and patient satisfaction. Am J Surg 2013 Dec;206(6):1007-14. DOI: https://doi.org/10.1016/j.amjsurg.2013.08.015.
2. ECRI Institute announces its top 10 health technology hazards for 2012 [Internet]. Plymouth Meeting, PA: ECRI Institute; 2011 Nov 8 [cited 2014 Apr 14]. Available from: www.ecri.org/press/Pages/Top-10-Health-Technology-Hazards-2012.aspx.
3. Govekar HR, Robinson TN, Varosy PD, et al. Effect of monopolar radiofrequency energy on pacemaker function. Surg Endosc 2012 Oct;26(10):2784-8. DOI: https://doi.org/10.1007/s00464-012-2279-3.
4. Nduka CC, Super PA, Monson JR, Darzi AW. Cause and prevention of electrosurgical injuries in laparoscopy. J Am Coll Surg 1994 Aug;179(2):161-70.
5. Sankaranarayanan G, Resapu RR, Jones DB, Schwaitzberg S, De S. Common uses and cited complications of energy in surgery. Surg Endosc 2013 Sep;27(9):3056-72. DOI: https://doi.org/10.1007/s00464-013-2823-9. Erratum in: Surg Endosc 2013 Dec;27(12):4758. DOI: https://doi.org/10.1007/s00464-013-3221-z.
6. Agarwal BB, Gupta M, Agarwal S, Mahajan K. Anatomical footprint for safe laparoscopic cholecystectomy without using any energy source: A modified technique. Surg Endosc 2007 Dec;21(12):2154-8. DOI: https://doi.org/10.1007/s00464-007-9320-y. Erratum in: Surg Endosc. 2010 Jun;24(6):1514. DOI: https://doi.org/10.1007/s00464-009-0717-7.
7. Gol M, Kizilyar A, Eminoglu M. Laparoscopic hysterectomy with retroperitoneal uterine artery sealing using LigaSure: Gazi hospital experience. Arch Gynecol Obstet 2007 Oct;276(4):311-4. DOI: https://doi.org/10.1007/s00404-007-0353-1.
8. Kriplani A, Garg P, Sharma M, Lal S, Agarwal N. A review of total laparoscopic hysterectomy using LigaSure uterine artery-sealing device: AIIMS experience. J Laparoendosc Adv Surg Tech A 2008 Dec;18(6):825-9. DOI: https://doi.org/10.1089/lap.2008.0034.
9. Polychronidis A, Tsaroucha AK, Karayiannakis AJ, Perente S, Efstathiou E, Simopoulos C. Delayed perforation of the large bowel due to thermal injury during laparoscopic cholecystectomy. J Int Med Res 2005 May-Jun;33(3):360-3. DOI: https://doi.org/10.1177/147323000503300312.
10. Siperstein A, Garland A, Engle K, et al. Local recurrence after laparoscopic radiofrequency thermal ablation of hepatic tumors. Ann Surg Oncol 2000 Mar;7(2):106-13. DOI: https://doi.org/10.1007/s10434-000-0106-x.
11. Darai E, Ackerman G, Bazot M, Rouzier R, Dubernard G. Laparoscopic segmental colorectal resection for endometriosis: Limits and complications. Surg Endosc 2007 Sep;21(9):1572-7. DOI: https://doi.org/10.1007/s00464-006-9160-1.
12. Peterson HB, Ory HW, Greenspan JR, Tyler CW Jr. Deaths associated with laparoscopic sterilization by unipolar electrocoagulating devices, 1978 and 1979. Am J Obstet Gynecol 1981 Jan 15;139(2):141-3. DOI: https://doi.org/10.1016/0002-9378(81)90435-x.
13. Willson PD, van der Walt JD, Moxon D, Rogers J. Port site electrosurgical (diathermy) burns during surgical laparoscopy. Surg Endosc1997 Jun;11(6):653-4. DOI: https://doi.org/10.1007/s004649900414.
14. Schwaitzberg SD. Evolution and revolutions in surgical energy. In: Feldman LS, Fuchshuber PR, Jones DB, editors. The SAGES manual on the fundamental use of surgical energy (FUSE). New York, NY: Springer; 2012. p 3-14.
15. O'Connor JL, Bloom DA. William T Bovie and electrosurgery. Surgery 1996 Apr;119(4):390-6. DOI: https://doi.org/10.1016/s0039-6060(96)80137-1.
16. Cormier B, Nezhat F, Sternchos J, Sonoda Y, Leitao MM Jr. Electrocautery-associated vascular injury during robotic-assisted surgery. Obstet Gynecol 2012 Aug;120(2 Pt 2):491-3. DOI: https://doi.org/10.1097/aog.0b013e31825a6f60.
17. LeBlanc KA, Elieson MJ, Corder JM 3rd. Enterotomy and mortality rates of laparoscopic incisional and ventral hernia repair: A review of the literature. JSLS 2007 Oct-Dec;11(4):408-14.
18. Bishoff JT, Allaf ME, Kirkels W, Moore RG, Kavoussi LR, Schroder F. Laparoscopic bowel injury: Incidence and clinical presentation. J Urol 1999 Mar;161(3):887-90. DOI: https://doi.org/10.1097/00005392-199903000-00039.
19. Market engineering research for the US market for general surgery laparoscopy access and closure instruments. Medical and healthcare marketplace guide, 1999 [Internet]. London, United Kingdom: Frost & Sullivan; 1999 [cited 2016 Aug 11]. Available from: www.dialogselect.com/business/cgi/present.

20. Chambers JJ, Saha AK. Electrocution during anaesthesia. Anaesthesia 1979 Feb;34(2):173-5. DOI: https://doi.org/10.1111/j.1365-2044.1979.tb06273.x.
21. Wills JH, Ehrenwerth J, Rogers D. Electrical injury to a nurse due to conductive fluid in an operating room designated as a dry location. Anesth Analg 2010 Jun 1;110(6):1647-9. DOI: https://doi.org/10.1213/ane.0b013e3181a89627.
22. Hefling K. Congressman: Murtha's intestine damaged in surgery. The Washington Post 2010 Feb 8.
23. Carroll L. Operating room fires hurt hundreds each year [Internet]. New York, NY: Today.com; updated 2011 May 11 [cited 2016 May 7]. Available from: www.today.com/id/45117440/ns/today-today_health/t/operating-room-fires-hurt-hundreds-each-year/.
24. Cassaro S. Delayed manifestations of laparoscopic bowel injury. Am Surg 2015 May;81(5):478-82.
25. Voyles CR, Tucker RD. Education and engineering solutions for potential problems with laparoscopic monopolar electrosurgery. Am J Surg 1992 Jul;164(1):57-62. DOI: https://doi.org/10.1016/s0002-9610(05)80648-8.
26. Tucker RD, Voyles CR. Laparoscopic electrosurgical complications and their prevention. AORN J 1995 Jul:62(1): 51-3, 55, 58-9 passim. DOI: https://doi.org/10.1016/s0001-2092(06)63683-1.
27. Harrell GJ, Kopps DR. Minimizing patient risk during laparoscopic electrosurgery. AORN J 1998 Jun;67(6):1194-6, 1199-205. DOI: https://doi.org/10.1016/s0001-2092(06)62606-9.
28. Wu MP, Ou CS, Chen SL, Yen EY, Rowbotham R. Complications and recommended practices for electrosurgery in laparoscopy. Am J Surg 2000 Jan;179(1):67-73. DOI: https://doi.org/10.1016/s0002-9610(99)00267-6.
29. Alkatout I, Schollmeyer T, Hawaldar NA, Sharma N, Mettler L. Principles and safety measures of electrosurgery in laparoscopy. JSLS 2012 Jan-Mar; 16(1):130-9. DOI: https://doi.org/10.4293/108680812X13291597716348.
30. Tucker RD. Laparoscopic electrosurgical injuries: Survey results and their implications. Surg Laparosc Endosc 1995 Aug;5(4):311-7.
31. Brill AI, Feste JR, Hamilton TL, et al. Patient safety during laparoscopic monopolar electrosurgery—principles and guidelines. Consortium on Electrosurgical Safety During Laparoscopy. JSLS 1998 Jul-Sep;2(3):221-5.
32. Recommended practices for electrosurgery. In: AORN. Perioperative standards and recommended practices. 2011 edition. Denver, CO: Association of periOperative Registered Nurses; 2011. p 99-118.
33. Feldman LS, Brunt LM, Fuchshuber P, et al; SAGES FUSE Committee. Rationale for the fundamental use of surgical energy (FUSE) curriculum assessment: Focus on safety. Surg Endosc 2013 Nov;27(11):4054-9. DOI: https://doi.org/10.1007/s00464-013-3059-4.
34. Feldman LS, Fuchshuber P, Jones DB, Mischna J, Schwaitzberg SD; FUSE (Fundamental Use of Surgical Energy) Task Force. Surgeons don't know what they don't know about the safe use of energy in surgery. Surg Endosc 2012 Oct;26(10):2735-9. DOI: https://doi.org/10.1007/s00464-012-2263-y. Erratum in: Surg Endosc 2013 Jan;27(1):349. DOI: https://doi.org/10.1007/s00464-012-2668-7.
35. The Patient Protection and Affordable Care Act of 2010. Public Law 111-148, 111th Congress, 124 Stat 119, HR 3590, enacted 2010 Mar 23.
36. Feldman LS, Fuchshuber PR, Jones DB, editors. The SAGES manual on the fundamental use of surgical energy (FUSE). New York, NY: Springer; 2012.
37. Surgical fundamentals online didactics [Internet]. Los Angeles, CA: Society of American Gastrointestinal and Endoscopic Surgeons; 2002-2016 [cited 2016 Aug 11]. Available from: www.fusedidactic.org.
38. Madani A, Watanabe Y, Vassiliou MC, et al. Impact of a hands-on component on learning in the Fundamental Use of Surgical Energy (FUSE) curriculum: A randomized-controlled trial in surgical trainees. Surg Endosc 2014 Oct;28(10):2772-82. DOI: https://doi.org/10.1007/s00464-014-3544-4.
39. Allen BF, Schwaitzberg SD, Jones DB, De S. Toward the development of a virtual electrosurgery training simulator. Stud Health Technol Inform 2014;196:11-3.
40. Robinson TN, Olasky J, Young P, et al. Fundamental Use of Surgical Energy (FUSE) certification: Validation and predictors of success. Surg Endosc 2016 Mar;30(3):916-24. DOI: https://doi.org/10.1007/s00464-015-4334-3.

## Necessary Conditions

The conditions necessary for the surgeon are four: first, he should be learned; second, he should be expert; third, he must be ingenious; and fourth, he should be able to adapt himself … Let the surgeon be bold in all things, and fearful in dangerous things.

— Guy de Chauliac, 1300-1368, French physician and surgeon

**CME** credits available for this article — see page 128.

**ORIGINAL RESEARCH & CONTRIBUTIONS**

# Morbidity in Pregnant Women Associated with Unverified Penicillin Allergies, Antibiotic Use, and Group B Streptococcus Infections

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## ABSTRACT

**Context:** The morbidity potentially associated with unverified penicillin *allergy* in pregnant women, with and without group B streptococcus (GBS) infections, is unknown. Penicillin allergy testing is safe during pregnancy but is done infrequently.

**Objective:** To determine morbidity associated with antibiotic use in a large cohort of pregnant women, with and without an unverified history of penicillin allergy, and with and without GBS.

**Design:** Retrospective. All pregnant women who delivered live infants in Kaiser Permanente Southern California between January 1, 2009, and December 31, 2014, were identified.

**Main Outcome Measures:** Penicillin allergy status at delivery, delivery method, maternal and infant hospital utilization, peripartum antibiotic exposures, new antibiotic-associated adverse drug reactions, and new *Clostridium difficile* infections.

**Results:** There were 170,379 unique women who had 201,316 pregnancies during the study period. There were 16,084 pregnancies in women with an active, but unverified, penicillin allergy at delivery. There were 42,524 pregnancies in GBS-positive women, and 3500 also had a penicillin allergy. Women with a penicillin allergy, with or without GBS, had significantly (about 10%) higher cesarean section rates and spent significantly more (about 0.1) days in the hospital after delivery. Among GBS-positive women, those with an unverified penicillin allergy were exposed to significantly more cefazolin, clindamycin, vancomycin, and gentamicin and had significantly higher rates of adverse drug reactions associated with all antibiotic use.

**Conclusions:** Unverified penicillin allergy is associated with more hospital utilization and additional morbidity. Penicillin allergy testing of pregnant women with a history of penicillin allergy may help reduce these unwanted outcomes.

## INTRODUCTION

An unconfirmed history of penicillin allergy is a well-known, major public health problem.[1] The Choosing Wisely initiative of the American Board of Internal Medicine Foundation has recommended that physicians minimize the use of non-β-lactam antibiotics in patients with a history of penicillin allergy, without an appropriate evaluation.[2] Other than in hospitalized patients in general, there are minimal data on predicting which specific patients with a history of penicillin allergy would most benefit from having their allergy confirmed or removed from the chart if incorrectly placed there.[3] Penicillin allergy testing has been shown to be safely performed in pregnant women with Group B streptococcus (GBS) infections but is rarely performed.[4,5] A better understanding of the potential morbidity associated with an unverified history of penicillin allergy may support more widespread adoption of penicillin allergy testing in this population.

Our primary objective was to determine morbidity associated with antibiotic use in a large cohort of pregnant women, with and without an unverified history of penicillin allergy, and with and without GBS.

This article restricts the word "allergy" to mean a clinically significant immunoglobulin E-mediated reaction. The term "*allergy*" will refer to an adverse reaction or intolerance associated with the previous use of a specific medication or medication class as noted in the patient's medical record.

## METHODS

This study was reviewed and approved by the Kaiser Permanente Southern California (KPSC) institutional review board. The Southern California Kaiser Foundation Health Plan has always maintained a single comprehensive medical record for each member, and the membership pool has been shown to reflect the socioeconomic diversity of the Southern California general population.[6] Since 2007, the medical record has been completely electronic.

All pregnant women who delivered between January 1, 2009, and December 31, 2014, were identified from the medical records. Those who had a positive culture for GBS before delivery were identified. Those with a history of an active penicillin *allergy* on the day of delivery were identified.

Maternal and infant hospital utilization within 6 months of delivery, method of delivery, antibiotic exposures within 3 days before or after delivery (a 7-day period), new antibiotic allergy reports within 30 days of peripartum antibiotic exposure, and new *Clostridium difficile* infections within 90 days of delivery were the primary outcome variables collected.

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A course of an antibiotic was defined as any systemic exposure, oral or parenteral, to a specific antibacterial antibiotic. "Oral" exposures included delivery by mouth as well as nasogastric tube or other direct route to the stomach. Parenteral exposures included intravenous, intramuscular, subcutaneous, intradermal, intraosseous, intraperitoneal, and intravesicular injections or infusions. Topical exposures were not considered for this analysis. Any exposure to the same antibiotic, by the same route, within 36 hours was considered part of the same course. Reports of new antibiotic *allergy* entered into the electronic health record within 30 days of the antibiotic exposure were identified.

All cases of anaphylaxis coded (International Classification of Diseases, Ninth Revision [ICD-9] 995.0) within 3 days before or after delivery were identified. Chart reviews were then performed to verify that the clinical symptoms that occurred met the current working definition of anaphylaxis and were plausibly associated with use of a specific antibiotic.[7] All cases of serious cutaneous adverse drug reactions coded (ICD-9 Codes 695.14, 695.13, and 695.15) within 30 days of receiving a peripartum antibiotic were identified. Chart review was then performed to verify that the clinical symptoms were compatible with the coded diagnosis and to identify the specific agent most likely associated with the adverse reaction noted.[8]

New *C difficile* infections within 90 days of delivery were identified by either a new report of *C difficile* coded (ICD-9 Code 008.45) or a positive microbiology culture or polymerase chain reaction for *C difficile* within 90 days of delivery.

Hypothesis testing for continuous variables was by means of Student *t*-test and for categorical variables by $\chi^2$. Nominal statistical significance was set at $p = 0.05$. All statistical analyses were performed using SAS statistical software (SAS Institute Inc, Cary, NC).

## RESULTS

### Study Cohort

There were 170,379 unique women who had 201,316 pregnancies during the study interval (January 1, 2009, to December 31, 2014) and delivered 204,885 live infants. Among the 14,233 women with an active, but unverified, penicillin *allergy* at delivery, there were 16,084 pregnancies (8.0%).

### Group B Streptococcus Status and Penicillin Allergy

There were 39,398 women (23.1%) who had 42,524 pregnancies and whose cultures were positive for GBS. Of these GBS-positive women, 3247 (8.8%; resulting in 3500 pregnancies) also had a penicillin *allergy*. There were 10,988 women (9.0%; 12,584 pregnancies) without GBS with an active penicillin *allergy* at delivery.

Table 1 shows the demographics of all pregnant women, with and without GBS, who delivered live infants. Demographics of all pregnant women who delivered, with and without penicillin allergy, are displayed in Table 2. The demographics of pregnant women who delivered, with GBS, and with and without penicillin allergy, are displayed in Table 3.

### Peripartum Antibiotic Exposure

The specific antibiotic exposures within 3 days of delivery and new antibiotic allergies noted within 30 days of the specific antibiotic exposures in pregnant women with GBS, and with and without penicillin allergy, are displayed in Table 4. Cephalosporins were the second most commonly used antibiotic class in women with a history of penicillin

**Table 1. Demographics of all pregnant women with and without group B streptococcus (GBS) infection who delivered between 2009 and 2014**

| Demographic characteristic | GBS positive | GBS negative | p value |
|---|---|---|---|
| Age, years, mean (SD) | 29.71 (5.78) | 29.59 (5.85) | < 0.0001 |
| Total deliveries[a] | 42,524 | 158,792 | |
| Number of unique women | 39,398 | 138,335 | |
| Active drug-class allergies before delivery, mean (SD) | 0.72 (0.64) | 0.69 (0.64) | < 0.0001 |
| Number of live births | 43,116 | 161,769 | |
| Cesarean deliveries, no. (%) | 11,825 (27.81) | 49,452 (31.34) | < 0.0001 |
| Total days in hospital from the date of initial admission for delivery to 6 months after delivery for all women, mean (SD) | 3.459(1.88) | 3.463 (2.06) | 0.7715 |
| Total days in hospital from the date of initial admission for delivery to 6 months after delivery for women with spontaneous vaginal delivery, mean (SD) | 3.100 (1.50)[b] | 3.152 (1.46)[c] | < 0.0001 |
| Total days in hospital from the date of delivery to 6 months after delivery for the infants, mean (CI) | 3.86 (3.79-3.93) | 4.42 (4.38-4.47) | < 0.0001 |
| Antibiotic exposure ± 3 days from delivery, no. (%) | 41,149 (96.77) | 70,294 (44.27) | < 0.0001 |
| Total antibiotic courses | 102,248 | 158,507 | < 0.0001[d] |
| Total new antibiotic allergies within 30 days of peripartum antibiotic exposures, mean (CI) | 0.0033 (0.0027-0.0038) | 0.0015 (0.00129-0.0017) | < 0.0001 |
| New *Clostridium difficile* infections within 90 days of delivery, no. (%) | 20 (0.05) | 73 (0.05) | 0.9119 |

[a] A woman may have multiple deliveries during the study interval, and each delivery is counted as an independent event. All descriptive statistics and statistical tests are at delivery level, not patient level.

[b] n = 30,699 women.

[c] n = 109,340 women.

[d] p value for testing whether the mean number of courses of antibiotic is different for those with GBS-positive cultures from those with GBS-negative cultures (among those exposed).

CI = confidence interval; SD = standard deviation.

allergy, after clindamycin, and virtually no penicillin allergy testing or graded cephalosporin challenges were performed before the cephalosporin exposures. The 6th through 10th most commonly used other antibiotics in women with an unverified history of penicillin allergy were metronidazole, nitrofurantoin, sulfamethoxazole, erythromycin, and doxycycline. In women without penicillin allergy, the 6th through 10th most commonly used other antibiotics were metronidazole, nitrofurantoin, erythromycin, sulfamethoxazole, and doxycycline.

### Comorbidities

Of the 39,024 GBS-positive women without a history of penicillin allergy,

**Table 2. Demographics of all pregnant women with and without a history of penicillin allergy who delivered between 2009 and 2014**

| Demographic characteristic | History of penicillin allergy | No history of penicillin allergy | p value |
|---|---|---|---|
| Age, years, mean (SD) | 30.34 (5.78) | 29.55 (5.83) | < 0.0001 |
| Total deliveries[a] | 16,084 | 185,232 | |
| Number of unique women | 14,233 | 163,500 | |
| Active drug-class allergies before delivery, mean (SD) | 1.48 (0.85) | 0.63 (0.57) | < 0.0001 |
| Number of live births | 16,387 | 188,498 | |
| Cesarean deliveries, no. (%) | 5198 (32.32) | 56,079 (30.28) | < 0.0001 |
| Total days in hospital from the date of initial admission for delivery to 6 months after delivery for women, mean (SD) | 3.55 (1.79) | 3.45 (2.04) | < 0.0001 |
| Total days in hospital from the date of initial admission for delivery to 6 months after delivery for women with spontaneous vaginal delivery, mean (SD) | 3.17 (1.45)[b] | 3.11 (1.50)[c] | < 0.0001 |
| Total days in hospital from the date delivery to 6 months after delivery for the infants, mean (CI) | 4.48 (4.33-4.62) | 4.29 (4.25-4.33) | |
| Antibiotic exposure ± 3 days from delivery, no. (%) | 9126 (56.74) | 102,317 (55.24) | 0.0002 |
| Total antibiotic courses | 18,755 | 242,000 | < 0.0001[d] |
| Total new antibiotic allergies within 30 days of peripartum antibiotic exposures, mean (CI) | 0.0106 (0.0089-0.0124) | 0.0011 (0.0009-0.0013) | |
| New *Clostridium difficile* infections within 90 days of delivery, no. (%) | 7 (0.04) | 85 (0.05) | 0.8928 |

[a] A woman may have multiple deliveries during the study interval, and each delivery is counted as an independent event. All descriptive statistics and statistical tests are at delivery level, not patient level.
[b] n = 10,886 women.
[c] n = 129,153 women.
[d] p value for testing whether the mean number of courses of antibiotic is different for those with penicillin allergy from those without penicillin allergy (among those exposed).
CI = confidence interval; SD = standard deviation.

**Table 3. Demographics of pregnant women with group B streptococcus infection, with and without a history of penicillin allergy, who delivered between 2009 and 2014**

| Demographic characteristic | History of penicillin allergy | No history of penicillin allergy | p value |
|---|---|---|---|
| Age, years, mean (SD) | 30.28 (5.64) | 29.66 (5.79) | < 0.0001 |
| Total deliveries[a] | 3500 | 39,024 | |
| Number of unique women | 3245 | 36,153 | |
| Active drug class allergies before delivery, mean (SD) | 1.485 (0.832) | 0.647 (0.570) | < 0.0001 |
| Number of live births | 3545 | 39,571 | |
| Cesarean deliveries, no. (%) | 1063 (30.37) | 10,757 (27.57) | 0.0004 |
| Total days in hospital from the date of initial admission for delivery to 6 months after delivery for women, mean (SD) | 3.55 (1.51) | 3.46 (2.00) | 0.002 |
| Total days in hospital from the date of initial admission for delivery to 6 months after delivery for women with spontaneous vaginal delivery, mean (SD) | 3.201 (1.14)[b] | 3.147 (1.48)[c] | 0.0304 |
| Total days in hospital from the date delivery to 6 months after delivery for the infants, mean (CI) | 4.05 (3.77-4.33) | 3.85 (3.78-3.91) | |
| Antibiotic exposure ± 3 days from delivery, no. (%) | 3392 (96.91) | 37,757 (96.75) | 0.606 |
| Total antibiotic courses | 6726 | 95,522 | < 0.0001[d] |
| Total new drug-class allergies within 30 days of peripartum antibiotic exposures, mean (CI) | 0.0269 (0.0211-0.0326) | 0.0011 (0.0008-0.0015) | |
| New *Clostridium difficile* infections within 90 days of delivery, no. (%) | 0 (0.00) | 20 (0.05) | 0.4037 |

[a] A woman may have multiple deliveries during the study interval, and each delivery is counted as an independent event. All descriptive statistics and statistical tests are at delivery level, not patient level.
[b] n = 2437 women.
[c] n = 28,267 women.
[d] p value for testing whether the mean number of courses of antibiotic is different for those with penicillin allergy from those without penicillin allergy (among those exposed).
CI = confidence interval; SD = standard deviation.

10,757 (27.57%) underwent a cesarean delivery and spent an average of 3.46 days (standard deviation = 2.00 days) in the hospital within 6 months of their delivery. Within 3 days of their delivery, GBS-positive women without a history of penicillin allergy received the following antibiotics, listed from most common to least common: penicillin, cefazolin, gentamicin, clindamycin, azithromycin, and vancomycin. The GBS-positive women without a history of penicillin allergy reported 15 (0.04%) new penicillin allergies, 19 (0.05%) new cephalosporin allergies, 3 (0.01%) new clindamycin allergies, 3 (0.01%) new vancomycin allergies, 3 (0.01%) new azithromycin allergies, 0 (0%) new gentamicin allergies, and 6 (0.02%) new other antibiotic allergies within 30 days of a peripartum antibiotic exposure. The GBS-positive women without a history of penicillin allergy had 20 (0.05%) new episodes of *C difficile* within 90 days of delivery.

**Table 4. Antibiotics used within 3 days of delivery and new drug-class allergies reported within 30 days of peripartum antibiotic exposures in pregnant women with group B streptococcus infection who delivered between 2009 and 2014**

| Peripartum antibiotic exposure | History of penicillin allergy (n = 3500)[a] | No history of penicillin allergy (n = 39,024)[a] | p value |
|---|---|---|---|
| **Penicillin pregnancies** | | | |
| Number (%) | 130 (3.77) | 32,657 (83.68) | < 0.0001[b] |
| Total courses | 262 | 71,739 | < 0.0001[c] |
| New penicillin allergy, no. (%) | NA | 15 (0.04) | — |
| **Clindamycin pregnancies** | | | |
| Number (%) | 2031 (58.03) | 1269 (3.25) | < 0.0001[b] |
| Total courses | 2232 | 1365 | 0.0365[c] |
| New clindamycin allergy, no. (%) | 12 (0.34) | 3 (0.01) | < 0.0001 |
| **Cefazolin pregnancies** | | | |
| Number (%) | 1332 (38.06) | 10,626 (27.23) | < 0.0001[b] |
| Total courses | 2379 | 14,504 | < 0.0001[c] |
| **Other cephalosporin pregnancies** | | | |
| Number (%) | 27 (0.77) | 274 (0.70) | 0.6395[b] |
| Total courses | 30 | 356 | 0.7661[c] |
| New cephalosporin allergy, no. (%) | 10 (0.29) | 19 (0.05) | < 0.0001 |
| **Vancomycin pregnancies** | | | |
| Number (%) | 481 (13.74) | 61 (0.16) | < 0.0001[b] |
| Total courses | 713 | 93 | 0.6879[c] |
| New vancomycin allergy, no. (%) | 22 (0.63) | 3 (0.01) | < 0.0001 |
| **Gentamicin pregnancies** | | | |
| Number (%) | 371 (10.60) | 2339 (5.99) | < 0.0001[b] |
| Total courses | 784 | 5664 | < 0.0001[c] |
| New gentamicin allergy, no. (%) | 4 (0.11) | 0 (0) | < 0.0001 |
| **Azithromycin pregnancies** | | | |
| Number (%) | 89 (2.54) | 665 (1.70) | 0.0003[b] |
| Total courses | 128 | 954 | 0.0045[c] |
| New azithromycin allergy, no. (%) | 1 (0.03) | 2 (0.01) | 0.2272 |
| **Other pregnancies (no antibiotic exposure)** | | | |
| Number (%) | 51 (1.46) | 315 (0.81) | 0.0001[b] |
| Total courses | 57 | 386 | 0.0095[c] |

[a] A woman may have multiple deliveries during the study interval, and each delivery is counted as an independent event. All descriptive statistics and statistical tests are at delivery level, not patient level.

[b] p value for testing whether the percentage exposed to specific antibiotic is different for those with penicillin allergy from those without penicillin allergy.

[c] p value for testing whether the mean number of courses exposed to specific antibiotic is different for those with penicillin allergy from those without penicillin allergy (among those exposed).

NA = not applicable.

The GBS-positive women with an active, but unverified, penicillin allergy (N = 3500) had a significantly higher (p = 0.0004) rate of cesarean deliveries, 30.37% (n = 1063). They also spent significantly more (p = 0.002) total days—a mean of 3.55 days (standard deviation = 1.51 days) longer—in the hospital within 6 months of their delivery, independent of the method of delivery. Within 3 days of their delivery, GBS-positive women with penicillin allergy received the following antibiotics, listed from most common to least common: clindamycin, cefazolin, azithromycin, vancomycin, and gentamicin. Those GBS-positive women with a history of penicillin allergy within 30 days of a peripartum antibiotic exposure reported higher statistically significant rates of adverse drug reactions with all antibiotics used, including 12 (0.34%) new clindamycin allergies, 10 (0.29%) new cephalosporin allergies, 22 (0.63%) new vancomycin allergies, 1 (0.03%) new azithromycin allergies, 4 (0.11%) new gentamicin allergies, and 3 (0.09%) new other antibiotic allergies. The GBS-positive women with penicillin allergy had no new episodes of *C difficile* within 90 days of delivery, which was not significantly different from those without penicillin allergy.

### Penicillin Exposure in Women with Unverified Penicillin Allergy

During the study interval, 130 women with an active, but unverified, penicillin allergy received 262 courses of penicillin-class antibiotics at delivery without any allergy testing or graded challenge before the exposure. The specific penicillin-class antibiotics administered were as follows: amoxicillin, 2 (0.76%); ampicillin, 91 (34.74%); and penicillin, 169 (64.50%). There were 2 (0.76%) oral and 260 (99.24%) parenteral exposures to penicillin-class antibiotics.

The most commonly listed reasons for overriding the electronic health record warning not to use a penicillin-class antibiotic in a pregnant woman with a penicillin allergy history were "benefits outweigh risks" in 184 cases (47.92%), "not a true allergy" in 86 (22.4%), "previously or currently tolerated" in 47 (12.24%), "low risk" in 30 (7.81%), "not clinically significant" in 29 (7.55%), "expected side effect" in 6 (1.56%), and "unverified" in 2 (0.52%). The penicillin-class antibiotics were prescribed by the obstetrician-gynecologist in 104 cases (39.69%) or other treating physicians (but not anesthesiologists) in 158 cases (60.31%).

Chart review of the discharge summaries, first postpartum obstetrics and gynecology notes, and any follow-up medical visits 30 days after receiving the antibiotic dose revealed no adverse reactions noted with these penicillin exposures. Only 7 (5.4%) of 130 patients who tolerated a peripartum penicillin exposure had the notation of penicillin allergy removed from their electronic health record during the follow-up period through June 30, 2015.

A total of 260,755 courses of antibiotics were administered to pregnant women during the study interval. There were 77,283 courses of penicillin-class antibiotics (35,895 women; 37,439 pregnancies) given to pregnant women without a history of penicillin allergy in the 3 days before delivery, and 55 (0.15%) resulted in a new penicillin allergy notation before delivery. Only 2 cases (0.0008%; 95% confidence interval = 0 to 1 in 54,644) of possible antibiotic-associated anaphylaxis occurred within 3 days before or after delivery for the entire 201,316 pregnancies. Neither case occurred in GBS-positive women. Both cases were associated with the use of cefazolin during anesthesia induction.

There were 83,953 total exposures to cefazolin, resulting in a possible anaphylaxis rate of 0.0024% (95% confidence interval = 0 to 1 in 17,593). Neither patient had an underlying history of penicillin allergy. One episode was associated with swelling, the sensation of shortness of breath, and a slight elevation in blood pressure, and was not treated with adrenaline. The second episode occurred during a surgical procedure for removal of a retained placenta the day after delivery and was associated with facial swelling and no rash or hypotension, but was treated with adrenaline.

There was only one possible, but unlikely, case of a serious cutaneous adverse drug reaction associated with peripartum antibiotic use, and it was coded as Stevens-Johnson syndrome by one consultant. This diagnosis was given after consultation in the Allergy Department about two weeks after onset of what may have been a contact dermatitis to benzoin on her abdomen, a delayed-onset reaction to cefazolin or cephalexin, or a combination of these events. Five days earlier the patient had been seen in the Obstetrics Department for routine postpartum follow-up and was given a diagnosis of erythema multiforme minor and contact dermatitis. She had been given cefazolin at the time of her cesarean delivery and then given cephalexin four days later, at hospital discharge, for a possible abdominal cellulitis. Contact dermatitis around the surgical site was noted in the hospital discharge summary. No treatment, other than antihistamines, was given for the rashes. No percentage of body surface area affected was noted in the record, and no skin biopsy specimen was obtained. She was seen in the Obstetrics Department again two days after the allergy consultation for management of her slow-to-resolve surgical site cellulitis and was treated with topical antibiotics.

### Perinatal Comorbidity

The 39,571 children born to GBS-positive women without a history of penicillin allergy spent a total of 139,738 days in the hospital within 6 months of delivery. The 3545 children born to GBS-positive women with a history of penicillin allergy spent a total of 13,109 days in the hospital within 6 months of delivery. The difference of +0.2 hospital days per infant born to a mother with penicillin allergy did not reach statistical significance (p = 0.1028).

Only 7 pregnant women with GBS had penicillin allergy testing before delivery in the KPSC Health Plan between January 1, 2009, and December 31, 2014, and 3 (42.86%) of the women were in the San Diego Service Area. Results for all 7 women were negative.

## DISCUSSION

True penicillin allergy occurs much less frequently than the rate at which this allergy is placed in the patient chart.[3,9,10] Patients who are labeled as penicillin-allergic receive alternate, often broad-spectrum, antibiotics, which may lead to substantial morbidity and increased health care utilization. It is notable in the current study that none of the 130 women listed with active unverified penicillin allergy who received penicillin had an adverse reaction. We found that an unverified history of penicillin allergy was associated with a higher cesarean delivery rate in all pregnant women, even those without GBS. The antibiotic utilization seen in our cohort closely matches that reported in a recent survey of American obstetricians,[11] and 13.7% of our penicillin-allergic group received vancomycin, which has the potential for several adverse effects. This type of poor adherence to national guidelines was found in another recent study as well; more than 50% of women with a penicillin allergy without anaphylaxis received an antibiotic other than penicillin or cefazolin.[12,13] We found that significantly more new adverse drug reactions occur with all alternative antibiotics used in GBS-positive women with an unverified penicillin allergy (see Table 3). Fortunately, there was no significant difference in the *C difficile* incidence in any of the subgroups. This is probably related to the very low overall use of third-generation and higher-generation cephalosporins in this population. Currently, cephalosporins are widely, safely, and appropriately used in pregnant women with an active, but unverified, penicillin allergy without any specific testing or challenge procedures.[14,15]

**True penicillin allergy occurs much less frequently than the rate at which this allergy is placed in the patient chart.**

A recent study showed no increased risk of penicillin allergy in fetuses exposed during the intrapartum period.[16] However, penicillin allergy testing is rarely performed in pregnant women, even in a health care system with no specific financial barrier to its performance. The cost of this test is approximately $145 per test. There have been several previous suggestions commenting on the economic utility of performing wide-scale allergy testing in patients with unverified penicillin allergy.[3,17,18]

Given the increase in morbidities and health care costs associated with unverified penicillin allergy, it seems quite reasonable to propose that any hospitalized patient with a clinical history of penicillin allergy should undergo allergy testing. In our case, penicillin allergy testing of all pregnant women with an unverified penicillin allergy and GBS would cost less than the 0.09 additional hospital days that these women, on average, currently utilize, which translates to a cost of at least $200 per occurrence. Although the cesarean delivery rate is increased in pregnant women with an active history of penicillin allergy, the increase in hospital days is independent of cesarean delivery compared with vaginal delivery (see Tables 2 and 3). This information, along with the known fact that penicillin allergy testing performed in pregnancy is safe and effective,[4,5] argues for a systemwide adaptation of penicillin testing for unverified allergy in this population. It is quite clear that any woman who would be eligible to receive a safer, equally effective medication in the penicillin class should be receiving this drug.

## CONCLUSIONS

An unverified penicillin allergy is associated with greater hospital utilization and additional morbidity. Penicillin allergy testing of pregnant women with a history of penicillin allergy may help reduce these unwanted outcomes. Any patient who does not have a true drug allergy should have the allergy listing removed from her chart. ❖

### Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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### References

1. Solensky R. Penicillin allergy as a public health measure. J Allergy Clin Immunol 2014 Mar;133(3):797-8. DOI: https://doi.org/10.1016/j.jaci.2013.10.032.
2. American Academy of Allergy, Asthma & Immunology. Ten things physicians and patients should question [Internet]. Philadelphia, PA: Choosing Wisely, ABIM Foundation; 2012 Apr 4 [updated 2014 Mar 3; cited 2016 Sep 20]. Available from: www.choosingwisely.org/wp-content/uploads/2015/02/AAAAI-Choosing-Wisely-List.pdf.
3. Macy E, Contreras R. Health care use and serious infection prevalence associated with penicillin "allergy" in hospitalized patients: A cohort study. J Allergy Clin Immunol 2014 Mar;133(3):790-6. DOI: https://doi.org/10.1016/j.jaci.2013.12.559.
4. Macy E. Penicillin skin testing in pregnant women with a history of penicillin allergy and group B streptococcus colonization. Ann Allergy Asthma Immunol 2006 Aug;97(2):164-8. DOI: https://doi.org/10.1016/s1081-1206(10)60007-5.
5. Philipson EH, Lang DM, Gordon SJ, Burlingame JM, Emery SP, Arroliga ME. Management of group B streptococcus in pregnant women with penicillin allergy. J Reprod Med 2007 Jun;52(6):480-4. DOI: https://doi.org/10.1016/j.ajog.2004.10.081.
6. Koebnick C, Langer-Gould AM, Gould MK, et al. Sociodemographic characteristics of members of a large, integrated health care system: Comparison with US Census Bureau data. Perm J 2012 Summer;16(3):37-41. DOI: https://doi.org/10.7812/tpp/12-031.
7. Campbell RL, Li JT, Nicklas RA, Sadosty AT; Members of the Joint Task Force; Practice Parameter Workgroup. Emergency department diagnosis and treatment of anaphylaxis: A practice parameter. Ann Allergy Asthma Immunol 2014 Dec;113(6):599-608. DOI: https://doi.org/10.1016/j.anai.2014.10.007.
8. Davis RL, Gallagher MA, Asgari MM, et al. Identification of Stevens-Johnson syndrome and toxic epidermal necrolysis in electronic health record databases. Pharmacoepidemiol Drug Saf 2015 Jul;24(7):684-92. DOI: https://doi.org/10.1002/pds.3778.
9. Macy E, Poon K-Y T. Self-reported antibiotic allergy incidence and prevalence: Age and sex effects. Am J Med 2009 Aug;122(8):778.e1-7. DOI: https://doi.org/10.1016/j.amjmed.2009.01.034.
10. Macy E. Penicillin and beta-lactam allergy: Epidemiology and diagnosis. Curr Allergy Asthma Rep 2014 Nov;14(11):476. DOI: https://doi.org/10.1007/s11882-014-0476-y.
11. Edward RK, Tang Y, Raglan GB, Szychowski JM, Schulkin J, Schrag SJ. Survey of American obstetricians regarding group B streptococcus: Opinions and practice patterns. Am J Obstet Gynecol 2015 Aug;213(2):299.e1-7. DOI: https://doi.org/10.1016/j.ajog.2015.03.047.
12. Briody VA, Albright CM, Has P, Hughes BL. Use of cefazolin for group B streptococci prophylaxis in women reporting penicillin allergy without anaphylaxis. Obstet Gynecol 2016 Mar;127(3):577-83. DOI: https://doi.org/10.1097/aog.0000000000001297.
13. Verani JR, McGee L, Schrag SJ; Division of Bacterial Diseases, National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention (CDC). Prevention of perinatal group B streptococcal disease—revised guidelines from CDC, 2010. MMWR Recomm Rep 2010 Nov 19;59(RR-10):1-36.
14. Macy E, Contreras R. Adverse reactions associated with oral and parenteral use of cephalosporins: A retrospective population-based analysis. J Allergy Clin Immunol 2015 Mar;135(3):745-52.e5. DOI: https://doi.org/10.1016/j.jaci.2014.07.062.
15. Macy E, Ho NJ. Adverse reactions associated with therapeutic antibiotic use after penicillin skin testing. Perm J 2011 Spring;15(2):31-7. DOI: https://doi.org/010.7812/tpp/11-025.
16. May SM, Hartz MF, Joshi AY, Park MA. Intrapartum antibiotic exposure for group B streptococcus treatment did not increase penicillin allergy in children. Ann Allergy Asthma Immunol 2016 Feb;116(2):134-8. DOI: https://doi.org/10.1016/j.anai.2015.11.013.
17. Sade K, Holtzer I, Levo Y, Kivity S. The economic burden of antibiotic treatment of penicillin-allergic patients in internal medicine wards of a general tertiary care hospital. Clin Exp Allergy 2003 Apr;33(4):501-6. DOI: https://doi.org/10.1046/j.1365-2222.2003.01638.x.
18. Rimawi RH, Mazer MA. Expanding the pool of healthcare providers to perform penicillin skin testing in the ICU. Intensive Care Med 2014 Mar;40(3):462-3. DOI: https://doi.org/10.1007/s00134-013-3196-1.

## Health

The art of medicine is valuable to us because it is conducive
to health, not because of its scientific interest.

— Marcus Tillius Cicero, 106 BC-43 BC, Roman philosopher, politician,
lawyer, orator, political theorist, consul, and constitutionalist

# Understanding Preferences for Osteoporosis Information to Develop an Osteoporosis Patient Education Brochure

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## ABSTRACT

**Context:** Patient education materials can provide important information related to osteoporosis prevention and treatment. However, available osteoporosis education materials fail to follow best-practice guidelines for patient education.

**Objective:** To develop an educational brochure on bone health for adults aged 50 years and older using mixed-method, semistructured interviews.

**Design:** This project consisted of 3 phases. In Phase 1, we developed written content that included information about osteoporosis. Additionally, we designed 2 graphic-rich brochures, Brochure A (photographs) and Brochure B (illustrations). In Phase 2, interviewers presented the text-only document and both brochure designs to 53 participants from an academic Medical Center in the Midwest and an outpatient clinic in the Southeastern region of the US. Interviewers used open- and closed-ended questions to elicit opinions regarding the brochures. In Phase 3, using feedback from Phase 2, we revised the brochure and presented it to 11 participants at a third site in the Southeastern US.

**Main Outcome Measures:** Participants' comprehension of brochure text and acceptability of brochure design.

**Results:** We enrolled 64 participants. Most were women, white, and college-educated, with an average age of 66.1 years. Participants were able to restate the basic content of the brochure and preferred Brochure A's use of photographs.

**Conclusions:** Using feedback from older adults, we developed and refined a brochure for communicating bone health information to older adults at risk of osteoporosis and fragility fractures. The methods outlined in this article may serve to guide others in developing health educational brochures for chronic medical conditions.

## INTRODUCTION

Half of women and one-fourth of men in the US aged 50 years and older will experience an osteoporosis-related fracture during their lifetime.[1] The gold-standard screening tool for osteoporosis is dual-energy x-ray absorptiometry (DXA), which is noninvasive, inexpensive, and effective at identifying patients at highest risk of fracture.[2] However, studies have shown that patients undergoing DXA receive inadequate information on their test results and the consequences, prevention, or treatment of osteoporosis.[3-6] Inadequate information is a barrier for patients making behavior changes in support of a lifestyle for good bone health, such as increasing their calcium intake or weight-bearing exercise.

One challenge to clinicians and DXA testing centers seeking to educate patients is a limited library of educational materials suitable for the general population. When searching for an osteoporosis educational brochure to use for a clinical trial (ClinicalTrials.gov NCT01507662),[7] we collected materials from leading bone health, women's health, and national health organizations for review. The Centers for Disease Control and Prevention (CDC) has created a guide for developing easy-to-understand health education materials. Their recommendations include to limit messages to 3 or 4, to identify action steps, to use 12-point to 14-point type with serif fonts, to use headings and bulleted lists, to eliminate medical jargon, to use active voice and short sentences, to use instructive images, to include 40% to 50% white space, and to use an attractive cover with the main message.[8] Additionally, health literacy experts recommend writing health education materials at a sixth-grade reading level and avoiding the use of more than 2 folds in a brochure.[9]

As we searched available osteoporosis materials, products that we identified all had important limitations to their readability and acceptability to older adults with differing characteristics. For instance, most of these materials were written for narrow patient subgroups (eg, patients who already had a diagnosis of osteoporosis, women, nonelderly populations, or highly literate populations).[10-14] Table 1 provides more details on the characteristics of the brochures we found in relation to best-practice guidelines for health education materials and the reasons we chose not to use each brochure for our study. Such focused materials may not be useful to the typical DXA clinic servicing a wide array of patients. Improving

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on existing osteoporosis-related materials can assist clinicians in educating their patients about osteoporosis and fracture prevention.

In concert with a large pragmatic trial,[7] the objective of this study was to report on our rigorous efforts to develop a bone health educational brochure that could be mailed to a broad audience of patients undergoing DXA in a typical testing center.

## METHODS

We conducted this project in three phases. In the first phase, we developed the written content and two sample brochures that merged excerpts of the written content with graphics and pictures. In the second phase, we pilot-tested the written content and the two brochure formats with a sample of participants at two study sites and analyzed the feedback. In the third phase, we revised the materials and conducted a second round of testing with a sample of participants at the third study site.

### Phase 1: Development Process

The Patient Activation After DXA Result Notification Study Investigators[7] are a team of health care practitioners and health education and communication experts in the fields of rheumatology, internal medicine, and public health. To determine the brochure's scope, we identified topics regarding bone health that we considered relevant to patients undergoing DXA. Topics included: 1) a brief overview of osteoporosis and DXA results; 2) recommended amounts of calcium and vitamin D; 3) weight-bearing and strengthening activities; 4) fall prevention; 5) smoking cessation and healthy amounts of alcoholic beverages; 6) a place to write questions for their clinician; and 7) where to find more information.

Next, we addressed these topics in a text-only document. After reviewing CDC guidelines on best practices for creating print materials, which recommended limiting content to three or four main ideas,[8] we drafted brochure text addressing all seven topics but emphasized the first four topics. This draft brochure text included a brief overview of osteoporosis, its risks, and DXA as well as "steps" for improving bone health. To ensure readability, we evaluated the draft for a sixth-grade reading level using The Health Literacy Advisor software (Health Literacy Innovations LLC, Bethesda, MD).

We next evaluated the draft with The Suitability Assessment of Materials.[15] This set of questions is designed to be used by content experts for evaluating factors of content (eg, purpose, topics, and summary), literacy demand (eg, reading grade level, writing style, sentence construction, vocabulary, and use of advanced organizers), and learning stimulation and motivation (eg, interactions, desired behaviors modeled, and motivation). Each factor was rated as *superior, adequate,* or *not suitable* by selected physicians and health communication experts on our team. We

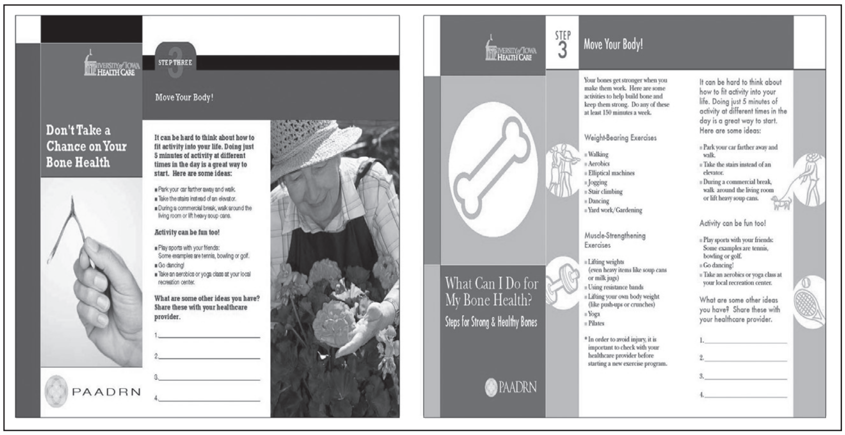
**Table 1. Characteristics of informational osteoporosis materials**

| Title | Osteoporosis: Understanding weakening of bone, its prevention and treatments[10] | Bone health for life: Easy-to-read information for patients and families[11] | How strong are your bones?[12] | Osteoporosis: What you need to know[13] | Osteoporosis: FAQ048[14] |
|---|---|---|---|---|---|
| Author/sponsor | Arthritis Foundation | National Institute of Arthritis and Musculoskeletal and Skin Diseases | National Osteoporosis Foundation | National Osteoporosis Foundation | American College of Obstetrics and Gynecology |
| Size and style | 15 pages, 7.6 x 22.9-cm (3 x 9-in) booklet | 20 pages, 12.7 x 20.3-cm (5 x 8-in) booklet | 15 pages, 12.7 x 20.3-cm (5 x 8-in) booklet | 6 pages, 21.6 x 27.9-cm (8.5 x 11-in) trifold | 14 pages, 7.6 x 22.9-cm (3 x 9-in) 7 folds |
| Reading grade level[a] | 12th | 7th | 11th | 9th | 8th |
| Font | 10 point, serif | 14 point, serif | 10 point, serif | 12 point, sans serif | 10 point, serif |
| Number of messages | 8 | 9 | 12 | 8 | 5 |
| Images | 1 cover illustration of an older woman taking calcium and 1 interior drawing of bone matrix with and without osteoporosis | About 1 every other page (black and white sketches of older and younger adults) | One per page (colored photos of diverse people) | 2 small, color photos of older adults | 2 illustrations of normal and osteoporotic bone and spine and 2 photos of white women on cover |
| Intended audience (based on cover) | Older women | People of diverse ages and race/ethnicity | People of diverse ages and race/ethnicity | Older adults of diverse race | Older white women |
| Reasons for not using in Patient Activation After DXA Result Notification trial | Poor readability (small font, too high a reading level, too much text) and did not include men or instructive visuals | Best of the 5 brochures but too long and not suitable to be mailed in legal-sized envelope | Poor readability (small font, too high a reading level, too much text) and not suitable to be mailed in legal-sized envelope | Poor readability (too high a reading level, too much text) | Poor readability (small font, too high a reading level, too much text, too many folds) and did not include men, other races, or instructive visuals |

[a] Readability based on Fry Graph Readability Formula.[1]
1. Fry E. A readability formula that saves time. J Reading 1968;11(7):513-6, 575-8.
DXA = dual-energy x-ray absorptiometry.

revised components they rated as *adequate* and *not suitable*.

This draft text was brought to a graphic designer for the development of 2 graphically rich formats (Figure 1). Brochure A used photographs of people of varying ages (50 years and older), races, and both sexes, as well as photographs supporting each topic (eg, calcium-rich foods). In contrast, Brochure B used simple line illustrations. To keep evaluation of the text and format separate, we created only a partial sample of each option rather than 2 complete brochures.



Don't Take a Chance on Your Bone Health

PAADRN

STEP THREE

Move Your Body!

**It can be hard to think about how to fit activity into your life. Doing just 5 minutes of activity at different times in the day is a great way to start. Here are some ideas:**

- Park your car farther away and walk.
- Take the stairs instead of an elevator.
- During a commercial break, walk around the living room or lift heavy soup cans.

**Activity can be fun too!**

- Play sports with your friends: Some examples are tennis, bowling or golf.
- Go dancing!
- Take an aerobics or yoga class at your local recreation center.

**What are some other ideas you have? Share these with your healthcare provider.**

1.____________________

2.____________________

3.____________________

4.____________________

What Can I Do for My Bone Health?

Steps for Strong & Healthy Bones

PAADRN

STEP 3

Move Your Body!

Your bones get stronger when you make them work. Here are some activities to help build bone and keep them strong. Do any of these at least 150 minutes a week.

Weight-Bearing Exercises

- Walking
- Aerobics
- Elliptical machines
- Jogging
- Stair climbing
- Dancing
- Yard work/Gardening

Muscle-Strengthening Exercises

- Lifting weights (even heavy items like soup cans or milk jugs)
- Using resistance bands
- Lifting your own body weight (like push-ups or crunches)
- Yoga
- Pilates

* In order to avoid injury, it is important to check with your healthcare provider before starting a new exercise program.

It can be hard to think about how to fit activity into your life. Doing just 5 minutes of activity at different times in the day is a great way to start. Here are some ideas:

- Park your car farther away and walk.
- Take the stairs instead of an elevator.
- During a commercial break, walk around the living room or lift heavy soup cans.

Activity can be fun too!

- Play sports with your friends: Some examples are tennis, bowling or golf.
- Go dancing!
- Take an aerobics or yoga class at your local recreation center.

What are some other ideas you have? Share these with your healthcare provider.

1.____________________

2.____________________

3.____________________

4.____________________

Figure 1. Sample of Brochure A (left) and of Brochure B (right) designs.

PAADRN = Patient Activation After DXA Result Notification (Study).

## Items from the Semistructured Interview Guide

**Questions used to assess brochure text**

If you were going to tell a friend or family member about this brochure, what would you tell him/her that it said?

Do you think the brochure does a good job of talking about how to help your bones? Please explain your answer.

Before reading the brochure, did you think taking care of your bones was easy or hard? Please explain your response.

After reading the brochure, do you think taking care of your bones is easy or hard? Please explain your response.

Please indicate how much you agree with each of the following statements (1 = Strongly disagree; 2 = Disagree; 3 = Neutral; 4 = Agree; 5 = Strongly agree):

The title tells me what the brochure is about.
The brochure is hard to read.
I can understand all of the medical words.
The amount of information is about right.
My questions about osteoporosis are answered.
The brochure clearly explains where to find more information.
The tables are easy to understand (T-score table and Calcium/Vitamin D table).

**Questions used to assess brochure design**

Would you pick up either of these brochures if you saw them on a table in the waiting room of your doctor's office? If yes, which one (A or B) would you be most likely to pick up first? Please explain.

Which brochure (A or B) do you think is best for people like you? Why?

What pictures do you like? Why?

Are there any pictures you don't like? Why?

How do you feel about the colors used?

Do you think the print/style of letters is easy to read? If not, is it too small, not the right style, or both?

How well do the covers explain what the brochure is about? Excellent, very good, good, fair, or poor? Please explain.

For each brochure, there are two different titles. Which title do you think does the best job at explaining what the brochure is about?

Which brochure look is your favorite (A or B) and why?

Does any part of either brochure seem distracting (or too busy)? If yes, what?

Is there anything else you want to tell me about the look of the brochure that might help us make it better?

### Phase 2: Pilot Testing with First Group

We recruited participants from patients and/or visitors aged 50 years and older at a large teaching hospital in the Midwestern US (Site A) or a private outpatient clinic in the Southeast US (Site B). We excluded those who were unable to understand English, prisoners, and those with mental disabilities. Research assistants approached potential participants in clinic waiting areas and lobbies (Site A), or they placed advertisements around the clinic (Site B). Participants received a parking voucher or $20 gift card for their time. The Human Subjects Office at the University of Iowa and the Kaiser Permanente of Georgia institutional review boards approved this research study. Site institutional review boards approved a waiver of written informed consent; thus, research assistants reviewed an elements of consent document with each participant.

We used a mixed-methods approach of quantitative survey questions and qualitative open-ended questions to gain an understanding of what participants liked and disliked with respect to each brochure. This approach allowed us to quantify overall preference trends and averages, and to identify themes in preferences to guide further brochure refinement.

During the first part of the interview, participants focused on the written content. Research assistants presented participants with a text-only document, and they audiorecorded the interviews and took notes. Participants evaluated the document in sections: 1) information about osteoporosis and the score from a DXA scan; 2) questions for their clinician and information about calcium and vitamin D;

3) weight-bearing and strengthening activities; and 4) alcohol use, tobacco use, summary, and additional resources.

After participants read each section, the research assistant asked them to identify words, sentences, or phrases that were hard to understand and those that were easy to understand or were well written. Section 1 included a table explaining T-score ranges and their corresponding impression (for example, a T-score of -2.5 or less signifies osteoporosis). To test comprehension, we presented each participant with a hypothetical T-score and asked in which bone density category that person would be.

**… we asked participants to read eight specific words: bone, activity, osteoporosis, supplements, density, calcium, dairy, and strengthening. Interviewers tracked words that participants had difficulty reading or pronouncing.**

Next, the interviewer asked each participant a series of questions about the entire brochure text. Items were adapted from other publications.[9,16] See Sidebar: Items from the Semistructured Interview Guide for an overview of assessed items.

Similar to the Rapid Estimate of Adult Literacy in Medicine-Short Form, a health literacy assessment tool,[17] we asked participants to read eight specific words from the brochure aloud to assess readability of words used in the brochure. These words were *bone, activity* (two simple words for practice)*, osteoporosis, supplements, density, calcium, dairy, and strengthening*. Interviewers tracked words that participants had difficulty reading or pronouncing.

Participants were then asked to review the two sample brochure designs, Brochures A and B (see Figure 1), with regard to format, visual appeal, pictures, colors, font, and titles (see Table 1).

Interviewers collected health history and demographic information from participants: bone health history (prior DXA scans, previous diagnosis of osteoporosis or low bone density, history of fractures), general health status, sex, year of birth, educational attainment, employment status, and race. We assessed health numeracy, the ability to understand numbers and risk,[18] using the 8-item Subjective Numeracy Scale.[19] We evaluated health literacy using 3 items developed by Chew et al[20]: "How often do you have someone help you read hospital materials?"; "How confident are you filling out medical forms by yourself?"; and "How often do you have problems learning about your medical condition because of difficulty understanding written information?" Interviews took 20 to 30 minutes to complete.

We analyzed quantitative data using univariate and bivariate methods to examine the association of participant demographics (eg, age, race, sex) and clinical characteristics (eg, history of prior DXA scans, history of osteoporosis or prior fracture) with preference for features of Brochure A vs Brochure B. We used SAS Version 9.2 (SAS Institute, Cary, NC) to conduct quantitative analyses, and we set an $\alpha$ level of 0.05 as statistically significant.

For the qualitative data, we used a concurrent mixed-methods framework[21] by examining the quantitative data, then coding open-ended interview items to inform what we learned from the quantitative analysis. The qualitative team reviewed data pertaining to brochure preferences and comprehension. To ensure internal validity and reliability, we used a team who independently coded the open-ended interview items. The qualitative team reviewed themes for face validity and the data were recoded using the revised codebook. We used MAXQDA (VERBI GmbH, Berlin, Germany) to analyze qualitative data.

### Phase 3: Revisions to Brochure and Pilot Testing with Second Group

After testing the brochure at Sites A and B, we thought it important to make some minor changes to the brochure before testing it at a third site (Site C). This approach allowed us to get feedback on the modifications. Changes made to the text-only document and the two designs (Brochure A and Brochure B) are described here:

1. Revised some text in the text-only document
   a. Replaced "Do any of these at least 150 minutes a week" with "Do any of these at least 30 minutes a day, 5 days a week. You can break these into 10-minute sessions."
   b. Revised the list of weight-bearing exercises to include "hiking," replacing "elliptical machines" with "golfing," and replacing "jogging" with "tennis"
2. Changed 3 photos in Brochure A
   a. Replaced a close-up of a milk carton with a photo of an older, Asian woman drinking a glass of milk
   b. Replaced a close-up of a piece of salmon with a photo of a piece of salmon on a plate with more vegetables
   c. Replaced a photo of an African American couple riding bikes with one of an older African American couple walking
3. Moved the illustrations in Brochure B from the left and right margins to the top margins to improve readability.

Participants for Phase 3 were drawn from a large teaching hospital in the Southern US (Site C). Using the same recruitment approach and interview guide criteria as in Phase 2, research assistants presented the revised brochure text document and sample design formats to Site C participants. The University of Alabama at Birmingham institutional review board approved this study and granted us a waiver of written informed consent.

Quantitative and qualitative data were analyzed using the methods described for Phase 2.

## RESULTS

### Participants

Among 53 participants who agreed to participate in Phase 2, most were white (69.8%), women (75.5%), and had attended college (70.0%), as shown in Table 2. The participants' ages ranged from 53 to 88 years, with the mean age being 66.1 years (standard deviation, ± 9.1 years). For Phase 3, we enrolled 11 participants from Site C (see Table 2). All but 1 participant was white (90.9%), all were women (100%), and 45.5% had a high school education or less. The mean age of Phase 3 participants was 68.1 years (standard deviation ± 10.9 years).

### Brochure Text

Participants reported that the brochure had the right amount of information, was easy to read, and answered all osteoporosis questions (Table 3). When participants read the table describing T-score values, most (86.8% from Phase 2 and 63.6% from Phase 3) comprehended the T-score table correctly to identify a T-score of -1.5 as a person having osteopenia. In an assessment of reading ability, 100% of participants correctly read the words *bone*, *activity*, *calcium*, and *dairy*, 98.4% could read the word *strengthening*, 96.9% could read the words *density* and *supplements*, and 87.5% could read the word *osteoporosis*. When asked how difficult they thought taking care of their bones was, 41.5% of Phase 2 participants and 45.5% of Phase 3 participants said it was easy before reading the brochure compared with 77.4% of Phase 2 participants and 81.8% of Phase 3 participants saying it was easy after reading the brochure. Approximately 42% of Phase 2 participants said they would increase their calcium intake, and 64% of Phase 2 participants said they would increase their physical activity after reading the text-only document.

**Table 2. Characteristics of patients by pilot phase**

| | Phase 2 | | Phase 3 | |
|---|---|---|---|---|
| Characteristic | Site A (n = 28, 43.8%) | Site B (n = 25, 39.1%) | Site C (n = 11, 17.2%) | All phases (N = 64) |
| Women, no. (%)[a] | 24 (85.7) | 16 (64.0) | 11 (100.0) | 51 (79.7) |
| Age, years, no. (%) | | | | |
| 50-59 | 12 (42.9) | 6 (24.0) | 2 (18.2) | 20 (31.3) |
| 60-69 | 6 (21.4) | 8 (32.0) | 4 (36.4) | 18 (28.1) |
| ≥ 70 | 10 (35.7) | 11 (44.0) | 5 (45.5) | 26 (40.6) |
| Education, no. (%) | | | | |
| High school or less | 8 (32.0) | 7 (28.0) | 5 (45.5) | 20 (32.8) |
| Some college | 6 (24.0) | 9 (36.0) | 4 (36.4) | 19 (31.2) |
| College graduate or more | 11 (44.0) | 9 (36.0) | 2 (18.2) | 22 (36.1) |
| Race, no. (%)[a] | | | | |
| White | 27 (96.4) | 10 (40.0) | 10 (90.9) | 47 (73.4) |
| Black | 0 (0) | 14 (56.0) | 0 (0) | 14 (21.9) |
| Other | 1 (3.6) | 1 (4.0) | 1 (9.1) | 3 (4.7) |
| General health, no. (%) | | | | |
| Excellent | 6 (24.0) | 3 (12.0) | 2 (18.2) | 11 (18.0) |
| Very good | 10 (40.0) | 7 (28.0) | 6 (54.6) | 23 (37.7) |
| Good | 9 (36.0) | 12 (48.0) | 2 (18.2) | 23 (37.7) |
| Fair | 0 (0) | 3 (12.0) | 1 (9.1) | 4 (6.6) |
| Poor | 0 (0) | 0 (0) | 0 (0) | 0 (0) |
| Bone health, no. (%) | | | | |
| History of previous DXA[a] | 13 (54.2) | 10 (40.0) | 11 (100.0) | 34 (56.7) |
| History of osteoporosis or osteopenia[a] | 6 (21.4) | 8 (32.0) | 9 (81.8) | 23 (35.9) |
| Fracture history | 6 (24.0) | 4 (16.0) | 4 (36.4) | 14 (23.0) |
| Other factors | | | | |
| Literacy score,[b] mean (SD)[a] | 4.4 (0.7) | 3.9 (0.8) | 4.3 (0.6) | 4.1 (0.7) |
| Numeracy score,[c] mean (SD) | 4.5 (1.1) | 4.1 (1.2) | 4.1 (0.8) | 4.3 (1.1) |

[a] Indicates characteristics for which the site participants are significantly different ($p < 0.05$).
[b] Literacy score ranges from 1-5.
[c] Numeracy score ranges from 1-6.
DXA = dual-energy x-ray absorptiometry; SD = standard deviation.

**Table 3. Participants' agreement with brochure text usability factors**

| | Average agreement (1-5)[a] | |
|---|---|---|
| Factor | Phase 2 (Sites A and B) | Phase 3 (Site C) |
| Title explains brochure | 4.47 | 4.18 |
| Brochure hard to read | 1.51 | 1.64 |
| Understand all medical words | 4.29 | 4.55 |
| Amount of information right | 4.26 | 4.46 |
| Questions about osteoporosis answered | 3.90 | 4.27 |
| Clear on where to find more information | 4.16 | 4.36 |
| Tables easy to understand | 4.20 | 4.36 |

[a] 1 = Strongly disagree; 2 = Disagree; 3 = Neutral; 4 =Agree; 5 = Strongly agree.

Noteworthy qualitative feedback about the brochure text included positive assessments, areas for improvement, and phrases participants had difficulties understanding. Most participants were able to restate the basic content of the brochure suggesting general comprehension of the text. When asked what they would say to a friend or family about the brochure, participants said

> *"Eating right and exercise will help you have stronger bones and can actually be a preventive measure in order to prevent bone breakage later."* (Participant 5, Site B, black man, age 52).
>
> *"It tells what osteoporosis is, how to keep bones healthy, and if they are in trouble how to get them on the right track."* (Participant 61, Site C, white woman, age 70).

The osteoporosis and activity sections of the brochure received the most positive appraisal. Participants stated that this section was clear, as evidenced by the following response:

> *"[The osteoporosis section] was very clear; it explains that osteoporosis is not the same as arthritis."* (Participant 7, Site A, white woman, age 72).

In the activity section of the brochure, participants reported both positive and negative feelings toward the types of exercises listed. For example, one participant stated:

> *"I think the examples of what you can do to build strong bones was good. I like that they included the daily household activities like chores."* (Participant 8, Site B, black woman, age 56).

However, there were concerns about the types of exercises listed; for example, 3 individuals did not know what an elliptical machine was. Also, 5 of 53 participants said the statement that someone should do 150 minutes of activity per week seemed like an unachievable amount of activity and suggested the amount should be broken down to seem smaller. After we revised the text-only document, retesting at Site C demonstrated improvements in the activity section, with all 11 Site C participants reporting this section as easy to understand.

Additionally, some participants questioned the amount or type of calcium and vitamin D supplements listed in the brochure, as noted in the following responses:

> *"I think the recommended vitamin D levels should be higher."* (Participant 52, Site A, white man, age 68).
>
> *"[The section about] how much calcium a person should be getting—the amount is controversial."* (Participant 6, Site A, white woman, age 53).

### Brochure Format

Overall, most participants preferred the format of Brochure A (73.5% for Phase 2 and 63.6% for Phase 3) as opposed to Brochure B (Phase 2: p = 0.001; Phase 3: p = 0.37; combined: p = 0.0008; see Figure 1). Preferences did not significantly differ by subgroup (sex, education, age, site, or race). Most participants also listed Brochure A over Brochure B as the most likely one they would pick up first (70.5% of Phase 2 participants and 60.0% of Phase 3 participants) and the "best for people like you" (66.0% for Phase 2 participants and 63.6% of Phase 3 participants). However, most participants (77.6% of Phase 2 participants and 72.7% of Phase 3 participants) thought the title in Brochure B provided a better explanation of the brochure.

Qualitative feedback received on the format of the brochure provided comments about the graphics, pictures, and colors. The picture that was most well liked was the one used in Brochure A of the woman gardening, with participants explaining that the woman looked "sweet," "healthy," and "happy." Overall, 46.9% of participants disliked one or more aspects of the pictures; 6 participants disliked the bone on the cover of Brochure B, 6 disliked all graphics in Brochure B, 5 participants disliked the milk carton used in Brochure A, and 5 disliked the salmon picture used in Brochure A. In particular, participants stated that the bone "looked like a dog bone" and seemed "juvenile." Participants from Phase 2 said that they were unsure what the milk and salmon photographs intended to show. Last, 3 of the 53 Phase 2 participants commented that the couple riding bikes on Brochure A looked "too young to have osteoporosis" and they were "too skinny." On the basis of feedback, we replaced each of these pictures, and in Phase 3 all participants were satisfied with the new pictures.

## DISCUSSION

In this article, we described the development of a bone health educational brochure following recommendations for constructing optimal health communication materials. To improve health education materials, the CDC and the Institute for Healthcare Advancement have created best practices for creating health education materials.[8,9] The five osteoporosis health education brochures we assessed before the development of our own brochure all failed to adhere to at least some of the recommendations. Thus, we embarked on our own effort to develop an improved bone-related patient education brochure.

Participants expressed preferences for how information was presented, in particular, in the section on activity. Phase 2 participants believed that breaking the exercise duration into smaller intervals seemed more manageable. They also liked having a choice of everyday activities (eg, chores or walking). Additionally, 38.1% more participants stated that they thought taking care of their bones was easy after reading the brochure than before reading the brochure. These findings suggest that this educational brochure increased bone-related self-efficacy. We are examining the effects this brochure has on osteoporosis-related self-efficacy and osteoporosis-related behavior changes such as adherence to recommended osteoporosis medications, calcium and vitamin D intake, weight-bearing exercise, smoking cessation, and alcohol reduction.

It is important to comment on the graphics and layout as well. We deliberately included pictures of a diverse spectrum of adults, including men and women, adults with varying skin tone or race, and different ages. These efforts were guided by CDC guidelines.[8] Feedback from our diverse group of participants failed to identify any concerns with respect to the diversity of the subjects displayed in our brochure, suggesting that our efforts at diversity were well received. We also found that participants preferred photographs to computer-generated illustrations or drawings. In total, the graphics and layout of our brochure were well received, and our multiphase testing approach led to tangible improvements in our final brochure draft.

In total, this exercise provides lessons into the development of a state-of-the-art bone health brochure, but also provides guidance to researchers attempting to develop health communication materials for other diseases and conditions. Using comments from clinicians, health communication experts, and older adults, we found that key bone health topics could be distilled into four key topic areas that could be conveyed to patients in a way that was easy to comprehend. We found that participants were able to restate the gist of the brochure, had opinions and preferences for how they wanted both textual and graphical information presented, and after reading the brochure they believed that taking control of their bone health was easier. Our findings are comparable to another project, which used similar methods to develop a brochure about coronary artery disease.[22] The authors also found that considerations in the format and readability were well received and that participants had suggestions for improving content and design.[22] Using an approach that elicits feedback from health care experts, health communication experts, and patients may help improve comprehension and acceptability of health education materials.

This study has limitations. By coincidence, our enrollment yielded an educated sample, with 67.3% of all participants attending college. A sample of participants with a lower educational attainment may have yielded different results. However, this brochure was written so that individuals with at least a sixth-grade reading level could read the brochure. Although our sample was composed of primarily white participants, 21.9% were black or African American, and 4.7% were another race, suggesting moderate diversity. A more racially diverse sample may have produced different responses from participants. However, our sample characteristics match those who undergo DXA screening at each of the 3 sites.

There are also limitations to the brochure, mainly regarding its content. One goal for clinicians is to improve patient adherence to recommended osteoporosis treatment. Our team decided to only briefly mention medications, because we believe this discussion should occur between patient and clinician because of the very personalized risk of side effects and contraindications. Decision aids have been created for osteoporosis treatment, and these might be better suited for educating patients whose clinicians deemed them in need of osteoporosis medication.[23,24]

## CONCLUSIONS

We used best practices for creating literacy-appropriate educational materials to develop the "What Can I Do for My Bone Health? Steps for Strong & Healthy Bones" brochure (final brochure may be seen at: www.ncbi.nlm.nih.gov/pmc/articles/PMC3525745/figure/F4/). We have shown it was effective at helping patients understand osteoporosis and reflects health education best-practice guidelines. Because this brochure was designed for a general audience of adults aged 50 years and older of both sexes and varying races, education levels, and bone-related health histories, clinicians may find this brochure useful in educating patients before or after a DXA screening. The final brochure is available on request or can be found in publication.[7] Future publications will describe the effect that this brochure, with an accompanying personalized letter providing the DXA result, has on patients' health behaviors.

Participants have preferences for how health education is presented to them, and many current osteoporosis-related health education materials have not followed best practices. Others wishing to provide their older adult patients with information on osteoporosis may use this brochure as a template. Researchers and clinicians wanting to develop education materials for other medical conditions can use our methods as a guide for eliciting patient feedback. ❖

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**Disclosure Statements**

*The author(s) have no conflicts of interest to disclose.*

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**References**

1. Office of the Surgeon General. Bone health and osteoporosis: a report of the surgeon general. Rockville, MD: US Department of Health and Human Services, Office of the Surgeon General; 2004.
2. US Preventive Services Task Force. Screening for osteoporosis: US preventive services task force recommendation statement. Ann Intern Med 2011 Mar 1;154(5):356-64. DOI: https://doi.org/10.7326/0003-4819-154-5-201103010-00307.
3. Cram P, Rosenthal GE, Ohsfeldt R, Wallace RB, Schlechte J, Schiff GD. Failure to recognize and act on abnormal test results: the case of screening bone densitometry. Jt Comm J Qual Patient Saf 2005 Feb;31(2):90-7.
4. Cadarette SM, Beaton DE, Gignac MA, Jaglal SB, Dickson L, Hawker GA. Minimal error in self-report of having had DXA, but self-report of its results was poor. J Clin Epidemiol 2007 Dec;60(12):1306-11. DOI: https://doi.org/10.1016/j.jclinepi.2007.02.010.
5. Giangregorio L, Dolovich L, Cranney A, et al. Osteoporosis risk perceptions among patients who have sustained a fragility fracture. Patient Educ Couns 2009 Feb;74(2):213-20. DOI: https://doi.org/10.1016/j.pec.2008.08.001.
6. Siris ES, Gehlbach S, Adachi JD, et al. Failure to perceive increased risk of fracture in women 55 years and older: the Global Longitudinal Study of Osteoporosis in Women (GLOW). Osteoporos Int 2011 Jan;22(1):27-35. DOI: https://doi.org/10.1007/s00198-010-1211-8.
7. Edmonds SW, Wolinsky FD, Christensen AJ, et al; PAADRN Investigators. The PAADRN study: a design for a randomized controlled practical clinical trial to improve bone health. Contemporary Clin Trials 2013 Jan;34(1):90-100. DOI: https://doi.org/10.1016/j.cct.2012.10.002.
8. Simply put: a guide for creating easy-to-understand materials. 3rd ed [Internet]. Atlanta, GA: Centers for Disease Control and Prevention; 2009 Apr [cited 2016 May 3]. Available from: www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf.
9. Doak CC, Doak LG, Root JH. Teaching patients with low literacy skills. 2nd ed. Philadelphia, PA: JB Lippincott Company; 1996.
10. Osteoporosis: Understanding weakening of bone, its prevention and treatments [brochure]. Atlanta, GA: Arthritis Foundation; 2009.
11. Bone health for life: easy-to-read information for patients and families [brochure]. Bethesda, MD: National Institute of Arthritis and Musculoskeltal and Skin Diseases; 2008.
12. How strong are your bones? [brochure]. Arlington, VA: National Osteoporosis Foundation; 2009.
13. Osteoporosis: what you need to know [brochure]. Arlington, VA: National Osteoporosis Foundation; 2011.
14. Osteoporosis [brochure]. Washington, DC: The American College of Obstetricians and Gynecologists; 2003.
15. Suitability assessment of materials (SAM). In: Doak CG, Doak LG, Root JH. Teaching patients with low literacy skills. 2nd ed. Philadelphia, PA: JB Lippincott Company; 1996. p 49-60.
16. Guidelines for target population usability testing [Internet]. Omaha, NE: Alegent Health; 2008 [cited 2011 March 31]. Available from: http://aspiruslibrary.org/literacy/UsabilityGuidelinesTesting.pdf.
17. Arozullah AM, Yarnold PR, Bennett CL, et al. Development and validation of a short-form, rapid estimate of adult literacy in medicine. Med Care 2007 Nov;45(11):1026-33. DOI: https://doi.org/10.1097/MLR.0b013e3180616c1b.
18. Understanding literacy and numeracy [Internet]. Atlanta, GA: Centers for Disease Control and Prevention; 2015 [cited 2016 May 24]. Available from: www.cdc.gov/healthliteracy/learn/understandingliteracy.html.
19. Fagerlin A, Zikmund-Fisher BJ, Ubel PA, Jankovic A, Derry HA, Smith DM. Measuring numeracy without a math test: development of the Subjective Numeracy Scale. Med Decis Making 2007 Sep-Oct;27(5):672-80. DOI: https://doi.org/10.1177/0272989x07304449.
20. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med 2004 Sep;36(8):588-94.
21. Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. 2nd ed. Thousand Oaks, CA: SAGE Publications Inc; 2011.
22. Redfern J, Ellis E, Briffa T, Freedman SB. Development and testing of innovative patient resources for the management of coronary heart disease (CHD): a descriptive study. BMC Health Serv Res 2006 Aug 6;6:95. DOI: https://doi.org/10.1186/1472-6963-6-95.
23. Montori VM, Shah ND, Pencille LJ, et al. Use of a decision aid to improve treatment decisions in osteoporosis: the osteoporosis choice randomized trial. Am J Med 2011 Jun;124(6):549-56. DOI: https://doi.org/10.1016/j.amjmed.2011.01.013.
24. Healthy bones: about osteoporosis [Internet]. Rockville, MD: Agency for Healthcare Research and Quality; 2016 [cited 2016 March 30]. Available from: www.effectivehealthcare.ahrq.gov/ehc/decisionaids/osteoporosis/.

**Bogenfels Rock, Namibia**
watercolor on paper

**Quentin Eichbaum, MD, PhD, MPH, MFA, MMHC, FCAP**

This original painting represents a major landmark (Bow Rock or "Bogenfels" in German) on the Namib desert coast of Namibia. As a medical metaphor, it may be seen as a dark arch, perhaps of illness, one may have to pass under in life to get to the light on the other side.

Dr Eichbaum grew up in Namibia before coming to the US to study medicine at Harvard Medical School. He has painted watercolors all his life and considers it a wonderfully regenerative pasttime that helps him to look at the world and its people (including patients) with a more curious eye. He is a Professor at the Vanderbilt School of Medicine in Nashville, TN.

**ORIGINAL RESEARCH & CONTRIBUTIONS**

# Understanding Faculty and Trainee Needs Related to Scholarly Activity in a Large, Nonuniversity Graduate Medical Education Program

**Davida Becker, PhD, MS; Hanna Garth, PhD, MPH; Rachel Hollander; Felice Klein, RN, MN; Marc Klau, MD, MBA**

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## ABSTRACT

**Context:** Graduate medical education (GME) programs must develop curriculum to ensure scholarly activity among trainees and faculty to meet accreditation requirements and to support evidence-based medicine.

**Objective:** Test whether research-related needs and interests varied across four groups: primary care trainees, specialty trainees, primary care faculty, and specialty faculty.

**Design:** We surveyed a random sample of trainees and faculty in Kaiser Permanente Southern California's GME programs. We investigated group differences in outcomes using Fisher exact and Kruskal-Wallis tests.

**Main Outcome Measures:** Research experiences, skills, barriers, motivators, and interests in specific research skills development.

**Results:** Participants included 47 trainees and 26 faculty (response rate = 30%). Among primary care faculty, 12 (71%) reported little or no research experience vs 1 (11%) for specialty faculty, 14 (41%) for primary care trainees, and 1 (8%) for specialty trainees ($p < 0.001$). Submission of research to the institutional review board, an abstract to a conference, or a manuscript for publication in the previous year varied across groups ($p = 0.001$, $p = 0.003$, and $p < 0.001$, respectively). Overall self-reported research skills also differed across groups ($p < 0.001$). Primary care faculty reported the lowest skill level. Research barriers that differed across groups included other work roles taking priority; desire for work-life balance; and lack of managerial support, research equipment, administrative support, and funding.

**Conclusion:** Faculty and trainees in primary care and specialties have differing research-related needs that GME programs should consider when designing curricula to support scholarly activity. Developing research skills of primary care faculty is a priority to support trainees' scholarly activity.

## INTRODUCTION

Participation in scholarly activity during residency training benefits trainees by promoting the practice of evidence-based medicine and quality patient care, providing skills for lifelong learning, and supporting critical thinking skills.[1] Additionally, participation in research may be necessary for residents interested in fellowship placements.[1] The Accreditation Council of Graduate Medical Education (ACGME) mandates participation in scholarly activity for residents and faculty in all specialties, and some specialty review committees have specified additional requirements.[2] Fulfilling the scholarly activity requirement means graduate medical education (GME) programs must develop curriculum and structures that support research, address research barriers, and foster a culture of inquiry.[1,3] The most effective and efficient programs address learners' needs and preferences, and account for the current level of research experience of targeted groups.[4-6]

For large GME institutions with training programs in diverse specialties, developing programs to support scholarly activity may present challenges if needs and preferences vary across groups. Barriers to research may be different or more pronounced in primary care programs, where levels of research experience and skills may be lower than in specialties.[3,7-9] Another complexity is that faculty may have different training needs than trainees do because their role involves both conducting research and mentoring trainees' scholarly activities.

Previous studies have documented trainees',[8,10-12] program directors',[7,13] and practicing physicians'[9,14] perspectives on research and the scholarly activity requirements. However, most studies were limited to a single specialty and population, such as residents or program directors. Few investigators have compared faculty and trainee perspectives across various specialties in a single study.

Kaiser Permanente Southern California (KPSC) is a large integrated health care system that provides care to more than 4 million individuals across Southern California at 14 Medical Centers and 221 medical offices. At 6 of these Medical Centers, KPSC sponsors 32 independent ACGME-accredited residency and fellowship programs, most (n = 19) of which are based at the Los Angeles Medical Center (LAMC). The other 13 programs are located at Medical Centers across the Region, including Fontana, Orange County, Riverside, Woodland Hills, and San Diego, CA. LAMC is where most specialty training takes places and as such has the greatest number of physicians engaged in research. Of all the KPSC-sponsored programs, 11 are primary care programs, including 6 Family Medicine, 2 Internal Medicine, 1 Pediatrics, and 2 Geriatrics programs. Each year, KPSC graduates around 114 trainees, approximately 60% from primary care programs.

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In 2014, KPSC's GME administration started a program to build research capacity in the GME programs. To inform the development of the program, a survey of faculty and trainees was conducted to measure research-related experiences, skills, barriers, motivators, and interest in skills development. We used data from this survey to test for differences in research-related needs and interests across four groups: primary care trainees, primary care faculty, specialty trainees, and specialty faculty. We hypothesized that research-related experiences, skills, and interests would be different for faculty and trainees affiliated with primary care programs compared with those in specialties.

## METHODS

We surveyed a random sample of faculty and trainees between January 2015 and July 2015. Eligibility criteria included primary affiliation with a KPSC GME program. Faculty and trainees were sampled separately. The sampling frames were administrative lists of all current residents and faculty. The GME office administered the survey as a baseline assessment to evaluate the research capacity building program launched in 2014; a follow-up survey is planned in 5 years. We estimated the sample size to detect a 15% increase in research-related skills from baseline to follow-up with 80% power and adjusted it for an anticipated 50% nonresponse rate. The final sample size was 160 trainees and 90 faculty. The KPSC institutional review board approved the study protocol.

Participants were e-mailed a link to an online survey (SurveyMonkey, Palo Alto, CA) from a Kaiser Permanente e-mail address and were sent 3 reminder e-mails over 2.5 months. We used a SurveyMonkey feature that allowed for tracking whether or not participants had responded but which stored all survey data anonymously. Because response to the online survey was lower than expected, we distributed printed copies of the survey to all nonresponders with instructions to return their survey in a sealed envelope using our interoffice mail system. Participants who completed the survey were offered the option to be entered into a raffle to win 1 of 2 backpacks (approximate value $50 each).

The questionnaire was adapted from the Research Capacity and Culture Tool, a validated instrument with high reliability that has been used previously to evaluate research capacity building initiatives.[15,16] Domains measured included research experience, research activities in the previous year, research skills, barriers and motivators to research, and interests in research skills development. We also measured program affiliation, role (trainee or faculty), age, sex, years of clinical experience, and primary training site. Participants who selected Family Medicine, Internal Medicine, Pediatrics, or Geriatrics as their program affiliation were categorized as primary care.[17] Residents and fellows were grouped as trainees. All participants were categorized into four mutually exclusive groups: primary care trainees, specialty trainees, primary care faculty, and specialty faculty.

We performed statistical analysis using Stata Version 14 (College Station, TX).[18] First, we compared characteristics of faculty and trainees in the sample with those who were included in the pool of eligible participants to assess for potential biases. Next,

**Table 1. Characteristics of survey participants**

| Characteristic | Trainees (n = 47), no. (%) | Faculty (n = 26), no. (%) |
|---|---|---|
| **Program affiliation** | | |
| Primary care | 35 (74) | 17 (65) |
| Specialty | 12 (26) | 9 (35) |
| **Medical Center location** | | |
| Los Angeles | 24 (51) | 10 (38) |
| Other | 23 (49) | 16 (62) |
| **Sex** | | |
| Men | 21 (45) | 19 (73) |
| Women | 26 (55) | 7 (27) |

**Table 2. Level of research experience and research activities completed in previous year among survey participants, by role and program**

| Parameter | Total, no. (%) | Trainees | | Faculty | | p value[a] |
|---|---|---|---|---|---|---|
| | | Primary care, no. (%) | Specialty, no. (%) | Primary care, no. (%) | Specialty, no. (%) | |
| **Level of research experience (n = 72)** | | | | | | |
| Little or none | 28 (39) | 14 (41) | 1 (8) | 12 (71) | 1 (11) | < 0.001 |
| Some | 35 (49) | 19 (56) | 9 (75) | 4 (24) | 3 (33) | |
| Substantial | 9 (13) | 1 (3) | 2 (17) | 1 (6) | 5 (56) | |
| **Research activities undertaken in past year** | | | | | | |
| Initiated research study (n = 71) | 31 (44) | 13 (37) | 7 (58) | 4 (27) | 7 (78) | 0.058 |
| Initiated quality-improvement (QI) project (n = 71) | 32 (45) | 17 (50) | 2 (17) | 9 (56) | 4 (44) | 0.172 |
| Participated in research study or QI project (n = 73) | 41 (56) | 18 (51) | 6 (50) | 11 (65) | 6 (67) | 0.717 |
| Submitted study to IRB for ethical review (n = 67) | 21 (31) | 7 (21) | 5 (45) | 2 (13) | 7 (88) | 0.001 |
| Submitted abstract to a regional, national, or international meeting (n = 73) | 26 (36) | 7 (20) | 7 (58) | 5 (29) | 7 (78) | 0.003 |
| Submitted manuscript for publication in a peer-reviewed journal (n = 72) | 18 (25) | 5 (14) | 5 (42) | 1 (6) | 7 (78) | < 0.001 |
| Mentored a resident or fellow on a research project (n = 26) | 12 (46) | NA | NA | 6 (35) | 6 (67) | 0.218 |

[a] p values were calculated using Fisher exact test.
IRB = institutional review board; NA = not applicable.

we estimated proportions for categorical variables, and medians and interquartile ranges for ordinal measures. We created a summary measure of overall self-reported research skills by averaging responses to individual questions on specific research skills (Cronbach $\alpha = 0.96$). We tested for differences in research-related skills, experience, barriers, motivators, and interests across the 4 groups using the Fisher exact test and Kruskal-Wallis test. P values less than 0.05 were considered statistically significant.

## RESULTS

Three individuals sent surveys were ineligible because of termination of a GME affiliation or medical leave. Eighty-five individuals responded to the survey; 50 participants responded to the e-mail survey, and 35 completed a paper copy. We excluded 10 participants who initiated a survey but left three-fourths of the questions blank and 2 participants who did not provide data on their program or role (trainee or faculty). The analytic sample comprised 73 participants, including 47 trainees and 26 faculty. The response rate for both the trainee and faculty samples was 30%, 47 of 159 trainees and 26 of 88 faculty. There were no significant differences between faculty and trainees in the sample and those in the pool of eligible participants by program affiliation (primary care vs specialty), site (LAMC vs other sites), or sex (men vs women).

Participants' program affiliations included the following: Family Medicine (n = 34), Internal Medicine (n = 7), Pediatrics (n = 5), Geriatrics (n = 5), Urology (n = 6), Orthopedics/Sports Medicine (n = 6), Emergency Medicine (n = 2), Obstetrics/Gynecology (n = 2), Gastroenterology (n = 1), Nephrology (n = 1), Neurology (n = 1), Hospice/Palliative Medicine (n = 1), and Diagnostic Radiology (n = 1). Program information was missing from 1 participant.[a] Thirty-five (74%) trainees and 17 (65%) faculty were affiliated with a primary care program (Table 1). Among trainees, 24 (51%) were based at LAMC compared with 10 (38%) of faculty. Twenty-one (45%) trainees were men compared with 19 (73%) faculty.

### Research Experience and Skills

Levels of research experience varied by role and program (Table 2). Among primary care faculty, 12 (71%) reported "little or no" research experience compared with 1 (11%) specialty faculty, 14 (41%) primary care trainees, and 1 (8%) specialty trainee ($p < 0.001$). Six (35%) primary care faculty and 6 (67%) specialty faculty reported mentoring a trainee's research in the previous year. Among specialty faculty who had mentored trainee research in the previous year, 4 (67%) reported "substantial" research experience and 2 (33%) reported "some" research experience. Among primary care faculty who had mentored trainee research in the previous year, 1 (17%) reported "substantial" research experience, 4 (67%) reported "some" research experience, and 1 (17%) reported "little or no" research experience.

When asked to report research activities undertaken in the previous year, the percentage who initiated a research study or a quality-improvement (QI) project and who participated in someone else's research or QI project did not differ by role or program. However, there were differences in the percentage who submitted research to the institutional review board ($p = 0.001$), an abstract to a conference ($p = 0.003$), and a manuscript to a peer-reviewed journal ($p < 0.001$). Primary care faculty and trainees had the lowest percentages for completing these activities.

When survey participants were asked to evaluate their individual research skills on a scale from 1 to 10 (with 10 being the highest skill), ratings differed across groups for all skills except data collection (Table 3). Median scores for overall self-reported

**Table 3. Medians and interquartile ranges for individual-level research skills among survey participants, by role and program[a]**

| | | | Trainees, median (IQR) | | Faculty, median (IQR) | | |
|---|---|---|---|---|---|---|---|
| Research skill | No. | Total, median (IQR) | Primary care | Specialty | Primary care | Specialty | p value[b] |
| Finding relevant literature | 72 | 8 (7-9) | 8 (7-9) | 7 (7-8) | 7 (5-8) | 9 (8-10) | 0.015 |
| Critically reviewing literature | 72 | 7 (6-8) | 7 (7-8) | 7 (6-8) | 5 (3-7) | 10 (7-10) | < 0.001 |
| Using a computer referencing system (eg, EndNote) | 65 | 6 (2-8) | 6 (2-8) | 6 (3-7) | 2 (1-6) | 7 (6-10) | 0.015 |
| Writing a research report | 70 | 5 (3-8) | 5 (3-7) | 7 (5-8) | 3 (1-4) | 9 (6-10) | < 0.001 |
| Writing for publication in peer-reviewed journals | 68 | 5 (3-7) | 4 (2-7) | 7 (7-8) | 3 (1-4) | 9 (7-10) | < 0.001 |
| Designing questionnaires | 65 | 5 (2-8) | 6 (2-8) | 5 (4-7) | 3 (1-7) | 8.5 (7-10) | 0.004 |
| Submitting research to IRB | 67 | 5 (2-7) | 3 (2-5) | 6.5 (4.5-7.5) | 1 (1-5) | 8 (8-9) | < 0.001 |
| Analyzing quantitative data | 72 | 5 (2-7) | 5.5 (2-8) | 7 (5-7.5) | 3 (1-5) | 6 (4-8) | 0.038 |
| Collecting data (eg, surveys, interviews) | 68 | 5 (2.5-8) | 5.5 (2.5-8.5) | 7 (5-8) | 3 (1-7) | 7 (5-8.5) | 0.079 |
| Analyzing qualitative data | 61 | 4 (2-7) | 5 (2-8) | 5 (5-7) | 1 (1-2) | 4 (1-8) | < 0.001 |
| Providing advice to less experienced researchers | 69 | 4 (2-7) | 4 (1-7) | 5.5 (4.5-7) | 3 (1-3) | 6 (5-7) | 0.001 |
| Writing a research protocol | 68 | 3.5 (2-7) | 3 (2-6) | 5 (4-8) | 2 (1-3) | 7 (6-9) | < 0.001 |
| Using computer data management systems | 66 | 3 (1-8) | 4.5 (1.5-8) | 6.5 (5-8) | 1 (1-2) | 5.5 (2-7) | 0.002 |
| Securing research funding | 65 | 3 (1-5) | 3 (1-5) | 5 (4-7) | 1 (1-2) | 5 (2-7) | 0.001 |
| Overall self-reported research skills | 73 | 5.6 (3.6-7.0) | 5.7 (3.6-7.4) | 6.7 (5.1-7.3) | 3.6 (2.1-5.0) | 7.4 (6.1-8.4) | < 0.001 |

[a] Items were measured on a 10-point scale from 1 = no skill/success to 10 = high skill/success. Participants who selected "unsure" were excluded from the denominator.

[b] p values were calculated using the Kruskal-Wallis test.

IQR = interquartile range; IRB = institutional review board.

research skills also varied across groups: 3.6 among primary care faculty, 7.4 among specialty faculty, 5.7 among primary care trainees, and 6.7 among specialty trainees ($p < 0.001$). Median scores for overall self-reported research skills also differed across research experience groups; among participants with “little or no” research experience, the median score was 3.3 compared with 6.0 for those who had “some” research experience, and 7.2 for those who had “substantial” research experience ($p < 0.001$).

### Research Barriers and Motivators

More than one-fifth of faculty and trainees identified the following factors among the top 3 barriers to research (Table 4): no dedicated time, 46 (63%); other work roles take priority, 33 (45%); desire for work-life balance, 18 (25%); not interested, 17 (23%); and lack of skills, 17 (23%). Of these, other work roles taking priority ($p = 0.012$), and a desire for work-life balance ($p = 0.026$) differed significantly across groups. Other barriers to research that differed across groups included lack of managerial support ($p = 0.002$), limited access to research equipment ($p = 0.032$), lack of administrative support ($p = 0.003$), and lack of funding ($p = 0.008$).

Factors identified by more than one-fifth of faculty and trainees as 1 of the top 3 motivators for research included the following: improving clinical practice, 29 (40%); a problem that needs changing, 27 (37%); developing skills, 23 (32%); improving critical thinking skills, 19 (26%); career advancement, 18 (25%);

**Table 4. Percentage of survey participants listing specific barriers as top-three barriers to research, by role and program**

| | | Trainees | | Faculty | | |
|---|---|---|---|---|---|---|
| Barrier to research | Total, no. (%) | Primary care, no. (%) | Specialty, no. (%) | Primary care, no. (%) | Specialty, no. (%) | p value[a] |
| No dedicated time | 46 (63) | 20 (57) | 7 (58) | 11 (65) | 8 (89) | 0.383 |
| Other work roles take priority | 33 (45) | 17 (49) | 8 (67) | 8 (47) | 0 (0) | 0.012 |
| Desire for work-life balance | 18 (25) | 14 (40) | 1 (8) | 3 (18) | 0 (0) | 0.026 |
| Not interested in research | 17 (23) | 11 (31) | 3 (25) | 3 (18) | 0 (0) | 0.236 |
| Lack of skills for research | 17 (23) | 10 (29) | 2 (17) | 5 (29) | 0 (0) | 0.291 |
| Lack of support from management | 12 (16) | 3 (9) | 1 (8) | 2 (12) | 6 (67) | 0.002 |
| Lack of a coordinated approach to research | 11 (15) | 7 (20) | 0 (0) | 3 (18) | 1 (11) | 0.427 |
| Lack of access to equipment for research | 9 (12) | 1 (3) | 2 (17) | 3 (18) | 3 (33) | 0.032 |
| Lack of administrative support | 9 (12) | 2 (6) | 1 (8) | 1 (6) | 5 (56) | 0.003 |
| Lack of suitable backfill | 8 (11) | 3 (9) | 3 (25) | 1 (6) | 1 (11) | 0.386 |
| Other personal commitments | 8 (11) | 5 (14) | 1 (8) | 1 (6) | 1 (11) | 0.943 |
| Lack of funds for research | 7 (10) | 2 (6) | 1 (8) | 0 (0) | 4 (44) | 0.008 |
| Other[b] | 26 (36) | 12 (34) | 4 (33) | 7 (41) | 3 (33) | 0.966 |

[a] p values were calculated using Fisher exact test.
[b] All “other” barriers were barriers selected by fewer than 10% of survey participants.

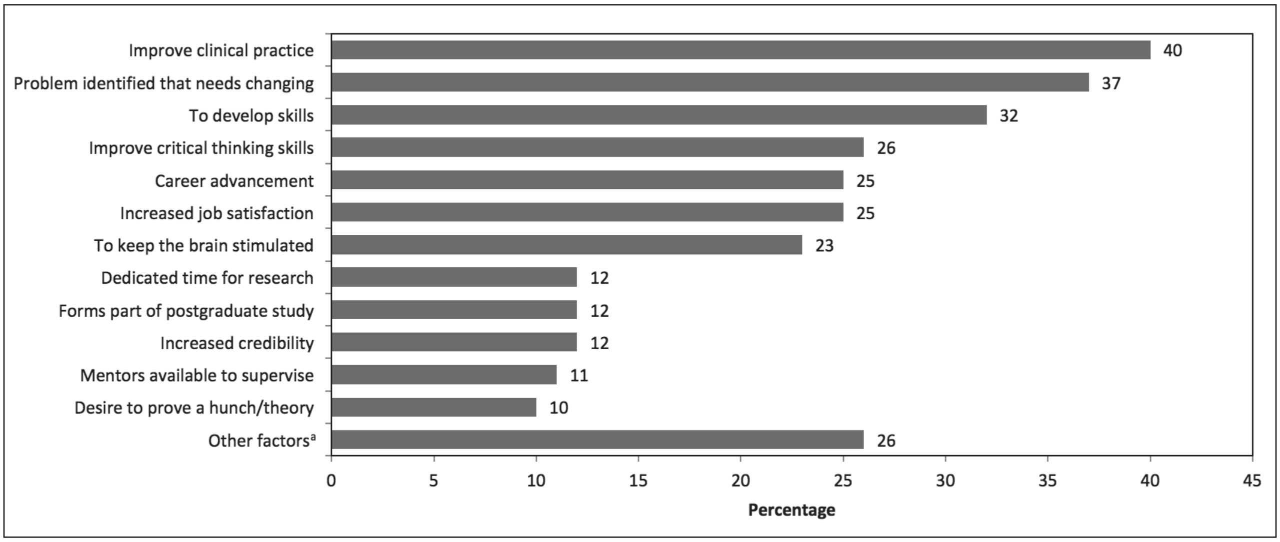

Figure 1. Specific factors selected as one of the top three motivators for research among faculty and trainees, N = 73.

[a] All “other factors” motivators were selected by fewer than 10% of participants.

job satisfaction, 18 (25%); and keeping the brain stimulated, 17 (23%; Figure 1). The only motivator that differed across groups was developing skills (not shown): primary care trainees, 12 (34%); specialty trainees, 8 (67%); primary care faculty, 3 (18%); and specialty faculty, 0 (0%); (p = 0.005).

### Research Skills Development Interests

When asked to rate their interests in developing specific research skills, more than two-thirds of faculty and trainees reported being "somewhat" or "very" interested in developing skills in the following areas: applying research findings to clinical practice, 59 (81%); finding relevant literature, 58 (79%); generating research ideas, 56 (77%); conducting a study using electronic medical record data, 55 (75%); educating and/or communicating research findings to patients, 54 (74%); analyzing and interpreting results, 53 (73%); critically reviewing literature, 51 (71%); publishing on a QI project, 50 (68%); and writing a case report or case series, 48 (67%; Figure 2).

Level of interest in developing specific research skills did not differ across groups except for using quantitative research methods (not shown): primary care trainees, 17 (49%); specialty trainees, 11 (92%); primary care faculty, 11 (65%); and specialty faculty, 7 (78%); (p = 0.039). Among primary care faculty, 8 (47%) reported being "somewhat" or "very" interested in developing research mentorship skills; this was 5 (56%) among specialty faculty. Faculty interest in developing research mentorship skills varied by level of research experience. Among faculty with "little or no" research experience, 3 (23%) expressed interest in developing research mentorship skills compared with 5 (71%) faculty with "some" research experience and 5 (83%) faculty with "substantial" research experience (p = 0.033). Among faculty who had mentored trainee research in the previous year, 10 (83%) expressed interest in developing their research mentorship skills, and interest was high, even among faculty reporting "substantial" (4 [80%]), or "some" (5 [83%]) research experience themselves.

## DISCUSSION

To meet ACGME requirements for scholarly activity, GME institutions must develop appropriate curricula and infrastructure to support scholarly work. Large institutions with training programs in multiple specialties face challenges when research-related training needs vary across groups, making it necessary to develop targeted programming; however, few previous studies have examined differences in research-related needs across specialties or roles (faculty vs trainees). To better understand these, we tested for differences in research-related experiences, skills, and interests among four groups: primary care trainees, specialty trainees, primary care faculty, and specialty faculty. We found significant differences in the amount and types of experience, skill levels, and several perceived barriers to conducting research. However, there were few differences across groups in factors motivating research involvement or specific research skills that participants were interested in developing.

Overall, primary care groups reported having less research experience and fewer research skills than did specialty groups, with the lowest levels among primary care faculty. This finding is consistent with those of previous studies,[3,14,19] highlighting the challenge primary care programs face to meet ACGME scholarly activity requirements and to provide adequate research mentorship.[1,3] For primary care-rich institutions like ours, these results suggest that an efficient GME research program focuses on building research capacity in primary care programs. A long-term goal

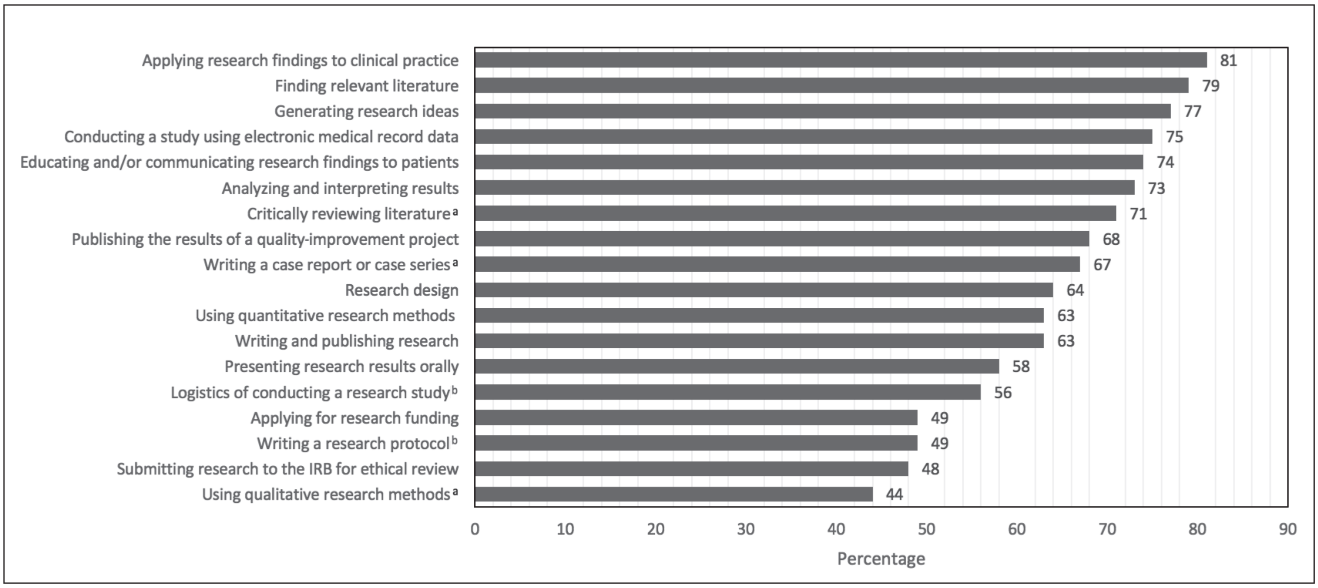

Figure 2. Percentage of faculty and trainees who reported being "very" or "somewhat" interested in developing specific research skills, N = 73.

[a] n = 71.

[b] n = 72.

IRB = institutional review board.

for programs similar to ours could be to develop primary care faculty "research champions." Others have recognized the essential role that faculty and program directors play as role models and mentors for research.[3,20,21] The current shortage of primary care faculty with research experience and skills limits faculty members' own research productivity and results in faculty mentors for trainee research who lack relevant knowledge and skills. This situation may contribute to unsuccessful or incomplete projects and dissatisfaction with the research experience for both trainees and faculty.

> **… faculty members' interest in developing research mentorship skills was associated with their own research experience.**

A noteworthy finding is that faculty members' interest in developing research mentorship skills was associated with their own research experience. Faculty with at least some research experience had higher interest in developing research mentorship skills than did those with little or no experience. A fruitful path forward may be to expose primary care faculty to research experience, which may result in increasing their own research skills and increasing their interest in mentoring trainee research.

The top reported barriers to conducting research reflected individual factors such as lack of time, skills, and interest, as well as institutional factors, including lack of managerial support and equipment. Previous studies have reported similar barriers,[1,4,11] supporting a multilevel approach to building research capacity addressing both individual and organizational factors.[5] Our results indicated differences across groups for several barriers, suggesting that effective programs should incorporate strategies to mitigate barriers for particular groups. Other than the top barrier of no dedicated time, specialty faculty did not select any of the next four most frequently cited barriers, all of which represent individual factors. Institutional barriers appear to be more salient for specialty faculty.

The most frequently cited motivators for research were improving clinical practice and solving an existing problem. Other motivators included developing skills, improving critical thinking, and career advancement. These findings are consistent with those of previous studies.[11,14] Research programs might motivate research participation by framing research as relevant to clinical practice and acknowledging intrinsic rewards such as personal and professional development.

When participants were asked to rate their level of interest in specific research skills, many of the skills rated of highest interest related to practicing evidence-based medicine. This supports incorporating evidence-based medicine topics in a research fundamentals curriculum. We identified few differences in the skills of interest across groups, suggesting the feasibility of using an institutionwide core curriculum for research. Additionally, a high percentage of faculty who mentored trainees on research were interested in developing their research mentorship skills, and this included faculty who had research experience themselves. This finding highlights the fact that skills needed to mentor research are different from those needed to conduct research. Faculty development on research mentorship skills would be valuable.

Our study has several limitations. Because the study was designed for program evaluation and not to test for group differences in outcomes, we had small sample sizes in each comparison group. Our results should be considered exploratory and must be validated in a larger study designed specifically to investigate group differences. Additionally, the response rate was low at 30%, although comparable with other surveys of physicians.[22] Participants may have also underreported or overreported their research experience and skills. Finally, we grouped participants into broad categories of primary care or specialty and trainee or faculty, and differences may exist in each of these categories.

## CONCLUSION

Institutions of GME should address differences in research-related needs of targeted groups when designing curricula to support scholarly activity. Primary care faculty, primary care trainees, specialty faculty, and specialty trainees were found to differ in amount and types of research experience, research skill levels, and several perceived barriers to research. However, there were few differences across groups in factors motivating research involvement or in the specific research skills that participants were interested in developing. Primary care faculty consistently reported the lowest levels of research skills and experience. Targeted efforts to develop research capacity among primary care faculty are warranted. ❖

[a] Participant specified his/her role at a Medical Center with only primary care programs and could therefore be included in the analysis.

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**Disclosure Statement**

*The author(s) have no conflicts of interest to disclose.*

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**How to Cite this Article**

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**References**

1. Rothberg MB. Overcoming the obstacles to research during residency: What does it take? JAMA 2012 Dec 5;308(21):2191-2. DOI: https://doi.org/10.1001/jama.2012.14587.
2. Philibert I, Lieh-Lai M, Miller R, Potts JR 3rd, Brigham T, Nasca TJ. Scholarly activity in the next accreditation system: Moving from structure and process to outcomes. J Grad Med Educ 2013 Dec;5(4):714-7. DOI: https://doi.org/10.4300/jgme-05-04-43.
3. Seehusen DA, Weaver SP. Resident research in family medicine: Where are we now? Fam Med 2009 Oct;41(9):663-8.
4. Hebert RS, Levine RB, Smith CG, Wright SM. A systematic review of resident research curricula. Acad Med 2003 Jan;78(1):61-8. DOI: https://doi.org/10.1097/00001888-200301000-00012.
5. Cooke J. A framework to evaluate research capacity building in health care. BMC Fam Pract 2005 Oct 27;6:44. DOI: https://doi.org/10.1186/1471-2296-6-44.
6. Farmer E, Weston K. A conceptual model for capacity building in Australian primary health care research. Aust Fam Physician 2002 Dec;31(12):1139-42.

7. DeHaven MJ, Wilson GR, Murphree DD, Grundig JP. Family practice residency program directors' views on research. Fam Med 1997 Jan;29(1):33-7.
8. Temte JL, Hunter PH, Beasley JW. Factors associated with research interest and activity during family practice residency. Fam Med 1994 Feb;26(2):93-7.
9. Leahy N, Sheps J, Tracy CS, Nie JX, Moineddin R, Upshur RE. Family physicians' attitudes toward education in research skills during residency: Findings from a national mailed survey. Can Fam Physician 2008 Mar;54(3):413-4.
10. Ledford CJ, Seehusen DA, Villagran MM, Cafferty LA, Childress MA. Resident scholarship expectations and experiences: Sources of uncertainty as barriers to success. J Grad Med Educ 2013 Dec;5(4):564-9. DOI: https://doi.org/10.4300/jgme-d-12-00280.1.
11. Rivera JA, Levine RB, Wright SM. Completing a scholarly project during residency training. Perspectives of residents who have been successful. J Gen Intern Med 2005 Apr;20(4):366-9. DOI: https://doi.org/10.1111/j.1525-1497.2005.04157.x.
12. Neacy K, Stern SA, Kim HM, Dronen SC. Resident perception of academic skills training and impact on academic career choice. Acad Emerg Med 2000 Dec;7(12):1408-15. DOI: https://doi.org/10.1111/j.1553-2712.2000.tb00499.x.
13. Levine RB, Hebert RS, Wright SM. Resident research and scholarly activity in internal medicine residency training programs. J Gen Intern Med 2005 Feb;20(2):155-9. DOI: https://doi.org/10.1111/j.1525-1497.2005.40270.x.
14. Bakken S, Lantigua RA, Busacca LV, Bigger JT. Barriers, enablers, and incentives for research participation: A report from the Ambulatory Care Research Network (ACRN). J Am Board Fam Med 2009 Jul-Aug;22(4):436-45. DOI: https://doi.org/10.3122/jabfm.2009.04.090017.
15. Holden L, Pager S, Golenko X, Ware RS. Validation of the research capacity and culture (RCC) tool: Measuring RCC at individual, team and organisation levels. Aust J Prim Health 2012;18(1):62-7. DOI: https://doi.org/10.1071/py10081.
16. Howard AJ, Ferguson M, Wilkinson P, Campbell KL. Involvement in research activities and factors influencing research capacity among dietitians. J Hum Nutr Diet 2013 Jul;26 Suppl 1:180-7. DOI: https://doi.org/10.1111/jhn.12053.
17. Primary care workforce facts and stats no. 1. The number of practicing primary care physicians in the United States. AHRQ pub no. 12-P001-2-EF [Internet]. Rockville, MD: Agency for Healthcare Research and Quality; 2011 Oct [cited 2015 Nov 12]. Available from: www.ahrq.gov/sites/default/files/publications/files/pcwork1.pdf.
18. StataCorp. Stata statistical software: Release 14. College Station, TX: StataCorp LP; 2015.
19. Jones A, Burgess TA, Farmer EA, et al. Building research capacity. An exploratory model of GPs' training needs and barriers to research involvement. Aust Fam Physician 2003 Nov;32(11):957-60.
20. DeHaven MJ, Wilson GR, O'Connor-Kettlestrings P. Creating a research culture: What we can learn from residencies that are successful in research. Fam Med 1998 Jul-Aug;30(7):501-7.
21. Crawford P, Seehusen D. Scholarly activity in family medicine residency programs: A national survey. Fam Med 2011 May;43(5):311-7.
22. Grava-Gubins I, Scott S. Effects of various methodologic strategies: Survey response rates among Canadian physicians and physicians-in-training. Can Fam Physician 2008 Oct;54(10):1424-30.

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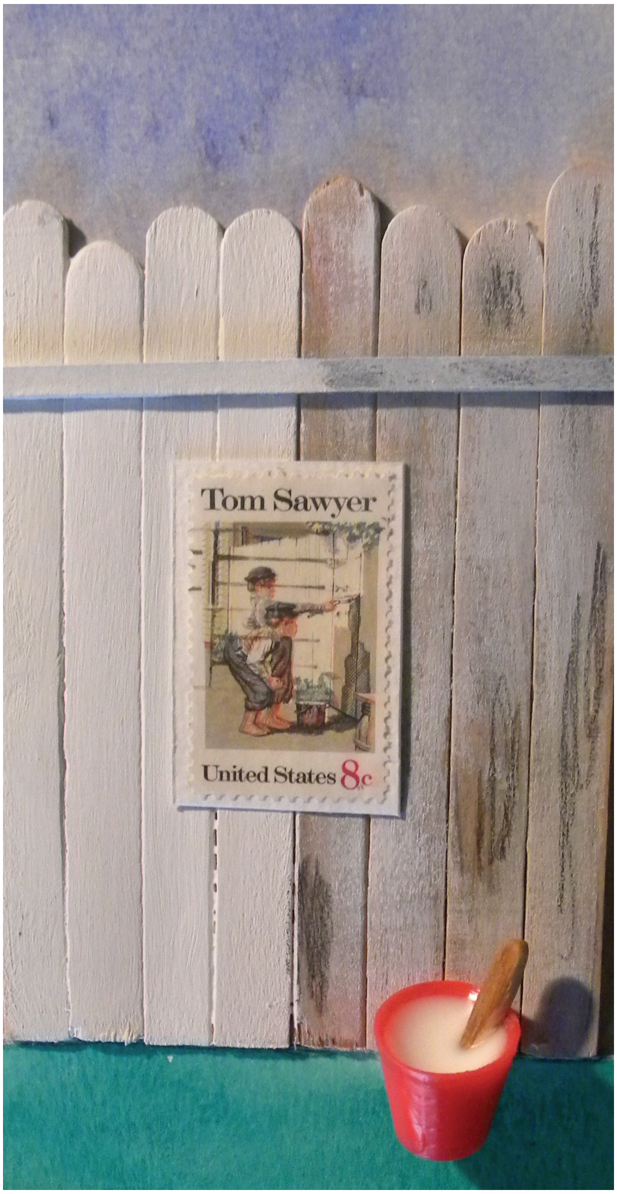
## The Germinating Seed

> University education becomes sterile the moment it is divorced from research … . The professor becomes older every year but his students remain eternally young, and the contact … is a great stimulus to him. It makes him look beyond the boundary of his generation, and he who in his research is working for the future, with and through his students, can help in shaping tomorrow's world … . When he follows them up in their professional life and sees the seed germinating, he feels a satisfaction equal to that of having procreated children.
>
> — Henry E Sigerist, MD, 1891-1957, Swiss medical historian



**Tom Sawyer Syndrome**
mixed media

**Phillip La Borie**

Tom Sawyer's adventure is so well known that the US Postal Service created a stamp in its honor. This original artwork was created with mixed media.

Phillip La Borie is an artist living in Murrells Inlet, SC.
More of his artwork can be seen in other issues of *The Permanente Journal*.

# The Evolution of the Medical School Deanship: From Patriarch to CEO to System Dean

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## ABSTRACT

Medical school deanship in the US has evolved during the past 200 years as the complexity of the US health care system has evolved. With the introduction of Medicare and Medicaid and the growth of the National Institutes of Health, the 19th-century and first half of the 20th-century role of the medical school dean as guild master transformed into that of resource allocator as faculty practice plans grew in scope and grew as an important source of medical school and university revenue. By 2000, the role of the medical school dean had transformed into that of CEO, with the dean having control over school mission and strategy, faculty practice plans, education, research dollars, and philanthropy. An alternative path to the Dean/CEO model has developed—the System Dean, who functions as a team player within a broader health system that determines the mission for the medical school and the related clinical enterprise. In this paper, the authors discuss the evolution of the medical school dean with respect to scope of authority and role within the health care system.

## INTRODUCTION

The role of the medical school dean has been an evolving one influenced by changing organizational culture, educational philosophy, and redirection of the health care system. Studies from various sources have confirmed the high expectations modern medical school deans face while performing a role that demands accountability to many stakeholders. This role occasionally features wide gaps between responsibility, authority, and resources available to complete assigned tasks.[1-3] This growing tension between responsibility and resources has arisen despite a century of progress in US medical education and unprecedented advances in innovative technology.[4] It is impossible to appreciate fully the nature and seriousness of the resource gap without the benefit of historical perspective.[2] Indeed, effective recruitment of medical school deans requires not only an understanding of this gap but an appreciation for the various management styles that these environs have produced. Different types of medical school organizations dictate which management style will best guide that environment. Although tempered by the unique culture of any given administrative structure, the role of new medical school deans should be viewed in the context of the evolution of medical school deanship in the past century.[5,6] The purpose of this work is to broaden that understanding and to guide recruitment efforts based on both historical and future leadership trends.

## A HISTORICAL PERSPECTIVE

Each medical school is a unique entity with its own history, traditions, and culture.[7] Research-oriented schools have strategies different from those of community-based institutions, often with competing priorities even within governing boards.[8] Schools founded to serve particular populations or demographic groups have had patterns of development different from those with more general charters.[8] Therefore, it might seem presumptuous to posit a general pattern for medical school leadership and administration. It is our intent to identify common developmental patterns in the evolution of medical school deanship that may be used as a model for future study and analysis of this pivotal role. The model we propose is a descriptive one, and all medical schools do not necessarily pass through any or all of these stages in their development.

It is our contention that the role of dean, which we trace from figurehead to autocrat to system CEO, is about to enter a new developmental phase. In this instance, we point to the announcement of a new medical school by Kaiser Permanente as evidence of an accelerating trend that has already been identified in earlier studies as that of the system dean.[9,10] In this configuration, the role and mission of the school are determined elsewhere by the sponsoring organization and transmitted to the school. In the instance of Kaiser Permanente, the preordained mission is to concentrate on primary care education and public health concerns. To a casual observer, it can be argued that this is no different from actions many state legislatures take on behalf of their constituents in establishing so-called community schools of medicine with similar foci and mission emphasis.

Weiner and colleagues[9] identified the subsidiary model as one combining "high clinical enterprise organization, high academic-clinical enterprise integration, and low academic authority over the clinical enterprise."[9] They further observe, "Yet the medical school faculty's clinical activity may constitute only a small portion of the organized delivery system's total clinical activity. As such, the financial interdependence between the academic and clinical enterprises is also asymmetrical."[9]

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They conclude that "The subsidiary model is most likely to be found among medical schools that have grown out of health care systems."[9]

In the case of the system school, we point to two prominent examples that presently exist. These are the Uniformed Services University of the Health Sciences and the Mayo Medical School. The Uniformed Services University is chartered by the federal government and is avowedly organized for the education of individuals who will practice in a uniformed service. As national rankings of US Service Academies demonstrate, there is no essential conflict between academic excellence and operation of the institution within the structure of the nation's military organization. The commandant or superintendent is a senior officer drawn from the ranks of military leadership and performs his or her responsibilities between the requirements of the sponsoring military branch on the one hand and the traditional perquisites of faculty governance on the other.

A somewhat more nuanced case is that of the Mayo Medical School, which is now also well established and nearing its 40th anniversary. Similar to the case of the Uniformed Services University of the Health Sciences, the Mayo Medical School derives its founding purpose and mission from the Mayo Clinic. In distinction from graduates of the Uniformed Services University of the Health Sciences, however, Mayo Medical School graduates are not expected to be employed at Mayo Clinic for their professional practice (although this is certainly not discouraged). Mayo Medical School has announced the opening of a new MD-granting campus in Scottsdale, AZ, in 2017, and the awarding of a cooperative degree in health systems in conjunction with Arizona State University (personal communication; Steven Rose, MD; 2016 Feb 29).[a]

The Mayo Medical School dean functions as part of a team of three leaders who collaborate in efforts to integrate education, research, and the practice of the clinic. These three leaders are members of the Mayo Medical School governing board chaired by the president of the Mayo Foundation. The annual budget of the school is set "within the system," although it is proposed and managed by the dean.

A new hybrid organization is emerging in which the clinical enterprise of the medical school (hospital and faculty practice plan) is consolidated with a community-based partner. A prominent recent example is that of Southwestern Health Resources, recently approved by the University of Texas Board of Regents. This system includes 27 hospitals and 3000 physicians drawn from the University of Texas Southwestern health sciences organization and the community faith-based nonprofit health system operator Texas Health Resources. The recently announced officers of the new delivery system do not include the dean of the medical school at University of Texas Southwestern, who is described as the chief academic officer of the school.[11] It is likely that affiliations of this sort will increase as organizational consolidation in the health care delivery system continues to intensify.

Examples of such integration of professional schools into delivery systems can be identified in other professions. A particular example is engineering and the establishment of the General Motors (GM) Institute. GM acquired the institute in 1926 to meet its needs for professionals specifically trained in engineering disciplines. A "co-op" model of education was introduced that required the trainee to align with a GM division for 6 to 12 weeks of practical instruction, an approach comparable with third- and fourth-year clerkships in medical school. In 1982, GM and the institute separated as GM reduced operations in Flint, MI, and the institute gradually evolved into Kettering University, as it is known today.

The evolution of the deanship of the medical school will be examined to assess how the emerging model of system dean contrasts with the other prominent contemporary model in health systems that has evolved from teaching hospitals and medical schools. This is the dean (chief academic officer) as CEO of an educational/health delivery system in which the faculty are at once both educators and direct care practitioners, and the institutional resources of the system exist to support the educational mission rather than the opposite. This model is in turn giving way to an emerging model of the system dean in which the dean functions within the mission and vision of a larger health care delivery organization.

## The Medical Guild Master (and Figurehead)

Early medical school deans coming into the 19th and 20th centuries followed a leadership tradition that stretched back at least to the Middle Ages.[12] Organized medicine in the New World arose from the European guild system, primarily concentrated among surgical practices, that provided a method of apprenticeship that formed the basis of the medical residency system used today.[13] The apprenticeship model emphasized personal relationships between student and solo practitioner as the substrate for teaching and learning, with little consideration for the complexity that would evolve as the industry of medicine progressed.

In America, the apprenticeship remained the most common mode of medical learning well into the 19th century in both university-based and proprietary medical schools.[14] In 1910, Flexner questioned the quality of medical education in the US. He suggested that medical schools include basic science departments, laboratories, and wards for student training. As the Flexnerian model of medical education rose to the level of a standard early in the 20th century, medical school deans had to foster relationships between teachers, scientists, and students.[15] It should be noted that Flexner's work described current trends in medical education but paid little attention to the management styles present at US medical schools at the time.

In the early 1900s, at the time of Flexner, the dean served as the medical master of apprentices and functioned largely as a patriarch. This dean-figurehead style assured a remarkable degree of stability and served as a source of power for the dean as the ultimate overseer of the "guild." This leadership model seemed common in an environment in which medical schools were small with few faculty, small budgets, and few students, allowing the dean ultimate control as in the case of a guild master.[9,15] The dean did not have to function as an organization manager on a daily basis but was able to balance simple administrative duties with an active teaching and clinical practice. The dean's visibility and assertiveness, and ability to teach, were crucial in gaining respect and trust from the faculty.[16] Such dean-figureheads were by definition quite authoritative.[17-20] In this model there was relatively little gap between responsibility and authority because such deans enjoyed all the power that guild masters had traditionally exercised. Application of the dean-figurehead model in a modern setting, where resources are limited and the dean's role in acquiring resources plays such an important role in decanal management success, would likely not work.[21] The model may be applicable only for the very rare institution in which resources are already plentiful.

The relatively small scale of medical school operations in the first half of the 20th century allowed the dean to function effectively with minimal support staff and without associate deans. Because the institution could not readily sustain any failure of the figurehead, the dean-figurehead had job security based in part on fear of institutional collapse in the event of a departure.[1] However, figurehead deans could not completely withdraw behind the bounds of their own institutions. These deans did have to occasionally negotiate with university presidents, state legislatures, and state medical societies. They were also sometimes called upon to mediate faculty disputes and help resolve interpersonal conflicts.[19,20] The dean-figurehead model often exposed many leadership deficiencies because the dean was the only recognized institutional leader. However, the figurehead model survived for several centuries in Europe and migrated to the New World, even outlasting the guild master trend seen in other trades. [22]

## Model Transition

The management style of figurehead dean could not survive the great shifts that occurred in the American educational system following World War II. As knowledge exploded and public interest in scientific research burgeoned, outside forces began to expand the dean's foothold in medical education. The new environment called for integration of medical schools with their home universities to a degree never before anticipated. This was further complicated as better integration was sought between universities, medical schools, and their major clinical enterprise.[9] As federal money entered the American medical industry in the form of research dollars as well as clinical dollars through Medicare and Medicaid, the demands of federal and state authorities also began to stiffen. Along with these influences came the various local, state, and federal guidelines and compliance mandates governing medical education and faculty relationships within both the medical school and the larger university.

This naturally changed the nature of the leader required.[9] Dean-figureheads with their narrow skill set and scope of responsibilities could not hope to maintain their personal, independent styles and attitudes in an era when accountability to outside stakeholders became an integral part of the job description.[9] The dean-spokesperson, typical of that transitional era following World War II, had to be willing to exercise leadership and management on a level beyond that of the medical school itself. Development of a leadership team was typical of medical schools in the US when the dean-spokesperson model was most common. Associate deans emerged for fiscal management, academic affairs, student services, and the like around this time to scrutinize resource allocation and distribute workflow. The introduction of this managerial layer deflected some actual responsibility from the dean and allowed a buffer from possible negative consequence.[21] Regardless, the administrative workload had expanded beyond the capacity of any one person irrespective of how skilled they were as a manager. One result of this change was that the dean-spokesperson could not exercise autocratic, sometimes impulsive or overly instinctive, and very personalized decision-making processes characteristic of the figurehead. The associate dean model, in many ways, facilitated a more scrutinized management of the dean's role itself. Medical schools were simply becoming too large, too complicated, and accountable to too many other entities, such as university presidents and governing boards. Obviously, institutions of this type, with multiple layers of current associate deans, would have to consider the varied management styles of the associate deans before the selection of a new dean.

Historically, the age of faculty committees, university senates, and layered hierarchies had dawned with expanding medical school faculty numbers. At this time, in addition to managing the faculty and academic missions, medical school deans faced pressures to embrace corporate capitalism by responding aggressively to the revenue opportunities that became available, not the least being the growth in the budget of the National Institutes of Health. The incredible impact of substantial and readily obtained National Institutes of Health grants arrived, and the development of faculty practice plans to manage revenue soon followed.[23] Clinical revenue was augmented by a variety of factors, including medical school-hospital relationships, particularly after the enactment of Medicare and Medicaid in 1965.[24] This more complex organization could lead to internal conflict among groups that had not been a consideration for earlier deans because internal power blocks might change at a pace different from that proposed by the dean. Thus, the dean-spokesperson had a new job description as fiscal manager and clearly needed a new skill set to function effectively in this emerging management role.

Yet, in all of this, certain requirements of the figurehead model did not vanish. There was still the expectation of a significant level of personal and visible leadership from the dean—it took on a paternalistic style because most deans of that era were men. Layers of associate deans created during this transitional period served to assist the dean and augment his ability to reach out to faculty, students, and alumni but could not substitute for him, especially in symbolic roles.[9] In an age of institutional expansion and bureaucratization, interpersonal skills became even more important because there was no substitute for building effective relationships through communication and trust. This applied both to internal constituencies (faculty, chairs, students, etc) and to the external partners, such as hospital directors, who were necessary if the medical school were to be effective. In dealing with internal leaders, particularly department chairs, the spokesman had to be perceived as the leader among leaders.[9,25] He also had to deal with the proliferation of cultures and "fiefdoms" that evolved their own governance mechanisms as departments and chairs became powerful through their own extramural funding.[14,23]

Throughout the 1970s and 1980s, the dean acquired other roles, including those of negotiator and resource allocator, especially as institutions became more complex and budgets became larger.[9] Lessons learned at many medical schools in the 1960s and 1970s made it clear that deans with high accountability but a widening responsibility/authority gap often exposed their lack of authority or alternatively became expendable when departments became stronger and garnered their own financial resources. Thus, schools that had alliance or coalition-type organizational models were more apt to benefit from the type of management style in which the dean facilitated but did not command resource acquisition and allocation.[9,21] It should not be surprising in retrospect that increased dean turnover accompanied this paradigm shift and resulted in a decline in decanal tenure from 6.7 years (1940-1959) to 3.5 years (1980-1992), a pattern that persisted through the 2000s.[1,18,26,27]

**Table 1. Ancillary titles of US medical school deans as listed by the Association of American Medical Colleges Council of Deans, 2000 and 2012[a]**

| Title | 2000 | 2012 |
|---|---|---|
| Vice president[b] | 48 (40%) | 46 (33%) |
| Vice chancellor[c] | 10 (8%) | 15 (11%) |
| Provost | 7 (6%) | 8 (6%) |
| President | 2 (2%) | 5 (4%) |
| Chancellor | 3 (3%) | 2 (1%) |
| CEO[d] | 2 (2%) | 14 (10%) |

[a] Some deans have multiple titles.
[b] Vice president includes senior vice president or executive vice president.
[c] Vice chancellor includes senior vice chancellor or executive vice chancellor.
[d] CEO includes chief medical officer or chief academic officer.

## Dean-CEOs and Dean-Presidents

The demands of the market in terms of research funding, resource dependency, and clinical competition began to dramatically affect the workload of the medical school dean in the mid-1980s.[27] A new skill set was needed for the modern era as the workload and accountability became more and more demanding and extraordinary. Deans of this era needed to combine skills in fiscal and human resource management with communication skills to be effective executives. Because of rapid changes in the health care market, being a change agent became a core element in the medical dean's job description. The 21st-century dean as CEO needed to be concerned with leading change while still being held accountable for accomplishing a variety of functions beyond traditional academic leadership, including leadership of the clinical enterprise of hospitals, managing professional practices, and in some instances negotiating with insurers.

The additional skill sets required by modern deans can be best seen in the current trend found in many institutions in which the roles and titles of the dean are combined with those of health sciences chancellor, vice president, or vice chancellor (Table 1). With this change in structure, the dean's style of leadership becomes more nuanced depending on whether the clinical enterprise related to the school is more or less financially dominant. Obviously, those schools with higher integration of clinical practice and school authority structure require deans to have better overall control and actual decision-making power over financial allocations. Despite a single individual holding several roles, the positions often exist apart from or even in competition with each other.[1,27] This trend developed in the 1970s and has intensified during the succeeding decades (Table 2). In assessing current medical school environments, the dean usually remains the senior leader for students and educational affairs. Super-executive titles imply greater responsibility and create an overall empowering effect.

The recent emergence of the dean-president role (Table 2) empowers deans as agents of change. The dean-president role has accompanied the organizational transformations of some academic medical centers in the US, such as that observed at the University of Pennsylvania,[24] where the "single ownership" of a fully integrated academic-clinical enterprise model including hospital, practice, and school lends itself well to a dean with a corporate leadership and management style with great authority and scope.[8,9] According to that model, the "chief executive's role, directly or indirectly, contains that of the traditional dean or vice president, including responsibility for the academic mission and the business operations of the integrated delivery system."[8] Although the leader of such mega-organizations could be referred

**Table 2. Evolution of the American medical school deanship, pre-1945 to present**

| Role | Era[a] | Characteristics |
|---|---|---|
| Dean-figurehead | Until 1945 | Personal leadership with restricted demands |
| Dean-spokesman | 1945-1965 | Institutional leadership with a broader scope and with increasing demands and resources |
| Dean CEO negotiator | 1965-1985 | Leadership of decentralized institutions with increasing demands, variable resources, and decreasing authority focusing on processes and procedures |
| Dean resource-allocator | 1985-2005 | Leadership of institutions in transition with increasing internal management demands, decreasing resources, and decreasing authority focusing on aligning teams for creativity through constructive change |
| Dean-president CEO[b] | 2005-present | Leadership with recentralized authority in heavily centralized institutions and with greatly increasing demands and decreasing resources focusing on efficient use of human resources and rationalized authority structures. |
| System dean | 2015-present | Liaison role dominates in managing relationships within the medical school as well as with the broader health system; dean is chief academic officer but reliant on system leadership for budgetary and mission final decisions |

[a] Dates of categorization based on authors' interpretation of historical trends.
[b] Dean-president refers to a role that emerged prominently near the end of the 20th century in which leaders serve as CEO of the entire academic medical center that includes the medical school, principal teaching hospital, and faculty practice plan. The designation "president" is derived from the enterprisewide, highly authoritarian nature of the role.

to as simply CEO, the term "president" is often used, conveying the strong empowerment and comprehensive scope of power more precisely. The dean-president resembles the dean guild master with regard to responsibility and power but requires the additional accountability of a super-executive. Although the resource base of the new model is strikingly different from that of the 1800s, it could be argued that during a century of evolution of US medical schools, deanship has to date essentially produced an empowerment structure very much like its original design.

## THE DEAN OF THE FUTURE: THE SYSTEM DEAN

The model of the dean as CEO is presently in fashion while academic health systems centralize operations of a wide array of clinical facilities and providers under a single governance structure united by the academic mission of the organization. This parallels the increasing consolidation of community and faculty providers into hierarchical organizations assisted by employed and network physician groups, such as that seen at the Memorial Hermann Health System, headquartered in Houston, TX. In this instance, the Memorial Hermann Health System network includes 2000 physicians in the network organization and 200 employed physicians.[28] By contrast, Aurora Health Care, headquartered in Milwaukee, WI, has 1730 physicians in its employed group and 1335 physicians in its network of independent physicians.[29]

In the example of the Banner Health system in Arizona, this trend has led to Banner Health acquiring the University of Arizona Health Network (UAHN). Kutscher describes this acquisition when she writes that "Banner executives describe the takeover as part of its mission to be a good steward of medical education in the state. UAHN was struggling, and Banner had the resources to help. But Banner can now impose its particular stamp on UAHN, which operates the state's only two medical schools, and transform physician education."[30]

As these clinical juggernauts continue to form, the model of practice has moved from solo and small group practice to large groups or institutional practice employed models. Fully one-third of graduates of specific medical schools now start their postresidency careers within a specific dominant health system. The needs of these systems for practitioners, versed in primary care and population health, will inevitably affect the educational offerings of the medical school irrespective of the organizational location of the school.

In the system model, the dean is a member of a broader leadership team rather than a quasi-autonomous CEO. The dean is no longer the final arbiter of the mission and vision of the medical school enterprise, including its clinical relationships (hospital and practice plan). Rather, the dean is a negotiator with a broader health system that will heavily influence or make the final determination of priorities for the school. Consequently, this would necessarily broaden the skill set of the effective dean to include graduate degrees in business, health care administration, public health, or other related fields dependent on the direction in which the school's mission is trending at the time of hire. Budgetary control may also be lodged outside the school in the health system, with the dean preparing a budget and receiving approval and authorization for expenditures and recruitment decisions from the sponsoring health delivery system. In this sense, this model is quite in contrast to the dean as CEO. In the Banner-University Medicine model, the academic relationship is managed by a newly created academic management council with equal representation from Banner Health and the UAHN.[30]

Modern medical education has moved toward team-based care with the physician as a central, but no longer always dominant, actor in the team. The system dean faces new challenges in preserving Flexnerian versions of medical education because of the potential dominance of the clinical practice mission and its importance in funding the entire enterprise. Thus, this new kind of leader must be a respected member of the team, a passionate advocator, and an excellent negotiator. As Ofri[31] has suggested in reviewing the Institute of Medicine's 2015 report Improving Diagnosis in Health Care, "Bravo to the Institute of Medicine for recognizing that diagnosis is often a team sport, and that time spent analyzing a case is as critically important as tests and procedures."[31] Mitchell, et al[32] have identified core principles and values of effective team-based health care in their 2012 report for the National Academy of Sciences.[32] In becoming a part of a larger team effort, the dean is being called upon to model the behavior expected of a future generation of physicians now in training.

**… problems require a unique type of leader—the system leader, a person who catalyzes collective leadership.**
**… influencing the team rather than "directing" them to change.**

Senge and colleagues[33] have written that the "deep changes necessary to accelerate progress against society's most intractable problems require a unique type of leader—the system leader, a person who catalyzes collective leadership." In the traditional medical education structures reviewed in this paper, the dean has been the dominant figure in the organization—initially academically, and subsequently in delivery system leadership. As such, it is essential that the dean be a change agent to meet the needs of a changing health care landscape. Furthermore, in the evolving role of the system dean, a more collaborative outlook and corresponding set of skills are required because the dean is a member of an ensemble cast and not necessarily the lead actor. This individual must have the ego strength, patience with tenacity, negotiating ability, and ability to achieve satisfaction if not gratification from influencing the team rather than "directing" them to change. We suggest that, although early in the next stage of the evolution of the deanship, the system dean will become the dominant model of the future as organizations such as Kaiser Permanente adopt more prominent positions and investments in direct medical education.

## FUTURE TRENDS AND PREDICTIONS

Taking the lessons of history into account, certain predictions can be made for the future of academic medicine dependent on the nature of the school itself. It is important for governing boards and search committees to understand that the culture of the individual school will determine the candidate type in palpable ways. Schools must first identify what kind of dean types they have had in the past and whether that is what they want in the future. Timing will also play a role in this process because schools naturally go through periods in which a figurehead dean is more attractive to the governing board than a CEO or any other combination. Should there be a major shift either at the board or at the university president level, that type of affinity could easily and suddenly change, as it often does. Given those obvious influences, there are certain trends for the future that can be based on the past.

First, the expectation that the dean must be "all things to all people" is likely to continue regardless of institutional organization. This will be especially true as the health care system continues to change with more government involvement. In addition, a new kind of decanal role will need to evolve as what may be called the health system dean assumes a broader role and ensures that medical education is integrated into large and often geographically distributed health care delivery systems. Education will have to be integrated across such systems, large groups of faculty will have to be placated, and the growing number of external forces will need to be aligned. The need for direction in times of limited resources, for instance, will require the dean to serve as an effective, almost "spiritual" leader with students, faculty, and upper administration to maintain optimism in whichever historical role best suits that environment.[34] This is a nuance somewhat changed from historical precedence and is further complicated by the potential that internal leadership may have not developed or may not be synchronized with that of the dean type. For instance, a school with figurehead chairs may not cooperate with a CEO dean or other dean type.

Mission-based management will complicate the dean's role in fiscal affairs in the context of the responsibility/authority gap.[35,36] Few individuals are likely to have the time, talent, and endurance to function successfully in the dean-president role for a prolonged period. It would not, therefore, be surprising if earlier models were to reemerge as schools reorganize in the future and address national mandates such as producing more primary care physicians. This underscores the importance of a fit between decanal management style and skill and the needs of the individual medical school in the future.

Not surprisingly, the lack of a cohesive, effective leadership team has been the downfall of many deans.[1,18,23,37,38] The ability and willingness to delegate effectively and empower fully the entire leadership team, both above and below, have become essential while balancing the needs of stakeholders, such as parent university presidents and hospital board members. Increasing sex and racial diversity, as well as diversity in medical school dean academic specialty, will characterize future deanships. Approximately half of medical school deans in the past century were internal medicine specialists.[27] A recent analysis shows a much more diverse medical specialty portfolio for deans over time.[39] It will be of great interest to determine whether the inevitable increasing diversity of deans is accompanied by improved effectiveness and longevity, given the growing complexity of current resource demands of medical education.

## CONCLUSION

The medical school dean is evolving from the medieval guild master to a system executive. In this contemporary version of the dean's role, the dean is a major player in setting organizational direction for the medical school within the mission and vision of a larger system of care. Taken in a historical context, one can only assume increasing complexities in the role of medical school dean as we move forward that may require a melding of these traditions. The failure or success of the dean in the future depends on the ability of the designated person to garner resources to best further the mission of the academic health center while maintaining the support of all stakeholders. ❖

[a] Steven Rose, MD, Dean and Designated Institutional Official, Mayo School of Graduate Medical Education, Rochester, MN.

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**References**

1. Yedidia MJ. Challenges to effective medical school leadership: Perspectives of 22 current and former deans. Acad Med 1998 Jun;73(6):631-9. DOI: https://doi.org/10.1097/00001888-199806000-00007.
2. Sachs BP, Krane NK, Kahn MJ. Medical school dean as a turnaround agent. Am J Med Sci 2008 Aug;336(2):181-4. DOI: https://doi.org/10.1097/maj.0b013e31818132c8.
3. Falcone CM, Earle P, Isaacson I, Schlosser J. Route to the top: Deans at North America's academic medical schools. Physician Exec 2007 Nov-Dec;33(6):58-62.
4. Mitsch P, Jensen AC. Streamlining administration at the University of Minnesota medical school. Acad Med 2007 Mar;82(3):252-7. DOI: https://doi.org/10.1097/acm.0b013e3180307113.
5. Rich RC, Magrane D, Kirch DG. Qualities of the medical school dean: Insights from the literature. Acad Med 2008 May;83(5):483-7. DOI: https://doi.org/10.1097/acm.0b013e31816becc9.
6. Lee A, Hoyle E. Who would become a successful dean of faculty of medicine: Academic or clinician or administrator? Med Teach 2002 Nov;24(6):637-41. DOI: https://doi.org/10.1080/0142159021000063970.
7. Cooke M, Irby DM, Sullivan W, Ludmerer KM. American medical education 100 years after the Flexner report. N Engl J Med 2006 Sep 28;355(13):1339-44. DOI: http://dx.doi.org10.1056/NEJMra055445.
8. Culbertson RA, Goode LD, Dickler RM. Organizational models of medical school relationships to the clinical enterprise. Acad Med 1996 Nov;71(11):1257-74. DOI: https://doi.org/10.1097/00001888-199611000-00026.
9. Weiner BJ, Culbertson R, Jones RF, Dickler R. Organizational models for medical school-clinical enterprise relationships. Acad Med 2001 Feb;76(2):113-24. DOI: https://doi.org/10.1097/00001888-200102000-00007.
10. Mathews AW. Kaiser Permanente to launch medical school [Internet]. New York, NY: The Wall Street Journal; 2015 Dec 17 [cited 2016 Sep 7]. Available from: www.wsj.com/articles/kaiser-permanente-to-launch-medical-school-1450368001.
11. Cowen J. Health network formed by UT Southwestern, Texas Health announces executives [Internet]. Dallas, TX: The Dallas Morning News; 2016 Mar 24 [cited 2016 Sep 2]. Available from: http://bizbeatblog.dallasnews.com/2016/03/health-network-formed-by-ut-southwestern-texas-health-announces-executives.html/.

12. Starr P. The social transformation of American medicine: The rise of a sovereign profession and the making of a vast industry. New York, NY: Basic Books; 1982.
13. Rutkow IM. Surgery: An illustrated history. St Louis, MO: Mosby; 1993.
14. Barsukiewicz CK, Raffel MW, Raffel NK. The US health system: Origins and functions. 6th ed. Clifton Park, NY: Delmar, Cengage Learning; 2012.
15. Flexner A. Medical education in the United States and Canada: A report to the Carnegie Foundation for the advancement of teaching. Washington, DC: Science and Health Publications; 1960.
16. Mintzberg H. The nature of managerial work. New York, NY: Harper and Row; 1973.
17. Keyes JA, Alexander H, Jarawan H, Mallon WT, Kirch DG. Have first-time medical school deans been serving longer than we thought? A 50-year analysis. Acad Med 2010 Dec;85(12):1845-9. DOI: https://doi.org/10.1097/acm.0b013e3181fa2794.
18. Gabbe SG, Webb LE, Moore DE, Harrell FE Jr, Spickard WA Jr, Powell R Jr. Burnout in medical school deans: An uncommon problem. Acad Med 2008 May;83(5):476-82. DOI: https://doi.org/10.1097/acm.0b013e31816bdb96.
19. Levin R, Bhak K, Moy E, Valente E, Griner PF. Organizational, financial, and environmental factors influencing deans' tenure. Acad Med 1998 Jun;73(6):640-4. DOI: https://doi.org/10.1097/00001888-199806000-00008.
20. Bananszak-Holl J, Greer DS. Turnover of deans of medicine during the last five decades. Acad Med 1994 Jan;69(1):1-7. DOI: https://doi.org/10.1097/00001888-199401000-00001.
21. Pfeffer J, Salancik GR. The external control of organizations: A resource dependence perspective. Stanford, CA: Stanford University Press; 2003.
22. Krause EA. Death of the guilds: Professions, states, and the advance of capitalism, 1930 to the present. New Haven, CT: Yale University Press; 1996.
23. Clawson DK, Wilson EA. The medical school dean: Reflections and directions. Kuttawa, KY: McClananhan Publishing; 1999.
24. The Social Security Amendments of 1965. Public Law 89-97, 89th Congress, 79 Stat 286, Title XVIII and Title XIX, enacted 1965 Jul 30.
25. Daugherty RM Jr. Leading among leaders: The dean in today's medical school. Acad Med 1998 Jun;73(6):649-53. DOI: https://doi.org/10.1097/00001888-199806000-00010.
26. Nonnemaker L, Griner PF. The effects of a changing environment on relationships between medical schools and their parent universities. Acad Med 2001 Jan;76(1):9-18. DOI: https://doi.org/10.1097/00001888-200101000-00007.
27. Wilson MP, McLaughlin CP. Leadership and management in academic medicine. San Francisco, CA: Jossey-Bass Inc Publishers; 1984. p 46-7.
28. Memorial Hermann 2015 Annual Report [Internet]. Houston, TX: Memorial Hermann Health System; 2015 [cited 2016 Sep 27]. Available from: www.memorialhermann.org/uploadedFiles/_Library/Memorial_Hermann/2015-mh-annual-report.pdf.
29. Aurora Health Care, Inc and Affiliates. Unaudited consolidated financial statements and other information for the year ended December 31, 2015 [Internet]. Milwaukee, WI: Aurora Health Care; 2016 May 13 [cited 2016 Sep 27]. Available from: www.aurorahealthcare.org/-/media/aurorahealthcareorg/documents/annual-report/unaudited-consolidated-financial-report-2015.pdf?la=en.
30. Kutscher B. As Phoenix booms, healthcare systems revamp to catch up. Mod Healthc 2016 May 30;46(22):10-2.
31. Ofri D. In diagnosis, fiendish elusiveness. The New York Times. 2015 Oct 17; Sect D:6.
32. Mitchell P, Wynia M, Golden R, et al. Core principles & values of effective team-based health care. Discussion paper [Internet]. Washington, DC: Institute of Medicine; 2012 Oct [cited 2016 Sep 9]. Available from: www.nationalahec.org/pdfs/VSRT-Team-Based-Care-Principles-Values.pdf.
33. Senge P, Hamilton H, Kania J. The dawn of system leadership. Stanford Social Innovation Review 2015 Winter;13(1):27-33.
34. Evans C. The dean as spiritual leader. Acad Med 1998 Jun;73(6):645-8. DOI: https://doi.org/10.1097/00001888-199806000-00009.
35. Karpf M, Schultze RG, Levey G. The decade of the nineties at the UCLA medical center: Responses to dramatic marketplace changes. Acad Med 2000 Aug;75(8):781-92. DOI: https://doi.org/10.1097/00001888-200008000-00007.
36. Watson RT. Managed education: An approach to funding medical education. Acad Med 1997 Feb;72(2):92-3. DOI: https://doi.org/10.1097/00001888-199702000-00007.
37. MacLeod SM. Change and the academic health science centre: A 1997 perspective. Clin Invest Med 1997 Dec;20(6):399-404.
38. Goodman L. Sick days. Philadelphia Magazine 2000;91:72-5,136-9.
39. Council of deans [Internet]. Washington, DC: Association of American Medical Colleges; c1995-2016 [cited 2013 Jul 30]. Available from: www.aamc.org/members/cod.

## Education

Graduate schools, to be sure, must train students for professions, must prepare them to play their part in society as teachers, physicians, scientists, lawyers, ministers, or engineers. But graduate education must be infinitely more than the imparting of technical knowledge. It must be education.

— Henry E Sigerist, MD, 1891-1957, Swiss medical historian

# Transcendental Meditation and Reduced Trauma Symptoms in Female Inmates: A Randomized Controlled Study

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## ABSTRACT

**Context:** Compared with the general population, trauma experiences are higher among incarcerated women.

**Objective:** To evaluate the effects of Transcendental Meditation (TM) on trauma symptoms in female offenders.

**Design:** Twenty-two inmates at the Coffee Creek Correctional Facility in Wilsonville, OR, with at least 4 months left of incarceration were enrolled in this randomized controlled pilot study. Subjects were randomly assigned to either the TM group (n = 11) or a wait-list control group (n = 11).

**Main Outcome Measures:** Subjects were measured at baseline and 4-month posttest using the Posttraumatic Stress Disorder Checklist-Civilian version (PCL-C; primary outcome) with intrusive thoughts, avoidance, and hyperarousal subscales (secondary outcomes). Twenty of the subjects (10 in each group) took part in their treatment assignment and completed posttesting.

**Results:** Significant reductions were found on total trauma ($p < 0.036$), intrusive thoughts ($p < 0.026$), and hyperarousal ($p < 0.043$) on the PCL-C. Effect sizes ranged from 0.65 to 0.99 for all variables. Eighty-one percent of the TM subjects were compliant with their program.

**Conclusion:** The results of this study indicate feasibility of the TM program in a female prison population and suggest that TM may be an effective tool for decreasing trauma symptoms. Future large-scale research is warranted.

## INTRODUCTION

Women have become the fastest growing population in prisons, nearly double the rate of increasing male incarcerations.[1] Along with the increasing confinement of female offenders, researchers have found that women carry the burden of proportionally high amounts of traumatic experiences, with higher rates of emotional trauma and sexual abuse than do men.[2-5] Rates of childhood abuse among incarcerated women also are elevated compared with women in the general population.[4,6,7] One estimate indicates 75% to 90% of incarcerated women as having a trauma event during their lifetime.[8]

High levels of trauma contribute to poor lifestyle choices, psychological and physical comorbidities, and increased risk of recidivism.[9-12] Research further shows an association between traumatic stress exposure and various forms of cancer in a predominantly female population.[13]

Meditation has been shown to significantly improve psychological, behavioral, and physical health.[14-16] Systematic reviews of meditation in various prison settings generally have shown positive effects of meditation on a wide range of psychosocial stress factors.[17] The Transcendental Meditation (TM)[a] program, in particular, has shown consistent reductions in psychological distress and recidivism in inmate populations.[17] The TM program has further shown reductions in symptoms of trauma, burnout, perceived stress, and depression in predominantly female populations outside a correctional setting.[18-20]

To our knowledge, there has been no research to date with this stress reduction program focusing on trauma symptoms in female prison inmates. Therefore, a randomized controlled pilot study was conducted to determine the feasibility and effects of the TM program on trauma symptoms in female inmates.

## METHODS

### Subjects

Twenty-five female inmates in the Coffee Creek Correctional Facility, a primarily medium-security prison in the northern part of Oregon (Wilsonville), attended a 45-minute presentation on a project to evaluate the effects of the TM program on inmate stress levels. Inmates heard about the presentation through word-of-mouth and prison postings. The presentation described the study and provided information on the TM program. Those who were interested were asked to stay behind and complete written informed consent and baseline testing forms.

Twenty-two inmates were interested in participating in the research project and were randomly assigned to either the TM group (n = 11) or a wait-list control group (n = 11). To be eligible for the study, inmates had to have at least 4 months left of incarceration.

### Measures

The primary outcome for this study was the Posttraumatic Stress Disorder Checklist-Civilian version (PCL-C) total trauma scale. Secondary outcomes included

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PCL-C subscales: intrusions, avoidance, and hyperarousal. Test administration was at baseline and four-month posttest.

The PCL-C is a 17-item self-report questionnaire of trauma symptoms, using a 5-point Likert scale ("not at all" to "extremely") with a range of 17 to 85 severity points.[18,21] Subjects are asked to respond to a list of problems and complaints that people sometimes have in response to stressful experiences, indicating how much they have been bothered by that problem during the past month. Test items include the following: "repeated, disturbing memories, thoughts or images of a stressful experience," "suddenly acting or feeling as if a stressful experience were happening again (as if you were reliving it)," "avoiding activities or situations because they reminded you of a stressful experience," "feeling emotionally numb or being unable to have loving feelings for those close to you," and "loss of interest in activities you used to enjoy." The PCL-C has been used in prior research on meditation and has been found to be sensitive to change owing to TM practice.[18]

Scores on the PCL-C correlate highly with scores on the Clinician-Administered Posttraumatic Stress Disorder Scale ($r = 0.93$).[22] For this study, Cronbach α equaled 0.91. The PCL-C contains 3 subscales: intrusions, avoidance, and hyperarousal.[23] Cronbach α for these subscales ranged from 0.75 to 0.91 in this study. The full PCL-C appears online.[24]

## INTERVENTIONS

### Transcendental Meditation Program

The TM technique is a simple technique for reducing mental stress and is practiced twice daily for approximately 20 minutes. Performed while sitting in a comfortable position, the technique allows the mind to experience finer levels of the thinking process and to achieve a state of deep restful alertness.[25] Unlike some meditation programs, the TM technique does not involve "guided meditation" procedures, visualization practices, or any other external mechanisms as part of the practice.

The TM program was used in this study because it includes a standardized and reproducible instruction format, a thorough certification program for instructors and widespread availability of instructors, and prior research findings in the area of mental health[19] and has been found to be especially effective in correctional settings because of ease of practice.[17,25,26]

The TM program was taught to study participants by certified teachers, using the same standardized procedures for teaching. After initial introductory and preparatory lectures and a brief personal interview with the teacher, subjects participated in an individual personal instruction session, followed by group meetings to verify the correctness of practice and to provide additional knowledge about the practice. The personal instruction and follow-up group meetings were held over four consecutive days (about an hour each day).

This program differs from other meditation programs in terms of electroencephalographic (EEG) activity during the practice.[26] Concentration techniques generally involve the purposeful focusing on objects and typically corresponds to gamma (20-Hz to 50-Hz) EEG waves, which is involved in attention-related activities. Open monitoring, or mindfulness, techniques produce theta (4-Hz to 8-Hz) waves, corresponding to inward monitoring of thoughts and maintaining a nonjudgmental attitude toward them.

Self-transcending through the TM technique involves the effortless thinking of a sound without meaning (mantra), which allows the mind to settle to quieter levels of thought until it achieves the silent state of transcendental consciousness, a process called transcending. The TM technique does not involve trying to alter one's breathing or other metabolic processes; the body more spontaneously gains a more balanced state of functioning. Practice of TM primarily increases EEG alpha-coherence and synchrony, especially in the prefrontal cortex, and is associated with deep relaxation and improved executive functioning.[27] Meta-analyses have found that the TM technique was more effective than other meditation and relaxation techniques for reducing trait anxiety.[28]

Participants were encouraged to practice their meditation program individually in their prison cells, sitting with eyes

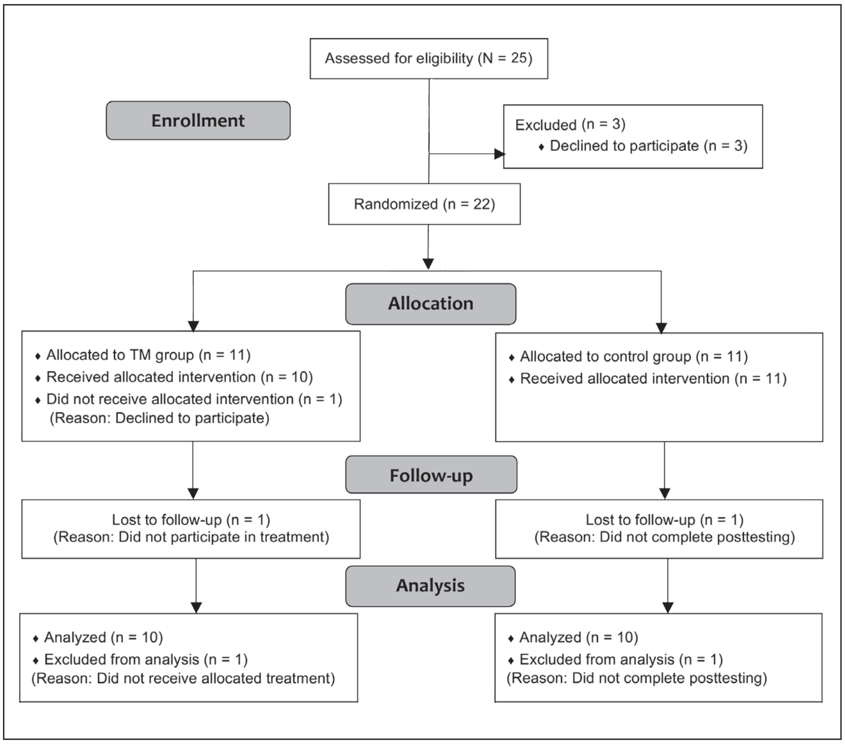

Figure 1. Consolidated Standards of Reporting Trials (CONSORT) flow diagram.

TM = Transcendental Meditation.

closed, twice a day for 20 minutes each session. They also were encouraged to attend 30- to 40-minute group meditation sessions, supervised by a TM teacher, twice a week during the 4-month intervention period.

### Wait-List Control

Subjects in the control group continued with their usual daily schedule and did not participate in the TM program during the intervention period. They were given the option to learn TM after 4-month posttesting.

All subjects in both groups continued to receive standard care. There was no cost to any of the participants for learning the TM program.

### Statistical Analysis

Analysis of covariance, adjusting for baseline dependent scores, was used to determine change in PCL-C total scores. Subjects who did not complete posttesting or did not attend any TM program instruction sessions were excluded from analysis. Cohen's *d* (mean posttest score difference between groups divided by pooled posttest standard deviation) was used to determine effect sizes for each variable. Alpha was set at 0.05, two-tailed.

### Evaluation of Adherence to Transcendental Meditation and Follow-up of Participants' Experiences

Compliance with TM was assessed by self-report. Adherence was defined as practicing TM at least once a day on average. As part of the study's qualitative component, TM participants were asked to provide written personal experiences, with an open-ended format, twice during the four-month treatment period.

## RESULTS

Of the original 22 randomized subjects, 20 took part in their group assignments and completed 4-month posttesting (Figure 1). One subject assigned to TM chose not to learn the TM program, and 1 control subject did not complete PCL-C posttesting. The average age of the women was 44.5 years, and 80% were white (Table 1). The average score on the PCL-C was 52.70, placing most of the women in the range of clinically significant posttraumatic stress. No statistically significant differences were found between groups on any demographic or baseline factors.

**Table 1. Background and demographic characteristics by group at baseline**

| Variable | Transcendental Meditation (n = 10) | Control (n = 10) | p value |
|---|---|---|---|
| Age, years, mean (SD) | 44.50 (11.20) | 44.64 (8.45) | 0.975 |
| Race/ethnicity, no. (%) | | | |
| White | 9 (90.00) | 7 (70.00) | 0.578 |
| Other | 1 (10.00) | 3 (30.00) | |
| PCL-C scores, mean (SD) | | | |
| Total trauma score | 53.00 (17.35) | 52.40 (13.05) | 0.931 |
| Intrusions subscale | 17.30 (6.24) | 14.90 (5.88) | 0.388 |
| Avoidance subscale | 19.50 (7.29) | 22.90 (4.36) | 0.221 |
| Hyperarousal subscale | 16.20 (5.63) | 14.60 (5.30) | 0.521 |

PCL-C = Posttraumatic Stress Disorder Checklist-Civilian version; SD = standard deviation.

**Table 2. Four-month adjusted posttest PCL-C scores by group[a]**

| Variable | Transcendental Meditation (n = 10) | Control (n = 10) | p value | $d^b$ |
|---|---|---|---|---|
| Total trauma score | 29.08 (2.63) | 41.02 (5.17) | 0.036 | 0.85 |
| Intrusions subscale | 9.00 (0.92) | 13.30 (1.55) | 0.026 | 0.99 |
| Avoidance subscale | 11.97 (1.16) | 15.83 (2.20) | 0.139 | 0.65 |
| Hyperarousal subscale | 8.14 (0.87) | 11.86 (1.77) | 0.043 | 0.82 |

[a] Data are mean (standard error).

[b] *d* = effect size based on Cohen's *d*.

PCL-C = Posttraumatic Stress Disorder Checklist-Civilian version.

Table 2 shows 4-month adjusted posttest scores in total trauma symptoms and subscales, as measured by the PCL-C. There was a significant reduction in total trauma symptoms in the TM group compared with controls ($F_{1,17}$ = 5.18, p = 0.036; TM posttest adjusted mean = 29.08, standard error [SE] = 2.63; control posttest adjusted mean = 41.02, SE = 5.17). Significant decreases were also found in the TM group compared with controls for the subscales for intrusions ($F_{1,17}$ = 5.96, p = 0.026; TM posttest adjusted mean = 9.00, SE = 0.92; control posttest adjusted mean = 13.30, SE = 1.55) and hyperarousal ($F_{1,17}$ = 4.76, p = 0.043; TM posttest adjusted mean = 8.14, SE = 0.87; control posttest adjusted mean = 11.86, SE = 1.77). Change in the avoidance subscale did not reach statistical significance ($F_{1,17}$ = 2.41, p = 0.139; TM posttest adjusted mean = 11.97, SE = 1.16; control posttest adjusted mean = 15.83, SE = 2.20).

Eight of the TM subjects showed a clinically meaningful change in total trauma symptoms (>10 points). Effect sizes were medium to large, ranging from 0.65 to 0.99.

Qualitative evaluation of participants indicated benefits ranging from reduced trauma and psychosocial stress to greater sense of inner freedom and resilience. The following are excerpts of three of these experiences:

- It has been difficult to find peace and happiness in such an environment [prison] … . Meditating twice a day has helped lessen my stress levels, allowed me to connect to and center myself at deeper levels, and to retreat, reflect, and problem solve. … Meditating helps facilitate my mental clarity, while at the same time calming me. TM has not only helped me mentally, my physical health has also improved. My blood pressure has gone down and my sleep, though I have insomnia, is deeper and more relaxed. I feel more energized.
- I feel so open and have gained such a deep sense of surrender to my life and the feelings surrounding my incarceration. I no longer feel imprisoned. I now feel my freedom from the inside of me. My relationships have blossomed and grown so much since I began using TM.

- Before I learned TM I was waking up several times a week with night terrors—literally screaming. I would only sleep a few hours per night because I was so frightened of my dreams. I had horrible flashbacks, nightmares, and severe PTSD [posttraumatic stress disorder]. Almost immediately I saw the beneficial effects of TM. … I am able to fully focus throughout the day and have an inner peace and understanding.

Compliance with TM treatment was 81%, with 9 of the original 11 randomized subjects practicing TM at least once a day (the criterion for compliance) during the 4-month intervention period. Nine subjects practiced the TM program twice a day, 1 practiced less than once a day, and 1 never learned the TM program.

## DISCUSSION

Results of this randomized controlled pilot study showed significant reductions in total trauma symptoms in female prison inmates practicing the TM program compared with wait-list controls. Participants in the TM group exhibited significant decreases on the intrusions subscale, which assesses repeated disturbing memories and thoughts, disturbing dreams, repeatedly reliving the trauma, and physical reactions when being reminded of the trauma experience. A significant reduction on the hyperarousal subscale, which includes trouble falling or staying asleep, difficulty concentrating, being superalert or on guard, and feeling jumpy or easily startled, was also observed because of TM practice.

Results showed medium to large effect sizes for all study outcomes, with approximately 80% of the TM participants showing clinically meaningful reductions in total trauma symptoms. Compliance with the TM program was good, with 81% practicing twice a day.

Very few interventions exist that target the unique needs of female prisoners, and even fewer programs are trauma informed.[29,30] This study suggests that TM may be a viable alternative treatment for reducing trauma symptoms in incarcerated women. Prior studies indicate that practice of the TM program reduces psychological and physiologic response to stress factors, including decreased sympathetic nervous system and hypothalamic-pituitary-adrenal axis, and reductions in elevated cortisol (stress hormone) levels.[31-33] Research also shows a more coherent and integrated style of brain functioning, evidenced by EEG imaging, which is associated with lower stress reactivity.[34,35] This research may provide possible explanations for how TM practice may reduce trauma symptoms in incarcerated women.

**A significant reduction on the hyperarousal subscale, which includes trouble falling or staying asleep, difficulty concentrating, being superalert or on guard, and feeling jumpy or easily startled, was also observed because of TM practice.**

The current research was undertaken as a pilot study, carried out in a difficult setting and targeted toward a challenging population. It is in this context that the study makes an important contribution to the fields of mental health and corrections. Strengths of the present study include a high adherence to the study intervention. A randomized controlled design was used, with subjects allocated to either immediate start of TM or a wait-list control group. The use of self-report outcome measures may have introduced some possibility of bias, although there is substantial prior research on the TM program with physiologic and biochemical stress-related measures that supports the findings of this study and TM program efficacy.[19,31-33]

Limitations include that this is a pilot study with fairly small numbers and conducted during a relatively short time. Future studies are encouraged to use larger numbers of subjects, be conducted over a longer period, and to include a more active control condition to account for time and attention.

## CONCLUSION

Female inmates practicing the TM program showed a significant reduction in total trauma symptoms and intrusions and hyperarousal subscales of the PCL-C during a four-month period, providing additional support for the value of TM in reducing trauma symptoms. Results of this study are consistent with prior research conducted in other populations with posttraumatic stress, including veterans and refugees, and sets a foundation for further exploration of research in female inmates with trauma symptoms. ❖

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[a] Transcendental Meditation and TM are service marks registered in the US Patent and Trademark Office, licensed to Maharishi Foundation, and used under sublicense.

### Disclosure Statement

*Blaze Compton, MA, is a part-time consultant to Maharishi Foundation USA, a nonprofit educational organization. The authors have no other conflicts of interest to disclose.*

### Authors' Contributions

*Sanford Nidich, EdD, and Randi Nidich, EdD, participated in the study design, analysis of data, and drafting and critical review of the final manuscript. Angela Seng participated in the management of data, statistical analysis, and drafting and critical review of the manuscript. Tom O'Connor, PhD, participated in the drafting and critical review of the final manuscript. Blaze Compton, MA, participated in the teaching of the Transcendental Meditation program and critical review of the final manuscript. John W Salerno, PhD, participated in the writing and final review of manuscript and preparation for publication. All authors have given final approval to the manuscript.*

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### References

1. Sabol WJ, Minton TD, Harrison PM. Prison and jail inmates at midyear 2006. Bureau of Justice statistics bulletin [Internet]. Washington, DC: US Department of Justice, Office of Justice Programs; 2007 Jun [revised 2008 Mar 12; cited 2016 Sep 27]. Available from: www.bjs.gov/content/pub/pdf/pjim06.pdf.
2. Fickenscher A, Lapidus J, Silk-Walker P, Becker T. Women behind bars: Health needs of inmates

in a county jail. Public Health Rep 2001 May-Jun;116(3):191-6.
3. Binswanger IA, Merrill JO, Krueger PM, White MC, Booth RE, Elmore JG. Gender differences in chronic medical, psychiatric, and substance-dependence disorders among jail inmates. Am J Public Health 2010 Mar;100(3):476-82. DOI: https://doi.org/10.2105/ajph.2008.149591.
4. Bloom B, Owen B, Covington S. Women offenders and the gendered effects of public policy. Review of Policy Research 2004 Jan;21(1):31-48. DOI: https://doi.org/10.1111/j.1541-1338.2004.00056.x.
5. Drapalski AL, Youman K, Stuewig J, Tangney J. Gender differences in jail inmates' symptoms of mental illness, treatment history and treatment seeking. Crim Behav Ment Health 2009;19(3):193-206. DOI: https://doi.org/10.1002/cbm.733.
6. Jordan BK, Schlenger WE, Fairbank JA, Caddell JM. Prevalence of psychiatric disorders among incarcerated women. II. Convicted felons entering prison. Arch Gen Psychiatry 1996 Jun;53(6):513-9. DOI: https://doi.org/10.1001/archpsyc.1996.01830060057008.
7. Singer MI, Bussey J, Song LY, Lunghofer L. The psychosocial issues of women serving time in jail. Soc Work 1995 Jan;40(1):103-13.
8. Messina N, Grella C. Childhood trauma and women's health outcomes in a California prison population. Am J Public Health 2006 Oct;96(10):1842-8. DOI: https://doi.org/10.2105/ajph.2005.082016.
9. Dedert EA, Calhoun PS, Watkins LL, Sherwood A, Beckham JC. Posttraumatic stress disorder, cardiovascular, and metabolic disease: A review of the evidence. Ann Behav Med 2010 Feb;39(1):61-78. DOI: https://doi.org/10.1007/s12160-010-9165-9.
10. Boscarino JA. Posttraumatic stress disorder and physical illness: Results from clinical and epidemiologic studies. Ann N Y Acad Sci 2004 Dec;1032:141-53. DOI: https://doi.org/10.1196/annals.1314.011.
11. Green BL, Miranda J, Daroowalla A, Siddique J. Trauma exposure, mental health functioning, and program needs of women in jail. Crime & Delinquency 2005 Jan;51(1):133-51. DOI: https://doi.org/10.1177/0011128704267477.
12. Donley S, Habib L, Jovanovic T, et al. Civilian PTSD symptoms and risk for involvement in the criminal justice system. J Am Acad Psychiatry Law 2012;40(4):522-9.
13. Hahn EE, Hays RD, Kahn KL, Litwin MS, Ganz PA. Post-traumatic stress symptoms in cancer survivors: Relationship to the impact of cancer scale and other associated risk factors. Psychooncology 2015 Jun;24(6):643-52. DOI: https://doi.org/10.1002/pon.3623.
14. Bowen S, Witkiewitz K, Dillworth TM, et al. Mindfulness meditation and substance use in an incarcerated population. Psychol Addict Behav 2006 Sep;20(3):343-7. DOI: https://doi.org/10.1037/0893-164x.20.3.343.
15. Sumter MT, Monk-Turner E, Turner C. The benefits of meditation practice in the correctional setting. J Correct Health Care 2009 Jan;15(1):47-57. DOI: https://doi.org/10.1177/1078345808326621.
16. Anderson JW, Liu C, Kryscio R. Blood pressure response to transcendental meditation: A meta-analysis. Am J Hypertens 2008 Mar;21(3):310-6. DOI: https://doi.org/10.1038/ajh.2007.65.
17. Himelstein S. Meditation research: The state of the art in correctional settings. Int J Offender Ther Comp Criminol 2011 Jun;55(4):646-61. DOI: https://doi.org/10.1177/0306624x10364485.
18. Rees B, Travis F, Shapiro D, Chant R. Significant reductions in posttraumatic stress symptoms in Congolese refugees within 10 days of Transcendental Meditation practice. J Trauma Stress 2014 Feb;27(1):112-5. DOI: https://doi.org/10.1002/jts.21883.
19. Elder C, Nidich S, Moriarty F, Nidich R. Effect of transcendental meditation on employee stress, depression, and burnout: A randomized controlled study. Perm J 2014 Winter;18(1):19-23. DOI: https://doi.org/10.7812/tpp/13-102.
20. Nidich SI, Fields JZ, Rainforth MV, et al. A randomized controlled trial of the effects of transcendental meditation on quality of life in older breast cancer patients. Integr Cancer Ther 2009 Sep;8(3):228-34. DOI: https://doi.org/10.1177/1534735409343000.
21. McDonald SD, Calhoun PS. The diagnostic accuracy of the PTSD checklist: A critical review. Clin Psychol Rev 2010 Dec;30(8):976-87. DOI: https://doi.org/10.1016/j.cpr.2010.06.012.
22. Forbes D, Creamer M, Biddle D. The validity of the PTSD checklist as a measure of symptomatic change in combat-related PTSD. Behav Res Ther 2001 Aug;39(8):977-86. DOI: https://doi.org/10.1016/s0005-7967(00)00084-x.
23. Xia ZY, Kong Y, Yin TT, Shi SH, Huang R, Cheng YH. The impact of acceptance of disability and psychological resilience on post-traumatic stress disorders in burn patients. International Journal of Nursing Sciences 2014 Dec;1(4):371-5. DOI: https://doi.org/10.1016/j.ijnss.2014.10.018.
24. US Department of Veterans Affairs, Mental Illness Research, Education and Clinical Centers. PTSD checklist—civilian version (PCL-C) [Internet]. Silver Spring, MD: Department of Defense Deployment Health Clinical Center; 2003 Dec [cited 2016 Sep 13]. Available from: www.mirecc.va.gov/docs/visn6/3_PTSD_CheckList_and_Scoring.pdf.
25. Roth R. Maharishi Mahesh Yogi's Transcendental Meditation. Washington, DC: Primus; 2002.
26. Travis F, Shear J. Focused attention, open monitoring and automatic self-transcending: Categories to organize meditations from Vedic, Buddhist and Chinese traditions. Conscious Cogn 2010 Dec;19(4):1110-8. DOI: https://doi.org/10.1016/j.concog.2010.01.007.
27. Orme-Johnson DW, Barnes VA. Effects of the transcendental meditation technique on trait anxiety: A meta-analysis of randomized controlled trials. J Altern Complement Med 2014 May;20(5):330-41. DOI: https://doi.org/10.1089/acm.2013.0204.
28. Eppley KR, Abrams AI, Shear J. Differential effects of relaxation techniques on trait anxiety: A meta-analysis. J Clin Psychol 1989 Nov;45(6):957-974. DOI: https://doi.org/10.1002/1097-4679(198911)45:6<957::aid-jclp2270450622>3.0.co;2-q.
29. Messina N, Grella CE, Cartier J, Torres S. A randomized experimental study of gender-responsive substance abuse treatment for women in prison. J Subst Abuse Treat 2010 Mar;38(2):97-107. DOI: https://doi.org/10.1016/j.jsat.2009.09.004.
30. Zlotnick C, Shea MT, Begin A, Pearlstein T, Simpson E, Costello E. The validation of the Trauma Symptom Checklist-40 (TSC-40) in a sample of inpatients. Child Abuse Negl 1996 Jun;20(6):503-10. DOI: https://doi.org/10.1016/0145-2134(96)00032-4.
31. Barnes VA, Treiber FA, Davis H. Impact of Transcendental Meditation on cardiovascular function at rest and during acute stress in adolescents with high normal blood pressure. J Psychosom Res 2001 Oct;51(4):597-605. DOI: https://doi.org/10.1016/s0022-3999(01)00261-6.
32. MacLean CR, Walton KG, Wenneberg SR, et al. Effects of the Transcendental Meditation program on adaptive mechanisms: Changes in hormone levels and responses to stress after 4 months of practice. Psychoneuroendocrinology 1997 May;22(4):277-95. DOI: https://doi.org/10.1016/s0306-4530(97)00003-6.
33. Walton KG, Schneider RH, Nidich S. Review of controlled research on the transcendental meditation program and cardiovascular disease. Risk factors, morbidity, and mortality. Cardiol Rev 2004 Sep-Oct;12(5):262-6. DOI: https://doi.org/10.1097/01.crd.0000113021.96119.78.
34. Travis F, Wallace RK. Autonomic and EEG patterns during eyes-closed rest and transcendental meditation (TM) practice: The basis for a neural model of TM practice. Conscious Cogn 1999 Sep;8(3):302-18. DOI: https://doi.org/10.1006/ccog.1999.0403.
35. Orme-Johnson DW, Schneider RH, Son YD, Nidich S, Cho ZH. Neuroimaging of meditation's effect on brain reactivity to pain. Neuroreport 2006 Aug 21;17(12):1359-63. DOI: https://doi.org/10.1097/01.wnr.0000233094.67289.a8.

## Best

He is the best physician who is the best inspirer of hope.

— Samuel Taylor Coleridge, 1772-1834, English poet, literary critic, and philosopher

**ORIGINAL RESEARCH & CONTRIBUTIONS**

# Pediatric Hip Fractures in California: Results from a Community-Based Hip Fracture Registry

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## ABSTRACT

**Context:** Hip fracture registries offer an opportunity to identify and to monitor patients with rare conditions and outcomes, including hip fractures in pediatric patients.

**Objective:** To report patient demographics and surgical outcomes of pediatric patients treated surgically for hip fractures in a large integrated health care system.

**Design:** Pediatric patients (< 21 years old at the time of fracture) with hip fractures were identified between 2009 and 2012 using our health care system's hip fracture registry.

**Main Outcome Measures:** Patient characteristics, type of fracture, surgical treatment, and short-term complications.

**Results:** Among 39 patients identified, 31 (79.5%) were male, and the median age was 15 years old (interquartile range: 11-17 years). Most patients were Hispanic (n = 17, 43.6%) or white (n = 14, 35.9%). There were 8 patients (20.5%) with 15 comorbidities. Delbet Type IV (intertrochanteric) fractures were the most common fracture type (n = 22, 56.4%), and fixation method was equally distributed between intramedullary, screw and sideplate, and screws (n = 12, 30.8% for each). Most surgeries were performed by medium-volume surgeons (n = 22, 56.4%) at medium- and high-volume hospitals (n = 37, 94.9%). Three 90-day readmissions (7.7%), 1 infection (2.6%), 1 malunion (2.6%), and 1 revision (2.6%) were observed in this cohort during the study period.

**Conclusion:** In our series using registry data, hip fractures younger than age 21 years were more common in boys and Hispanic patients. Intertrochanteric fractures (Delbet Type IV) were the most frequently observed type in our community-based hip fracture registry. Short-term complications were infrequent.

## INTRODUCTION

Hip fractures in the pediatric population, defined here as infants, children, and adolescents younger than age 21 years, are rare, comprising less than 1% of all fractures in this age group.[1,2] The primary mechanism for hip fractures in this age group is that of high-energy trauma, but pathologic fractures can also occur.[2] The risk of complication and lifelong disability from hip fracture is high. As a result of anatomical differences, complications observed in pediatric patients with hip fracture tend to differ from those in adults, making this specific patient population and proper surgical management important to characterize.[1-5] With only single-institution case series available in the literature, the need exists for large, multicenter studies to allow for the proper sample size required to evaluate best treatment practices and hip fracture outcomes in pediatric patients.[6-9]

Hip fracture registries offer an opportunity to identify and to monitor patients with rare conditions and outcomes,[10] including hip fractures in pediatric patients. Therefore, we used data from a hip fracture registry to identify a cohort of pediatric patients who had a hip fracture. The purpose of this descriptive article is to report preliminary patient demographics and short-term surgical outcomes of this rare patient population.

## METHODS

### Setting and Population

The Kaiser Permanente (KP) Hip Fracture Registry is a tool for monitoring hip fracture cases in our integrated health care system, which includes 6.9 million members in California. The KP population is demographically and socioeconomically representative of the general California population.[11,12] Details on the data collection mechanisms, definitions, and coverage of the hip fracture registry have been previously published.[10] In brief summary, the registry uses electronic medical records and administrative datasets to identify hip fractures in the health care system. Postoperative surgical outcomes are validated using a combination of manual chart review by trained clinical experts and diagnosis codes from the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM).[13]

Patients with hip fracture younger than age 21 years with primary surgeries performed in Northern and Southern California between January 2009 and December 2012 were included in the study sample. Patients with pathologic fractures or slipped capital femoral epiphysis were not included. This study was approved by the institutional review board (no. 6375) before its commencement.

### Patient Characteristics and Outcomes

This report describes patient characteristics, including age, sex, body mass index, and race. Additionally, surgical characteristics such as time to surgery, fracture type, fixation type, comorbidities,

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fellowship training, surgeon volume, and hospital volume were described. Fracture type was classified according to the 4-part system described by Delbet: Type I, transepiphyseal separation; Type II, nondisplaced or displaced transcervical fracture; Type III, nondisplaced or displaced cervicotrochanteric fracture; and Type IV, intertrochanteric fracture.[14] Surgeon volume was categorized as low (< 10), medium (10-29), and high (≥ 30) on the basis of average number of surgical procedures performed annually. Hospital volume was categorized as low (< 60), medium (60-129), and high (≥ 130) on the basis of average number of surgical procedures performed annually.

Short-term outcomes of interest described for this series included mortality, all-cause readmission, revision, deep venous thrombosis, dislocation, myocardial infarction, pneumonia, pressure ulcer, pulmonary embolism, and deep surgical site infection. Malunion, nonunion, and avascular necrosis also were described.

### Statistical Analysis

Descriptive statistics, including frequencies, proportions, means, standard deviations, medians, interquartile ranges (IQR), and ranges, were computed using SAS Version 9.4 (SAS Institute, Cary, NC). Crude complication rates for all outcomes were provided as proportions of events, with the total pediatric hip fracture population included as the denominator.

## RESULTS

Thirty-nine pediatric patients with hip fractures meeting the inclusion criteria were identified during the study period (Table 1). Most patients were male (n = 31, 79.5%), and the median age was 15 years old (IQR = 11.0 to 17.0 years). The median body mass index was 20.0 kg/m$^2$ (IQR = 18.3 to 23.2 kg/m$^2$). Hispanic patients comprised the majority of this cohort (n = 17, 43.6%), followed by whites as the next largest racial/ethnic group (n = 14, 35.9%). Most fractures occurred on the right side (n = 21, 53.8%). Fracture types were as follows: Type IV (n = 22, 56.4%), Type III (n = 8, 20.5%), Type II (n = 5, 12.8%), and femoral head (n = 4, 10.3%). Median time from admission to operation was 10.8 hours (IQR = 3.6 to 18.5). Fixation was as follows: intramedullary (n = 12, 30.8%), screw and sideplate (n = 12, 30.8%), screw only (n = 12, 30.8%), and open fixation (n = 2, 5.1%); 1 patient (2.6%) had no internal fixation. At least 1 comorbidity was present in 8 patients (20.5%); the most common comorbidities were chronic pulmonary disease (n = 4, 10.3%) and obesity (n = 3, 7.7%).

Procedures were performed by 34 surgeons in 19 Medical Centers; see Table 2 for a description of surgeon and hospital characteristics. Of the 39 hip fractures identified, 6 were treated by surgeons who had prior fellowship training (15.4%). Most surgeries were performed by medium-volume surgeons (10-29 cases per year, n = 22, 56.4%) and at high-volume hospitals (≥ 130 cases per year, n = 20, 51.3%).

The crude 90-day readmission rate was 7.7% (n = 3) and the rate of deep surgical site infections was 2.6% (n = 1). There were 1 malunion (2.6%) and 1 aseptic revision (2.6%) during the study period postoperatively. No other complications were observed for this cohort (Table 3).

**Table 1. Study sample patient characteristics after hip fracture surgery, January 2009 to December 2012 (N = 39)**

| Characteristic | No. (%)[a] |
|---|---|
| **Age (years)** | |
| Mean (SD) | 14.5 (4.1) |
| Median (IQR) | 15.0 (11.0-17.0) |
| Range | 6.0-21.0 |
| **Sex** | |
| Male | 31 (79.5) |
| Female | 8 (20.5) |
| **Body mass index (kg/m$^2$)[b]** | |
| Mean (SD) | 21.3 (5.1) |
| Median (IQR) | 20.0 (18.3-23.2) |
| Range | 13.0-34.8 |
| **Race/ethnicity** | |
| Asian | 2 (5.1) |
| Black | 4 (10.3) |
| White | 14 (35.9) |
| Hispanic | 17 (43.6) |
| Other/multiracial | 1 (2.6) |
| Not documented | 1 (2.6) |
| **Side of fracture** | |
| Left | 18 (46.2) |
| Right | 21 (53.8) |
| **Fracture type** | |
| Type IV | 22 (56.4) |
| Type III | 8 (20.5) |
| Type II | 5 (12.8) |
| Femoral head | 4 (10.3) |
| **Time to surgery (hours)[c]** | |
| Mean (SD) | 15.5 (27.5) |
| Median (IQR) | 10.8 (3.6-18.5) |
| Range | 0.4-166.2 |
| **Fixation type** | |
| Intramedullary | 12 (30.8) |
| Screw and sideplate | 12 (30.8) |
| Screws | 12 (30.8) |
| Open fixation | 2 (5.1) |
| No internal fixation | 1 (2.6) |
| **Comorbidities** | |
| No. of patients with at least 1 comorbidity | 8 (20.5) |
| Chronic pulmonary disease | 4 (10.3) |
| Obesity | 3 (7.7) |
| Deficiency anemias | 2 (5.1) |
| Alcohol abuse | 1 (2.6) |
| Chronic blood loss anemia | 1 (2.6) |
| Drug abuse | 1 (2.6) |
| Other neurologic disorders | 1 (2.6) |
| Paralysis | 1 (2.6) |
| Weight loss | 1 (2.6) |

[a] Data are presented as no. (%) except in age, body mass index, and time to surgery categories.

[b] One patient (2.5%) was missing data on body mass index.

[c] Four patients (10.0%) were missing data on time to surgery.

IQR = interquartile range; SD = standard deviation.

## DISCUSSION

Hip fractures in the pediatric population are rare, and the rate of complications is low, as evidenced by the hip fractures identified in this large integrated health care system during a four-year study period. Most published single-institution reports include only a limited number of pediatric patients with hip fracture over many years, making identification of an appropriate cohort for the study of predictors for complications and optimal standardized treatment nearly impossible. We present what we believe is the first report using registry data to describe a fully captured pediatric hip fracture population in an integrated health care system.

Most of the pediatric patients in this report were male, older, and Hispanic. Boys represented the large majority of the population, in line with other previously published reports.[2,3,6,15] Although our cohort's median age was older at 15 years compared with that in other studies, this finding is most probably because of a broader age range for our inclusion criteria (0-21 years) rather than any actual difference in our patient population. Most pediatric patients in the report were nonwhite (61.6%), and the greatest proportion of hip fractures was observed in Hispanic patients (43.6%). To our knowledge, this is the first report including race and ethnicity data, contributing to the currently limited literature describing this uncommon patient population. Similarly, this is the first series of which we are aware to include data on comorbid conditions, most likely because the pediatric population is healthier overall. Few patients in our series had any comorbidities (20.5%), with the most frequent being chronic pulmonary disease (10.3%).

Most of the fractures were intertrochanteric fractures (Delbet Type IV, 56.4%). This observation is in contrast to prior reports identifying nondisplaced or displaced transcervical fractures (Delbet Type II) as the most common hip fracture type in the pediatric population, followed by nondisplaced or displaced cervicotrochanteric fractures (Delbet Type III), then intertrochanteric fractures (Delbet Type IV), with transepiphyseal separations (Delbet Type I) being the least common.[2,3,5,9,15-17] One potential explanation for this might be that patients in our report received their care in an integrated health system, in contrast to prior reports from tertiary children's hospitals. Delbet classification typically is used in the treatment and prognosis of hip fractures in pediatric patients because of its correlation with the incidence of complications; the risk of complications decreases from Delbet Type I to Type IV fractures.[8]

Median time to surgery in our series was 10.8 hours, and most surgical procedures (92.3%) were performed within 24 hours. Although there is general agreement that early treatment and internal fixation is the best clinical practice, controversy exists regarding the relationship between delay in treatment and increased risk of complications. Two reports found a positive correlation between increased time from injury and reduction and risk of complications[6,8]; however, other reports found no association.[9,17] Complications may also be associated with the type of treatment and the surgeon's level of experience. Internal fixation utilization in our cohort was almost evenly distributed between intramedullary, screw and sideplate, and screws. This is in contrast to studies by Flynn et al[18] and Shrader et al,[6] both reporting use of screws as the predominate method of fixation. Togrul et al[19] also suggested complications are more likely to occur with inexperienced surgeons. Most hip fractures in our pediatric cohort were treated by medium- and high-volume surgeons (75.0%) at medium- and high-volume hospitals (95.0%).

Complications of hip fractures well known to occur in adults were rarely encountered. Specifically, there were no deaths, nor were there any complications from deep venous thrombosis, dislocation, myocardial infarction, pneumonia, pressure ulcer, or pulmonary embolism. Of the 5 complications observed, 3 were directly related to the hip fracture injury: 1 infection, 1 malunion, and 1 revision surgery. Our low infection rate corresponds with that reported in a recent systematic review.[8] However, 2 complications were less directly related to hip pathology, both readmissions within 90 days. One patient was readmitted because of nephrolithiasis, and another because of acute abdominal pain related to perforated diverticulitis. Aside from infection and malunion, other complications commonly

**Table 2. Characteristics of surgeon and hospital for study sample patients after hip fracture surgery, January 2009 to December 2012 (N = 39)**

| Characteristic | No. (%) |
|---|---|
| **Surgeon had fellowship training** | |
| Yes | 6 (15.4) |
| No | 15 (38.5) |
| Unknown | 18 (46.2) |
| **Surgeon volume category (average per year)** | |
| Low (< 10) | 10 (25.6) |
| Medium (10-29) | 22 (56.4) |
| High (≥ 30) | 7 (17.9) |
| **Hospital volume category (average per year)** | |
| Low (< 60) | 2 (5.1) |
| Medium (60-129) | 17 (43.6) |
| High (≥ 130) | 20 (51.3) |

**Table 3. Ninety-day quality outcomes after hip fracture surgery in pediatric patients, January 2009 to December 2012 (N = 39)**

| Complication | No. (%) |
|---|---|
| No. of patients with at least 1 complication[a] | 5 (12.8) |
| Readmission | 3 (7.7) |
| Malunion | 1 (2.6) |
| Aseptic Revision | 1 (2.6) |
| Surgical site infection (any) | 1 (2.6) |
| Deep vein thrombosis | 0 (0.0) |
| Dislocation | 0 (0.0) |
| Mortality | 0 (0.0) |
| Myocardial infarction | 0 (0.0) |
| Pneumonia | 0 (0.0) |
| Pressure ulcer | 0 (0.0) |
| Pulmonary embolism | 0 (0.0) |

[a] One patient experienced 2 complications.

reported after the treatment of hip fractures in pediatric patients, including avascular necrosis, nonunion, and premature closure of the proximal femoral physis/limb length discrepancy,[7] were not observed in our cohort. One explanation for this may be because most hip fractures observed were Delbet Type IV, intertrochanteric. This region of the femur is well vascularized and has a lower risk for development of complications such as avascular necrosis. Furthermore, although common pediatric complications can develop as early as 6 weeks after injury, patients were not followed-up during a long enough period to adequately assess these complications in our cohort. Extended follow-up to skeletal maturity using the hip fracture registry data over several years is necessary to determine whether long-term complications occur.[4,15]

Limitations of this report include a reliance on diagnostic and procedure codes (ICD-9-CM). Additionally, this report includes patients whose hip fracture received surgical treatment only; no description of patients treated by closed reduction or other nonoperative means is included. Other limitations include limited data capture, including the absence of information on fracture displacement, a strong predictor of complications, and a small amount of missing data.[1,2] Furthermore, this report is purely descriptive, looking at short-term postoperative outcomes only; no conclusions may be made as to causality of specific variables with hip fracture outcomes in pediatric patients. Future studies using the registry's cohort with longer follow-up accrual for clinical outcomes will address these limitations, which are relevant for the pediatric hip fracture population.

The major strength of this report is the quality of the KP Hip Fracture Registry data. Single-institution case series can span several decades, and changes in patient demographics and treatment over time can create a diverse cohort. Findings from meta-analyses with larger sample sizes are limited because of bias from inclusion of clinically and methodologically heterogeneous studies.[8,17] In contrast, a variety of outcomes are monitored in registries through a prospective data collection method with a high level of internal validation, thus reducing bias.[10,20] Validation of outcomes after surgery is performed through review of the electronic health record and verified through additional sources. Finally, registries offer the opportunities to investigate rare events.

## CONCLUSION

In a large integrated health care system, hip fractures in a pediatric population were rare and complication rates were low. Hip fractures were more common in boys and Hispanic patients. Few patients had any comorbidities (20.5%). Although this article provides descriptive information on surgically treated pediatric patients and their outcomes, future studies are necessary to evaluate longer-term outcomes, identify predictors of complications, and determine optimal surgical treatment for this patient population. ❖

### Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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**How to Cite this Article**

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### References

1. Ratliff AH. Fractures of the neck of the femur in children. J Bone Joint Surg Br 1962 Aug;44-B:528-42.
2. Canale ST, Bourland WL. Fracture of the neck and intertrochanteric region of the femur in children. J Bone Joint Surg Am 1977 Jun;59(4):431-43.
3. Lam SF. Fractures of the neck of the femur in children. J Bone Joint Surg Am 1971 Sep;53(6):1165-79.
4. Leung PC, Lam SF. Long-term follow-up of children with femoral neck fractures. J Bone Joint Surg Br 1986 Aug;68(4):537-40.
5. Davison BL, Weinstein SL. Hip fractures in children: A long-term follow-up study. J Pediatr Orthop 1992 May-Jun;12(3):355-8. DOI: https://doi.org/10.1097/01241398-199205000-00014.
6. Shrader MW, Jacofsky DJ, Stans AA, Shaughnessy WJ, Haidukewych GJ. Femoral neck fractures in pediatric patients: 30 years experience at a level 1 trauma center. Clin Orthop Relat Res 2007 Jan;454:169-73. DOI: https://doi.org/10.1097/01.blo.0000238794.82466.3d.
7. Bimmel R, Bakker A, Bosma B, Michielsen J. Paediatric hip fractures: A systematic review of incidence, treatment options and complications. Acta Orthop Belg 2010 Feb;76(1):7-13.
8. Yeranosian M, Horneff JG, Baldwin K, Hosalkar HS. Factors affecting the outcome of fractures of the femoral neck in children and adolescents: A systematic review. Bone Joint J 2013 Jan;95-B(1):135-42. DOI: https://doi.org/10.1302/0301-620x.95b1.30161.
9. Riley PM Jr, Morscher MA, Gothard MD, Riley PM Sr. Earlier time to reduction did not reduce rates of femoral head osteonecrosis in pediatric hip fractures. J Orthop Trauma 2015 May;29(5):231-8. DOI: https://doi.org/10.1097/bot.0000000000000226.
10. Inacio MC, Weiss JM, Miric A, Hunt JJ, Zohman GL, Paxton EW. A community-based hip fracture registry: Population, methods, and outcomes. Perm J 2015 Summer;19(3):29-36. DOI: https://doi.org/10.7812/TPP/14-231.
11. Koebnick C, Langer-Gould AM, Gould MK, et al. Sociodemographic characteristics of members of a large, integrated health care system: Comparison with US Census Bureau data. Perm J 2012 Summer;16(3):37-41. DOI: https://doi.org/10.7812/TPP/12-031.
12. Karter AJ, Ferrara A, Liu JY, Moffet HH, Ackerson LM, Selby JV. Ethnic disparities in diabetic complications in an insured population. JAMA 2002 May 15;287(19):2519-27. DOI: https://doi.org/10.1001/jama.287.19.2519.
13. Paxton EW, Kiley ML, Love R, Barber TC, Funahashi TT, Inacio MC. Kaiser Permanente implant registries benefit patient safety, quality improvement, cost-effectiveness. Jt Comm J Qual Patient Saf 2013 Jun;39(6):246-52.
14. Colonna PC. Fracture of the neck of the femur in children. Am J Surg 1929 Jun;6(6):793-7. DOI: https://doi.org/10.1016/s0002-9610(29)90726-1.
15. Azouz EM, Karamitsos C, Reed MH, Baker L, Kozlowski K, Hoeffel JC. Types and complications of femoral neck fractures in children. Pediatr Radiol 1993;23(6):415-20. DOI: https://doi.org/10.1007/bf02012436.
16. Morsy HA. Complications of fracture of the neck of the femur in children. A long-term follow-up study. Injury 2001 Jan;32(1):45-51. DOI: https://doi.org/10.1016/s0020-1383(00)00109-1.
17. Moon ES, Mehlman CT. Risk factors for avascular necrosis after femoral neck fractures in children: 25 Cincinnati cases and meta-analysis of 360 cases. J Orthop Trauma 2006 May;20(5):323-9. DOI: https://doi.org/10.1097/00005131-200605000-00005.
18. Flynn JM, Wong KL, Yeh GL, Meyer JS, Davidson RS. Displaced fractures of the hip in children. Management by early operation and immobilisation in a hip spica cast. J Bone Joint Surg Br 2002 Jan;84(1):108-12. DOI: https://doi.org/10.1302/0301-620X.84B1.11972.
19. Togrul E, Bayram H, Gulsen M, Kalaci A, Ozbarlas S. Fractures of the femoral neck in children: Long-term follow-up in 62 hip fractures. Injury 2005 Jan;36(1):123-30. DOI: https://doi.org/10.1016/j.injury.2004.04.010.
20. Inacio MC, Paxton EW, Dillon MT. Understanding orthopaedic registry studies: A comparison with clinical studies. J Bone Joint Surg Am 2016 Jan 6;98(1):e3. DOI: https://doi.org/10.2106/JBJS.N.01332.

**ORIGINAL RESEARCH & CONTRIBUTIONS**

# Participation in Activities Associated With Quality of Life for Long-Term Survivors of Rectal Cancer

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## ABSTRACT

**Context:** Cancer patients' participation in social, recreational, and civic activities is strongly associated with quality of life (QOL), but these activities are not well integrated into cancer survivorship research or interventions.

**Objective:** Test the hypothesis that for long-term ($\geq$ 5 years) survivors of rectal cancer, clinical factors (type of surgery and bowel function) are associated with long-term participation in activities and that participation in activities is associated with long-term QOL.

**Design:** Observational study with longitudinal and cross-sectional components.

**Main Outcome Measures:** Participation in activities and QOL. Tumor registry records were used to identify patients and obtain clinical data; surveys assessed participation and QOL. Using general linear models, we analyzed participation in activities in relation to type of surgery and bowel function after adjustment for potential confounders. We analyzed overall QOL relative to participation in activities after adjustment.

**Results:** A total of 567 rectal cancer survivors completed a mailed questionnaire. Overall response rate was 61%. The type of operation ($p < 0.0001$), receipt of radiation therapy ($p = 0.002$), and bowel function ($p < 0.0001$) were associated with participation in activities. Participation in activities was the strongest predictor of QOL ($p < 0.0001$), explaining 20% of the variance ($R^2$) in QOL, with all other variables together accounting for another 18% of the variance.

**Conclusion:** The importance of participation in activities on rectal cancer survivors' QOL is underappreciated. We recommend revising QOL instruments used in cancer care and research to include questions about participation in activities. Interventions should address maintenance of preferred activities and adoption of new, fulfilling activities.

## INTRODUCTION

Cancer treatment often results in long-term disabilities and decrements in quality of life (QOL). Patients' and clinicians' understanding of these effects can influence treatment choices. Researchers also must understand how treatment affects QOL to design measures and interventions to improve QOL.

Participation in activities, a well-established concept in rehabilitation,[1,2] is less clearly conceptualized and measured in relation to QOL,[2,3] a critical outcome for measuring the effects of cancer treatment. Participation, defined as "involvement in life situations," includes ability to work, engage in family and other social interactions and relationships, pursue recreation, and participate in civic and community life.[4]

Advances in rehabilitation science show promise for clarifying concepts and measures of the long-term effects of cancer treatment. Ultimately, these improved concepts and measures could translate to better treatment decisions, supportive interventions, and long-term outcomes for cancer survivors.[5,6] This opportunity is highlighted for patients with cancer of the low and midrectum, who often face a decision between sphincter-sparing surgery (anterior resection resulting in anastomosis with or without temporary ostomy) and complete excision of the rectum (abdominoperineal excision with permanent ostomy).

Approximately 40,000 new rectal cancer cases are diagnosed annually in the US, with 68% of these patients surviving at least 5 years.[7] Even though sphincter-sparing surgery is more common than permanent ostomy, the decision to undergo sphincter-sparing surgery or permanent ostomy has vexed surgeons and patients alike.[8] Although these surgeries have equivalent oncologic outcomes, they result in very different defecation practices and bodily appearance. Preoperatively, most patients choose sphincter-sparing surgery in the hopes of maintaining bowel function and avoiding the stigma of a permanent ostomy.[9] However, bowel control after sphincter-sparing surgery can be poor. Although the prevailing wisdom is that sphincter-sparing surgery results in better QOL, this belief was refuted by a 2012 evidence synthesis that found no difference in QOL outcomes between surgery types.[10]

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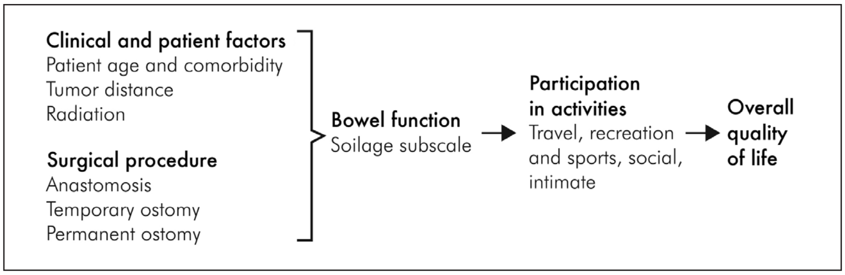

Figure 1. Conceptual model.[1]

[1] Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995 Jan 4;273(1):59-65. DOI: https://doi.org/10.1001/jama.1995.03520250075037.

We assessed the roles of clinical and patient factors in relation to participation in activities as well as the role of participation in activities with overall QOL. We specifically hypothesized that 1) surgical approach and bowel function (as measured through soilage) interfere with participation in activities, and 2) participation in activities reduces overall QOL (see Figure 1 for our conceptual model).[1,11]

## METHODS

This cross-sectional study included Kaiser Permanente members in Northern California, Northern Oregon, and Southwestern Washington. The institutional review boards at Kaiser Permanente and the University of Arizona coordinating center approved this study. Tumor registry data were used to identify eligible patients and their diagnosis dates. Surgery dates and comorbidity data were extracted from Health Plan data about procedures and diagnoses. We assessed soilage, activity participation, and overall QOL through mailed questionnaires. Smaller numbers in all our measures represented worse outcomes.

### Study Population

The population included adults who were Health Plan members at the time of diagnosis and at the time of the survey (2010-2011). All had received a diagnosis of rectal cancer (International Classification of Diseases, Ninth Revision Codes C20.9 and C19.9) at least 5 years before the survey and had undergone surgery as part of their treatment. Patients with a temporary ostomy were considered separately because they had undergone additional surgery to reverse the ostomy and because they were likely to have lower anastomosis or other factors that elevate the risk of postoperative complications or deleterious long-term effects of treatment. We excluded patients with a diagnosis of severe mental illness, cognitive impairment, or local resections of rectal tumors. For this analysis, we excluded individuals with a permanent ostomy who did not regularly wear an ostomy bag.

### Data Collection

In 2010 and 2011, we mailed questionnaires to eligible Health Plan members.[12] Electronic medical record data were used to determine each patient's surgery type (sphincter-sparing surgery, ostomy, temporary ostomy) and other clinical information. Abstractors reviewed participants' charts to ascertain the distance between the tumor and the anal verge. We used a mailed survey[13] to confirm surgery type and ascertain patient-reported bowel function, participation in activities, and overall QOL. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Informed consent was obtained from each patient through mailed surveys.

We measured bowel function using an adaptation of the Memorial Sloan Kettering Cancer Center bowel function index, which was developed and validated with rectal cancer survivors who had sphincter-sparing surgery.[14] The 18-item questionnaire contains 3 subscales—soilage, dietary, and frequency—with respective test-retest reliabilities of 0.87, 0.62, and 0.74 (0.84 overall). We adapted the bowel function index to measure bowel function in rectal cancer survivors with ostomy, established its reliability and validity, and found that the soilage subscale has the best comparability across patients with ostomy and sphincter-sparing surgery.[12]

For the soilage subscale we asked, "Over the past 4 weeks, how often have you had soilage (leakage of stool) of your garments during the day?," "… how often have you had soilage of your garments when you go to bed?," and "… did you use a tissue, napkin and/or pad in your garments in case of stool leakage?" Responses to each item could range from 1 (all the time) to 5 (never). We used the mean of each participant's responses to obtain a summary score ranging from 1 (worst) to 5 (best). The fourth item in the bowel function index asks, "How often have you had to alter your activities because of your bowel function [or, for people with an ostomy, because of the

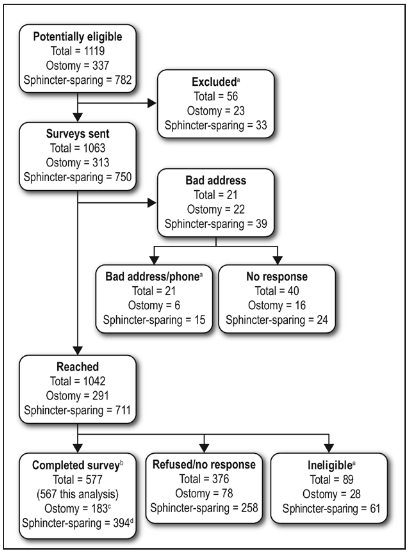

Figure 2. Flow diagram of participant recruitment.

[a] Ineligible (dead, not rectal cancer, etc) after initial search, after wrong address and phone number, or after return of survey with patient reporting no rectal cancer or no intraabdominal surgery.

[b] Response rates (completed/eligible): 66.8% ostomy; 58.6% sphincter-sparing; 60.5% total.

[c] Seven patients of the 182 with ostomy were excluded because they reported not regularly wearing ostomy bag.

[d] Three patients of the 394 with sphincter-sparing surgery were excluded because information they provide about the type of surgery was ambiguous.

number of times you changed or emptied your bag]?" We did not use this item because it conflated two constructs we were trying to analyze separately (bowel function and activity limitation).

Participation in activities was ascertained using the modified City of Hope Quality of Life questionnaire,[12] which we adapted to use for both patients with anastomosis and those with ostomy.[13] The questionnaire assesses the impact of rectal cancer surgery on well-being: we selected 4 items about participation that corresponded well with the World Health Organization's International Classification of Functioning, Disability and Health (ICF)[4,13]: "At this time, how much does [your operation] interfere with your ability to travel?," "… recreational/sports activities?," "… social activities?," and "… ability to be intimate?" Responses to each item could range from 0 (not at all) to 10 (completely). We created a summary measure of participation in activities by calculating the mean value of the 4 responses and then inverting it to obtain a score ranging from 0 (worst) to 5 (best).

Overall QOL was ascertained from the following question: "How good is your overall quality of life?," with 0 being "extremely poor" and 10 being "excellent." We also asked survey respondents to write about the greatest challenge they experienced related to their cancer surgery. We coded responses using previously reported theme analysis techniques[15] to understand the type of activity limitations that survey respondents found most challenging.

### Statistical Analysis

All quantitative data analyses were performed using SAS Version 9.13 software (SAS Institute Inc, Cary, NC). We used general linear models to estimate associations of patient demographic and clinical factors with 2 outcomes: 1) participation in activities and 2) overall QOL. We tested whether a variable improved the model's fit with the F test comparing nested models with and without that variable.

Table 1 shows 14 demographic and clinical variables that were considered potential confounders. Because information on tumor distance was missing for 17.6% of patients, we conducted

**Table 1. Demographic and clinical characteristics of rectal cancer survivors (N = 567)[a]**

| Characteristics | Permanent ostomy (n = 176) | Sphincter-sparing (n = 324) | Temporary ostomy (n = 67) | p value |
|---|---|---|---|---|
| Sex, women | 34.1 | 44.8 | 37.3 | 0.21 |
| Mean age at survey, years | 74.9 | 73.1 | 69.6 | 0.003 |
| Race | | | | |
| White | 88.1 | 81.5 | 88.1 | 0.55 |
| African American | 2.8 | 3.4 | 1.5 | |
| Asian, Pacific Islander | 6.3 | 9.9 | 6.0 | |
| Other | 0.6 | 1.9 | 3.0 | |
| Unknown | 2.3 | 3.4 | 1.5 | |
| Education level | | | | |
| Less than high school | 4.6 | 7.1 | 1.5 | 0.0006 |
| High school | 32.4 | 16.4 | 22.4 | |
| Some college | 33.0 | 25.4 | 35.8 | |
| College graduate | 13.1 | 22.5 | 7.5 | |
| Graduate school | 11.9 | 18.3 | 21.0 | |
| Unknown | 5.1 | 10.5 | 11.9 | |
| Household income, $US | | | | |
| < 30,000 | 33.0 | 25.3 | 25.4 | 0.34 |
| 30,000 to 75,000 | 38.6 | 39.8 | 47.8 | |
| > 75,000 | 21.0 | 25.9 | 19.4 | |
| Unknown | 7.4 | 9.0 | 7.5 | |
| Body mass index at survey completion, $kg/m^2$ | | | | |
| ≤ 26 | 57.4 | 54.0 | 49.3 | 0.17 |
| 27-29 | 19.9 | 17.9 | 16.4 | |
| ≥ 30 | 21.6 | 25.9 | 34.3 | |
| Data missing | 1.1 | 2.2 | 0 | |
| Charlson-Deyo comorbidity index | | | | |
| 0 | 51.7 | 63.6 | 59.7 | 0.07 |
| 1 | 19.3 | 20.4 | 11.9 | |
| ≥ 2 | 29.0 | 16.1 | 28.4 | |
| Year of first rectal cancer-directed surgery | | | | |
| 1989 or earlier | 12.5 | 7.7 | 4.5 | 0.82 |
| 1990-1994 | 14.8 | 15.1 | 9.0 | |
| 1995-1999 | 21.0 | 27.5 | 23.9 | |
| 2000-2001 | 10.2 | 15.7 | 14.9 | |
| 2002-2009 | 30.7 | 30.9 | 44.8 | |
| Data missing | 10.8 | 3.1 | 3.0 | |
| Tumor stage | | | | |
| Localized | 44.9 | 51.5 | 50.8 | 0.06 |
| Regional | 48.9 | 45.4 | 46.3 | |
| Metastatic | 1.1 | 0.6 | 1.5 | |
| Unknown | 5.1 | 2.5 | 1.5 | |
| Tumor distance to anal verge, cm | | | | |
| 0-4 | 31.8 | 2.8 | 6.0 | < 0.0001 |
| 5-9 | 34.1 | 18.5 | 47.8 | |
| 10-14 | 8.5 | 36.1 | 22.4 | |
| 15-19 | 3.4 | 20.4 | 6.0 | |
| ≥ 20 | 0.6 | 6.5 | 1.5 | |
| Data missing | 21.6 | 15.7 | 16.4 | |
| Other clinical characteristics | | | | |
| Chemotherapy | 56.8 | 45.7 | 53.7 | 0.78 |
| History of radiation therapy | 47.2 | 31.5 | 49.3 | 0.85 |

[a] Data are percentages except for mean age.

**Table 2. Adjusted associations with participation in activities and overall quality of life (N = 567)**

| | Association with participation in activities (0-worst to 5-best) | | Association with overall quality of life (0-worst to 10-best) | |
|---|---|---|---|---|
| **Factors** | **Adjusted value[a]** | **p value** | **Adjusted value[a]** | **p value** |
| Operation | | | | |
| Sphincter-sparing surgery (n = 324) | 2.9 | < 0.0001 | 6.5 | 0.79 |
| Ostomy (n = 176) | 2.0 | | 6.7 | |
| Temporary ostomy (n = 67) | 2.9 | | 6.5 | |
| Soilage | | | | |
| Always (n = 18) | 1.5 | < 0.0001 | 6.3 | 0.07 |
| Most of the time (n = 61) | 2.0 | | 6.8 | |
| Sometimes (n = 114) | 2.7 | | 6.9 | |
| Rarely (n = 186) | 3.2 | | 6.3 | |
| Never (n = 179) | 3.6 | | 6.6 | |
| Participation in activities[b] | | | | |
| 0 (interferes a great deal) | | | 4.4 | < 0.0001 |
| 1 | | | 5.6 | |
| 2 | | | 5.9 | |
| 3 | | | 6.7 | |
| 4 | | | 8.2 | |
| 5 (interferes not at all) | | | 8.5 | |
| Sex | | | | |
| Men | 2.4 | 0.01 | 6.6 | 0.94 |
| Women | 2.8 | | 6.6 | |
| Mean age at survey, years | | | | |
| ≤ 64 | 2.4 | 0.48 | 6.7 | < 0.0001 |
| 65-74 | 2.6 | | 7.2 | |
| 75-84 | 2.7 | | 6.3 | |
| ≥ 85 | 2.7 | | 6.1 | |
| Household income, $US | | | | |
| ≤ 15,000 | 2.2 | 0.007 | 6.1 | 0.15 |
| 15,000 to 30,000 | 2.3 | | 6.6 | |
| 30,001 to 50,000 | 2.9 | | 6.6 | |
| 50,001 to 75,000 | 2.7 | | 6.8 | |
| 75,001 to 100,000 | 2.7 | | 6.2 | |
| ≥ 100,000 | 3.1 | | 7.0 | |
| Not reported | 2.6 | | 6.6 | |
| Time since surgery, years | | | | |
| 5-9 | 2.6 | 0.95 | 6.4 | 0.02 |
| 10-14 | 2.6 | | 7.0 | |
| ≥ 15 | 2.7 | | 6.6 | |
| Data missing | 2.6 | | 6.2 | |
| Body mass index at survey completion, kg/m$^2$ | | | | |
| ≤ 26 | 2.9 | 0.17 | 6.6 | 0.18 |
| 27-29 | 2.6 | | 6.2 | |
| ≥ 30 | 2.6 | | 6.4 | |
| Data missing | 2.4 | | 7.0 | |
| Charlson-Deyo comorbidity index | | | | |
| 0 | 2.5 | 0.05 | 6.8 | 0.17 |
| 1 | 2.5 | | 6.5 | |
| ≥ 2 | 2.9 | | 6.4 | |
| History of radiation therapy | | | | |
| No | 2.8 | 0.002 | 6.7 | 0.01 |
| Yes | 2.4 | | 7.2 | |
| Data missing | 2.8 | | 5.7 | |

[a] Values were adjusted for potential confounders.

[b] Data in this category for the “Association with participation in activities” columns are the dependent variables for this table.

sensitivity analysis comparing multivariable models that did and did not include tumor distance, to assess the magnitude of potential confounding by this variable among the subset of patients who did have this information. We removed chemotherapy from the models because it was strongly correlated with radiotherapy. We compared nested models to estimate the proportion of variance ($R^2$) in overall QOL that was attributable to participation in activities.

## RESULTS

An initial search of the electronic medical record followed by further review identified 1063 potentially eligible patients, of whom we reached 1002. Of the 1002, a total of 913 were eligible, but 336 declined, resulting in participation by 577 individuals (183 ostomy recipients and 394 patients with sphincter-sparing surgery). The participation rate was 60.5%. Information needed for the present analysis was complete for 567 participants (Figure 2).

Differences among rectal cancer survivors with ostomy, sphincter-sparing surgery, or temporary ostomy were most pronounced in relation to age at survey, education, Charlson-Deyo comorbidity index, and tumor distance to the anal verge (Table 1).

### Associations with Participation in Activities

After multivariable adjustment, participation in activities was associated with surgery type (p < 0.0001; Table 2). The adjusted mean level of participation on a scale of 0 to 5 was 2.0 for ostomy, 2.9 for sphincter-sparing surgery, and 2.9 for temporary ostomy.

Among the patients with sphincter-sparing surgery, participation in activities was associated with soilage (p < 0.0001; 2.1 and 4.1 in those with the most vs least soilage, respectively) and radiation therapy (p = 0.0006; 2.6 and 3.2 in those with and without radiation therapy, respectively). These and other covariates included in our model explained 34% of the variance in participation among patients with sphincter-sparing surgery.

For patients with an ostomy, participation in activities was associated with income (p = 0.01), comorbidity (p = 0.06), and soilage ($p = 0.06$). The adjusted participation level was 0.7 and 3.0 in those with the worst and best bowel function, respectively. Income, comorbidity, soilage, and the other covariates included in our model explained only 15% of the variance in reported participation among patients with an ostomy.

### Associations with Overall Quality of Life

After multivariable adjustment, overall QOL was associated with age ($p < 0.0001$) and participation in activities ($p < 0.0001$; Table 2). The adjusted mean QOL (scale = 0-10) ranged from 4.4 for those whose operation interfered with their participation "a great deal" to 8.5 for those whose operation "did not at all" interfere with participation, representing a 4.1-point difference on an 11-point scale (Figure 3). In adjusted analyses, overall QOL was not associated with operation type ($p = 0.79$) or soilage ($p = 0.07$). The $R^2$ in QOL explained in the complete model was 37.8%. The $R^2$ explained by participation was 20.0%. We repeated the analysis among patients with data on distance to the anal verge (n = 467) and found that including tumor distance in the model did not change the parameter estimates in our model to an important degree.

### Responses about Constraints on Valued Activities

Thirty-nine of 440 respondents who answered the open-ended question about the greatest challenge experienced after cancer surgery provided a response that was coded under the theme "interference with valued activities." The types of reported barriers to participation were similar across surgery types. They included

1. barriers to returning to work (caused by bowel dysfunction, depression, fatigue, pain, and postoperative recovery problems)
2. social activities away from home, such as eating at a restaurant or traveling (caused by needing to control diet, access to bathrooms, or ostomy self-care routines)
3. unpredictability about being homebound during bouts of severe constipation or diarrhea
4. sexual or intimate contact (because of pain, impotence, embarrassment, or partner's reactions after surgery)
5. physical activities (because of neuropathy, weakness, and poor balance).

## DISCUSSION

We assessed the relationship of participation in activities with QOL and took into consideration the type of rectal cancer surgery (sphincter-sparing, ostomy) and level of soilage. Our major findings were that surgery type and soilage were largely associated with participation in activities but were only indirectly associated with overall QOL, through their effect on participation in activities. The strength and consistency of the association of participation on overall QOL were large, with 20.0% of variance in overall QOL attributable to participation and 17.8% attributable to many other variables. Patients with ostomy reported greater interference with participation than did patients with sphincter-sparing surgery, but after accounting for participation, we observed no differences in overall QOL. Thus, our results demonstrate that patients with ostomy and those with sphincter-sparing surgery have similar QOL after activity limitations are taken into account.[10]

QOL frameworks seek to elucidate patient-centered outcomes in a manner that supports measurement, prediction, decision support, and intervention. These frameworks may not capture what matters most to patients, particularly with respect to drivers of impairment and disability. The QOL model used most widely in the US[1] is useful for health outcomes research because it denotes causal pathways of influence on QOL. This model, however, emphasizes symptoms and physical functioning while deemphasizing participation in activities.

Our study suggests that the ability to participate in life activities, as opposed to bowel function or surgery type, has a strong association with QOL among rectal cancer survivors and should be evaluated as a causal factor in reduced QOL. The consistency and strength of the relationship were striking. Although few reports have addressed the relationship of participation

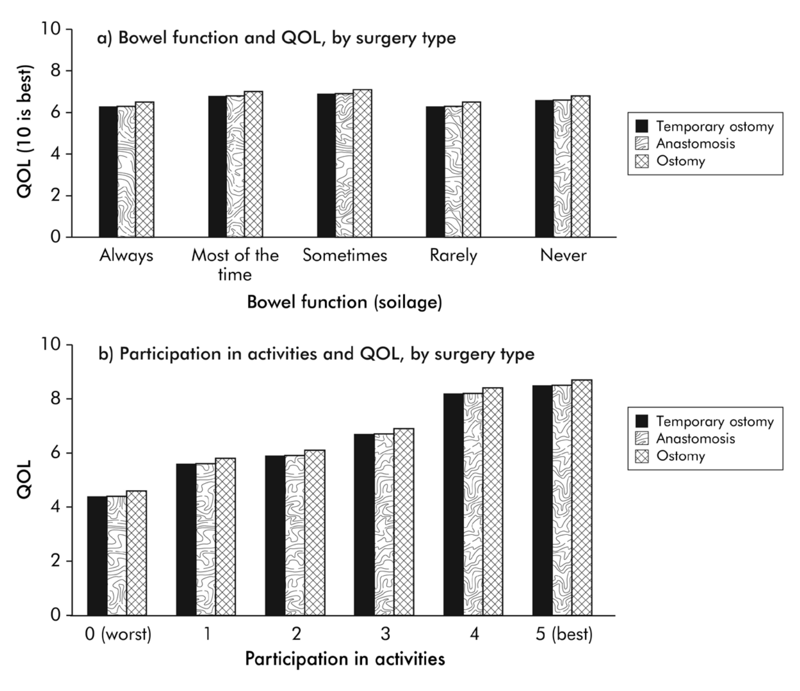

Figure 3. Quality of life (QOL) of long-term rectal cancer survivors is related to participation in activities ($p < 0.0001$), not bowel function ($p = 0.07$) or surgery type ($p = 0.79$).[a]

[a] Predicted values from multivariate model (Table 2).

and QOL among cancer survivors, activity limitation has been shown to be strongly associated with QOL among patients with breast cancer and lymphedema[16,17] and patients with soft-tissue sarcoma.[18] Moreover, cancer survivors experience more disability than do their healthy peers,[19] and physical disability is a primary driver of emotional distress among cancer survivors.[20]

The widespread adoption of the ICF model[21] has brought attention to activity and participation as drivers of patients' well-being. For cancer rehabilitation, the ICF model productively moves inquiry and intervention away from the cause of impairments (difficult to change) to the impact of impairments (amenable to intervention).[22] Interventions targeting physical function and participation have been developed for survivors of breast cancer, but participation has not been sufficiently addressed as a component of cancer survivorship care.[23]

**… surgery type and mode of defecation affect overall QOL through their effects on participation in activities.**

Because impairment limits participation in complex ways, factoring participation into treatment decisions can be complicated. Although sphincter-sparing reconstructions aim to preserve bowel function, 52% of recipients of sphincter-sparing surgery in our study reported soilage always or most of the time. In contrast, although less than 5% of ostomy recipients reported soilage always or most of the time, 28% nonetheless restricted participation in activities because of their surgery, with issues such as body image and embarrassment perhaps playing a role.[15,24]

This study's strengths include the community-based sample, confirmation of surgical and medical characteristics through self-report, electronic data and chart review, and systematic collection of patient-reported outcomes. The key limitation of our study was a lack of detailed information on activity participation, although patients specifically reported changes in various activities because of their surgery or ostomy. Although our cross-sectional design has some limitations, it gives us valuable information for subsequent prospective research. Future studies should also explore a wider range of activities, and our findings should be confirmed among other populations of cancer survivors.

## CONCLUSION

Patients with rectal cancer should be made aware during preoperative discussions that, to a large degree, surgery type and mode of defecation affect overall QOL through their effects on participation in activities. Our findings also suggest new avenues for surveillance and supportive care interventions related to maintenance of participation. Multidimensional cancer survivor rehabilitation programs have shown benefit and cost-effectiveness for survivors of breast cancer.[6] Our findings suggest the need to build the evidence for such interventions in other cancer survivor populations as well. Given the tremendous influence of participation in activities on rectal cancer survivors' QOL, interventions to help patients maintain their activities and adopt new, fulfilling activities should be developed. In addition, routine assessment of participation in activities should become part of patients' follow-up care. ❖

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**Disclosure Statement**

*The author(s) have no conflicts of interest to disclose.*

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**References**

1. Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL. Conceptual model of health-related quality of life. J Nurs Scholarsh 2005;37(4):336-42. DOI: https://doi.org/10.1111/j.1547-5069.2005.00058.x.
2. Sullivan KJ, Cen SY. Model of disablement and recovery: Knowledge translation in rehabilitation research and practice. Phys Ther 2011 Dec;91(12):1892-904. DOI: https://doi.org/10.2522/ptj.20110003.
3. van der Mei SF, Dijkers MP, Heerkens YF. Participation as an outcome measure in psychosocial oncology: Content of cancer-specific health-related quality of life instruments. Qual Life Res 2011 Dec;20(10):1617-27. DOI: https://doi.org/10.1007/s11136-011-9900-0.
4. International classification of functioning, disability and health (ICF) [Internet]. Geneva, Switzerland: World Health Organization; 2001 [cited 2013 Oct 1]. Available from: www.who.int/classifications/icf/en/.
5. Stubblefield MD, Hubbard G, Cheville A, Koch U, Schmitz KH, Dalton SO. Current perspectives and emerging issues on cancer rehabilitation. Cancer 2013 Jun 1;119 Suppl 11:2170-8. DOI: https://doi.org/10.1002/cncr.28059.
6. Mewes JC, Steuten LM, Ijzerman MJ, van Harten WH. Effectiveness of multidimensional cancer survivor rehabilitation and cost-effectiveness of cancer rehabilitation in general: A systematic review. Oncologist 2012;17(12):1581-93. DOI: https://doi.org/10.1634/theoncologist.2012-0151.
7. Cancer facts & figures 2013 [Internet]. Atlanta, GA: American Cancer Society; 2013 [cited 2013 Oct 1]. Available from: www.cancer.org/Research/CancerFactsFigures/CancerFactsFigures/2013-cancer-facts-and-figures.pdf.
8. Mulsow J, Winter DC. Sphincter preservation for distal rectal cancer—a goal worth achieving at all costs? World J Gastroenterol 2011 Feb 21;17(7):855-61. DOI: https://doi.org/10.3748/wjg.v17.i7.855.
9. Cornish JA, Tilney HS, Heriot AG, Lavery IC, Fazio VW, Tekkis PP. A meta-analysis of quality of life for abdominoperineal excision of rectum versus anterior resection for rectal cancer. Ann Surg Oncol 2007 Jul;14(7):2056-68. DOI: https://doi.org/10.1245/s10434-007-9402-z.
10. Pachler J, Wille-Jørgensen P. Quality of life after rectal resection for cancer, with or without permanent colostomy. Cochrane Database Syst Rev 2012 Dec 12;12:CD004323. DOI: https://doi.org/10.1002/14651858.CD004323.pub4.
11. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA 1995 Jan 4;273(1):59-65. DOI: https://doi.org/10.1001/jama.1995.03520250075037.

12. Wendel CS, Grant M, Herrinton L, et al. Reliability and validity of a survey to measure bowel function and quality of life in long-term rectal cancer survivors. Qual Life Res 2014 Dec;23(10):2831-40. DOI: https://doi.org/10.1007/s11136-014-0724-6.
13. Mohler MJ, Coons SJ, Hornbrook MC, et al. The health-related quality of life in long-term colorectal cancer survivors study: Objectives, methods and patient sample. Curr Med Res Opin 2008 Jul;24(7):2059-70. DOI: https://doi.org/10.1185/03007990802118360.
14. Temple LK, Bacik J, Savatta SG, et al. The development of a validated instrument to evaluate bowel function after sphincter-preserving surgery for rectal cancer. Dis Colon Rectum 2005 Jul;48(7):1353-65. DOI: https://doi.org/10.1007/s10350-004-0942-z.
15. McMullen CK, Hornbrook MC, Grant M, et al. The greatest challenges reported by long-term colorectal cancer survivors with stomas. J Support Oncol 2008 Apr;6(4):175-82.
16. Tsauo JY, Hung HC, Tsai HJ, Huang CS. Can ICF model for patients with breast-cancer-related lymphedema predict quality of life? Support Care Cancer 2011 May;19(5):599-604. DOI: https://doi.org/10.1007/s00520-010-0857-2.
17. Dawes DJ, Meterissian S, Goldberg M, Mayo NE. Impact of lymphoedema on arm function and health-related quality of life in women following breast cancer surgery. J Rehabil Med 2008 Aug;40(8):651-8. DOI: https://doi.org/10.2340/16501977-0232.
18. Schreiber D, Bell RS, Wunder JS, et al. Evaluating function and health related quality of life in patients treated for extremity soft tissue sarcoma. Qual Life Res 2006 Nov;15(9):1439-46. DOI: https://doi.org/10.1007/s11136-006-0001-4.
19. Hewitt M, Rowland JH, Yancik R. Cancer survivors in the United States: Age, health, and disability. J Gerontol A Biol Sci Med Sci 2003 Jan;58(1):82-91. DOI: https://doi.org/10.1093/gerona/58.1.m82.
20. Silver JK, Baima J, Mayer RS. Impairment-driven cancer rehabilitation: An essential component of quality care and survivorship. CA Cancer J Clin 2013 Sep;63(5):295-317. DOI: https://doi.org/10.3322/caac.21186.
21. ICF checklist. Version 2.1a, clinician form: For International Classification of Functioning, Disability and Health [Internet]. Geneva, Switzerland: World Health Organization; 2003 Sep [cited 2013 Oct 1]. Available from: www.who.int/classifications/icf/training/icfchecklist.pdf.
22. Gilchrist LS, Galantino ML, Wampler M, Marchese VG, Morris GS, Ness KK. A framework for assessment in oncology rehabilitation. Phys Ther 2009 Mar;89(3):286-306. DOI: https://doi.org/10.2522/ptj.20070309.
23. Supplement: A prospective surveillance model for rehabilitation for women with breast cancer. Cancer 2012 Apr 15;118(8 Suppl):2187-334.
24. Krouse RS, Herrinton LJ, Grant M, et al. Health-related quality of life among long-term rectal cancer survivors with an ostomy: Manifestations by sex. J Clin Oncol 2009 Oct 1;27(28):4664-70. DOI: https://doi.org/10.1200/JCO.2008.20.9502.

## Cure

*Hippocrates* in his aphorisme, as *Galen* writeth sure,
Saith, foure things are needful to every kinde of cure.
The first, saith he, to God belongeth the chiefest part,
The second to the Surgeon, who doth apply the art.
The third unto the medicine, that is dame Natures friend,
The fourth unto the patient, with whom I heere will end.
How then may a Surgeon appoint a time, a day or houre,
when three parts of the cure are quite without his power.

— William Clowes the Elder, 1543-1604, English surgeon

**Autumn Dream**
photograph

**Sapna Reddy, MD**

Deep in the heart of Great Smoky Mountains National Park, soft light diffused by the rain clouds, autumn foliage, cascading water, and rising mist combine to create a visual symphony.

Dr Reddy is a Radiologist at the Walnut Creek Medical Center in CA and is pursuing a dual career as a landscape/nature photographer. More of her work can be seen at www.sapnareddy.com, and on the cover of this issue of *The Permanente Journal*.

**CME** credits available for this article — see page 128.

ORIGINAL RESEARCH & CONTRIBUTIONS

# End-Stage Renal Disease Outcomes among the Kaiser Permanente Southern California Creatinine Safety Program (Creatinine SureNet): Opportunities to Reflect and Improve

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## ABSTRACT

**Objectives:** The Kaiser Permanente Southern California (KPSC) creatinine safety program (Creatinine SureNet) identifies and outreaches to thousands of people annually who may have had a missed diagnosis for chronic kidney disease (CKD). We sought to determine the value of this outpatient program and evaluate opportunities for improvement.

**Methods:** Longitudinal cohort study (February 2010 through December 2015) of KPSC members captured into the creatinine safety program who were characterized using demographics, laboratory results, and different estimations of glomerular filtration rate. Age- and sex-adjusted rates of end-stage renal disease (ESRD) were compared with those in the overall KPSC population.

**Results:** Among 12,394 individuals, 83 (0.7%) reached ESRD. The age- and sex-adjusted relative risk of ESRD was 2.7 times higher compared with the KPSC general population during the same period (94.7 vs 35.4 per 100,000 person-years; $p < 0.001$). Screening with the Chronic Kidney Disease Epidemiology Collaboration (vs Modification Diet in Renal Diseases) equation would capture 44% fewer individuals and have a higher predictive value for CKD. Of those who had repeated creatinine measurements, only 13% had a urine study performed (32% among patients with confirmed CKD).

**Conclusion:** Our study found a higher incidence of ESRD among individuals captured into the KPSC creatinine safety program. If the Chronic Kidney Disease Epidemiology Collaboration equation were used, fewer people would have been captured while improving the accuracy for diagnosing CKD. Urine testing was low even among patients with confirmed CKD. Our findings demonstrate the importance of a creatinine safety net program in an integrated health system but also suggest opportunities to improve CKD care and screening.

## INTRODUCTION

Screening for chronic kidney disease (CKD) remains controversial. Among high-risk populations, screening and surveillance for CKD is recommended.[1-3] However, organizations such as the US Preventive Services Task Force and the American College of Physicians do not recommend routine screening for asymptomatic individuals in the general population.[4,5] The method of assessing kidney function with estimated glomerular filtration rate (eGFR) derived from blood creatinine measurements has also been an area of ambiguity. The eGFR calculations all have inherent accuracy and reliability concerns.[6] Among them, the Chronic Kidney Disease Epidemiology Collaboration equation (CKD-EPI) has been shown to have superior accuracy and prognostic value compared with others such as the Cockcroft-Gault and the Modification Diet in Renal Diseases (MDRD) equations.[7,8] Another important consideration is the role of urine studies because they help to define and prognosticate CKD.[9-12]

CKD is highly prevalent and associated with adverse outcomes, including end-stage renal disease (ESRD), cardiovascular events, and all-cause mortality.[8,13-15] Among adults in the US, the estimated prevalence is around 14%.[13] Unfortunately, CKD is not always identified and managed in an optimal and timely manner.[16,17]

We previously described the Kaiser Permanente Southern California (KPSC) creatinine safety program (Creatinine SureNet), which was designed to identify and to reach potential patients with CKD who otherwise would have been missed.[18] This program leveraged the health system and central laboratory data to create a surveillance system to identify and to outreach to more than 12,000 individuals who did not have a follow-up creatinine test after an initial abnormal creatinine measurement.

Our current study sought to determine the importance of the KPSC creatinine safety program and to identify areas for improvement. We sought to determine the overall rate of ESRD among this presumed high-risk creatinine safety program cohort compared with the rest of the KPSC population. We also evaluated how often patients with confirmed CKD received important complementary studies such as urine analyses and urine protein quantitation. Finally, we sought to compare the rate of capture into the KPSC creatinine safety program if the CKD-EPI had been used to calculate eGFR instead of the existing MDRD equation.

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## METHODS

A longitudinal cohort study was performed from February 1, 2010, through December 31, 2015, among KPSC members with blood creatinine laboratory studies whose results indicated a reduced eGFR using the MDRD formula. KPSC is an integrated health system composed of 14 Medical Centers, more than 200 satellite clinics, and more than 6000 physicians who care for greater than 4 million members in Southern California. Information on demographics, laboratory results, comorbidities, and clinical events that were captured as part of routine clinical care were extracted from the electronic health records. All laboratory measurements were performed and reported from an American College of Pathology/Clinical Laboratory Improvement Act (CLIA) certified laboratory. Kidney function is reported in the electronic health record as eGFR, calculated using the modified 4-variable MDRD equation.[19] For the purpose of our current study, we also calculated eGFR in the same individuals using the CKD-EPI equation.[7] End-stage renal disease was defined as any individual receiving dialysis or who received a renal transplant. The study population was followed-up until they reached ESRD, died, or lost KPSC membership, or until the end of study observation (December 31, 2015). This study was approved by the local institutional review board and exempted from the need for informed consent (no. 10572).

The details of the KPSC creatinine safety program have been previously described.[18] Born from the KPSC Complete Care program established in 2009, the creatinine safety program (called Creatinine SureNet) was one of many safety nets implemented to capture clinical care gaps using electronic health surveillance and multidisciplinary outreach.[20] The Creatinine SureNet uses the concept of electronic clinical surveillance to identify an abnormal creatinine measurement that was not followed-up with a repeated measurement.[21] Individuals with a single creatinine measurement that computed to an eGFR less than 60 mL/min (MDRD equation) and had no repeated eGFR measurement 90 days or more later were included. Individuals who fit the following formula—eGFR + ½ age > 85 years—were excluded.[22] From February 1, 2010, to March 1, 2014, more than 12,000 members were identified by the Creatinine SureNet. A coordinated effort between a centralized regional nurse and clinicians was used to communicate with patients to obtain a second measurement.

### Outcomes and Analyses

All individuals who were included in the Creatinine SureNet cohort were characterized by eGFR and whether they had a follow-up creatinine measurement or other urine tests. The primary outcome was incident ESRD. Age- and sex-adjusted

**Table 1. Study population characteristics by KPSC Creatinine SureNet follow-up status[a]**

| Characteristic | No follow-up | Follow-up | Total | p value |
|---|---|---|---|---|
| Population | 5414 (43.7) | 6980 (56.3) | 12,394 (100.0) | |
| Female sex | 2289 (42.3) | 3878 (55.6) | 6167 (49.8) | < 0.001 |
| **First eGFR (mL/min/$m^2$)** | | | | |
| Mean (SD) | 52.1 (7.6) | 52.1 (7.2) | 52.1 (7.3) | 0.231 |
| < 15 | 14 (0.3) | 9 (0.1) | 23 (0.2) | |
| 15 ≤ 30 | 93 (1.7) | 85 (1.2) | 178 (1.4) | |
| 30 ≤ 45 | 626 (11.6) | 817 (11.7) | 1443 (11.6) | |
| 45 ≤ 60 | 4681 (86.5) | 6069 (86.9) | 10,750 (86.7) | |
| > 60 | — | — | — | |
| **Age at index date (years)** | | | | |
| Mean (SD) | 47.5 (12.38) | 50.9 (12.54) | 49.4 (12.58) | < 0.001 |
| 18-39 | 1299 (24) | 1152 (16.5) | 2451 (19.8) | |
| 40-64 | 3631 (67.1) | 4825 (69.1) | 8456 (68.2) | |
| 65-85 | 454 (8.4) | 939 (13.5) | 1393 (11.2) | |
| > 85 | 30 (0.6) | 64 (0.9) | 94 (0.8) | |
| **Race/ethnicity** | | | | |
| Hispanic | 1046 (19.3) | 1272 (18.2) | 2318 (18.7) | < 0.001 |
| White, non-Hispanic | 2423 (44.8) | 3897 (55.8) | 6320 (51) | |
| Black, non-Hispanic | 645 (11.9) | 753 (10.8) | 1398 (11.3) | |
| Asian, non-Hispanic | 373 (6.9) | 509 (7.3) | 882 (7.1) | |
| Other, non-Hispanic | 927 (17.1) | 549 (7.9) | 1476 (11.9) | |
| **Charlson Comorbidity Index** | | | | |
| 0 | 3300 (61) | 3366 (48.2) | 6666 (53.8) | < 0.001 |
| 1-2 | 1723 (31.9) | 2819 (40.4) | 4542 (36.7) | |
| ≥ 3 | 384 (7.1) | 794 (11.4) | 1178 (9.5) | |
| **Comorbidities** | | | | |
| Hypertension | 1491 (27.5) | 2562 (36.7) | 4053 (32.7) | < 0.001 |
| Diabetes mellitus | 418 (7.7) | 679 (9.7) | 1097 (8.9) | < 0.001 |
| History of systemic lupus | 1 (0.0) | 4 (0.1) | 5 (0.0) | 0.286 |
| Stroke | 114 (2.1) | 201 (2.9) | 315 (2.5) | 0.007 |
| Congestive heart failure | 76 (1.4) | 66 (0.9) | 142 (1.1) | 0.017 |
| **Outcomes** | | | | |
| All-cause mortality | 142 (2.6) | 159 (2.3) | 301 (2.4) | 0.216 |
| End-stage renal disease | 27 (0.5) | 56 (0.8) | 83 (0.7) | 0.04 |
| **Length of follow-up (years)[b]** | | | | |
| Mean (SD) | 4.2 (2.99) | 4.1 (2.22) | 4.2 (2.59) | < 0.001 |
| Median (IQR) | 3.5 (2.1-5.4) | 3.8 (2.64.9) | 3.7 (2.4-5.1) | |
| Range | 0-18.9 | 0.3-18.7 | 0-18.9 | |

[a] Data are presented as no. (%) unless indicated otherwise.

[b] Follow-up was estimated from the date of first creatinine measurement through the earliest of 1) death, 2) end of KPSC membership, 3) December 31, 2015, or 4) date of diagnosis of end-stage renal disease.

eGFR = estimated glomerular filtration rate; IQR = interquartile range; KPSC = Kaiser Permanente Southern California; SD = standard deviation.

ESRD incidence rates by year were determined for the SureNet cohort and for the KPSC general population for comparison. Age and sex adjustments were standardized to the US Census 2010 population.[23] The relative risk (RR) of the SureNet cohort relative to the KPSC general population was estimated, for each year and for all years combined, as the ratio of the 2 incidence rates. A 2-sided test of the null hypothesis that RR = 1 was performed. All-cause mortality information and rates were also determined using data through December 31, 2014.

We also evaluated the proportion of individuals who had urine studies performed, particularly among those who had confirmed CKD by repeated creatinine measurement. Urine studies included urine dipstick, urine microscopy analysis, 24-hour urine protein quantitation, spot urine protein-to-creatinine ratio, and/or spot urine albumin-to-creatinine ratio. Last, we used the CKD-EPI equation to calculate eGFR and then stratified the study population using the new results. We compared the proportion of individuals who would have met the inclusion criteria for the creatinine safety program by the CKD-EPI formula vs the MDRD equation (which was originally used). The ESRD incidence and receiver operating characteristics curve were computed by the different equations for eGFR calculation. Also evaluated were multivariable Cox proportional hazards models examining ESRD or all-cause mortality outcomes adjusted for the confounding effects of baseline eGFR, age at first eGFR measurement, sex, race/ethnicity, Charlson Comorbidity Index, presence of proteinuria, and a history of stroke.

For descriptive statistics, continuous variables were reported as mean with standard deviation, median and interquartile range, and categorical variables were reported as the number and proportion at each level. Differences between groups for continuous variables or tests of association for categorical variables were made using *t*-test or nonparametric Wilcoxon rank sum tests and $\chi^2$ or Fisher exact test, respectively, and as appropriate. Shapiro-Wilks test was used to determine normality for parametricity. All hypothesis tests conducted were 2-sided and considered significant at the 5% Type I error rate. All analyses and data management were conducted using SAS Enterprise Guide Version 5.1 (SAS Institute Inc, Cary, NC).

## RESULTS

A total of 12,394 individuals were captured into the creatinine safety program in the period February 1, 2010, through March 1, 2014 (Table 1). On the basis of the initial abnormal creatinine measurement, 86.7% of the study population had an eGFR between 45 and 59 mL/min/$m^2$. Among the 6980 individuals who eventually had a repeated creatinine measurement, 53.3% were found to have CKD (eGFR < 60 mL/min/$m^2$).

### End-stage Renal Disease and Mortality Outcomes

In the follow-up period up to December 31, 2015, a total of 83 individuals reached ESRD (56 among those with repeated creatinine measurements and 27 among those who did not follow-up with a repeated measurement; see Table 1). The mean follow-up was 4.2 years. The rate of ESRD by different categories of initial eGFR shows that most patients who reached ESRD came from the lower eGFR groups (< 45 mL/min/$m^2$). The age- and sex-adjusted incidence of ESRD for the creatinine safety cohort during the study period was 94.7 per 100,000 person-years. Among the KPSC general population during the same period, the age- and sex-adjusted ESRD incidence was 35.4 per 100,000 person-years. Overall, the age- and sex-adjusted relative risk of ESRD was 2.68 times higher for the safety program cohort compared with the KPSC population ($p < 0.001$, Table 2, Figure 1). Among the study cohort, 301 patients died (159 who repeated and 142 patients who did not repeat their creatinine measurement).

Among the safety program cohort, multivariable adjusted Cox proportional

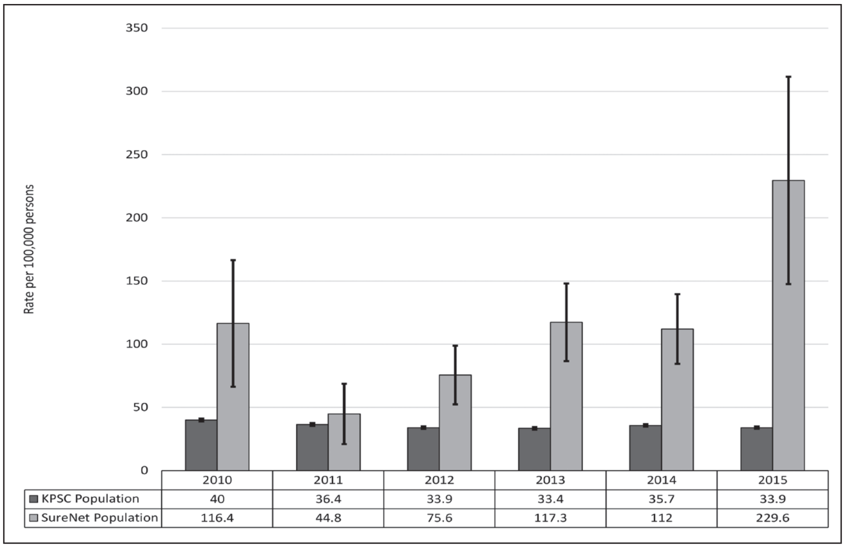
**Table 2. Age- and sex-adjusted incidence of end-stage renal disease in KPSC population and Creatinine SureNet population, by year and all years combined, 2008-2015**

| Population | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | All years combined |
|---|---|---|---|---|---|---|---|
| **KPSC population, excluding cohort** | | | | | | | |
| New cases | 1279 | 1212 | 1178 | 1215 | 1362 | 1383 | 7629 |
| Population at risk | 3,244,757 | 3,383,365 | 3,479,530 | 3,544,815 | 3,662,032 | 3,902,995 | 21,217,493 |
| Rate[a] | 40.0 | 36.4 | 33.9 | 33.4 | 35.7 | 33.9 | 35.4 |
| Standard error | 1.1 | 1.1 | 1.0 | 1.0 | 1.0 | 0.9 | 0.4 |
| **SureNet population** | | | | | | | |
| New cases | 8 | 5 | 12 | 18 | 18 | 22 | 83 |
| Population at risk | 6041 | 7835 | 9093 | 9826 | 9771 | 9092 | 61,228 |
| Rate[a] | 116.4 | 44.8 | 75.6 | 117.3 | 112.0 | 229.6 | 94.7 |
| Standard error | 50.1 | 23.9 | 23.2 | 30.7 | 27.6 | 82.0 | 12.8 |
| **SureNet population relative to the overall KPSC population[b]** | | | | | | | |
| Relative risk | 2.91 | 1.23 | 2.23 | 3.51 | 3.14 | 6.77 | 2.68 |
| Standard error | 0.43 | 0.53 | 0.31 | 0.26 | 0.25 | 0.36 | 0.14 |
| p value | 0.013 | 0.698 | 0.009 | < 0.001 | < 0.001 | < 0.001 | < 0.001 |

[a] All rates are reported as per 100,000 KPSC members.

[b] Relative risk (RR) is the ratio of the SureNet population relative to the overall KPSC population, and the reported p value is for the 2-sided test of the null hypothesis that RR = 1.

KPSC = Kaiser Permanente Southern California.



| | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 |
|---|---|---|---|---|---|---|
| ■ KPSC Population | 40 | 36.4 | 33.9 | 33.4 | 35.7 | 33.9 |
| ■ SureNet Population | 116.4 | 44.8 | 75.6 | 117.3 | 112 | 229.6 |

Figure 1. Incidence rates of end-stage renal disease by year and population.

KPSC = Kaiser Permanente Southern California.

hazards models for ESRD demonstrated that higher eGFR (hazard ratio [HR] = 0.57, 95% confidence interval [CI] = 0.53-0.62 for every 5-unit increase), male sex (HR = 0.58, 95% CI = 0.36-0.93), and older age at first eGFR (HR = 0.80, 95% CI = 0.74-0.87 for every 5-year increment) were associated with a reduced hazard for ESRD. Proteinuria was a substantial risk factor for ESRD in these models (HR = 5.37, 95% CI = 3.35-8.62) in addition to higher Charlson Comorbidity Index scores. Similar associations were seen for all-cause mortality, but higher age at first eGFR and male sex increased the hazard for death, demonstrating a competing risk between death and ESRD (Table 3, available online at: www.thepermanentejournal.org/files/2017/16-143Table3.pdf).

### Urine Studies Performed

Among the study cohort, 1602 individuals (12.9%) had any urine study performed (Table 4, available online at: www.thepermanentejournal.org/files/2017/16-143Table4.pdf) within 180 days of their creatinine measurement. Among the individuals who went for a repeated creatinine measurement, 23.0% had a urine study performed. For those with confirmed CKD (second eGFR < 60 mL/min/m$^2$), the proportion with a urine test of any kind within 180 days of the second eGFR was 31.8%. Among those with confirmed CKD and a repeated eGFR below 45 mL/min/m$^2$, only 44.1% had a urine study of any kind performed. In total, 1619 of the 6980 with a repeated measurement had any urine test of any kind within 180 days of that measurement (Table 5).

### Comparison of Equations

The redistribution of the study cohort based on the initial eGFR calculated using the CKD-EPI equation demonstrated that 4732 individuals (43.5%) would have had a calculated eGFR of 60 mL/min/m$^2$ and higher. Thus, these individuals would not have been captured into the safety program if the CKD-EPI instead of MDRD equation had been used (Table 6, available online at: www.thepermanentejournal.org/files/2017/16-143Table6.pdf). Only 5 of these individuals reached ESRD during our observation period. Thus, the CKD-EPI equation captured 56.5% of the original MDRD-based cohort but still included almost all patients who reached ESRD. With confirmed CKD based on the second eGFR as the predictive outcome, 67.8% of individuals captured by CKD-EPI would have had confirmed CKD compared with 52.3% using MDRD. Furthermore, using a logistic regression model to estimate the area under the receiver operating characteristics curve demonstrated that using the CKD-EPI equation for eGFR has higher validity compared with the MDRD equation (area under the curve = 0.943 vs 0.931, p = 0.025).

## DISCUSSION

We sought to evaluate the impact of a creatinine safety program within the clinical care environment and infrastructure of an integrated health system (Kaiser Permanente). Our study evaluated ESRD outcomes on more than 12,000 individuals with single abnormal creatinine measurements who were captured into the KPSC creatinine safety program. We were able to demonstrate higher ESRD incidence rates among those who were captured into the safety program and still higher among those who had a repeated creatinine measurement. Black race, female sex, and proteinuria were associated with higher risk of ESRD in the safety program cohort. These findings support our assertion that the safety net is useful in identifying and outreaching to a high-risk population. We also found a potential care gap in that most of those who had confirmation of their CKD did not receive a urine study within 6 months. Last, our study findings demonstrated that using the CKD-EPI instead of the MDRD equation would have resulted in substantially fewer people being captured into the safety program while capturing almost all of those who progressed to ESRD.

Determining the added value of this creatinine safety program would validate the current efforts and help pave the way to improve the program moving forward. Most of our safety program population had early-stage CKD; 87% had eGFR in the range of 45 to 59 mL/min/m$^2$. This population is not considered at high risk of ESRD or mortality as are later stages of CKD.[14,24] Our findings demonstrate that a high-risk population for CKD was indeed identified while we were able to track pertinent practice patterns and CKD-related outcomes. The main assumption is that the program will lead to interventions that result in better overall CKD and CKD-related care. Early CKD education and management have been shown to result in improved pre-ESRD and post-ESRD outcomes,[25] and this KPSC safety program was implemented to prevent delays in the diagnosis and treatment of CKD.

The method of screening and diagnosing CKD is an area of uncertainty. Measurement of eGFR is one way of assessing kidney function, but it is usually estimated with equations. KPSC laboratories report the eGFR using the MDRD calculation. However, the MDRD equation has systemic biases in that it was derived from a population already with a diagnosis of CKD.[6,19] It has been described that up to 29% of healthy people had their kidney function underestimated on the basis of the MDRD equation.[6] The CKD-EPI equation derived from people with and without CKD has been demonstrated to be superior to the MDRD equation, especially in the higher ranges of eGFR.[7] This is particularly relevant to our current study cohort in which most patients were initially identified with marginally low eGFR. Furthermore, the CKD-EPI is a better prognosticator of ESRD and mortality outcomes.[8,26] Similar to the findings of our study, the global estimate of CKD was lowered by 24% when CKD-EPI was used instead of the MDRD equation.[8] Although it would identify some patients as having CKD that MDRD would not, the net persons identified with CKD would be less using the CKD-EPI equation.[27] Given our findings, there may be an opportunity to refine the creatinine safety program by using a different eGFR equation. Using the MDRD equation may put the population at risk of overdiagnosis, potentially unnecessarily alarming patients. In addition, it may unnecessarily divert cost and resources from other clinical priorities. Within KPSC, had the CKD-EPI equation been used, 44% fewer individuals would have been contacted by the safety program.

The overall low rate of urine studies among patients with confirmed CKD in our study cohort appears alarming. Among patients with confirmed CKD in our study, only one-third had a urine study performed within six months. However, individuals with proteinuria had five

**Table 5. Study population characteristics by KPSC Creatinine SureNet follow-up groups for estimated glomerular filtration rate (mL/min/$m^2$)[a]**

| Characteristic | < 15 | 15 ≤ 30 | 30 ≤ 45 | 45 ≤ 60 | ≥ 60 | Total | p value |
|---|---|---|---|---|---|---|---|
| Population | 21 (0.3) | 123 (1.8) | 783 (11.2) | 2730 (39.1) | 3323 (47.6) | 6980 (100.0) | |
| Female sex | 9 (42.9) | 58 (47.2) | 409 (52.2) | 1537 (56.3) | 1865 (56.1) | 3878 (55.6) | 0.051 |
| **Age at index date (years)** | | | | | | | |
| Mean (SD) | 51.5 (13.14) | 62.0 (16.65) | 63.8 (13.27) | 53.5 (10.07) | 45.3 (10.66) | 50.9 (12.54) | < 0.001 |
| 18-39 | 5 (23.8) | 11 (8.9) | 33 (4.2) | 209 (7.7) | 894 (26.9) | 1152 (16.5) | |
| 40-64 | 12 (57.1) | 53 (43.1) | 358 (45.7) | 2086 (76.4) | 2316 (69.7) | 4825 (69.1) | |
| 65-85 | 4 (19) | 49 (39.8) | 345 (44.1) | 428 (15.7) | 113 (3.4) | 939 (13.5) | |
| > 85 | 0 (0) | 10 (8.1) | 47 (6) | 7 (0.3) | 0 (0) | 64 (0.9) | |
| **Race/ethnicity** | | | | | | | |
| White, non-Hispanic | 6 (28.6) | 53 (43.1) | 426 (54.4) | 1706 (62.5) | 1706 (51.3) | 3897 (55.8) | < 0.001 |
| Black, non-Hispanic | 4 (19) | 16 (13) | 80 (10.2) | 251 (9.2) | 402 (12.1) | 753 (10.8) | |
| Hispanic | 8 (38.1) | 35 (28.5) | 141 (18) | 367 (13.4) | 721 (21.7) | 1272 (18.2) | |
| Asian, non-Hispanic | 3 (14.3) | 13 (10.6) | 72 (9.2) | 186 (6.8) | 235 (7.1) | 509 (7.3) | |
| Other, non-Hispanic | 0 (0) | 6 (4.9) | 64 (8.2) | 220 (8.1) | 259 (7.8) | 549 (7.9) | |
| **Charlson Comorbidity Index** | | | | | | | |
| 0 | 0 (0) | 2 (1.6) | 77 (9.8) | 1043 (38.2) | 2244 (67.5) | 3366 (48.2) | < 0.001 |
| 1-2 | 9 (42.9) | 59 (48) | 415 (53) | 1369 (50.1) | 967 (29.1) | 2819 (40.4) | |
| ≥ 3 | 12 (57.1) | 62 (50.4) | 291 (37.2) | 318 (11.6) | 111 (3.3) | 794 (11.4) | |
| Any urinalysis laboratory test or procedure | 13 (61.9) | 57 (46.3) | 343 (43.8) | 752 (27.5) | 454 (13.7) | 1619 (23.2) | < 0.001 |
| **Previous comorbidities** | | | | | | | |
| Hypertension | 19 (90.5) | 103 (83.7) | 592 (75.6) | 1121 (41.1) | 727 (21.9) | 2562 (36.7) | < 0.001 |
| Diabetes mellitus | 6 (28.6) | 42 (34.1) | 208 (26.6) | 267 (9.8) | 156 (4.7) | 679 (9.7) | < 0.001 |
| History of systemic lupus | 0 (0) | 0 (0) | 2 (0.3) | 2 (0.1) | 0 (0) | 4 (0.1) | 0.113 |
| Stroke | 4 (19) | 9 (7.3) | 71 (9.1) | 57 (2.1) | 60 (1.8) | 201 (2.9) | < 0.001 |
| Congestive heart failure | 1 (4.8) | 5 (4.1) | 24 (3.1) | 21 (0.8) | 15 (0.5) | 66 (0.9) | < 0.001 |
| **Outcomes** | | | | | | | |
| All-cause mortality | 7 (33.3) | 19 (15.4) | 59 (7.5) | 51 (1.9) | 23 (0.7) | 159 (2.3) | < 0.001 |
| End-stage renal disease | 15 (71.4) | 19 (15.4) | 16 (2) | 5 (0.2) | 1 (0) | 56 (0.8) | |
| **Length of follow-up (years)** | | | | | | | |
| Mean (SD) | 2.1 (1.33) | 3.4 (2.18) | 3.6 (1.87) | 4.0 (2.01) | 4.4 (2.41) | 4.1 (2.22) | < 0.001 |
| Median (IQR) | 1.4 (1.0-3.0) | 3.0 (2.0-4.1) | 3.3 (2.2-4.6) | 3.8 (2.5-4.8) | 4.1 (2.8-5.3) | 3.8 (2.6-4.9) | |
| Range | 0.6-4.6 | 0.8-18.6 | 0.4-18.4 | 0.5-16.5 | 0.3-18.7 | 0.3-18.7 | |

[a] Data are presented as no. (%) unless indicated otherwise.

IQR = interquartile range; KPSC = Kaiser Permanente Southern California; SD = standard deviation.

times greater risk of progressing to ESRD compared with those without proteinuria. Markers of kidney damage such as proteinuria, hematuria, and anatomic abnormalities help define and prognosticate outcomes in CKD.[12,28] Specifically, urine protein studies are recommended to use as a marker to manage CKD.[29] Proteinuria has been associated with worsened cardiovascular outcomes, ESRD, and mortality.[9-11] Although screening for CKD may be controversial, urine testing among patients with CKD is advocated by organizations such as the Kidney Disease Improving Global Outcomes, National Kidney Foundation, and American Diabetes Association.[1,12]

Chronic kidney disease is not always identified in an optimal and timely manner. Overall, there is low patient awareness and low clinician identification and documentation of CKD.[16,17,30] Establishing a diagnosis of CKD is difficult because of a multitude of systemic, physician, and patient-oriented barriers.[31,32] The chronicity needed for diagnosis, the lack of symptoms for many of the patients, and the large volume of laboratory results that flow through the routine clinical practice environment all contribute to a potential care gap leading to missed CKD diagnoses.

Although it appears that the creatinine safety program captures a high-risk population, patients who have severe or more urgent CKD were likely already captured and managed by the KPSC health system. One example is that members who have higher Charlson Comorbidity Index scores are less likely to be captured into the creatinine safety net (unpublished internal data, 2016). Another example is that when the KPSC SureNet program was started in February 2010, we dated our search to laboratory results from January 1997. However, only 13.5% of the safety program cohort was captured in the 13-year period from 1997 through 2009 compared with the remainder that were identified from 2010 through 2014.[18] Already, KPSC has certain infrastructures in place to care for patients with a diagnosis of chronic conditions.[33] Patients who have more obvious manifestations of CKD will more likely utilize the access to care that is readily available for all members. The Complete Care model at KPSC is inclusive of many of the tools and personnel needed to adequately ensure the success of safety nets such as the Creatinine SureNet.[20] It takes advantage of the electronic health records and the integrated health system. It also has a model of being proactive toward patient care at all encounters and levels of care. One example is that the electronic charts have best-practice alerts that populate the screen for clinicians during patient encounters. Clinicians also have a proactive care screen section accessible during visits. The patients can use tools, such as the Internet portal (www.kp.org), to help awareness, communication, and follow-up. These online personal action tools have enabled faster closure of care gaps in KPSC.[34]

### Future Direction of Creatinine Safety Research

Our research is currently funded (Agency for Healthcare Research and Quality, R01HS024437, principal investigator: KND), and we are studying more detailed aspects of care related to the creatinine safety program. Specifically, what are the contributors and barriers from a physician perspective that lead to care gaps and subsequent capture into the safety program? We are in the early stages of studying and identifying systemic, patient, and provider-related factors. Using our current and future findings, we hope to develop and implement preventive strategies to minimize the care gap. We need to continuously reflect on ways to "best cast the safety net" for the betterment of patient care.

## CONCLUSION

Our study found a higher incidence of ESRD among individuals captured into the KPSC creatinine safety program. We found that the CKD-EPI instead of the MDRD equation would have identified 44% fewer individuals for the safety net while capturing almost all patients whose CKD progressed to ESRD. Among patients with confirmed CKD, 68% of patients did not receive urine testing in a timely manner. Although the creatinine safety program has an important role and place in an integrated health system such as Kaiser Permanente, our findings also suggest opportunities to improve CKD care and screening by refining this program. ❖

### Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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### References

1. American Diabetes Association. Executive summary: Standards of medical care in diabetes—2011. Diabetes Care 2011 Jan;34 Suppl 1:S4-10. DOI: https://doi.org/10.2337/dc11-s004.
2. Brosius FC 3rd, Hostetter TH, Kelepouris E, et al; American Heart Association Kidney and Cardiovascular Disease Council; Council on High Blood Pressure Research; Council on Cardiovascular Disease in the Young; Council on Epidemiology and Prevention; Quality of Care and Outcomes Research Interdisciplinary Working Group. Detection of chronic kidney disease in patients with or at increased risk of cardiovascular disease: A science advisory from the American Heart Association Kidney and Cardiovascular Disease Council; the Councils on High Blood Pressure Research, Cardiovascular Disease in the Young, and Epidemiology and Prevention; and the Quality of Care and Outcomes Research Interdisciplinary Working Group: Developed in collaboration with the National Kidney Foundation. Circulation 2006 Sep 5;114(10):1083-7. DOI: https://doi.org/10.1161/CIRCULATIONAHA.106.177321.
3. Chobanian AV, Bakris GL, Black HR, et al; National Heart, Lung, and Blood Institute Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure; National High Blood Pressure Education Program Coordinating Committee. The seventh report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure: The JNC 7 report. JAMA 2003 May 21;289(19):2560-72. DOI: https://doi.org/10.1001/jama.289.19.2560.

4. Fink HA, Ishani A, Taylor BC, et al. Screening for, monitoring, and treatment of chronic kidney disease stages 1 to 3: A systematic review for the U.S. Preventive Services Task Force and for an American College of Physicians Clinical Practice Guideline. Ann Intern Med 2012 Apr 17;156(8):570-81. DOI: https://doi.org/10.7326/0003-4819-156-8-201204170-00008.
5. Saunders MR, Cifu A, Vela M. Screening for chronic kidney disease. JAMA 2015 Aug 11;314(6):615-6. DOI: https://doi.org/10.1001/jama.2015.9425.
6. Rule AD, Larson TS, Bergstralh EJ, Slezak JM, Jacobsen SJ, Cosio FG. Using serum creatinine to estimate glomerular filtration rate: Accuracy in good health and in chronic kidney disease. Ann Intern Med 2004 Dec 21;141(12):929-37. DOI: https://doi.org/10.7326/0003-4819-141-12-200412210-00009.
7. Levey AS, Stevens LA, Schmid CH, et al; CKD-EPI (Chronic Kidney Disease Epidemiology Collaboration). A new equation to estimate glomerular filtration rate. Ann Intern Med 2009 May 5;150(9):604-12. DOI: https://doi.org/10.7326/0003-4819-150-9-200905050-00006.
8. Matsushita K, Mahmoodi BK, Woodward M, et al; Chronic Kidney Disease Prognosis Consortium. Comparison of risk prediction using the CKD-EPI equation and the MDRD study equation for estimated glomerular filtration rate. JAMA 2012 May 9;307(18):1941-51. DOI: https://doi.org/10.1001/jama.2012.3954.
9. Astor BC, Matsushita K, Gansevoort RT, et al. Lower estimated glomerular filtration rate and higher albuminuria are associated with mortality and end-stage renal disease. A collaborative meta-analysis of kidney disease population cohorts. Kidney Int 2011 Jun;79(12):1331-40. DOI: https://doi.org/10.1038/ki.2010.550.
10. Chronic Kidney Disease Prognosis Consortium, Matsushita K, van der Velde M, Astor BC, et al. Association of estimated glomerular filtration rate and albuminuria with all-cause and cardiovascular mortality in general population cohorts: A collaborative meta-analysis. Lancet 2010 Jun 12;375(9731):2073-81. DOI: https://doi.org/10.1016/S0140-6736(10)60674-5.
11. Gansevoort RT, Matsushita K, van der Velde M, et al; Chronic Kidney Disease Prognosis Consortium. Lower estimated GFR and higher albuminuria are associated with adverse kidney outcomes. A collaborative meta-analysis of general and high-risk population cohorts. Kidney Int 2011 Jul;80(1):93-104. DOI: https://doi.org/10.1038/ki.2010.531.
12. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. Kidney Int Suppl 2013 Jan;3(1):1-150.
13. Saran R, Li Y, Robinson B, et al. US renal data system 2015 annual data report: Epidemiology of kidney disease in the United States. Am J Kidney Dis 2016 Mar;67(3 Suppl 1):Svii, S1-305. DOI: https://doi.org/10.1053/j.ajkd.2015.12.015.
14. Go AS, Chertow GM, Fan D, McCulloch CE, Hsu CY. Chronic kidney disease and the risks of death, cardiovascular events, and hospitalization. N Engl J Med 2004 Sep;351(13):1296-305. DOI: https://doi.org/10.1056/nejmoa041031. Erratum in: N Engl J Med 2008;18(4):4.
15. van der Velde M, Matsushita K, Coresh J, et al. Lower estimated glomerular filtration rate and higher albuminuria are associated with all-cause and cardiovascular mortality. A collaborative meta-analysis of high-risk population cohorts. Kidney Int 2011 Jun;79(12):1341-52. DOI: https://doi.org/10.1038/ki.2010.536.
16. de Lusignan S, Chan T, Stevens P, et al. Identifying patients with chronic kidney disease from general practice computer records. Fam Pract 2005 Jun;22(3):234-41. DOI: https://doi.org/10.1093/fampra/cmi026.
17. Plantinga LC, Boulware LE, Coresh J, et al. Patient awareness of chronic kidney disease: Trends and predictors. Arch Intern Med 2008 Nov 10;168(20):2268-75. DOI: https://doi.org/10.1001/archinte.168.20.2268.
18. Sim JJ, Rutkowski MP, Selevan DC, et al. Kaiser Permanente creatinine safety program: A mechanism to ensure widespread detection and care for chronic kidney disease. Am J Med 2015 Nov;128(11):1204-11.e1. DOI: https://doi.org/10.1016/j.amjmed.2015.05.037.
19. Levey AS, Bosch JP, Lewis JB, Greene T, Rogers N, Roth D. A more accurate method to estimate glomerular filtration rate from serum creatinine: A new prediction equation. Modification of Diet in Renal Disease Study Group. Ann Intern Med 1999 Mar 16;130(6):461-70. DOI: https://doi.org/10.7326/0003-4819-130-6-199903160-00002.
20. Kanter MH, Lindsay G, Bellows J, Chase A. Complete care at Kaiser Permanente: Transforming chronic and preventive care. Jt Comm J Qual Patient Saf 2013 Nov;39(11):484-94. DOI: https://doi.org/10.1016/s1553-7250(13)39064-3.
21. Danforth KN, Smith AE, Loo RK, Jacobsen SJ, Mittman BS, Kanter MH. Electronic clinical surveillance to improve outpatient care: Diverse applications within an integrated delivery system. EGEMS (Wash DC) 2014 Jun 24;2(1):1056. DOI: https://doi.org/10.13063/2327-9214.1056.
22. Rutkowski M, Mann W, Derose S, et al. Implementing KDOQI CKD definition and staging guidelines in Southern California Kaiser Permanente. Am J Kidney Dis 2009 Mar;53(3 Suppl 3):S86-99. DOI: https://doi.org/10.1053/j.ajkd.2008.07.052.
23. United States Census Bureau [Internet]. Washington, DC: US Census Bureau; c2016 [cited 2016 Aug 10]. Available from: www.census.gov.
24. Kovesdy CP, Coresh J, Ballew SH, et al; CKD Prognosis Consortium. Past decline versus current eGFR and subsequent ESRD risk. J Am Soc Nephrol 2016 Aug;27(8):2447-55. DOI: https://doi.org/10.1681/asn.2015060687.
25. Kurella Tamura M, Li S, Chen SC, et al. Educational programs improve the preparation for dialysis and survival of patients with chronic kidney disease. Kidney Int 2014 Mar;85(3):686-92. DOI: https://doi.org/10.1038/ki.2013.369.
26. Ku E, Xie D, Shlipak M, et al; CRIC Study Investigators. Change in measured GFR versus eGFR and CKD outcomes. J Am Soc Nephrol 2016 Jul;27(7):2196-204. DOI: https://doi.org/10.1681/asn.2015040341.
27. Rocco MV, Chapman A, Chertow GM, et al; SPRINT Research Group. Chronic kidney disease classification in systolic blood pressure intervention trial: Comparison using modification of diet in renal disease and CKD-epidemiology collaboration definitions. Am J Nephrol 2016;44(2):130-40. DOI: https://doi.org/10.1159/000448722.
28. Sim JJ, Batech M, Hever A, et al. Distribution of biopsy-proven presumed primary glomerulonephropathies in 2000-2011 among a racially and ethnically diverse US population. Am J Kidney Dis 2016Oct;68(4):533-44. DOI: https://doi.org/10.1053/j.ajkd.2016.03.416.
29. de Jong PE, Curhan GC. Screening, monitoring, and treatment of albuminuria: Public health perspectives. J Am Soc Nephrol 2006 Aug;17(8):2120-6. DOI: https://doi.org/10.1681/asn.2006010097.
30. Jolly SE, Navaneethan SD, Schold JD, et al. Chronic kidney disease in an electronic health record problem list: Quality of care, ESRD, and mortality. Am J Nephrol 201;39(4):288-96. DOI: https://doi.org/10.1159/000360306.
31. Gandhi TK, Kachalia A, Thomas EJ, et al. Missed and delayed diagnoses in the ambulatory setting: A study of closed malpractice claims. Ann Intern Med 2006 Oct 3;145(7):488-96. DOI: https://doi.org/10.7326/0003-4819-145-7-200610030-00006.
32. Kanter M. Casting a wider net. Manag Care 2011 Jun;20(6):27-31.
33. Sim JJ, Handler J, Jacobsen SJ, Kanter MH. Systemic implementation strategies to improve hypertension: The Kaiser Permanente Southern California experience. Can J Cardiol 2014 May;30(5):544-52. DOI: https://doi.org/10.1016/j.cjca.2014.01.003.
34. Henry SL, Shen E, Ahuja A, Gould MK, Kanter MH. The online personal action plan: A tool to transform patient-enabled preventive and chronic care. Am J Prev Med 2016 Jul;51(1):71-7. DOI: https://doi.org/10.1016/j.amepre.2015.11.014.

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## Selective Reabsorption

It is clear … that the formation of the urine cannot be explained on the basis of filtration and reabsorption of a fluid of constant and invariable composition. Selective reabsorption or secretion, or both, must be called into play.

— Starling EH, Verney EB. The secretion of urine as studied on the isolated kidney. Proceedings of the Royal Society c1924;B:97.

**Haleakala Sunrise**
photograph

**Jae Lim, MD, PhD**

This photograph was taken from the summit of Haleakala mountain (10,023 ft) on the island of Maui, HI.

Dr Lim is an Otolaryngologist for the Hawaii Permanente Medical Group and enjoys photographing nature in Hawaii. More of his work can be seen at www.lim-photography.com.

# Physicians' Perceptions of Volunteer Service at Safety-Net Clinics

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## ABSTRACT

**Background:** Volunteer physicians are crucial for the operation of safety-net clinics, which provide medical care for uninsured and underinsured populations. Thus, identifying ways to maximize the number of physicians volunteering at such clinics is an important goal.

**Objective:** To investigate the perceptions, motivations, functions, and barriers associated with physician volunteering in four safety-net clinics in San Bernardino County, Southern California, a location of great medical need with many barriers to care.

**Methods:** The study participants are physicians belonging to the Southern California Permanente Medical Group who use a combination of discretionary time (during regular work hours) and personal time in evening and weekend hours to volunteer their services. The experimental design incorporates a mixed methodology: an online survey of 31 physicians and follow-up interviews with 8 of them.

**Results:** Physicians conveyed uniformly positive perceptions of their volunteer service, and most were motivated by humanitarian or prosocial desires. Volunteering also provided a protective "escape hatch" from the pressures of the physicians' regular jobs. Physicians cited few challenges to volunteering. The most common personal barrier was a lack of time. The most common professional barriers were organizational and supply issues at the clinic, along with the patients' social, transportation, and financial challenges.

**Conclusion:** The results suggest that appealing to physicians' values and faith, and highlighting the burnout-prevention qualities of volunteering, may be key to recruitment and retention of volunteer physicians who serve underserved and underinsured populations in community clinics.

## BACKGROUND

The poor state of medical care for the uninsured and underinsured population in the US is a continuing challenge. The full rollout of the Patient Protection and Affordable Care Act in 2014[1] led to a sharp decline in the nationwide uninsured rate in the US, from 18% in the third quarter of 2013 to 11.4% in the second quarter of 2015.[2] More than 36 million people continue to be uninsured, however, and many have no access to government-sponsored health programs like Medicaid and/or to Federally Qualified Health Clinics.[3,4] This group faces numerous health challenges, including poor access to quality health care and increasing rates of chronic, long-term medical conditions.[5-8] These medically uninsured and underserved people, many of whom are undocumented, are the clientele for whom safety-net clinics are designed. Safety-net clinics often operate on small budgets and thus often rely on volunteer physicians.[4,9,10] Despite the ongoing need for safety-net clinics, the number of physicians volunteering at these clinics is declining.[10-12] A nationwide study of volunteer physicians in community clinics in 2000 revealed many barriers to volunteering at safety-net clinics, including administrative burdens; a lack of supplies, equipment, and medical follow-up at the clinics; a lack of social services for patients; patient noncompliance; insufficient time to volunteer; and concerns about malpractice insurance.[13-15] The resulting deficiency in volunteer physicians means that recruitment and retention of volunteers is a pressing concern in such clinics. The problems above are not unique to volunteers in safety-net clinics. Physicians employed directly by community clinics experience many of the same challenges facing volunteers, leading to similar difficulties in recruitment and retention.[16-21]

Many studies have focused on how to recruit and retain employed physicians in community clinics.[16,18-21] One way is to tailor such programs to the physicians' motivations for working with the underserved. Many clinicians working in community clinics are specifically attracted to the missions of such clinics.[16,18-20,22] Curlin et al[23] and Cole et al[18] found that the physicians' faith/religion was a common motivator for working with underserved populations at community clinics, but that aspects of the physicians' personalities (such as the desire to "make a difference") may be of more fundamental importance. Stevenson et al[24] recorded physicians stating that working in community clinics "was the right thing to do" and a source of significant satisfaction. Li et al[25] found that physicians working in community clinics tended to state that such work aligned with their overall values and sense of social justice. Exposure to people from such underserved populations while growing up or during medical training appeared to help physicians avoid developing prejudices toward these populations. This led to an overall attraction to the mission of community clinics. Appealing to these values may be very helpful in physician recruitment to community clinic service. Li et al[25] also determined that group support and being part of a team were key ways that physicians supported each other and avoided burnout. More structured hours, so that working did not intrude upon personal time, also appeared to be helpful.

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One useful theoretical framework for examining the motivation for volunteerism in physicians is that of Clary et al.[26] Their work determined six categories of functions for volunteer activity (Table 1). These functions range from providing tangible career and social benefits to manifesting more pure humanitarianism. Some research[24,27] suggests that volunteering tends to serve a prosocial role, in that it benefits others but not at the expense of oneself. Prior research using focus groups[25] and interviews[23] of physicians employed at community clinics have investigated the reasons behind prosocial career choices of physicians, but studies focusing on volunteer physicians are less common.

To serve the growing population of medically underserved individuals, it is imperative to increase the number of physicians volunteering at safety-net clinics.[28,29] Toward this goal, in this work we examine the perceptions, motivations, functions, and barriers associated with volunteering in safety-net clinics in a population of physicians belonging to the Southern California Permanente Medical Group (SCPMG) in Southern California. Our results may have implications for increasing physician volunteerism as well as for illuminating the motivations and functions for volunteering.

## METHODS

This study uses a mixed-method approach, comprising a survey instrument with Likert-scale responses and additional invited written responses as well as subsequent face-to-face interviews with a semistructured format.

### Survey

#### Survey participants and location

A total of 40 online surveys were distributed to current and past participants in a physician volunteer program supported by SCPMG and its affiliated large health care organization (Kaiser Foundation Health Plan) in Southern California. The physicians volunteer at 3 non-federally funded safety-net clinics and one Federally Qualified Health Clinic that provide both primary and specialty care to underserved and uninsured populations in the area. These clinics are located in an area identified as a Health Professional Shortage Area and a Medically Underserved Area by the US Department of Health and Human Services.[30] This region has also been assigned a high Community Need Index, which measures the number of barriers to care that the population experiences, such as unemployment and inability to acquire insurance.[31] It is also an area with a recent significant increase in chronic medical conditions, such as diabetes and hypertension.[31] The geographic area in this study exemplifies the "inverse care law": "The availability of good medical care tends to vary inversely with the need for it in the population served."[32]

In the physicians' Medical Group, physicians are given various options for the professional enrichment/service aspect of their jobs. One option is volunteering during discretionary time (time during regular work hours devoted to physician education and personal enrichment) at safety-net clinics in the area. Participating physicians typically volunteer one half-day per month, and

**Table 1. Functions of volunteering from Clary et al[26] and frequencies of interview responses**

| Functional categories[26] | Description of functional categories[26] | No. of physicians responding[a] | Total responses, no. (%)[b] | Example respondent answers |
|---|---|---|---|---|
| Values | The individual volunteers to express or act on important values like humanitarianism | 8 | 38 (45) | "It's the right thing to do"<br>"I want to give back"<br>"People need help"<br>"If I don't do it, nobody will"<br>"It's part of my faith"<br>"It was part of my training" |
| Understanding | The volunteer is seeking to learn more about the world or to exercise skills that are often unused | 5 | 6 (7) | "I like seeing patients in different settings"<br>"It makes you think outside the box and you have to be creative, and you are challenged in a different way" |
| Enhancement | One can grow and develop psychologically through volunteer activities | 6 | 15 (18) | "It makes me feel good"<br>"I do it for a selfish feeling" |
| Career | The volunteer has the goal of gaining career-related experience through volunteering | 0 | 0 | |
| Social | Volunteering allows an individual to strengthen his/her social relationships | 3 | 5 (6) | "I do see other volunteers around, so I do have some peer support"<br>"It's nice to hear that they are also kinda struggling with similar things that I am; we encourage each other" |
| Protective | The individual uses volunteering to reduce negative feelings, such as guilt, or to address personal problems | 6 | 20 (24) | "I see it as part of my burnout prevention"<br>"I feel like doing things like volunteering is a coping strategy for my burnout on my regular job"<br>"It keeps me sane" |

[a] n = 8.
[b] n = 84.

some add personal volunteer hours on evenings and weekends. This program contrasts with volunteer programs in prior literature,[28,29] in which volunteer physicians were not compensated for their time at all. Another key component of the program in the current study is that the sponsoring Kaiser Foundation Health Plan assumes responsibility for malpractice liability for all volunteer situations.

### Survey questionnaire development

The survey questions were designed to explore issues relevant to physician volunteers serving in safety-net clinics. The survey included demographic questions, 9 structured attitudinal items rated on a 5-point Likert scale (strongly disagree, disagree, neither disagree nor agree, agree, strongly agree), and the opportunity to provide written comments for each Likert block, for a total of 49 items. Two split-half reliability assessments supported the reliability of the survey ($t_b$ 0.787 and 0.907, respectively; $p < 0.0005$). A Chronbach alpha further demonstrated survey reliability for 8 of the 9 Likert blocks ($\alpha > 0.7$).

### Survey administration

After approval from the University of Phoenix institutional review board, the survey was administered via SurveyMonkey (SurveyMonkey, Palo Alto, CA). A request to participate in the survey, including a link, was e-mailed to all 40 physicians in the volunteer program. The first page of the survey handled informed consent, and completion of the survey demonstrated implied consent. Responses were recorded anonymously; neither e-mail nor Internet Protocol addresses were collected. Thirty-one physicians completed the survey, with most doing so between October 2014 and November 2014.

## Interview

### Interview question development

Follow-up interview questions were derived from an analysis of the survey to further elucidate perceptions underlying the survey responses. The interview schedule addressed personal motivation, personal meaning of volunteer work in the program, and personal and professional challenges to volunteering.

### Interview participants

After the conclusion of the survey, all participants received a letter inviting them to participate in a confidential interview with the first author. Eight of the 40 physicians in the volunteer program agreed to the face-to-face interviews; all 8 confirmed they had also taken the survey. The interviews took place March 2015 to May 2015. The interviewees signed consent forms to be interviewed and recorded; the first author (LM) recorded and transcribed all interviews.

### Data analysis

The first author (LM) analyzed interview transcripts with a general inductive approach using qualitative content analysis. The analysis of questions concerning personal motivation and personal meaning highlighted several themes that aligned with the functional categories of volunteerism proposed by Clary et al.[26] In addition, inductive codes were developed for the questions concerning personal and professional challenges. We recorded the number of physicians who cited each theme or function, as well as the number of times a certain theme or function was cited across all physicians. The patterns of these two sets of numbers were qualitatively quite similar to each other. Data were coded using NVivo software, version 10.2 (QSR International, Melbourne, Australia).

**Table 2. Demographic characteristics of 31 survey participants**

| Variable | Value[a] |
|---|---|
| Sex | |
| Men | 11 (35) |
| Women | 19 (61) |
| Other | 1 (3) |
| Ethnicity (may check more than 1) | |
| Asian/Pacific Islander | 11 (35) |
| Black | 3 (10) |
| Hispanic/Latino | 5 (16) |
| White | 10 (32) |
| Other | 4 (13) |
| Declined to state | 1 (3) |
| Religion | |
| Christian | 18 (58) |
| Hindu | 1 (3) |
| Muslim | 5 (16) |
| Other | 2 (6) |
| None | 4 (13) |
| Declined to state | 1 (3) |
| Relationship status | |
| Committed relationship | 25 (81) |
| Single | 4 (13) |
| Other | 1 (3) |
| Declined to state | 1 (3) |
| Physicians with dependent children in household | |
| Yes | 20 (65) |
| No | 10 (32) |
| Declined to state | 1 (3) |
| Medical specialty | |
| Primary care (family medicine, internal medicine, pediatrics) | 15 (48) |
| Specialist (all others) | 16 (52) |
| Active volunteer currently | |
| Yes | 23 (74) |
| No | 8 (26) |
| Currently volunteering outside volunteer program | |
| Yes | 15 (48) |
| No | 15 (48) |
| Declined to state | 1 (3) |
| Have volunteered before volunteer program | |
| Yes | 26 (84) |
| No | 4 (13) |
| Declined to state | 1 (3) |
| Other variables | |
| Age, median years (range) | 49 (31-66) |
| Median no. hours worked in regular job | 49 |
| Median no. times volunteered | 10 |

[a] Data are no. (%) unless stated otherwise.

## RESULTS

### Survey

Thirty-one of the volunteer physicians (78%) completed the online survey (demographic characteristics in Table 2). Most respondents were women; they were predominantly Asian/Pacific Islander or white; more than 80% identified with some religion; the median age was 49; and more than 60% had dependent children living in their households. There was an equal distribution of primary care physicians and specialists. Approximately 74% were active volunteers who had volunteered an average of 10 times. Of 31 surveyed physicians, 5 volunteered at least partially on weekends and 4 volunteered at least partially at night (periods for which their volunteering hours would not be compensated).

The survey produced remarkably uniform results for perceptions of conditions at the safety-net clinics, with positive views about volunteering. More than 75% agreed or strongly agreed with a variety of positive statements concerning perceptions of conditions at their safety-net clinics, indicating a high degree of trust in clinic leadership, high levels of interactions and engagement with clinic staff, and feeling like a part of the group at the clinic. No more than 17% either disagreed or strongly disagreed with any of these statements.

Survey results also revealed information about the personal motivations of physicians in the program. All of the physicians agreed or strongly agreed that volunteering gives them a sense of personal satisfaction, and 96% of them agreed or strongly agreed that they feel positive about their volunteer experience. Personal faith also played a part in personal motivation, with 81% agreeing or strongly agreeing that volunteering is aligned with their faith (note that almost 84% of respondents identified with a religion). Furthermore, 91% of the physicians agreed or strongly agreed that they plan to continue volunteering in the physician volunteer program, and 80% would recommend the program to others.

Consistent with positive feelings about volunteering and agreement about positive motivations was a corresponding rejection of statements about personal and professional challenges to volunteering. Few of the challenges garnered more than 50% "agree" or "strongly agree" responses. In contrast to the uniformity of responses to positive statements, there was a diversity of opinions about specific challenges to volunteer service. The standout personal challenge was that volunteering takes too much personal time, to which 42% of the participants agreed or strongly agreed. The most commonly cited professional challenges were limited supplies at the clinic (58% agreed or strongly agreed), subpar equipment at the clinic (55% agreed or strongly agreed), and that the patients' social, transportation, and financial challenges impacted medical care (77% agreed or strongly agreed).

In the survey, 4 open-ended questions (associated with Likert blocks) allowed respondents to volunteer written comments. Of 13 comments recorded, 5 were related to motivations for volunteering. Examples include "I find it refreshing to occasionally get away from my normal clinic work setting and offer patients care in a different environment," and "I see many unusual conditions that improve my skills and understanding of disease pathophysiology." Eight of the comments were related to professional (organizational and resource-related) challenges to volunteering, such as "In my opinion, the clinic lacks good leadership," and "Some patients will have needs that I will not be able to provide much for without additional resources." Comments about personal challenges included "I stopped volunteering because I don't have time. My daily clinic is more than enough." These comments aided in the development of questions for the interview section of the study.

### Interview

The interview portion of the study had a 20% response rate. Our interview participants consisted of 5 men and 3 women, with an even split between specialists and primary care physicians (Table 3). All 8 interview participants had previously taken the survey.

**Table 3. Demographic characteristics of 8 interview participants**

| Participant[a] | Sex | Specialty | No. of years volunteering |
|---|---|---|---|
| 1 | Man | Primary care | 4.5 |
| 2 | Man | Primary care | 4 |
| 3 | Man | Primary care | 5 |
| 4 | Man | Specialist | 3 |
| 5 | Man | Specialist | 2.5 |
| 6 | Woman | Primary care | 2.5 |
| 7 | Woman | Specialist | 1 |
| 8 | Woman | Specialist | 1.5 |

[a] All interview participants were current volunteers.

**Table 4. Frequencies and responses for questions about personal challenges to volunteering**

| Challenge | No. of physicians responding[a] | Total responses, no. (%)[b] | Example responses |
|---|---|---|---|
| Time | 8 | 28 (61) | "The time commitment itself is difficult just because I'm so busy"<br>"Very, very difficult for people to volunteer, I mean, constraints, time, money, and whatever" |
| Feeling burned out at regular job | 7 | 16 (35) | "I think it is busier now than ever; we are more overwhelmed"<br>"The practicing physicians [in their regular clinics] are frantically trying to catch up on all of this stuff they can't get done, because we have so much more to do, the computer has made you a slave" |
| Emotional toll | 2 | 2 (4) | "Sometimes, I cannot do anything, of course it gives you a heavy feeling" |

[a] n = 8.
[b] n = 46.

### Personal meaning and motivation for volunteer service

The Volunteer Functions Inventory[26] was used to interpret both the answers to posed questions and the spontaneous statements of the interview participants. All questions were analyzed to tabulate the number of citations of specific functions, and most of the citations were found in two questions: 1) What motivated you to be a volunteer in this program? 2) What does your volunteer work mean to you personally?

The most cited function was Values, defined by Clary et al[26] as "The individual volunteers in order to express or act on important values like humanitarianism" (Table 1). All 8 interviewed physicians cited this function, which had 38 separate survey citations (45% of all function citations). The next most commonly cited function was Protective: "The individual uses volunteering to reduce negative feelings, such as guilt, or to address personal problems." Six interviewees cited this function, with 20 separate citations across all physicians (24% of function citations). Less commonly cited was the Enhancement function: "One can grow and develop psychologically through volunteer activities." Six interviewees also cited this function, but it had only 15 citations across all physicians (18% of the function citations). A smaller number of physicians cited the 3 remaining functional categories (Understanding, Social, and Career), and each of these functions comprised a significantly smaller percentage (< 8%) of the citations across all physicians.

The two most commonly cited functions merit additional analysis. The Values function, in which the physicians are volunteering because such behavior is aligned with their personal values (such as humanitarianism), was defined broadly during the interviews, including statements expressing that volunteering is "doing the right thing," recognizing that "people need help," that volunteer service is "part of my faith," and that prior experience is an influence (eg, "I have always volunteered," "I want to give back," and "it was part of my training"). Personal satisfaction associated with the Values function was seen in a wide variety of statements, including these:

> *"It actually makes me feel like I'm helping someone, and that in itself is really kind of gratifying to me, and also within my faith. It is not required, but it is highly encouraged to help your neighbor."*

Some physicians reported that it was in their moral code to "give back" if they had been recipients of generosity in the past:

> *"I just want to give back. I got so much, so I thought I should give back something. So, it's just, you know, my background is different. … I got people who come out to help me, volunteer people."*

Many physicians stated that volunteering provided benefits that were perceived by the physicians as beyond those that they received from their home clinics (another Values item):

> *"It kind of brings an extra dimension to what work itself is, like, it takes my skills and makes it more than something that I use to earn money."*

Physicians also expressed statements that demonstrated how their volunteer service served the Protective function, which is related to preventing or alleviating negative feelings in one's life. In many cases, physicians stated that volunteering served as a break from their normal duties:

> *"No, the volunteering does not add to the burnout. I'll be honest with you, if I feel burnout, I would not be volunteering. However, it is a positive feedback, it actually helps to alleviate my burden with my regular work."*

### Challenges to volunteering

In addition to illuminating the various functions of volunteering, the interviews also investigated personal (Table 4) and professional (Table 5) challenges associated with volunteering. By far the most common personal challenge cited was time. Physicians expressed statements such as "but you know, we are so busy, with family, with life, with career." Some volunteers noted that often they would rather do something more relaxing than volunteering, such as reading papers, or catching up on professional paperwork during their discretionary time. Many physicians also cited time concerns as a primary reason for feelings of burnout in their regular jobs. Several cited the role of the electronic medical record (EMR) in taking time from patient interactions in their regular clinics (eg, "The computer has made you a slave"). In contrast, many physicians stated that their volunteer time was not as dominated by paperwork and an overwhelming array of responsibilities as their standard duties; as noted in the Protective function analysis above, they found that volunteering served as relief from the stresses of their normal job.

The interviewees cited a large and varied array of professional challenges to volunteering (Table 5). The most commonly cited professional challenge was the organization of the safety-net clinic; all 8 physicians cited this challenge, which accounted for 31% of all the professional challenges cited. Physicians noted that the number of clinic staff was often too small to be effective, the staff lacked adequate training, and follow-up or tracking of patients was inadequate. Additionally, scheduling was sometimes ineffective, with volunteer physicians sitting around with no patients to treat at times, and too many patients at other times ("They called me and said, 'Can you see 6 patients?' and I said, 'Can you get 6 patients in the room?'").

The second most commonly cited professional challenge was problems with supplies at the clinic; 7 physicians cited this challenge, which accounted for 21% of the total. These problems included a lack of supplies for patient care, as well as a lack of EMR and computers. The third most commonly cited professional challenge was the organization at the physician's home medical organization, which administers the volunteer program. This challenge was cited by all 8 physicians and was 19% of the challenge citations. In particular, physicians reported a need for more flexible scheduling from the home medical organization, more incentives to volunteer, and more mentoring for the volunteers. Challenges cited at a smaller rate included problems with the patient population (including noncompliance with medical advice and a lack of money and insurance), and a lack of mental health services, social work, and other specialized procedures at clinics. Two physicians initially stated that there were very few barriers to their volunteering, although they later did cite some challenges.

## DISCUSSION

The results of the combined survey and interviews describe a physician population that is highly motivated and possesses quite positive perceptions about volunteering in safety-net clinics. These results concur with previous studies that show positive perceptions towards volunteering by US physicians,[10,15] as well a commitment of physicians to social justice and the mission of helping underserved populations.[18,23-25]

The physicians in this study reported feeling appreciated at their safety-net clinics, which has been shown to be associated with resilience in community clinics.[9,33] Survey participants indicated that they felt like part of the group when volunteering

**Table 5. Frequencies and responses to questions about professional challenges to volunteering**

| Challenges | No. of physicians responding[a] | Total responses, no. (%)[b] | Example responses |
|---|---|---|---|
| Organization at clinic | 8 | 33 (31%) | "Of course they are short staffed"<br>"Even when I was going every month, my clinic was awful … I was sitting there waiting for patients"<br>"It's antiquated, the way they do things"<br>"They are very inefficient"<br>"But if something is too complex, then they just don't handle it"<br>"I think the biggest challenge these days is the support staff"<br>"The three clinics, four clinics, that I worked at have had varying degrees of understanding about how do you track good care"<br>"They do have not very patient-friendly policies" |
| Supplies in clinic | 7 | 22 (21%) | "Professionally, it gets a little frustrating because the resources that I'm used to having aren't there, so having to work around that and kind of limiting what I can and can't do it is a little bit frustrating"<br>"Well, you have to remember how to work without a computer"<br>"The electronic medical record is not at any of the clinics that I worked at, it would help, actually"<br>"There are no patient education materials that I can give to my patients; I feel that is a very important part of my job. There is just not a process to do that" |
| The relationship between the sponsoring HCO and the clinics | 8 | 20 (19%) | "But maybe making it easier, maybe during lunch hour or something, instead of requiring them to go outside of work, or on a Saturday, or a lot of physicians have families, so if you make it more of a family event, maybe it would be easier for them to do that"<br>"Maybe hearing from those clinics where they get the volunteers, those clinic administrators come and talk to our group here, this is what we did, and this is how you guys are making a difference in our work. That would help"<br>"So I think if we had better relationship between [the sponsoring HCO] and the clinic administration, if there would be a way to help them out"<br>"Somehow if they could make it easier for the physicians to volunteer, I think a lot of people have those good impulses, but I think they see it as a pain, or it is difficult, or they don't have the time, so if there is any way to make it easier."<br>"Just kinda make sure that, sort of, that the environment is ready for what they are going to volunteer to do."<br>"I really do think it should be mandatory for physicians though. Because mine is done during my education time, so I'm already getting paid" |
| Patients (compliance, lack of insurance, money) | 6 | 13 (12%) | "Social issues are always a big deal"<br>"The patients themselves, like anywhere else, you see patients with more problems than other people, you deal with it"<br>"Sometimes the patients are not willing to do what I recommend, which you can't change that, they are adults they have to make their own decisions"<br>"Patients don't have insurance, therefore there is a lot of things I can't give them, they won't be able to afford"<br>"Sometimes they can't pay even the five dollars, they can't get a machine to check their sugars" |
| No barriers | 2 | 10 (9) | "No, no barriers, they make it very simple"<br>"Volunteering is easy, and it is a nice break. It is the easiest part of the week for me"<br>"No, I don't find it challenging. It is a nice break" |
| Lack of services at clinic for patients | 5 | 8 (8) | "If we could have somebody in the clinic to help with finances, it would be like a social worker"<br>"I think, probably the biggest gap out there is good mental health resources, and the kids with attention deficit disorder" |

[a] n = 8.
[b] n = 106.
HCO = health care organization.

and interacting with other providers at the clinic. This finding may be an important indicator of physician wellness, which has been studied in physicians' regular clinics[34] and has been cited as a key factor for other providers who work in community health.[25] Feeling like part of the group is consistent with the Social volunteering function of Clary et al.[26] However, none of the eight interviewed physicians mentioned the Social function in answering questions about personal meaning and motivation. This seemingly contradictory result between the survey and the interviews may imply that although the physicians in our study recognize that the social aspect of volunteering is positive, it is not forefront in their concerns.

**… employed physicians working in community clinics cited many of the same motivations and sources of satisfaction as our current study on volunteer physicians.**

Our surveyed physicians agreed with a wide array of potential motivating factors for volunteering, from personal satisfaction to positive statements about community health (including an admiration for the underserved population) and volunteering being an asset to their professional careers. This result is consistent with that of Stevenson et al,[24] who showed that admiration for the patient population can help sustain physicians working in challenging conditions.

In contrast to the relative agreement in the survey about many different positive factors, there was no such consensus on challenges to volunteering (with the exception of time concerns). As noted above, only 3 of 21 potential challenges listed in the survey produced a majority of agree or strongly agree responses. Indeed, the follow-up interviews identified some physicians who claimed that there were no significant barriers to their volunteering. Previous surveys have cited professional challenges to volunteering[15] similar to those in our survey. However, in agreement with qualitative research by Stevenson et al,[24] physicians in the current study downplayed these challenges in their personal interviews.

Both the survey results and the results of the interviews indicate that the primary motivations and benefits of volunteering for the physicians relate to the Values and Protective functions of Clary et al.[26] The relationship between volunteering and Values is quite logical; in both the survey and the interviews, physicians indicated that volunteering was part of their moral code and often aligned with their faith. An emphasis on personal values and faith is consistent with the results of focus group[25] and interview[23] studies with physicians employed at community health clinics. In particular, Li et al[25] found that employed physicians working in community clinics cited many of the same motivations and sources of satisfaction as our current study on volunteer physicians. Many physicians in our study, like those in the work of Li et al,[25] also had previous experience with underserved populations in their medical training, and had previous experience with volunteering. It should be noted that many of the Value function examples cited by the physicians correspond to prosocial behaviors (ie, behaviors that benefit others, but not at the expense of the self).[24,27] Previous research has suggested that an emphasis on the "prosocial, rather than the purely altruistic" aspect of volunteerism may help recruit and retain volunteers.[27]

Perhaps surprising is the idea, highly cited in the interviews, that volunteering serves the Protective purpose of Clary et al[26]—specifically as protection from feelings of burnout. Prior studies of physician well-being[34] indicate that the parts of physicians' jobs that are most frustrating and tend to lead to burnout are nonmedical, including EMR, documentation, and dealing with regulations. Another large factor in burnout is the need to deal long-term with patients with complicated medical problems or severe illnesses.[35] The present results indicate that volunteering may help alleviate both of these causes of burnout in physicians. Because the volunteer physicians are part-time at the safety-net clinics, they are not responsible for many of the nonmedical duties, so they can focus more on patients (although some do complain about the lack of EMR at the clinics). In prior work, interviews with physicians in Australia revealed that relief from such organizational problems and control over the number of hours worked led to a greater sense of well-being.[24] Because patients at the safety-net clinics are treated on an outpatient basis, the volunteer physicians in our study do not typically have the "heart sink" of long-term follow-up with patients with complicated medical issues.[24] Rather than being difficult owing to spillover of stress or burnout from the physicians' primary clinic, volunteering can serve as an effective relief from work-related pressures for these physicians. Promoting the idea that volunteerism may provide relief or prevention from burnout may also prove useful in recruitment and retention of volunteer physicians.

An important personal challenge to volunteering illuminated by both the survey results and the interviews is time—the intrusion of volunteering on one's personal time and one's time at work to perform nonmedical tasks. Lack of time was one of the most highly agreed challenges on the survey, and the single most highly cited challenge in the interviews. This result is in agreement with prior work with physicians at community clinics.[18] Our results, consistent with those of Li et al,[25] imply that better time management in volunteer programs, including the ability to set one's own hours, may be a key improvement for better recruitment and retention in such programs. Our volunteers, however, perhaps owing to the smaller number of hours worked and the fact that much of this work was part of their discretionary time, do not consider time concerns to render their work unsustainable, in contrast to some of the employed community clinic physicians in Cole et al.[18]

The current study has some limitations that must be noted. Although the survey sample included 75% of the physicians in the volunteer program, those physicians still may not be representative of the physicians of the entire SCPMG, or of physicians in the area as a whole. Because our subjects by definition have already chosen to participate in the volunteer program, they may differ in important ways from physicians who have not chosen to participate; as an obvious example, they may be more highly motivated to volunteer.[33] Also, it is possible that those who volunteer primarily on their personal time may differ in significant ways from those who volunteer during their discretionary (paid) time, but our data do not allow us to break these groups apart from each other. The follow-up interview pool is even smaller than our survey pool. Those who volunteered to be interviewed may differ in systematic ways from those who took the survey but chose not to be interviewed. One may speculate that those with more negative perceptions of the volunteer program may not be comfortable being interviewed, even with the assurance of anonymity. Those who chose to be interviewed also may be more resilient to the challenges of volunteering. Finally, volunteer physicians working in other geographic areas may serve different patient populations, and may face different challenges, so our results should not be overgeneralized.

## CONCLUSION

The results of this study may have implications for the recruitment and retention of physicians at safety-net clinics and for the delivery of medical care to underserved populations in Southern California and beyond. This is a burning issue that has been studied in the context of employed[19-21] and volunteer[28,29] physicians. As noted by Clary and Snyder[36] and documented by Ahmed and Maurana[28] and Shuman et al,[29] recruitment and retention should match the functions that volunteering serves for the volunteer population. An obvious first-order point is that the physicians in the current study have very positive opinions overall of their volunteer experience; this positivity could be made much clearer to potential volunteers for recruitment. In particular, appeals to physicians' sense of values (and perhaps targeted appeals to physicians of different faiths[22]) could draw more physicians to such programs. An additional point that could be made is that volunteering may serve as a crucial "escape hatch" from the stresses of their regular jobs—in other words, volunteering could have a valuable function in burnout prevention. Conversely, given the lack of emphasis that the physicians placed on technical skill and career advancement, stressing these benefits may not be as effective. Direct personal contact may be key in emphasizing the benefits of volunteering to potential new volunteers.[28] It may also be possible to target for recruitment physicians whose personal attributes (eg, faith, prosocial tendencies, a sense of social justice) lend themselves to deriving satisfaction from work with underserved people at community clinics. As suggested by Li et al[25] and Curlin et al,[23] it may be possible to teach such values in medical school, and specifically nurture candidates with these traits and steer them toward participation in community clinics.

Once physicians have joined a safety-net clinic or volunteer program, this study suggests that fostering a sense of being part of the group in the clinic may be a subtle but important factor in increasing physician satisfaction and improving retention; proper mentoring may also be important. Organization at the clinics in our study may need some improvement, although many of the issues at the clinics (including lack of EMR, supplies, pharmaceuticals, and transportation and follow-up for patients) are not easily solvable without significant additional funding.[4] In addition, this study indicates the importance of having regular work time set aside for volunteering. It also may be quite helpful to find ways to keep volunteering from intruding on personal time, as well as to have more effective and efficient scheduling of patients. It is hoped that studies such as this may help organizers structure their volunteer programs to better meet the needs of volunteer physicians, and thus more effectively attract and retain participants. Even with the advent of nationwide health care reform in recent years, the need for safety-net clinics targeted to underserved populations is not diminishing, and may in fact be growing. More work is clearly necessary to recruit physicians to volunteer at such facilities. ❖

### Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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### References

1. Bureau of Primary Health Care, Health Resources and Services Administration. HRSA health center program [Internet]. Rockville, MD: Health Resources and Services Administration; 2014 [cited 2016 Mar 23]. Available from: http://bphc.hrsa.gov/about/healthcenterfactsheet.pdf.
2. Marken S. US uninsured rate at 11.4% in second quarter [Internet]. Washington, DC: Gallup, Inc; 2015 Jul 10 [cited 2016 Mar 23]. Available from: www.gallup.com/poll/184064/uninsured-rate-second-quarter.aspx.
3. Adashi EY, Geiger HJ, Fine MD. Health care reform and primary care—the growing importance of the community health center. N Engl J Med 2010 Jun 3;362(22):2047-50. DOI: https://doi.org/10.1056/nejmp1003729.
4. Katz MH. Future of the safety net under health reform. JAMA 2010 Aug 11;304(6):679-80. DOI: https://doi.org/10.1001/jama.2010.1126.
5. Gertz AM, Frank S, Blixen CE. A survey of patients and providers at free clinics across the United States. J Community Health 2011 Feb;36(1):83-93. DOI: https://doi.org/10.1007/s10900-010-9286-x.
6. Nadkarni MM, Philbrick JT. Free clinics and the uninsured: the increasing demands of chronic illness. J Health Care Poor Underserved 2003 May;14(2):165-74. DOI: https://doi.org/10.1177/1049208903014002002.
7. Nadkarni MM, Philbrick JT. Free clinics: a national survey. Am J Med Sci 2005 Jul;330(1):25-31. DOI: https://doi.org/10.1097/00000441-200507000-00005.
8. Notaro SJ, Khan M, Bryan N, et al. Analysis of the demographic characteristics and medical conditions of the uninsured utilizing a free clinic. J Community Health 2012 Apr;37(2):501-6. DOI: https://doi.org/10.1007/s10900-011-9470-7.
9. Darnell JS. Free clinics in the United States: a nationwide survey. Arch Intern Med 2010 Jun 14;170(11):946-53. DOI: https://doi.org/10.1001/archinternmed.2010.107.
10. Grande D, Armstrong K. Community volunteerism of US physicians. J Gen Intern Med 2008 Dec;23(12):1987-91. DOI: https://doi.org/10.1007/s11606-008-0811-x.
11. Cunningham PJ, Hadley J. Effects of changes in incomes and practice circumstances on physicians' decisions to treat charity and Medicaid patients. Milbank Q 2008 Mar;86(1):91-123. DOI: https://doi.org/10.1111/j.1468-0009.2007.00514.x.
12. Cunningham PJ, May JH. A growing hole in the safety net: physician charity care declines again. Track Rep 2006 Mar;(13):1-4.
13. Isaacs SL, Jellinek P. Is there a (volunteer) doctor in the house? Free clinics and volunteer physician referral networks in the United States. Health Aff (Millwood) 2007 May-Jun;26(3):871-6. DOI: https://doi.org/10.1377/hlthaff.26.3.871.

14. Salinsky E. Necessary but not sufficient?: physician volunteerism and the health care safety net [Internet]. Washington, DC: National Health Policy Forum; 2004 Apr 2 [cited 2015 Apr 4]. Available from: www.nhpf.org/library/details.cfm/2445.
15. Scott HD, Bell J, Geller S, Thomas M. Physicians helping the underserved: the Reach Out program. JAMA 2000 Jan 5;283(1):99-104. DOI: https://doi.org/10.1001/jama.283.1.99.
16. Abayasekara A. Addressing clinician workforce shortages in underserved areas. J Health Care Poor Underserved 2015 Feb;26(1):1-4. DOI: https://doi.org/10.1353/hpu.2015.0027.
17. Abayasekara A, DiPadova P. Key informant interview report [Internet]. McLean, VA: Association of Clinicians for the Underserved; 2014 Dec [cited 2016 Mar 23]. Available from: http://chcworkforce.org/sites/default/files/ACU%20Key%20Informant%20Interview%20Report%20-%20FINAL.pdf.
18. Cole AM, Chen FM, Ford PA, Phillips WR, Stevens NG. Rewards and challenges of community health center practice. J Prim Care Community Health 2014 Apr 1;5(2):148-51. DOI: https://doi.org/10.1177/2150131913501519.
19. Fiscella K, Geiger HJ. Caring for the poor in the 21st century: enabling community health centers for a new era. J Health Care Poor Underserved 2014 Nov;25(4):2044-52. DOI: https://doi.org/10.1353/hpu.2014.0182.
20. Savageau JA, Ferguson WJ, Bohlke JL, Cragin LJ, O'Connell E. Recruitment and retention of primary care physicians at community health centers: a survey of Massachusetts physicians. J Health Care Poor Underserved 2011 Aug;22(3):817-35. DOI: https://doi.org/10.1353/hpu.2011.0071.
21. Wright B, Damiano PC, Bentler SE. Assessing the capacity of Iowa's community health centers to respond to the opportunities and challenges of the Affordable Care Act. J Health Care Poor Underserved 2014 Nov;25(4):2032-43. DOI: https://doi.org/10.1353/hpu.2014.0175.
22. Curlin FA, Dugdale LS, Lantos JD, Chin MH. Do religious physicians disproportionately care for the underserved? Ann Fam Med 2007 Jul-Aug;5(4):353-60. DOI: https://doi.org/10.1370/afm.677.
23. Curlin FA, Serrano KD, Baker MG, Carricaburu SL, Smucker DR, Chin MH. Following the call: how providers make sense of their decisions to work in faith-based and secular urban community health centers. J Health Care Poor Underserved 2006 Nov;17(4):944-57. DOI: https://doi.org/10.1353/hpu.2006.0120.
24. Stevenson AD, Phillips CB, Anderson KJ. Resilience among doctors who work in challenging areas: a qualitative study. Br J Gen Pract 2011 Jul;61(588):e404-10. DOI: https://doi.org/10.3399/bjgp11x583182.
25. Li LB, Williams SD, Scammon DL. Practicing with the urban underserved. A qualitative analysis of motivations, incentives, and disincentives. Arch Fam Med 1995 Feb;4(2):124-33. DOI: https://doi.org/10.1001/archfami.4.2.124.
26. Clary EG, Snyder M, Ridge RD, et al. Understanding and assessing the motivations of volunteers: a functional approach. J Pers Soc Psychol 1998 Jun;74(6):1516-30. DOI: https://doi.org/10.1037/0022-3514.74.6.1516.
27. Bishop JP, Rees CE. Hero or has-been: is there a future for altruism in medical education? Adv Health Sci Educ Theory Pract 2007 Aug;12(3):391-9. DOI: https://doi.org/10.2139/ssrn.2155781.
28. Ahmed SM, Maurana CA. Reaching out to the underserved: a collaborative partnership to provide health care. J Health Care Poor Underserved 1999 May;10(2):157-68. DOI: https://doi.org/10.1353/hpu.2010.0277.
29. Shuman AG, Aliu O, Simpson K, et al. Patching the safety net: establishing a free specialty care clinic in an academic medical center. J Health Care Poor Underserved 2014 Nov;25(4):1810-20. DOI: https://doi.org/10.1353/hpu.2014.0127.
30. Health professional shortage areas (HPSAs) [Internet]. Rockville, MD: Health Resources and Services Administration; 2015 [cited 2016 Mar 23]. Available from: http://bhpr.hrsa.gov/shortage/hpsas/.
31. California hospital medial center. Community benefit report 2014. Community benefit implementation plan 2015 [Internet]. Los Angeles, CA: Dignity Health; 2014 [cited 2016 Mar 23]. Available from: www.dignityhealth.org/stellent/groups/public/@xinternet_con_sys/documents/webcontent/196178.pdf.
32. Hart JT. The inverse care law. Lancet 1971 Feb 27;297(7696):405-12. DOI: https://doi.org/10.1016/s0140-6736(71)92410-x.
33. Grieve S. Measuring morale—does practice area deprivation affect doctors' well-being? Br J Gen Pract 1997 Sep;47(422):547-52.
34. Williams ES, Manwell LB, Konrad TR, Linzer M. The relationship of organizational culture, stress, satisfaction, and burnout with physician-reported error and suboptimal patient care: results from the MEMO study. Health Care Manage Rev 2007 Jul-Sep;32(3):203-12. DOI: https://doi.org/10.1097/01.hmr.0000281626.28363.59.
35. Shanafelt TD, Balch CM, Bechamps GJ, et al. Burnout and career satisfaction among American surgeons. Ann Surg 2009 Sep;250(3):463-71. DOI: https://doi.org/10.1097/sla.0b013e3181ac4dfd.
36. Clary EG, Snyder M. The motivations to volunteer: theoretical and practical considerations. Curr Dir Psychol Sci 1999 Oct;8(5):156-9. DOI: https://doi.org/10.1111/1467-8721.00037.

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## Nourishment

> The interior joy we feel when we have done a good deed
> is the nourishment the soul requires.
>
> — Albert Schweitzer, OM, 1875-1965, French-German theologian, philosopher, and physician

**CME** credits available for this article — see page 128.

**ORIGINAL RESEARCH & CONTRIBUTIONS**

# Implementation and Evaluation of the Safety Net Specialty Care Program in the Denver Metropolitan Area

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## ABSTRACT

**Objectives:** In response to limited access to specialty care in safety-net settings, an integrated delivery system and three safety-net organizations in the Denver, CO, metropolitan area launched a unique program in 2013. The program offers safety-net providers the option to electronically consult with specialists. Uninsured patients may be seen by specialists in office visits for a defined set of services. This article describes the program, identifies aspects that have worked well and areas that need improvement, and offers lessons learned.

**Methods:** We quantified electronic consultations (e-consults) between safety-net clinicians and specialists, and face-to-face specialist visits between May 2013 and December 2014. We reviewed and categorized all e-consults from November and December 2014. In 2015, we interviewed 21 safety-net clinicians and staff, 12 specialists, and 10 patients, and conducted a thematic analysis to determine factors facilitating and limiting optimal program use.

**Results:** In the first 20 months of the program, safety-net clinicians at 23 clinics made 602 e-consults to specialists, and 81 patients received face-to-face specialist visits. Of 204 primary care clinicians, 103 made e-consults; 65 specialists participated in the program. Aspects facilitating program use were referral case managers' involvement and the use of clear, concise questions in e-consults. Key recommendations for process improvement were to promote an understanding of the different health care contexts, support provider-to-provider communication, facilitate hand-offs between settings, and clarify program scope.

**Conclusion:** Participants perceived the program as responsive to their needs, yet opportunities exist for continued uptake and expansion. Communitywide efforts to assess and address needs remain important.

## INTRODUCTION

Limited access to specialty care services for the uninsured and underinsured is a national concern. Up to 25% of visits to community health centers result in medically necessary referrals for care not provided on-site at their facilities.[1] Poor access to specialty care is especially pronounced for the uninsured, who often rely on hospital Emergency Departments for specialized services.[1,2] Although insurance coverage has expanded under the Affordable Care Act, an estimated 23 million people in the US remain uninsured, including undocumented immigrants and those with gaps in insurance coverage.[3] Individuals benefiting from Medicaid expansion also face an increasingly difficult time accessing specialty care. There is an ongoing need to identify ways to increase access to specialty care for underserved populations.

Optimal specialty care access in community health centers focuses on comprehensiveness (bringing services into primary care) and coordination (building relationships with services outside primary care).[4] This integration can occur through development of informal relationships and partnerships with hospitals, contracts with specialists to work on-site, use of telehealth or electronic communication, collaboration with a teaching community, and participation in integrated systems.[5]

Multiple specialty care access programs have been implemented nationally to meet the needs of uninsured and underinsured patients.[6] Specialist consultation can provide information to reduce clinical uncertainty, to increase access to specific procedures, to permit comanagement of complex patients, and to transfer patients from primary to specialty care.[6] Components of specialty care programs include referral hubs, teleconferencing programs, and electronic-consultation (e-consult) programs. Specialty care referral hubs connect safety-net primary care clinics to volunteer specialists and are primarily funded by grants and donated services; many specialists are linked to academic medical centers.[2,7,8] Teleconferencing programs may or may not include direct patient engagement. One example that has been adopted nationally and internationally is the Extension for Community Healthcare Outcomes (ECHO) model, which began as a way to expand access to treatment of hepatitis C in rural communities by allowing primary care clinicians to discuss a patient case with specialists virtually.[9,10] E-consult programs link primary care clinicians in the safety net

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to specialists through secure messaging; some of these programs are limited to electronic exchange, whereas others include referral for face-to-face visits.[11,12]

E-consult systems can reduce the need for in-person specialist visits, expand primary care clinicians' scope of work, and improve aspects of care coordination while maintaining informational value.[13,14] Other potential benefits include improved communication between clinicians and patients, and between clinicians facilitating information transfer and aiding decision-making processes, as well as improved care quality, less travel time, and better timeliness of care.[15] Additional research is needed to assess potential cost savings and to fully evaluate the impact on practice workflow.[16,17] Prescreening through e-consult has been proposed to improve the efficiency and utility of in-person specialty care referrals.[18] Given the potential efficiencies, there have been calls to identify which clinical circumstances lend themselves well to asynchronous e-consult.[6]

Recognizing the need for specialty care access for underserved patients in the Denver, CO, metropolitan area, Kaiser Permanente (KP) Colorado (KPCO) collaborated with the Colorado Health Institute in 2010 to 2011 to conduct a statewide specialty care needs assessment in the Colorado health care safety net, as well as an associated demand study in three metropolitan Denver federally qualified health centers.[19,20]

The needs assessment confirmed barriers to specialty care access, especially for uninsured patients. Access was particularly difficult for neurosurgery, orthopedics, and endocrinology but was impaired for many more medical and surgical specialties.[19] The assessment also identified e-consult as a potentially useful resource for primary care clinicians. Drawing on the findings from the needs assessment and meetings with local existing programs to improve specialty care access, the KP Safety Net Specialty Care Program was launched in March 2013. Also considered in launching the program was the capacity of the KPCO specialty departments to take part in the program, as determined by the Operations Department leadership.

This evaluation describes the program during the first 20 months of implementation, identifies aspects that have worked well and areas for process improvement, and shares lessons learned for other emerging specialty care access programs.

## METHODS

### Evaluation Overview and Study Design

From December 2014 through June 2015, we conducted an evaluation of the Safety Net Specialty Care Program to synthesize and document lessons learned and to identify areas for program development and process improvement. This evaluation received ethical approval from the KPCO institutional review board (CO-12-1840). We used a mixed-methods design, combining descriptive quantitative information with qualitative interviews.

### Setting

A nonprofit integrated health care delivery system, KPCO primarily serves the Denver metropolitan area and north and south of Denver along the Colorado "Front Range." To develop and to implement the program, KPCO collaborated with 3 federally qualified health centers in the Denver metropolitan area: Clinica Family Health Services, Metro Community Provider Network, and Salud Family Health Centers. Together, these centers serve a population of more than 150,000 patients, of which approximately 57,500 are uninsured adults, according to the 2014 Uniform Data System.[21] The 3 centers serve a patient population that includes a sizable number of uninsured migrant, low-income working, and homeless individuals and families.

### Description of the Program

The program includes three components: e-consults, face-to-face visits, and continuing medical education (CME).

#### E-Consults

E-consults are electronic medical consultations between primary care clinicians in the safety net and KPCO specialists, conducted through a clinical messaging portal enabled by a third party and compliant with the Health Insurance Portability and Accountability Act. Consultations are available to primary care clinicians for any uninsured adult patient with a condition relevant to one of the eight participating specialty departments: allergy/immunology, cardiology, dermatology, endocrinology, gastroenterology, ophthalmology, pulmonology, and rheumatology. E-consults are submitted to a specialist on call from the designated department, who then replies electronically.

#### Face-to-Face Visits

When warranted, a specialist may suggest a face-to-face visit from a menu of available services to supplement an e-consult. The menu of face-to-face services addresses selected conditions that can be resolved in the KPCO system and focuses on treatments that can improve a patient's health within approximately 90 days. This care is provided at no cost to the patient; however, referring safety-net practices take responsibility for prescriptions—including injections, infusions, and durable medical equipment—and for arranging transportation for patients. If needed, a face-to-face visit may require 1 or more follow-up visits. After a face-to-face visit, the patients are reconnected to their primary care provider for ongoing health care needs.

#### Continuing Medical Education

As part of the program, KPCO specialty care clinicians provide periodic in-person CME lectures on topics identified by safety-net clinicians. Topics have included new guidelines and best practices on topics such as hepatitis C, preoperation physical examinations, and polycystic ovarian syndrome. This component of the program is not the focus of this article because only 1 CME session took place during the initial 20-month period.

### Community Partners and Staff

The 3 participating safety-net organizations were selected on the basis of their participation in the 2010-2011 needs assessment, leadership support, strong existing relationships with KPCO, geographic proximity to KPCO specialty care centers, and proficiency with electronic medical records, which were needed to capture meaningful, comparable, and accurate information on specialty care referrals.[20] Although having proficiency with electronic medical records was an initial requirement, the e-consult platform does not interface with each safety-net organization's own electronic health record system. Table 1 summarizes the roles and staffing of community partners for the program during the initial 20-month period.

### Administrative Process and Financial Accounting

The program is supported by an ongoing financial commitment from KPCO's Community Benefit and Relations (CB&R) department.

Before launching the program, the CB&R staff identified the secure messaging vendor and facilitated legal, compliance, and information technology security verification. Although specialist physicians are salaried, their departments are reimbursed by KPCO CB&R for physician time dedicated to answering e-consults, with the reimbursement based on the average departmental specialist's salary. Each e-consult, which may include multiple exchanges about the same patient, is reimbursed at the average departmental salary for a 30-minute period. The value of direct care services is based on the Medicare fee schedule, and these services are paid for by CB&R through its Community Medical Financial Assistance program.[22] In-person interpreter services are funded by KPCO CB&R and provided by KP translation services or contracts. The role of Denver-based Colorado Community Health Network as administrator was also supported by KPCO CB&R through grant funding.

### Evaluation Data Collection

All e-consults conducted between November 1, 2014, and December 31, 2014, were retrospectively reviewed to determine the number of exchanges, response time, reason or reasons for the e-consult, specialist's response, and subsequent safety-net primary care provider's response to the specialist. We interviewed a purposive sample of safety-net clinicians and staff, participating KPCO specialists, and patients. Brief interviews also were conducted with key program staff at Colorado Community Health Network and KPCO. All interviews were conducted over the phone, with the exception of one in-person interview with a safety-net clinician at an administrative building. Interviews with clinicians took 10 to 15 minutes and with patients took up to 30 minutes. Interview questions are included in the Sidebar: Interview Guide for Patients and Clinicians in the Safety Net Specialty Care Program Evaluation, available from: www.thepermanentejournal.org/files/16-022Questionnaire.pdf.

Interviews were conducted with 18 of 204 safety-net clinicians (9%) and 3 referral coordinators (1 from each of the safety-net organizations) including physicians, nurse practitioners, and physician assistants. At least 5 clinicians from each of the safety-net organizations were interviewed, including those with high use (on 4 or more occasions), low use (1-3 times using the system), and no experience using the e-consult system. Safety-net clinicians were asked about their decision to use the program, why clinicians might not use the program, how they use the program, usefulness of advice, ability to convey patients' needs and preferences, information that should be included in e-consults, for what types of advice the program is appropriate, patients' hesitations about and experience with face-to-face visits, turnaround time, how the program fits within workflow, and recommendations. Referral coordinators were asked about their role in the system and how referrals work elsewhere in the community.

Twelve of 65 participating KPCO specialists (18%) were interviewed. At least 1 specialist was interviewed from each of the 8 participating departments, and others were interviewed if they were available. Specialists were asked the same questions as safety-net primary care clinicians and were also asked about the quality of questions asked via electronic communication, differences in communication with clinicians within KPCO, whether they had used an alternative form of communication, and potential program expansion.

Ten of 81 patients (12%) who had received at least 1 face-to-face visit were interviewed. Patients were randomly selected within strata representing each specialty department and safety-net organization. Patients were asked about specialty care received before their KPCO visit, concerns about their visit, information

**Table 1. Safety Net Specialty Care Program community partner organizations and roles**

| Organization | Staffing | Role |
|---|---|---|
| Kaiser Permanente Colorado (KPCO) | Administrative staff (0.6 FTE) | Evaluate initial e-consults; ensure that e-consults are addressed promptly; assist with scheduling face-to-face visits; track specialists' time and the cost of direct care visits |
| | Community Benefit and Relations staff (1.5 FTE) | Facilitate communication between safety-net and KPCO leaders and internal and external stakeholders; oversee maintenance of legal, compliance, budgetary, and information technology security issues related to the program |
| | Community Benefit-supported clinician time (0.3 FTE) | Manage communication and relationships with medical leadership and the participating specialty departments |
| | Specialists | Review and respond to incoming e-consults as needed; see uninsured patients for face-to-face visits, when considered necessary |
| Colorado Community Health Network | Administrative staff person (0.4 FTE) | Liaison to all safety-net clinicians; track and summarize e-consults on a monthly basis; help safety-net partners identify topics for continuing education; maintain the contract with NetChemistry Inc, a company based in Newport Beach, CA, which designed the software platform for e-consult exchanges (initially, and then this was transferred to KPCO) |
| Safety-net organizations | Internally defined (physicians, nurse practitioners, physician assistants, and care coordinators) | Clinicians submit questions via e-consult platform to KPCO specialists; in some safety-net organizations, a care coordinator fills out the information in the e-consult platform. An identified person at each safety-net organization coordinates with the KPCO administrative staff person to arrange face-to-face visits |

E-consults = electronic consultations; FTE = full-time equivalent.

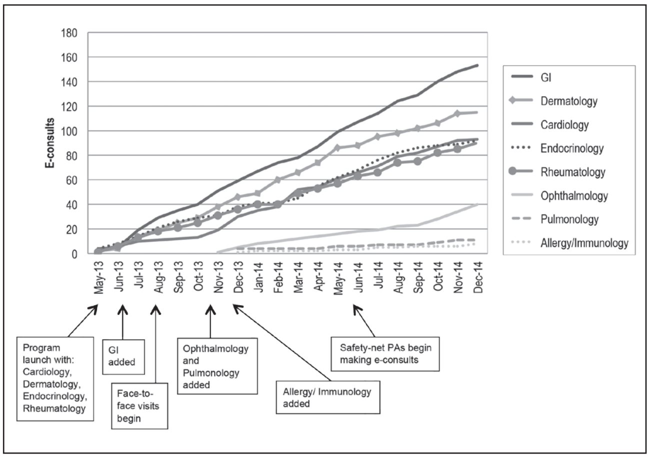

Figure 1. E-consults and program timeline from May 2013 to December 2014.

13 = 2013; 14 = 2014; Aug = August; Dec = December; E-consults = electronic consultations; Feb = February; GI = Gastroenterology; Jan = January; Jul = July; Jun = June; Oct = October; Mar = March; Nov = November; PA = physician assistant.

and arrangements before their visit, interactions with KPCO specialists and staff on the day of their visit, their understanding of the visit process and follow-up plan, care they received afterward, and the extent to which their situation was resolved.

## Data Analysis

We described e-consults by specialty department, by clinician type, and by each clinician. Face-to-face visits were described by specialty department, by safety-net clinic, and by patient characteristics. Two reviewers (MPF and EAB) independently categorized e-consult exchanges and classified e-consults into categories that reflected common primary-specialty care interactions. Differences were resolved through discussion.

Patient interviews were recorded and reviewed for themes and representative quotes.[23] Safety-net clinicians and staff and KPCO specialists were interviewed individually, and detailed notes were taken during interviews. Interview notes were transcribed and coded using a thematic analysis approach aided by qualitative data management software (ATLAS.ti Version 7 for Windows, Scientific Software Development GmbH, Berlin, Germany). The primary coder started the process by closely reading all the transcripts from interviews with clinicians and looking for emerging themes. A codebook was generated and updated after a second reading of all transcripts, and a final codebook was used to code all interviews. A general inductive approach was used to analyze the interviews with clinicians,[24] and the primary categories are described and presented with illustrative quotes in the Results section.

## RESULTS

### Utilization Summary: E-Consults

Between May 2013 and December 2014, 103 of 204 (50%) safety-net clinicians at 23 clinics in the 3 participating organizations used the Safety Net Specialty Care Program. Among those who used the program at least once, the mean number of e-consults by clinician was 5.6, with a range of 1 to 31. During the same period, 65 specialists from the 8 participating specialty departments took part in the program.

Figure 1 illustrates e-consults between the program's launch in May 2013 and December 2014, by participating specialty department. There was a lag time of 2 months, with the first e-consult submitted in May 2013. Of the 602 e-consults, gastroenterology received the most with 153, followed by dermatology, cardiology, endocrinology, and rheumatology, all with 90 e-consults or more, and then ophthalmology, pulmonology, and allergy/immunology. Primary changes to the program during the time period are highlighted.

**Table 2. Characteristics of patients in face-to-face visits, August 2013 to December 2014**

| Patient characteristics | Patients (N = 81)[a] |
|---|---|
| Mean age, years (SD) | 45 (13) |
| **Sex** | |
| Men | 27 (33) |
| Women | 54 (67) |
| **Specialty department visited** | |
| Allergy/Immunology<br>Services available for asthma, allergic rhinitis, food allergy, chronic sinusitis, urticaria | 1 (1) |
| Cardiology<br>Services available for echocardiograms, Holter monitor, event monitor, treadmill, and nuclear treadmill | 17 (21) |
| Dermatology<br>Services available for acute and chronic disorders of the skin, nails, and hair | 3 (4) |
| Endocrinology<br>Services available for hypothyroidism, hyperthyroidism, medication adjustment recommendations for diabetes Types 1 and 2, osteoporosis, hyperparathyroidism, vitamin D deficiency, low testosterone levels | 0 (0) |
| Gastroenterology<br>Services available for select symptomatic and diagnostic colonoscopies | 45 (56) |
| Ophthalmology<br>Services available for cataract evaluation and removal, severe conjunctivitis unresponsive to treatment, severe dry eyes, and pterygium | 13 (16) |
| Pulmonology<br>Services available for chronic obstructive pulmonary disease | 0 (0) |
| Rheumatology<br>Services available for gout | 2 (2) |
| **Interpreter service used during visit** | |
| Yes | 51 (63) |
| No | 30 (37) |
| **Home safety net** | |
| Clinica Family Health Services: Site 1 | 59 (73) |
| Metro Community Provider Network: Site 2 | 17 (21) |
| Salud Family Health Centers: Site 3 | 5 (6) |

[a] Data are presented as no. (%) unless otherwise indicated.
SD = standard deviation.

### Utilization Summary: Face-to-Face Visits

Table 2 summarizes characteristics of patients receiving face-to-face visits between August 2013, when face-to-face visits were initially offered, and December 2014. Table 2 includes the menu of available services for face-to-face visits. During this period, 81 patients were seen at least once and 58 received follow-up visits. Of the 81 patients, 54 (67%) were women, and the average age was 45 years (standard deviation = 13 years). Gastroenterology provided the most visits (n = 45, 56%), followed by cardiology (n = 17, 21%) and ophthalmology (n = 13, 16%). Fifty-one patients (63%) used an interpreter during their face-to-face visit. Most interpretation requests were for Spanish, with additional requests for Cantonese, Mandarin, Nepali, and Vietnamese. An additional 37 individuals were offered appointments but were not seen. Four patients canceled, 4 no longer needed services, 19 were not reachable, 5 declined, 2 did not show up for the appointment, 1 person's records were not received (a requirement before face-to-face care), and 2 became insured through Medicaid and were thus no longer eligible.

### Review of e-Consult Exchanges

Table 3 summarizes the sample of 54 e-consults. On average, there were 2.3 electronic exchanges per consultation. The primary reasons for e-consults were as follows: treatment recommendations (44%), advice about further evaluation (43%), and diagnosis confirmation (41%). Electronic responses from specialists included advice about medication management (41%), continued monitoring (32%), and laboratory evaluation and procedure recommendations (24% each). Of this sample, 22% of patients were recommended for face-to-face visits. Most specialist recommendations were not followed by explicit responses from primary care clinicians. Response time varied by department, with average turnaround time being 3 days at the beginning of the program and 4 days by the end of 2014.

**Table 3. Summary of review of electronic exchanges, November to December 2014**

| Electronic consult (e-consult) factors | E-consults[a] |
|---|---|
| Patients receiving e-consults | 54 (100) |
| Mean number of electronic exchanges | 2.3 |
| E-consults with attached image or chart | 32 (59) |
| **Reason for safety-net provider originated e-consult** | |
| Diagnosis confirmation | 22 (41) |
| Treatment recommendations | 24 (44) |
| Advice about further evaluation | 23 (43) |
| **Specialist response** | |
| Medication management | 22 (41) |
| Continued monitoring | 17 (32) |
| Recommended procedure | 13 (24) |
| Laboratory evaluation | 13 (24) |
| Recommended face-to-face visit at Kaiser Permanente | 12 (22) |
| **Safety-net provider response** | |
| No response | 41 (76) |
| Accepts care plan | 8 (15) |
| Other | 5 (9) |

[a] Data are presented as no. (%) unless otherwise indicated. Percentages do not add to 100 because multiple factors in the same category applied in some e-consults.

### Interview Findings

Table 4 summarizes characteristics of interview participants. The 18 safety-net clinicians had an average of 10.4 years (range = 0.7-26 years) in practice, and the 3 case managers were relatively experienced (range = 4-15 years). The 12 KP specialists had an average of 12.9 years in practice (range = 1-29 years). Three men and 7 women patients were interviewed, averaging 48 years of age (standard deviation = 13 years).

In keeping with the evaluation goal of informing process improvement, we identified the following primary themes from interviews with clinicians and patients: the program's responsiveness to a need in the community, how and why the program is being used, the patient experience, and specific areas for process improvement.

### Responsiveness to Community Need

Both clinicians and patients agreed that the program responds to a defined need. A safety-net primary care clinician said: "*Knowing what the next steps are for diagnosis and workup [is important]. … The face-to-face visits completely change the patients' lives. They have the workup and diagnosis that never would have been possible without a face-to-face visit.*" A referral case manager at a safety-net organization commented: "*We don't have anyone who will see our uninsured patients. … It is great for [the] doctors and especially the patients.*"

**Table 4. Characteristics of interview participants: patients, safety-net primary care clinicians and staff, and Kaiser Permanente specialists**

| Characteristic | Safety-net clinicians and staff (n = 21) | Kaiser Permanente specialists (n = 12) | Patients (n = 10) |
|---|---|---|---|
| **Sex, no. (%)** | | | |
| Men | 6 (29) | 9 (75) | 3 (30) |
| Women | 15 (71) | 3 (25) | 7 (70) |
| Mean age, years (SD) | — | — | 48 (13) |
| Mean years in practice (SD) | 10 (9) | 13 (9) | N/A |
| **Primary care clinician type, no. (%)** | | | |
| Physician (MD, DO) | 11 (53) | N/A | N/A |
| Midlevel (NP, PA) | 7 (33) | NA | N/A |
| Referral case managers | 3 (14) | N/A | N/A |
| **Specialty department, no.** | | | |
| Allergy/Immunology | N/A | 1 | 1 |
| Cardiology | N/A | 1 | 2 |
| Dermatology | N/A | 2 | 1 |
| Endocrinology | N/A | 1 | 0 |
| Gastroenterology | N/A | 3 | 3 |
| Ophthalmology | N/A | 1 | 3 |
| Pulmonology | N/A | 1 | 0 |
| Rheumatology | N/A | 2 | 1 |

DO = doctor of osteopathy; MD = medical doctor; N/A = not applicable; NP = nurse practitioner; PA = physician assistant; SD = standard deviation; — = not collected.

For KPCO specialists, the program is seen as rewarding and an opportunity to feel like they are making a difference in the community. One said: "*It is really nice to do this kind of work. The patients are very appreciative. They are so grateful. You feel like you are really doing something good with this program*."

Patients described having limited options in accessing specialty care and that specialty care services were prohibitively expensive: "*I did not have money, I did not have insurance. … I was falling into a depression, and they took me out of it.*"

### Program Applications

Safety-net primary care clinicians found the e-consult portion of the program to be useful for interpreting results, defining next steps for diagnosis and additional tests, reassuring that they were on track, referring patients for procedures, and as an alternative to in-person specialty care referrals. In addition to seeking advice, primary care clinicians used the program with the hope of having patients be seen for a face-to-face visit if needed. A safety-net primary care clinician said: "*Typically there is a plan. Either the consultant confirms diagnosis, or [s/he] would tell us: 'You might think about this—Plan A if B, or otherwise try this.' They have sent a plan to follow that I have used prior to going back for more advice. Including 1 to 2 steps in the future is quite useful.*"

Primary care clinicians were conscious of their patients' limited resources, and the e-consult exchange in some cases provided them assurance that they need not refer their patients to a specialist. A safety-net clinician stated: "*It gives us a little more assurance if something is necessary vs unnecessary. It reduces the financial risk to [the patients].*" Another safety-net clinician remarked that the e-consult was sufficient and a patient did not have to be seen for a face-to-face visit: "*I got really good advice. We got the patient on [medications], and so [s/he] didn't need to be seen.*"

Safety-net primary care clinicians also described factors detracting from use of the program. These included time required to complete the e-consult, limited knowledge about the program, the added step to log into the system, considering a phone call or face-to-face visit to have more value, ability to have their questions answered elsewhere, uncertainty about patient eligibility, patients' increased access to Medicaid (making them ineligible for the program), and patient needs beyond the scope of the program. One safety-net clinician who had used the program on multiple occasions mentioned technology challenges: "*Getting data to a specialist can be challenging. I have to take a photo, send it to my work e-mail, download it to my desktop, and then put it into e-consult.*"

Neither e-consults nor direct specialty care fully addressed the lack of resources in caring for safety-net patients. For example, one specialist mentioned that his/her advice in some cases might not be applicable, such as "*when we ask for imaging or [laboratory studies] that the patient can't afford to pay for.*" A safety-net clinician described the limitations of the face-to-face menu of services in the program: "*The response was 'the patient just needs surgery', but that is not an option [financially]. … Sometimes there is a disconnect.*"

### Aspects Facilitating Program Use

Safety-net clinicians made several suggestions to improve program efficiency. For example, one safety-net system uses referral case managers to improve e-consult referral efficiency; the primary care clinician flags a patient's chart in the internal medical records system, and a referral case manager submits the e-consult. After proving effective at one clinic, this process was extended to all clinics in that safety-net organization. A safety-net clinician observed how the e-consult program has become a part of the workflow: "*It is now part of our regular referral process, so it has improved.*" Another clinician described the time savings of having referral case managers put information into the KP system as "life-changing."

Safety-net clinicians also emphasized the importance of clear clinical questions to optimize e-consult communication and including the program as a part of training for new clinicians to encourage their use of the system. A safety-net clinician said: "*I try to ask a pointed clinical question. I try to be very specific, and that is probably why I get a detailed response.*"

### Department-Specific Use

Demand for e-consult and face-to-face care differed by department. Gastroenterology experienced the most requests for face-to-face care, primarily for procedures. "*We do not get so many questions. We get a lot of cases where they just need a 'scope.'*" The Ophthalmology Department also focused on face-to-face visits: "*For Ophthalmology, typically the primary care clinician does not treat the patient. They do not ask how to treat the patient. In the e-consults, they describe the patient in great detail and then add a picture. I would not personally make treatment recommendations third hand. I would not treat without seeing the patient in person.*" Cardiology also experienced a relatively large number of e-consults that resulted in face-to-face visits.

By viewing images attached to e-consults, Dermatology provided primarily electronic advice, supplemented by a few face-to-face visits for dermatologic procedures. Likewise, Endocrinology and Rheumatology provided primarily electronic advice through e-consults. Rheumatology recommendations were limited somewhat by high medication costs. A Pulmonology Department specialist considered chest-imaging review via e-consult to be the most appropriate use of the program for that department.

Turnaround time for e-consults also varied by department. One KP specialist pointed out: "*It depends on the department, almost everything in [endocrinology] is not acute. We try to reply in 24 hours. For [cardiology], sometimes it probably needs to be in less time.*"

### Volume and Potential to Expand

Many specialists believed there was room to expand the program beyond the current volume of e-consults; however, this perception varied by department, with high-volume or lower-staff-ratio departments expressing interest in maintaining the program at its current size. Safety-net clinicians commented that expansion to other specialties would be beneficial, specifically mentioning Neurology and Orthopedics.

### The Patient Experience

Overall, patients reported positive experiences in face-to-face visits with specialists and the KPCO system. They expressed gratitude recognizing that the cost of services would have been too expensive had they tried to obtain care elsewhere. Logistic challenges were mitigated by providing patients with information on system and visit navigation ahead of time and providing in-person or phone-based language interpreters. Transient logistic challenges that were subsequently resolved included a "no show" of an interpreter and incorrectly being charged for care.

When asked about other options, patients reported that they did not have other options for obtaining specialty care. An Ophthalmology Department patient stated: *"The operation was very expensive. … I didn't have the money. … [My eyes] really bothered me. … It would have cost me around $10,000, and they did it for free. I am really happy."*

Definitive tests were considered very beneficial. One patient remarked: *"One simple study makes the difference between being okay or not."* In some cases patients' health issues were not resolved after their face-to-face visit; some sought care elsewhere afterward, and others described an ongoing need for care. A number of patients expressed hope or the expectation of being seen again by a KPCO specialist in the short or long term.

### Areas for Process Improvement

Both specialty and primary care clinicians identified areas for process improvement.

#### Different Contexts

Given the differences in health care delivery contexts, both KPCO specialists and safety-net primary care clinicians believed that increased sharing of information about each other's expectations and limitations could increase the value of specialty recommendations. Specifically, clinicians mentioned that sharing internal KPCO specialty guidelines and clarifying available on-site resources at the safety nets would be helpful.

A safety-net clinician said: *"I know from providers who work within the KPCO system that there are guidelines: after you do this—x, y, and z—then you can make a referral. It would be helpful to know them. Potentially, if those internal standards were shared with us, it might be useful."* A parallel comment from a KPCO specialist included the need for *"providing more information to specialists about where community health center providers are coming from, what resources they have access to, [and] what training they have (eg, if they know how to do a biopsy), to know what kind of advice to give them and what to ask them to do. … Also, it would be good to know, do they have pathology services available?"*

#### Clinician-to-Clinician Communication

Some KPCO specialists were uncertain about the usefulness of their advice because of limited feedback from safety-net primary care clinicians. One KPCO specialist commented: *"With the e-consults, I have not received communication back. I have not received any feedback. I assume that they get the answer, and that is what they need. It is more of a question-and-answer communication."* Some safety-net clinicians wished for feedback regarding the quality of submitted e-consults. Specialists believed that the questions were appropriate and comparable to the kinds of questions that they received from KPCO primary care clinicians.

Back-and-forth exchanges in an e-consult could also be seen as inefficient. A KPCO specialist recommended: *"Just look at it once instead of the back-and-forth. Then we have to follow-up to ask about the specifics. 'Oh, did you ask this?' The exchanges take a lot of time."* Another specialist said: *"I think it may almost be better to do a phone call than to do the back-and-forth over e-mail since that can be cumbersome. I wonder whether maybe telephone advice or a telephone consultation line wouldn't be better."* Several KPCO specialists mentioned that they had used the phone to communicate, whereas others had left their numbers but had not received calls.

#### Patient Hand-off and Ownership

Although patients received information on navigating the KPCO system, pre- or postvisit information did not always make it to the safety-net clinicians. *"For one, the patient was supposed to go for a face-to-face [visit], but there were difficulties with communication, and I am not sure what happened. It was for an [echocardiogram], and I am not aware of the patient going."* In a different situation, a safety-net primary care clinician said: *"I just received [laboratory] results. The patient may or may not have received something. I was looking for a specialist's plan. It is good for me to see a note, … and it looks bad if I see the patient again and I don't know what was recommended."* In another example, a safety-net clinician commented: *"The patient came back and shared information with me. Over the e-consult program I received a message 'We will see this patient for a face-to-face visit' and then nothing came back afterward, or at least not that I am aware of."*

These logistic challenges were seen as similar to referrals elsewhere in the community: *"You get a message, 'Your patient will be seen for a face-to-face' [visit] … . There is not good communication around [when] your patient has an appointment, and then, what [happens] next? It is one of the more frustrating parts of the program—not knowing what happens from there. In the community, with other specialists, it is difficult across the board."* One solution suggested by a safety-net clinician was as follows: *"A point person at my clinic could help, or having something in the system with the status, for example, if the patient has been contacted or not."*

#### Program Scope and Processes

Both safety-net clinicians and KPCO specialists expressed uncertainty about patient eligibility, the process for having a face-to-face visit, and the specific services that could be offered during a face-to-face visit. One safety-net clinician recommended: *"There is nothing in the [e-consult] system about how to initiate a face-to-face visit. More specific information and a step-by-step process of this would be helpful."* Another clinician suggested: *"I would recommend sharing how often patients get a face-to-face [visit]. It makes it more hopeful for us."* A KPCO specialist was somewhat uncertain about qualifying services for a face-to-face visit: *"The challenge was when it was converted to a face-to-face [visit]. E-mails are helpful, about 90% can be done via e-mail—can be taken care of that way. I can do a face-to-face appointment and get a history and do a physical [examination], but after that, getting anything else is what I can't guarantee."*

## DISCUSSION

This partnership between an integrated delivery system and 3 safety-net organizations illustrates a novel approach to providing specialty care services to uninsured individuals in the Denver area. Although the scope of the Safety Net Specialty Care Program was limited by a finite menu of services and specialties, lessons learned from the first 20 months' experience will inform program expansion and can be applied to other specialty care/safety-net partnerships.

The evaluation showed a number of positive aspects. For several of the specialty departments, such as dermatology, endocrinology, and rheumatology, there were a large number of e-consults and a small number of face-to-face visits that occurred. As such, the e-consult platform presented an alternative to referring patients for in-person appointments with a specialist. Before the program, uninsured patients at the three safety-net organizations did not have a defined mechanism for receiving face-to-face specialty care, at no cost, for the menu of services in the eight participating departments.

**… the e-consult platform presented an alternative to referring patients for in-person appointments with a specialist.**

Findings from this evaluation suggest several possible dimensions for program improvement and expansion. There is room for expansion in participating specialty departments and the menu of services for face-to-face visits. Other safety-net organizations, specialties, and services may wish to adopt e-consults. Because only half of eligible safety-net primary care clinicians used the program, there is potential for continued program uptake. Uptake may be facilitated by having clinicians share information on program efficiencies (eg, referral case managers) and by acting on recommendations for process improvement (eg, communication about care delivery contexts). More facile communication between clinicians and systems will help build professional relationships—a process that should become self-enhancing. Increased comfort with, and investment in, the e-consult system should prompt ongoing communication about the program's scope.

The biggest challenge for the program is that although it responds to a defined community need and hopes to expand, it is neither designed for nor capable of resolving all specialty care needs. On an individual level, the current menu of services has limitations, and goals for expansion are unlikely to be easily or completely resourced. The limited scope affects not only uninsured patients who do not meet clinical eligibility criteria but also safety-net patients whose Medicaid insurance disqualifies them from program access. Specialty care needs for Medicaid patients have been highlighted by the Medicaid expansion under the Affordable Care Act and remain a community concern.[25] Community-facing delivery systems, such as KPCO, have an opportunity to collectively address specialty care gaps. One effective mechanism may be through regional health alliances focused on improving specialty care access for underserved populations. For example, a safety-net specialty care initiative in California required that grant recipients build on existing collaborative efforts or form coalitions, recognizing that addressing specialty care access requires the involvement of multiple institutions in the community.[26]

This experience offers a number of lessons for organizations interested in implementing similar programs. Factors considered to be essential to the program's launching and continued implementation include support from KPCO leadership; dedicated administrative staff time; approval from KPCO Legal, Compliance, and Information Technology Security departments; engaged specialists and safety-net clinicians; established working relationships with safety-net partners; a secure messaging vendor and e-consult platform; and proficiency with electronic medical records. Factors that enabled success were communication about the program and support within departments and safety-net sites, a defined menu of services, and the use of referral case managers in some safety-net settings. Factors that limited uptake include inadequate clinician awareness of the program, the need to log on to another site, and confusion about the scope of the program and which cases are eligible.

This evaluation has a number of limitations. Interviews were conducted with a small number of individuals because of the scope of the evaluation, and this article represents only the perspectives of clinicians and patients who were interviewed. Safety-net primary care clinicians who had not used the e-consult system were underrepresented relative to those who had used the system; their insights may have been particularly useful on how to increase uptake. The three participating safety-net organizations are all federally qualified health care centers and are the largest safety nets in the Denver metropolitan area unaffiliated with the integrated Denver Health and Hospitals system; smaller safety-net practices may have different e-consult and referral patterns, and they may have fewer staff or resources necessary to streamline successful adoption of the program, such as referral coordinators. The evaluation was not structured with a comparison group as it is offered to all clinicians and all eligible patients at the three participating safety-net organizations. Unresolved issues were identified during interviews with patients; however, this information was not captured for all patients who received face-to-face visits. In the future, follow-up interviews with each patient after their care experience would be a way to quantify the extent to which unresolved issues affect patients. There are a number of additional aspects that will be important to evaluate in the future, including patient outcomes, the extent to which Emergency Department utilization is reduced, and the CME portion.

This evaluation raises new operational questions for specialty care programs. For example, it will be important to ask how to most efficiently meet the demand for procedural face-to-face visits, ensure that e-consults are focused on consultative questions that substitute for visits rather than procedure requests, and minimize time-consuming technology-related hassles such as logging onto the e-consult system.[2] It will also be crucial to identify and assess new collaborations that can provide hospital and inpatient services as part of specialty care for safety-net patients. Finally, ongoing, community-based, specialty care needs assessments are important to identify high-priority areas for future intervention.

## CONCLUSIONS

To our knowledge, the Safety Net Specialty Care Program is one of the first examples nationally of an integrated delivery system partnering with safety-net clinics to offer specialty care and is one of a small number of programs using a combination of e-consults and face-to-face visits. This combination offers a new approach to offer specialty care advice to safety-net clinicians and needed specialty care services for uninsured patients. Key process improvement recommendations from the first 20 months of implementation are to understand the difference in context between the specialty care and the safety-net settings, to support communication and relationship building between clinicians, to identify ways to make hand-offs between settings smoother, and to clarify program scope. Although the program meets the needs of some patients with limited access to specialty care services, ongoing participation in communitywide efforts to evaluate and to address continued needs remains important. ❖

## Disclosure Statement

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## References

1. Cook NL, Hicks LS, O'Malley AJ, Keegan T, Guadagnoli E, Landon BE. Access to specialty care and medical services in community health centers. Health Aff (Millwood) 2007 Sep-Oct;26(5):1459-68. DOI: https://doi.org/10.1377/hlthaff.26.5.1459.
2. Hall MA. Organizing uninsured safety-net access to specialist physician services. J Health Care Poor Underserved 2013 May;24(2):741-52. DOI: https://doi.org/10.1353/hpu.2013.0076.
3. Summer L. The impact of the Affordable Care Act on the safety net [Internet]. Washington, DC: AcademyHealth; 2011 Apr [cited 2016 Jun 6]. Available from: www.academyhealth.org/files/FileDownloads/AHPolicybrief_Safetynet.pdf.
4. Olayiwola JN, Bodenheimer T, Dubé K, Willard-Grace R, Grumbach K. Facilitating care integration in community health centers: A conceptual framework and literature review on best practices for integration into the medical neighborhood [Internet]. San Francisco, CA: UCSF Center for Excellence in Primary Care; 2014 Mar [cited 2016 Jun 6]. Available from: www.blueshieldcafoundation.org/sites/default/files/publications/downloadable/BSCF_Facilitating_Care_Integration_Mar_2014.pdf.
5. Neuhausen K, Grumbach K, Bazemore A, Phillips RL. Integrating community health centers into organized delivery systems can improve access to subspecialty care. Health Aff (Millwood) 2012 Aug;31(8):1708-16. DOI: https://doi.org/10.1377/hlthaff.2011.1261.
6. Kirsh SR, Ho PM, Aron DC. Providing specialty consultant expertise to primary care: An expanding spectrum of modalities. Mayo Clin Proc 2014 Oct;89(10):1416-26. DOI: https://doi.org/10.1016/j.mayocp.2014.04.016.
7. Spatz ES, Phipps MS, Wang OJ, et al. Expanding the safety net of specialty care for the uninsured: A case study. Health Serv Res 2012 Feb;47(1 Pt 2):344-62. DOI: https://doi.org/10.1111/j.1475-6773.2011.01330.x.
8. Shuman AG, Aliu O, Simpson K, et al. Patching the safety net: Establishing a free specialty care clinic in an academic medical center. J Health Care Poor Underserved 2014 Nov;25(4):1810-20. DOI: https://doi.org/10.1353/hpu.2014.0173.
9. Arora S, Thornton K, Murata G, et al. Outcomes of treatment for hepatitis C virus infection by primary care providers. N Engl J Med 2011 Jun 9;364(23):2199-207. DOI: https://doi.org/10.1056/NEJMoa1009370.
10. University of New Mexico School of Medicine; Project ECHO. Project ECHO: A revolution in medical education and care delivery [Internet]. Albuquerque, NM: Project ECHO; c2016 [cited 2016 Jun 6]. Available from: http://echo.unm.edu/.
11. Chen AH, Kushel MB, Grumbach K, Yee HF Jr. Practice profile. A safety-net system gains efficiencies through "eReferrals" to specialists. Health Aff (Millwood) 2010 May;29(5):969-71. DOI: https://doi.org/10.1377/hlthaff.2010.0027.
12. Scheibe MM, Imboden JB, Schmajuk G, et al. Efficiency gains for rheumatology consultation using a novel electronic referral system in a safety-net health setting. Arthritis Care Res (Hoboken) 2015 Aug;67(8):1158-63. DOI: https://doi.org/10.1002/acr.22559.
13. Bergus GR, Emerson M, Reed DA, Attaluri A. Email teleconsultations: Well formulated clinical referrals reduce the need for clinic consultation. J Telemed Telecare 2006;12(1):33-8. DOI: https://doi.org/10.1258/135763306775321434.
14. Palen TE, Price D, Shetterly S, Wallace KB. Comparing virtual consults to traditional consults using an electronic health record: An observational case-control study. BMC Med Inform Decis Mak 2012 Jul 8;12:65. DOI: https://doi.org/10.1186/1472-6947-12-65.
15. Rodriguez KL, Burkitt KH, Bayliss NK, et al. Veteran, primary care provider, and specialist satisfaction with electronic consultation. JMIR Med Inform 2015 Jan 14;3(1):e5. DOI: https://doi.org/10.2196/medinform.3725.
16. Vimalananda VG, Gupte G, Seraj SM, et al. Electronic consultations (e-consults) to improve access to specialty care: A systematic review and narrative synthesis. J Telemed Telecare 2015 Sep;21(6):323-30. DOI: https://doi.org/10.1177/1357633X15582108.
17. Kim Y, Chen AH, Keith E, Yee HF Jr, Kushel MB. Not perfect, but better: Primary care providers' experiences with electronic referrals in a safety net health system. J Gen Intern Med 2009 May;24(5):614-9. DOI: https://doi.org/10.1007/s11606-009-0955-3.
18. Mehrotra A, Forrest CB, Lin CY. Dropping the baton: Specialty referrals in the United States. Milbank Q 2011 Mar;89(1):39-68. DOI: https://doi.org/10.1111/j.1468-0009.2011.00619.x.
19. Colorado Health Institute; Center for the Study of the Safety Net. 2010 Colorado safety net specialty care assessment: Final report [Internet]. Denver, CO: Colorado Health Institute; 2011 Mar [cited 2016 Jun 6]. Available from: www.coloradohealthinstitute.org/uploads/downloads/2010_SpecialtyCare.pdf.
20. 2010 Colorado specialty care demand study: Final report [Internet]. Denver, CO: Colorado Health Institute; 2011 [cited 2016 Oct 13]. Available from: www.coloradohealthinstitute.org/key-issues/detail/safety-net-1/2010-colorado-safety-net-specialty-care-assessment-final-report.
21. 2014 Health Center Data: Colorado Program Grantee Data [Internet]. Rockville, MD: Health Resources and Services Administration. US Department of Health and Human Services; 2014 [cited 2016 Oct 13]. Available from: http://bphc.hrsa.gov/uds/datacenter.aspx?q+d&year=2014&state=CO#glist.
22. Fee schedules—general information [Internet]. Baltimore, MD: Centers for Medicaid and Medicare Services; 2015 May 19 [cited 2016 Jun 6]. Available from: www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/FeeScheduleGenInfo/index.html.
23. Neal JW, Neal ZP, VanDyke E, Kornbluh M. Expediting the analysis of qualitative data in evaluation: A procedure for the rapid identification of themes from audio recordings (RITA). Am J Eval 2014 May 27;36(1):118-32. DOI: https://doi.org/10.1177/1098214014536601.
24. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. Am J Eval 2006 Jun;27(2):237-46. DOI: https://doi.org/10.1177/1098214005283748.
25. Felland LE, Lechner AE, Sommers A. Improving access to specialty care for Medicaid patients: Policy issues and options [Internet]. New York, NY: The Commonwealth Fund; 2013 Jun 6 [cited 2016 Jun 16]. Available from: www.commonwealthfund.org/publications/fund-reports/2013/jun/improving-access-to-speciality-care.
26. Canin L, Wunsch B. Specialty care in the safety net: Efforts to expand timely access [Internet]. Oakland, CA: California Health Care Foundation; 2009 May [cited 2016 Jun 6]. Available from: www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/PDF%20S/PDF%20SpecialtyCareOverview.pdf.

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# Reducing Unnecessary Postoperative Complete Blood Count Testing in the Pediatric Intensive Care Unit

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## ABSTRACT

**Context:** Complete blood count (CBC) testing commonly occurs to determine the need for blood transfusions after surgical procedures. Many clinicians believe postoperative CBCs are "routine."

**Objective:** To decrease unnecessary routine CBC testing in a low-risk cohort of postoperative patients in the pediatric intensive care unit (PICU) at The Children's Hospital of Philadelphia by 50% in 6 months.

**Design:** Quality-improvement study. Data from our institution regarding frequency of ordering laboratory studies and transfusion requirements were collected for prior quality-improvement work demonstrating the safety and feasibility of avoiding routine postoperative CBCs in this cohort. Baseline survey data were gathered from key stakeholders on attitudes about and utilization of routine postoperative laboratory testing. Patient and clinician data were shared with all PICU clinicians. Simple Plan-Do-Study-Act cycles involving education, audit, and feedback were put into place.

**Main Outcome Measures:** Percentage of postoperative patients receiving CBCs within 48 hours of PICU admission. Balancing measures were hemoglobin level below 8 g/dL in patients for whom CBCs were sent and blood transfusions up to 7 days postoperatively for any patients in this cohort.

**Results:** Sustained decreases below our 50% goal were seen after our interventions. There were no hemoglobin results below 8 g/dL or surgery-related blood transfusions in this cohort within 7 days of surgery. Estimated hospital charges related to routine postoperative CBCs decreased by 87% during 6 postintervention months.

**Conclusion:** A simple approach to a systemic problem in the PICU of unnecessary laboratory testing is feasible and effective. By using local historical data, we were able to identify a cohort of patients for whom routine postoperative CBC testing is unnecessary.

## INTRODUCTION

Prior studies at large academic centers have demonstrated the high cost and high variability of common laboratory testing in the intensive care unit (ICU).[1-3] These costs are reflected not just in dollar amounts but also in resultant anemia. In the pediatric intensive care unit (PICU), blood draws have been shown to account for 73% of daily blood loss and can lead to the need for blood transfusions.[4] These transfusions are associated with greater number of days of mechanical ventilation, longer length of stay in the PICU, increased mortality, and cardiorespiratory dysfunction.[4] Other institutions have demonstrated that a focused educational effort on current utilization of common laboratory testing can result in decreased utilization in a safe manner.[5-7] In postoperative pediatric cardiac patients, interventions removing standing laboratory order panels have resulted in decreased utilization of laboratory testing with no resultant differences in mortality or extubation failure.[8] We sought to develop a unique evidence-based approach to reducing laboratory testing in low-risk postoperative patients in the PICU.

Complete blood count (CBC) testing commonly occurs in postoperative patients to identify or to follow-up large-volume blood loss and need for blood transfusions. Data from our own institution of 30,545 patients (Figure 1), which had been collected for a prior quality-improvement (QI) project, allowed us to retrospectively identify patients with very low risk of transfusion and who therefore should not require routine CBC testing postoperatively. This cohort included postoperative patients who had undergone the following procedures: tonsillectomy and adenoidectomy, ventriculoperitoneal shunt placement, endoscopic third ventriculostomy, laryngotracheal reconstruction, and laminectomy. The largest groups of procedures reviewed were patients undergoing tonsillectomy and adenoidectomy (22,291 patients) and those patients undergoing ventriculoperitoneal shunt placement (3501 patients).

Our aim was to decrease unnecessary routine CBC testing in this cohort of postoperative patients in the PICU at The Children's Hospital of Philadelphia by 50% within 6 months.

## METHODS

### Setting

This QI intervention took place in a large tertiary care medical-surgical PICU with 55 beds that has averaged more than 3500 admissions per year during the past

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5 years. Ordering clinicians include ICU attendings, fellows, residents, and nurse practitioners. The cardiac surgical ICU and neonatal ICU were excluded. We received institutional support in the form of a clinical QI advisor and data analyst who facilitated the QI project. The background information that informed this project was part of a study approved by the institutional review board at The Children's Hospital of Philadelphia.

## Measures

Initial baseline survey data were gathered from key ordering clinicians regarding the utilization and necessity of routine postoperative laboratory testing. This data informed the metric selection. Our primary outcome measure was the percentage of patients within the low-risk postoperative cohort receiving routine CBC with or without differential. Secondary outcomes included estimated total hospital charges and costs for CBCs. Balancing measures included hemoglobin level below 8 g/dL in patients for whom CBCs were sent and blood transfusions up to 7 days postoperatively for any patients in this cohort. A conservative threshold of hemoglobin level below 8 g/dL was chosen as a balancing measure despite evidence that in critically ill children, a transfusion threshold of 7 g/dL limits risks without decreasing the benefit to these patients.[9] Cost and charge data were estimated on the basis of known average hospital charges and costs for CBC testing (differences included for CBC with and without differential) for these patients. Because the bundling of PICU payments for certain ages and procedures varies by both insurance and region, charges and costs were estimated on the basis of the overall decrease in the number of CBCs both with and without differential.

## Planning Key Interventions

Initially we collected baseline survey data to gather key stakeholders' thoughts on the utilization of routine postoperative laboratory testing for this cohort. We collected survey data from 95% of attending physicians (21 of 22), from 69% of fellow physicians (11 of 16), and from 60% of frontline clinicians (12 of 20). From this data, we derived a key driver diagram (Figure 2). Attending physicians were either unlikely or very unlikely to order laboratory

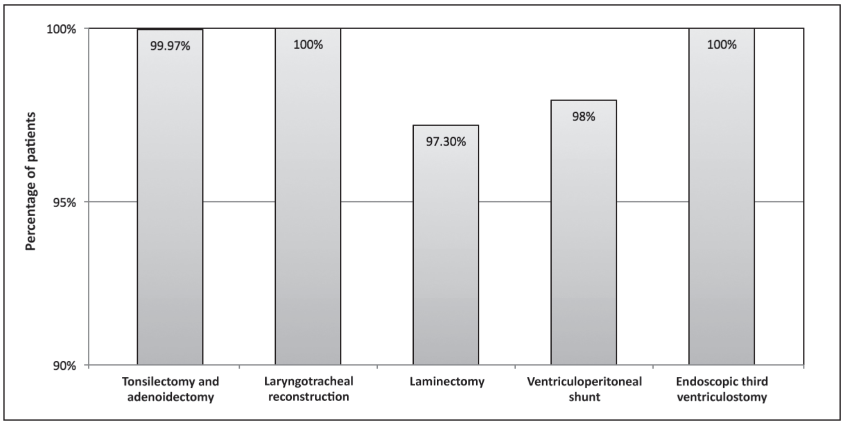

Figure 1. Percentage of patients not requiring intraoperative and postoperative transfusions from 2000 to 2010.

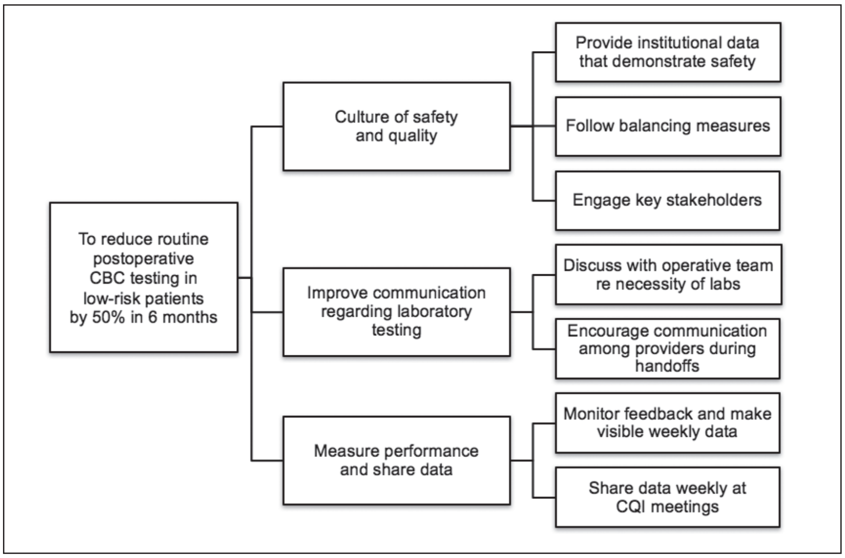

Figure 2. Key driver diagram derived from key stakeholder survey results and improvement team development.

CBC = complete blood count; CQI = continuous quality improvement; labs = laboratory studies; re = regarding.

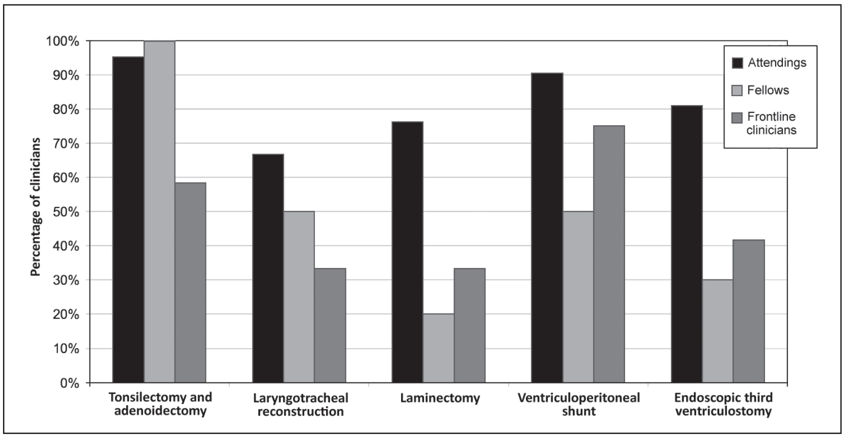

Figure 3. Survey from key stakeholders regarding initial opinions on necessity of any postoperative laboratory studies for this cohort.

testing for this cohort, with the largest agreement for no testing (95%) in the ventriculoperitoneal shunt group and the lowest agreement (67%) for patients who underwent laryngotracheal reconstruction. Fellows and frontline clinicians were more likely to order routine postoperative testing than were attending physicians for 4 of the 5 procedures (Figure 3).

After engaging key stakeholders and presentation of the baseline data regarding lack of postoperative or intraoperative transfusions in this cohort, as well as the high utilization of laboratory testing, we initiated our first Plan-Do-Study-Act (PDSA) cycle with education regarding our institutional data in this low-risk cohort. Initial education was done at weekly clinical QI meetings with video clips as well as reviews of attending survey data and current utilization demonstrating the variations in beliefs among different clinicians. Workplace reminders were posted in all stationary clinical ordering areas. Discussion of routine postoperative testing was added to our postoperative handoff tool to encourage discussion of the necessity by the attending physician with the team at the time of arrival to the PICU from the operating room.

The second PDSA cycle focused on audit and feedback. Postoperative laboratory ordering was tracked, and feedback was given monthly. Realizing that many orders are placed on workstations on wheels during rounds, laminated reminder cards were placed on these workstations as part of this second PDSA cycle. Further draft PDSA cycles were developed but never implemented because of decreases below the goal line with these simple interventions alone.

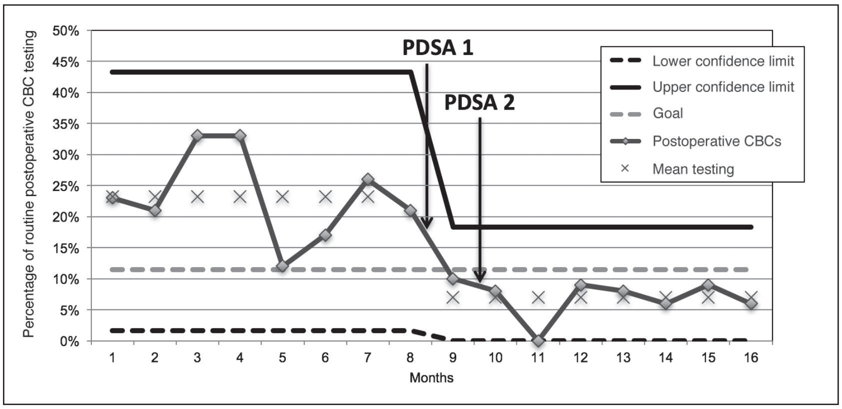

Figure 4. Statistical control chart of retrospective and prospective local data used for decision support shows overall decrease to below 10% after 2 Plan-Do-Study-Act (PDSA) cycles.

CBC = complete blood count.

## Analysis

We used run charts generated with QI Macros SPC software (KnowWare International Inc, Denver, CO) for Excel (Microsoft, Redmond, WA). A run chart was used to depict the percentage of the low-risk postoperative cohort receiving CBCs. Data analyst support provided weekly tracking of metrics through the utilization of a data visualization application, QlikView (QlikTech, Radnor, PA), available for viewing. Information regarding hemoglobin results was also tracked and displayed in a scatterplot as a balancing metric. Cost and charge data were estimated on the basis of known hospital charges and costs for CBC testing (differences were included for CBC with and without differential) for these patients.

## RESULTS

Baseline measurements for the 6 months before the intervention demonstrated that 12% to 33% of cohort patients received routine postoperative CBCs within 48 hours of the procedure (Figure 4). Approximately 30 to 40 patients per month fit this cohort. The median time to first CBC was 17.4 hours, and all postoperative hemoglobin levels checked during this 6-month period

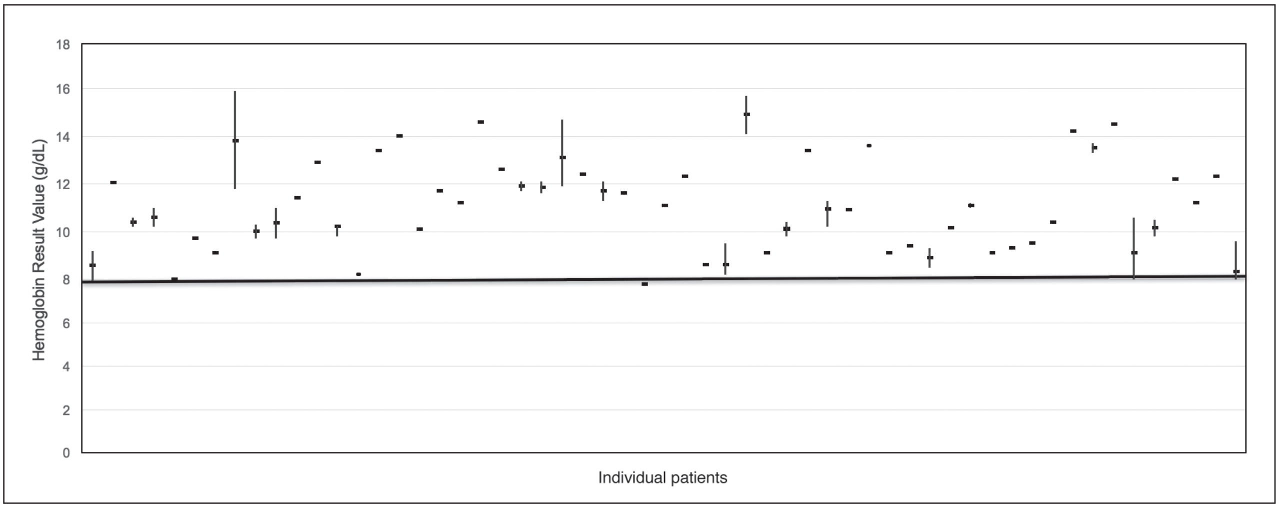

Figure 5. Balancing metrics included hemoglobin results from patients who did have complete blood counts (CBCs) to demonstrate safety. The vertical lines indicate the minimum and maximum values of CBCs drawn per patient.

were above 8 g/dL and therefore above transfusion thresholds (Figure 5). No patients in the cohort received blood transfusions related to their surgical procedure in the 7 days after surgery. After initiation of our first PDSA cycle, we saw a decrease in utilization of routine postoperative CBCs to less than 10%, achieving the 50% reduction aim. This number has stayed consistent more than 6 months postintervention.

Hospital charges also were estimated for routine postoperative CBCs in this cohort. Estimated preintervention hospital charges because of postoperative CBCs totaled $27,643.84 during a 6-month period. Estimated postintervention hospital charges because of postoperative CBCs was $3702.30 during 6 months, demonstrating decreased hospital charges of 87%.

## DISCUSSION

The high cost and high variability of laboratory testing in the ICU has been well described,[1,3] and prior studies have shown that up to 67.9% of inpatient laboratory tests ordered do not result in improved patient care.[10] Prior studies to reduce laboratory testing have mainly focused on restriction through the use of limitations in the clinician computer order entry system.[5-8] By limiting the use of standing or repeating laboratory orders, we were able to demonstrate sustained decreases in laboratory testing. Other interventions have focused on displays of cost data to encourage decreased utilization of testing, and although successful, the decreases have been small (less than 10%).[11] We sought to use the power of our own historical experience to convince clinicians of the safety of decreasing routine postoperative CBCs in this cohort. Partnering with our anesthesia colleagues who were working to reduce unnecessary preoperative type and screen testing,[12] we were able to use the same large historical data set to display the safety of eliminating routine postoperative CBCs in this cohort.

Because education alone often does not lead to sustained change in quality improvement, we linked our successes to the robustness of the data presented and the willingness of the clinicians to change their ordering habits. Through the review of our own historical data, we were able to identify five postoperative patient populations for which routine CBC testing was unnecessary. Utilizing the information gathered from our key stakeholders regarding the necessity of routine postoperative testing, we highlighted our current data and added simple low-cost interventions to change perceptions and utilization.

This study had multiple limitations. First, it was a focused effort on a small cohort of patients in a single center. Although the approach was unique, the ability to access a local institution's historical data may not be available to all clinicians as an approach to change culture. In addition, the historical data used were at least five years old at the time of this project. Although we do not expect that the bleeding risk for these patients would change over this time, it remains a limitation of this study. Furthermore, the ability to spread from this small cohort to a larger patient population is difficult in a PICU whose patients are at a perceived higher risk of complications. Spread from this project would likely involve limitations of further postoperative testing to protocol-based testing rather than removal overall. We hope that this initial QI initiative encourages our clinicians to think more proactively about the necessity of all laboratory testing.

There were also multiple lessons learned. The opinions of our key stakeholders allowed us to form a concise and focused driver diagram. This diagram enabled us to choose very simple and targeted PDSA cycles to lead to sustained change. Furthermore, the robustness of local historical data encouraged all clinicians, including our late adopters, to be supportive of this project. Long-term sustainability will be based on continued updating of the clinician group with the results and continued education of frontline care clinicians, who have a high turnover.

## CONCLUSION

A simple approach to a systemic problem in the PICU of unnecessary laboratory testing is feasible and effective. By using local historical data, we were able to identify a cohort of patients for whom routine postoperative CBC testing is unnecessary and therefore make strong recommendations regarding the avoidance of postoperative CBCs in this cohort. ❖

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**References**

1. Spence J, Bell DD, Garland A. Variation in diagnostic testing in ICUs: a comparison of teaching and nonteaching hospitals in a regional system. Crit Care Med 2014 Jan;42(1):9-16. DOI: https://doi.org/10.1097/CCM.0b013e3182a63887.
2. Clark SL, Cunningham JL, Rabinstein AA, Wijdicks EF. Electrolyte orders in the neuroscience intensive care unit: worth the value or waste? Neurocrit Care 2011 Apr;14(2):216-21. DOI: https://doi.org/10.1007/s12028-010-9416-4.
3. Ezzie ME, Aberegg SK, O'Brien JM Jr. Laboratory testing in the intensive care unit. Crit Care Clin 2007 Jul;23(3):435-65. DOI: https://doi.org/10.1016/j.ccc.2007.07.005.
4. Bateman ST, Lacroix J, Boven K, et al; Pediatric Acute Lung Injury and Sepsis Investigators Network. Anemia, blood loss, and blood transfusions in North American children in the intensive care unit. Am J Respir Crit Care Med 2008 Jul 1;178(1):26-33. DOI: https://doi.org/10.1164/rccm.200711-1637OC.
5. Attali M, Barel Y, Somin M, et al. A cost-effective method for reducing the volume of laboratory tests in a university-associated teaching hospital. Mt Sinai J Med 2006 Sep;73(5):787-94.
6. Calderon-Margalit R, Mor-Yosef S, Mayer M, Adler B, Shapira SC. An administrative intervention to improve the utilization of laboratory tests within a university hospital. Int J Qual Health Care 2005 Jun;17(3):243-8. DOI: https://doi.org/10.1093/intqhc/mzi025.
7. Wang TJ, Mort EA, Nordberg P, et al. A utilization management intervention to reduce unnecessary testing in the coronary care unit. Arch Intern Med 2002 Sep 9;162(16):1885-90. DOI: https://doi.org/10.1001/archinte.162.16.1885.
8. Delgado-Corcoran C, Bodily S, Frank DU, Witte MK, Castillo R, Bratton SL. Reducing blood testing in pediatric patients after heart surgery: a quality improvement project. Pediatr Crit Care Med 2014 Oct;15(8):756-61. DOI: https://doi.org/10.1097/PCC.0000000000000194.
9. Parker RI. Transfusion in critically ill children: indications, risks, and challenges. Crit Care Med 2014 Mar;42(3):675-90. DOI: https://doi.org/10.1097/CCM.0000000000000176.
10. Miyakis S, Karamanof G, Liontos M, Mountokalakis TD. Factors contributing to inappropriate ordering of tests in an academic medical department and the effect of an educational feedback strategy. Postgrad Med J 2006 Dec;82(974):823-9. DOI: https://doi.org/10.1136/pgmj.2006.049551.
11. Feldman LS, Shihab HM, Thiemann D, et al. Impact of providing fee data on laboratory test ordering: a controlled clinical trial. JAMA Intern Med 2013 May 27;173(10):903-8. DOI: https://doi.org/10.1001/jamainternmed.2013.232.
12. Gálvez JA, Ahumada L, Simpao AF, et al. Visual analytical tool for evaluation of 10-year perioperative transfusion practice at a children's hospital. J Am Med Inform Assoc 2014 May-Jun;21(3):529-34. DOI: https://doi.org/10.1136/amiajnl-2013-002241.

# Comprehensive Description of Comorbidity for Autism Spectrum Disorder in a General Population

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## ABSTRACT

**Context:** Few published studies of autism spectrum disorder (ASD) and comorbidity are population based.

**Objective:** To describe the comorbidity of ASD and disorders listed in the main classes of the International Classification of Diseases, Ninth Revision (ICD-9) in a general population.

**Design:** Direct physician billing data for the city of Calgary, Alberta, Canada, for the treatment of any presenting concern in the Calgary Health Zone (n = 763,449) from 1994 to 2009 were extracted. Diagnosed ICD-9 disorders (independent variable) were grouped into 17 categories using ICD-9 diagnosis codes. ASD (dependent variable) was classified under ICD-9 Code 299. Individuals with and without independent disorder classes were counted by the presence or absence of any ASD. Odds ratios (ORs) and 95% confidence intervals of the association were calculated.

**Main Outcome Measures:** ORs of ASD comorbidities.

**Results:** Annual rates of ASD increased 3.9-fold for males and 1.4-fold for females. Diagnosed disorders ranked by OR in the independent ICD-9 categories indicated that males with ASD had overall higher ORs (> 1.0) in 11 main ICD-9 classes, and females with ASD had higher ORs (> 1.0) in 12 main ICD-9 classes. Males with ASD had lower ORs in 4 main ICD-9 disease classes; females with ASD had lower ORs related only to the main class "complications of pregnancy and childbirth." Five main ICD-9 classes were not significant for males or females.

**Conclusions:** Patients with ASD have significant comorbidity of physical disorders. This finding may inform other areas of research and assessment in clinical management.

## INTRODUCTION

The annual prevalence of autistic spectrum disorder (ASD) is increasing and in 2014 was found to be 2.24% in children[1] and 1% in the general population.[2] Often, these disorders are long term and debilitating. A literature review of ASD focusing on comorbidity revealed few articles that were based on population studies.[3,4] Studies of comorbidity with ASD focus primarily on other psychiatric disorders,[5-23] neurologic disorders,[24-28] or congenital disorders.[29-32] Few studies focused on physical disorders,[33-35] and fewer still focused on adults.[36] In this study, the physical comorbidities associated with ASD and the main disorder classes from the International Classification of Diseases, Ninth Revision (ICD-9) were examined in a population including children and adults.

## METHODS

Using a population-based sample, the unique identifiers of 763,449 individuals (46% male) were selected from the regional health service registry in the Calgary Health Zone (Calgary, Alberta, Canada). These identifiers were merged with all direct physician billings (n = 90,611,984) from 1993 to 2010 for treatment of any presenting concern, resulting in 16 years of data (1994-2009). Each billing record pertained to services rendered to patients on specified dates, resulting in the assignment of an ICD diagnostic code, including V-codes. This study employed an anonymous data set that included ICD-9 diagnoses, visit date, age at index visit, sex, and visit cost paid to the attending physician.

The annual population rates were calculated for ASD using the number of unique individuals who received a diagnosis from a physician in any given year, denominated by the annual civic census from 1994 to 2009. The 16-year prevalence rate was based on a standard population estimate (eg, 2002). Additionally, the average 16-year cost per patient for ASD was calculated and compared with those costs for any other mental disorder and those for patients with no mental disorders.

The data were collapsed into 2 groups representing the dependent variable. Counts in the major class ICD-9 diagnostic groupings given the presence or absence of any ASD were expressed as the odds ratio (OR = [AD/BC]) of the remaining classes of ICD-9 disorders (independent variables) compared to those without ASD. A, B, C, and D (columns in Table 1) refer to the corresponding 2 X 2 cells in the OR formula (as defined in the footnote to Table 1 and used to calculate the ORs in Table 2). Differences were based on the comparison of overlapping and nonoverlapping 95% confidence intervals (95% CIs). For rates, significant statistical differences between proportions in any given year were estimated by comparison of the 95% CIs using the standard formula, wherein nonoverlapping 95% CIs represent significant differences ($p < 0.05$, with $z$ set to 1.96). The comorbidity of ASD within the main ICD-9 classes of disorders was examined. Diagnosed ICD-9 disorders (independent variable) were grouped into 17 categories on the basis of ICD-9 Codes 001 to 319 and 360 to 999. The dependent variable, ASD, was classified as ICD-9 Codes 320 to 359. Data for each sex was analyzed separately.

## RESULTS

The sample consisted of 583 females (286 < 19 years old) and 1457 males (1207 < 19 years old) with ASD. On the first

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diagnosis for all ages, females' age averaged 29 years (median = 19 years) and males' age averaged 14 years (median = 11 years). On the first diagnosis for those younger than age 19 years, females' age averaged 11 years (median = 10.7 years) and males' age averaged 10 years (median = 9.6 years).

The 16-year cumulative rate of ASD in the population was 2.1 per 1000 for females and 8.7 per 1000 for males younger than age 19 years. The total population annual rate between 1994 and 2009 increased 4.5-fold for males from 2 to 9 per 10,000 and for females 1.6-fold from 2.5 to 4 per 10,000.

As shown in Table 3, the group with ASD had a greater overall 16-year average total visit cost per patient than those with any other mental disorder or those without any mental disorder (eg, only somatic or biomedical disorders).

Table 1 provides the counts in each cell constructing the OR calculation for males and females. The counts in each cell represent the unique individuals in that group required to calculate the OR. A indicates patients with neither ASD nor ICD-9 disorder; B and C, those with one and not the other; and D, those with both disorders. Note in Table 1 that complications of pregnancy and childbirth (ICD-9 Codes 630-679) refer in males to newborns or fetuses (n = 32), whereas in females it refers to both newborns or fetuses and adolescent females of childbearing age (n = 97).

Table 2 shows the ORs for males and females across 17 independent ICD-9 physical/biomedical disorder categories. The ORs were based on the cell values in Table 1 used in the OR formula (mentioned in the Methods section) given the presence or absence of ASD. Males with ASD were significantly less likely than males without ASD to have disorders related to the endocrine system, musculoskeletal system and connective tissue, neoplasms, or circulatory system. Females with ASD were significantly less likely to have disorders related to complications of pregnancy and childbirth.

Males with ASD were significantly more likely to have perinatal conditions; diseases of the sense organs or the respiratory system; congenital anomalies; symptoms, signs, and ill-defined conditions; diseases of the skin and subcutaneous tissue; infectious diseases; nervous system diseases, complications of pregnancy and childbirth, diseases of the digestive system or the genitourinary system, or injury and poisoning. Females with ASD were significantly more likely to have disorders related to congenital anomalies; sense organs; symptoms, signs, and ill-defined conditions; respiratory system; skin and subcutaneous tissue; injury and poisoning; digestive system; infectious diseases; nervous system; perinatal conditions; endocrine, nutritional, and metabolic diseases, and immunity disorders; and blood and blood-forming organs. ORs for males were greater overall for males compared with females, because males more frequently had ASD (see Table 2).

## DISCUSSION

The literature reports ASD occurring in 1% to 4% of the population.[1] The present study summarized the 16-year cumulative

**Table 1. Counts in respective cells constructing odds ratio formula**[a]

| | A | | B | | C | | D | |
|---|---|---|---|---|---|---|---|---|
| **Main ICD-9 diagnostic class** | **Females** | **Males** | **Females** | **Males** | **Females** | **Males** | **Females** | **Males** |
| Infectious and parasitic diseases | 319,191 | 296,266 | 374 | 1123 | 94,994 | 52,240 | 209 | 334 |
| Neoplasms | 250,405 | 253,349 | 373 | 1208 | 163,780 | 95,157 | 210 | 249 |
| Endocrine, nutritional, and metabolic diseases, and immunity disorders | 247,105 | 235,070 | 292 | 1116 | 167,080 | 113,436 | 291 | 341 |
| Diseases of the blood and blood-forming organs | 341,750 | 317,074 | 453 | 1309 | 72,435 | 31,432 | 130 | 148 |
| Mental disorders | 306,559 | 291,110 | 366 | 1104 | 107,626 | 57,396 | 217 | 353 |
| Diseases of the nervous system and sense organs | 119,376 | 121,085 | 74 | 169 | 294,809 | 227,421 | 509 | 1288 |
| Diseases of the circulatory system | 238,083 | 225,425 | 344 | 1183 | 176,102 | 123,081 | 239 | 274 |
| Diseases of the respiratory system | 57,965 | 66,822 | 35 | 89 | 356,220 | 281,684 | 548 | 1368 |
| Diseases of the digestive system | 199,818 | 185,619 | 183 | 630 | 214,367 | 162,887 | 400 | 827 |
| Diseases of the genitourinary system | 89,960 | 228,306 | 128 | 894 | 324,225 | 120,200 | 455 | 563 |
| Complications of pregnancy, childbirth, and the puerperium[b] | 303,519 | 343,418 | 486 | 1425 | 110,666 | 5088 | 97 | 32 |
| Diseases of the skin and subcutaneous tissue | 108,172 | 118,487 | 74 | 310 | 305,888 | 230,019 | 509 | 1147 |
| Diseases of the musculoskeletal system and connective tissue | 109,204 | 113,812 | 158 | 649 | 304,981 | 234,694 | 425 | 808 |
| Congenital anomalies | 389,222 | 330,859 | 493 | 1224 | 24,963 | 17,647 | 90 | 233 |
| Certain conditions originating in the perinatal period | 385,130 | 336,072 | 522 | 1208 | 29,055 | 12,434 | 61 | 249 |
| Symptoms, signs, and ill-defined conditions | 34,564 | 47,690 | 19 | 79 | 379,621 | 300,816 | 564 | 1378 |
| Injury and poisoning | 89,306 | 69,540 | 68 | 258 | 324,879 | 278,966 | 515 | 1199 |

[a] Odds ratio formula: Odds ratio = (AD/BC), where A = patients with neither autism spectrum disorder (ASD) nor that ICD-9 disorder; B = those with ASD but not the ICD-9 disorder; C = those without ASD but with the ICD-9 disorder; and D = those with both disorders.

[b] Complications of pregnancy and childbirth (ICD-9 Codes 630-679) refer in males to newborns or fetuses (n = 32), whereas in females it refers to both newborns or fetuses and adolescent females of childbearing age (n = 97).

ICD-9 = International Classification of Diseases, Ninth Revision.

**Table 2. Odds ratios with 95% confidence intervals for females and males with autism spectrum disorder**

| Main ICD-9 class | Odds ratio (95% CI) Females | Odds ratio (95% CI) Males |
|---|---|---|
| Perinatal conditions | 1.55 (1.19-2.02) | 5.57 (4.86-6.39) |
| Sense organs | 2.79 (2.18-3.55) | 4.06 (3.46-4.76) |
| Respiratory system | 2.55 (1.81-3.59) | 3.65 (2.94-4.52) |
| Congenital anomalies | 2.85 (2.27-3.56) | 3.57 (3.1-4.11) |
| Symptoms, signs, ill-defined conditions | 2.7 (1.71-4.27) | 2.77 (2.2-3.47) |
| Skin and subcutaneous tissue | 2.43 (1.91-3.1) | 1.91 (1.68-2.16) |
| Infectious diseases | 1.88 (1.59-2.22) | 1.69 (1.49-1.91) |
| Nervous system | 1.69 (1.43-2.0) | 1.62 (1.44-1.83) |
| Complications of pregnancy, childbirth | 0.55 (0.44-0.68) | 1.52 (1.07-2.15) |
| Digestive system | 2.04 (1.71-2.43) | 1.5 (1.35-1.66) |
| Genitourinary system | 0.99 (0.81-1.2) | 1.2 (1.08-1.33) |
| Injury and poisoning | 2.08 (1.62-2.68) | 1.16 (1.01-1.33) |
| Blood and blood-forming organs | 1.35 (1.11-1.65) | 1.14 (0.96-1.35) |
| Endocrine, nutritional, and metabolic diseases, and immunity disorders | 1.47 (1.25-1.73) | 0.63 (0.56-0.71) |
| Musculoskeletal system and connective tissue | 0.96 (0.8-1.16) | 0.6 (0.54-0.67) |
| Neoplasms | 0.86 (0.73-1.02) | 0.55 (0.48-0.63) |
| Circulatory system | 0.94 (0.8-1.11) | 0.42 (0.37-0.48) |

CI = confidence interval; ICD-9 = International Classification of Diseases, Ninth Revision.

prevalence and overall changes in annual rates of ASD. The cumulative rate reported here is closest to the lower limit reported in the literature. The differences may be because the higher rates reported in the literature were based on results of a national survey, whereas this study was based on a physician-assigned diagnosis. The rate of all physician-diagnosed mental disorders has increased for children.[37] Similarly, there has been an increase in the annual rate of ASD that was greater for males than females, although not as great as that reported in the literature. The reasons for the increased ASD rates are multifold and include any or all of the following: more diagnostic precision (reduction in false-negatives), increased public awareness (inflation of false-positives), or a real increase in the ASD rate.

**Table 3. Average 16-year index of total cost of physician visit per patient by group**

| Group | Sex | Average cost (CAD) |
|---|---|---|
| Autism spectrum disorder | Female | 1802 |
| | Male | 1329 |
| Any mental disorder | Female | 1532 |
| | Male | 1166 |
| No mental disorder | Female | 669 |
| | Male | 518 |

CAD = Canadian dollars.

Recent studies focusing on the relationship between ASD and comorbid disorders have tended, in part, to focus on general psychiatric comorbidity,[38] with most studies focusing on specific psychiatric disorders, such as primarily attention deficit-hyperactivity disorder[39-41]and, less frequently, anxiety, epilepsy, and neurologic disorders.[41] One study of physical disorders focused only on motor skills.[34] Although less frequent, genetic studies tended to examine comorbidity in relation to identifying potential overlapping phenotypic or genetic homology, or both.

Most comparable to the results of the present study was a time-series study of an electronic health record.[33] However, that study focused on distinguishing between fragile X syndrome and other ASD-associated syndromes. Aligned with this finding is the relatively high occurrence of congenital anomalies in patients with ASD for both sexes. Congenital defects are beyond the scope of the present study, which has described the physical and biomedical comorbidities of ASD, nevertheless each broad diagnostic category includes the range of subsumed diagnoses. When studied in a single large population, the interrelationship of comorbid disorders is revealed, and these patterns may be compared between disorders such as other ASD syndromes and disorders, such as fragile X. The present population-based description of the physical and biomedical disorders of ASD makes such comparative study possible. Most focused comparative study of symptom comorbidity, such as with epilepsy, has been used to provide insight into the origin of ASD, yet, unlike the present study, the samples have been too small to provide conclusive evidence of association.

Studies of ASD comorbidity have sought to understand issues of etiology[42] and mechanism. For example, disruption of the microbiota-gut-brain axis has recently become a focus of study in ASD.[38,43-46] The ability to examine ASD comorbidities in a population over time holds the potential to rank-order the relative importance of a specific comorbid disorder associated with ASD and to inform research. Being able to accomplish the ranked comparison, as illustrated in Table 2, in terms of the comorbidity of ASD and the main ICD-9 classes of disorder, permits more precise examination related to the comparative magnitude and prevalence of the comorbidities.

## Importance of Present Findings

The present study examined comorbidity in the population. As it stands, this study makes an original contribution to the study of ASD comorbidity, against which there are few, if any, studies to compare. Substantial differences and similarities were found between males and females (see Table 2). For example, perinatal conditions are comparatively high for males, whereas females are less likely than males to have complications of pregnancy and childbirth. The present work supports the contention that there is a relationship between perinatal conditions, complications of pregnancy and childbirth, and ASD.[47,48] Otherwise, although males with ASD are more intensely affected than females, males and females are comparable on the basis of the relative order of sensory organ and respiratory disorders.

The results of the present study comparing the relationship between ASD and the main classes of ICD-9 disorders suggest that a great deal of research must yet be undertaken to understand the intricacies of these relationships in more precise terms. For example, there are about 1000 main diagnoses and more than 13,000 subdiagnoses within 19 main categories of disorder. This article serves as a simple example of a method for proceeding with further study. The broad-stroke approach to analysis has revealed that more precise relationships must exist within these data.

## Study Limitations

The limitations of the approach taken to the study of comorbidity in this study have been described.[37] The usual threat to validity is the reliability of physician-assigned diagnoses, which is assumed to be a normally distributed source of error.

Another limitation lies in examining only main categories of ICD-9 disorders. This approach reveals associations observable within these broad categories, yet masks relationships between ASD and more specific subclasses of disorder. The present study points to the need for a more detailed disorder-specific analysis.

Examination of the temporal order of the classes of disorders and specific disorders associated with ASD was beyond the scope of the present study. Analysis of temporal order has for other disorders revealed potential mechanisms underpinning disease processes.[49] Comprehensive temporal-order analysis represents an important next step in the evolution of the presented approach to the population-based analysis of comorbidity.

## CONCLUSIONS

Traditionally, study of comorbidity has largely focused on the relationship between one comorbid disorder, or only a few comorbid disorders, and a primary disorder of interest. With the advent of large integrated data repositories, it is possible to comprehensively examine comorbidity. For example, an examination of comorbidity has given rise to a novel population health index and provided evidence in support of the Adverse Childhood Experiences Study.[50-52]

This article provides a thumbnail sketch of ASD comorbidity. For every individual with an ASD, there is a temporal order in which the patterns of disease arise, and understanding these patterns may help elucidate a more formal understanding of the etiology and prognosis of sets of disorders within given groups of individuals. The results of such future research may serve to inform other approaches to the study of ASD. At the very least, the present study orients clinicians to the need to consider the physical and biomedical comorbidities in relation to ASD assessment, care, and service integration planning. ❖

### Disclosure Statement

*The author(s) have no conflicts of interest to disclose.*

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### References

1. Zablotsky B, Black LI, Maenner MJ, Schieve LA, Blumberg SJ. Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 National Health Interview Survey. Natl Health Stat Report 2015 Nov 13;(87):1-20.
2. Rybakowski F, Bialek A, Chojnicka I, et al. [Autism spectrum disorders—epidemiology, symptoms, comorbidity and diagnosis]. [Article in Polish]. Psychiatr Pol 2014 Jul-Aug;48(4):653-65.
3. Schendel DE, Overgaard M, Christensen J, et al. Association of psychiatric and neurologic comorbidity with mortality among persons with autism spectrum disorder in a Danish population. JAMA Pediatr 2016 Mar;170(3):243-50. DOI: https:/ doi.org/10.1001/jamapediatrics.2015.3935.
4. Garg S, Lehtonen A, Huson SM, et al. Autism and other psychiatric comorbidity in neurofibromatosis type 1: Evidence from a population-based study. Dev Med Child Neurol 2013 Feb;55(2):139-45. DOI: https://doi.org/10.1111/dmcn.12043.
5. Paula-Pérez I, Martos-Pérez J. [Asperger's syndrome and high-functioning autism: Comorbidity with anxiety and mood disorders]. [Article in Spanish]. Rev Neurol 2009 Feb 27;48 Suppl 2:S31-4.
6. Geurts HM, Deprey L, Ozonoff S. [Assessment of comorbidity in autism spectrum disorders]. [Article in Dutch]. Tijdschr Psychiatr 2010;52(11):753-61.
7. Banaschewski T, Poustka L, Holtmann M. [Autism and ADHD across the life span. Differential diagnoses or comorbidity?] [Article in German]. Nervenarzt 2011 May;82(5):573-80. DOI: https://doi.org/10.1007/s00115-010-3239-6.
8. Singh SK, Hellemans H, Dom G. [Autism spectrum disorder and substance use disorder: An unknown comorbidity?]. [Article in Dutch]. Tijdschr Psychiatr 2012;54(10):893-7.
9. Noterdaeme MA, Wriedt E. [Comorbidity in autism spectrum disorders - I. Mental retardation and psychiatric comorbidity]. [Article in German]. Z Kinder Jugendpsychiatr Psychother 2010 Jul;38(4):257-66. DOI: https://doi.org/10.1024/1422-4917/a000045.
10. Berenguer-Forner C, Miranda-Casas A, Pastor-Cerezuela G, Roselló-Miranda R. [Comorbidity of autism spectrum disorder and attention deficit with hyperactivity. A review study]. [Article in Spanish]. Rev Neurol 2015 Feb 25;60 Suppl 1:S37-43.
11. Ragunath P, Chitra R, Mohammad S, Abhinand P. A systems biological study on the comorbidity of autism spectrum disorders and bipolar disorder. Bioinformation 2011;7(3):102-6. DOI: https://doi.org/10.6026/97320630007102.
12. Gargaro BA, Rinehart NJ, Bradshaw JL, Tonge BJ, Sheppard DM. Autism and ADHD: How far have we come in the comorbidity debate? Neurosci Biobehav Rev 2011 Apr;35(5):1081-8. DOI: https://doi.org/10.1016/j.neubiorev.2010.11.002.
13. Vannucchi G, Masi G, Toni C, Dell'Osso L, Marazziti D, Perugi G. Clinical features, developmental course, and psychiatric comorbidity of adult autism spectrum disorders. CNS Spectr 2014 Apr;19(2):157-64. DOI: https://doi.org/10.1017/s1092852913000941.
14. Bonde E. Comorbidity and subgroups in childhood autism. Eur Child Adolesc Psychiatry 2000 Mar;9(1):7-10. DOI: https://doi.org/10.1007/s007870050110.
15. Hepburn SL, Stern JA, Blakeley-Smith A, Kimel LK, Reaven JA. J Ment Health Res Intellect Disabil 2014;7(4):359-78. DOI: https://doi.org/10.1080/19315864.2014.932476.
16. Joshi G, Biederman J, Petty C, Goldin RL, Furtak SL, Wozniak J. Examining the comorbidity of bipolar disorder and autism spectrum disorders: A large controlled analysis of phenotypic and familial correlates in a referred population of youth with bipolar I disorder with and without autism spectrum disorders. J Clin Psychiatry 2013 Jun;74(6):578-86. DOI: https://doi.org/10.4088/jcp.12m07392.
17. Munesue T, Ono Y, Mutoh K, Shimoda K, Nakatani H, Kikuchi M. High prevalence of bipolar disorder comorbidity in adolescents and young adults with high-functioning autism spectrum disorder: A preliminary study of 44 outpatients. J Affect Disord 2008 Dec;111(2-3):170-5. DOI: https://doi.org/10.1016/j.jad.2008.02.015.
18. van Steensel FJ, Bögels SM, de Bruin EI. Psychiatric comorbidity in children with autism spectrum disorders: A comparison with children with ADHD. J Child Fam Stud 2013 Apr;22(3):368-76. DOI: https://doi.org/10.1007/s10826-012-9587-z.
19. Joshi G, Wozniak J, Petty C, et al. Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: A comparative study. J Autism Dev Disord 2013 Jun;43(6):1314-25. DOI: https://doi.org/10.1007/s10803-012-1679-5.
20. Buck TR, Viskochil J, Farley M, et al. Psychiatric comorbidity and medication use in adults with autism spectrum disorder. J Autism Dev Disord 2014 Dec;44(12):3063-71. DOI: https://doi.org/10.1007/s10803-014-2170-2.
21. Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. J Am Acad Child Adolesc Psychiatry 2008 Aug;47(8):921-9. DOI: https://doi.org/10.1097/chi.0b013e318179964f.
22. Antshel KM, Zhang-James Y, Faraone SV. The comorbidity of ADHD and autism spectrum disorder.

Expert Rev Neurother 2013 Oct;13(10):1117-28. DOI: https://doi.org/10.1016/j.rasd.2016.07.003.

23. Joshi G, Petty C, Wozniak J, et al. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. J Autism Dev Disord 2010 Nov;40(11):1361-70. DOI: https://doi.org/10.1007/s10803-010-0996-9.
24. Noterdaeme MA, Hutzelmeyer-Nickels A. [Comorbidity in autism spectrum disorders - II. Genetic syndromes and neurological problems]. [Article in German]. Z Kinder Jugendpsychiatr Psychother 2010 Jul;38(4):267-72. DOI: https://doi.org/10.1024/1422-4917/a000046.
25. Gabis L, Pomeroy J, Andriola MR. Autism and epilepsy: Cause, consequence, comorbidity, or coincidence? Epilepsy Behav 2005 Dec;7(4):652-6. DOI: https://doi.org/10.1016/j.yebeh.2005.08.008.
26. Steffenburg S, Steffenburg U, Gillberg C. Autism spectrum disorders in children with active epilepsy and learning disability: Comorbidity, pre- and perinatal background, and seizure characteristics. Dev Med Child Neurol 2003 Nov;45(11):724-30. DOI: https://doi.org/10.1111/j.1469-8749.2003.tb00881.x.
27. Khetrapal N. Overlap of autism and seizures: Understanding cognitive comorbidity. Mens Sana Monogr 2010 Jan;8(1):122-8. DOI: https://doi.org/10.4103/0973-1229.58823.
28. Malow BA. Searching for autism symptomatology in children with epilepsy—a new approach to an established comorbidity. Epilepsy Curr 2006 Sep-Oct;6(5):150-2. DOI: https://doi.org/10.1111/j.1535-7511.2006.00127.x.
29. Trillingsgaard A, Østergaard JR. Autism in Angelman syndrome: An exploration of comorbidity. Autism 2004 Jun;8(2):163-74. DOI: https://doi.org/10.1177/1362361304042720.
30. Polyak A, Kubina RM, Girirajan S. Comorbidity of intellectual disability confounds ascertainment of autism: Implications for genetic diagnosis. Am J Med Genet B Neuropsychiatr Genet 2015 Oct;168(7):600-8. DOI: https://doi.org/10.1002/ajmg.b.32338.
31. Hogart A, Wu D, LaSalle JM, Schanen NC. The comorbidity of autism with the genomic disorders of chromosome 15q11.2-q13. Neurobiol Dis 2010 May;38(2):181-91. DOI: https://doi.org/10.1016/j.nbd.2008.08.011.
32. Abbeduto L, McDuffie A, Thurman AJ. The fragile X syndrome-autism comorbidity: What do we really know? Front Genet 2014 Oct 16;5:355. DOI: https://doi.org/10.3389/fgene.2014.00355.
33. Doshi-Velez F, Ge Y, Kohane I. Comorbidity clusters in autism spectrum disorders: An electronic health record time-series analysis. Pediatrics 2014 Jan;133(1):e54-e63. DOI: https://doi.org.10.1542/peds.2013-0819.
34. Matson ML, Matson JL, Beighley JS. Comorbidity of physical and motor problems in children with autism. Res Dev Disabil 2011 Nov-Dec;32(6):2304-8. DOI: https://doi.org/10.1016/j.ridd.2011.07.036.
35. Bejerot S, Humble MB, Gardner A. Endocrine disruptors, the increase of autism spectrum disorder and its comorbidity with gender identity disorder—a hypothetical association. Int J Androl 2011 Oct;34(5 Pt 2):e350. DOI: https://doi.org/10.1111/j.1365-2605.2011.01149.x.
36. Gadke DL, McKinney C, Oliveros A. Autism spectrum disorder symptoms and comorbidity in emerging adults. Child Psychiatry Hum Dev 2016 Apr;47(2):194-201. DOI: https://doi.org/10.1007/s10578-015-0556-9.
37. Cawthorpe D. A novel population-based health index for mental disorder. Perm J 2013 Spring;17(2):50-4. DOI: https://doi.org/10.7812/TPP/12-081.
38. Al-Salehi SM, Al-Hifthy EH, Ghaziuddin M. Autism in Saudi Arabia: Presentation, clinical correlates and comorbidity. Transcult Psychiatry 2009 Jun;46(2):340-7. DOI: https://doi.org/10.1177/1363461509105823.
39. Liao TC, Lien YT, Wang S, Huang SL, Chen CY. Comorbidity of atopic disorders with autism spectrum disorder and attention deficit/hyperactivity disorder. J Pediatr 2016 Apr;171:248-55. DOI: https://doi.org/10.1016/j.jpeds.2015.12.063.
40. Pitzianti M, D'Agati E, Pontis M, et al. Comorbidity of ADHD and high-functioning autism: A pilot study on the utility of the overflow movements measure. J Psychiatr Pract 2016 Jan;22(1):22-30. DOI: https://doi.org/10.1097/pra.0000000000000120.
41. Boye H, Etting AM, Jørgensen OS. [Comorbidity of infantile autism and blindness]. [Article in Danish]. Ugeskr Laeger 1999 Feb 8;161(6):800-1.
42. Mayer EA, Padua D, Tillisch K. Altered brain-gut axis in autism: Comorbidity or causative mechanisms? Bioessays 2014 Oct;36(10):933-9. DOI: https://doi.org/10.1002/bies.201400075.
43. Li Q, Zhou JM. The microbiota-gut-brain axis and its potential therapeutic role in autism spectrum disorder. Neuroscience 2016 Jun 2;324:131-9. DOI: https://doi.org/10.1016/j.neuroscience.2016.03.013.
44. Mangiola F, Ianiro G, Franceschi F, Fagiuoli S, Gasbarrini G, Gasbarrini A. Gut microbiota in autism and mood disorders. World J Gastroenterol 2016 Jan 7;22(1):361-8. DOI: https://doi.org/10.3748/wjg.v22.i1.361.
45. Fulceri F, Morelli M, Santocchi E, et al. Gastrointestinal symptoms and behavioral problems in preschoolers with Autism Spectrum Disorder. Dig Liver Dis 2016 Mar;48(3):248-54. DOI: https://doi.org/10.1016/j.dld.2015.11.026.
46. Kushak RI, buie TM, Murray KF, et al. Evaluation of intestinal function in children with autism and gastrointestinal symptoms. J Pediatr gastroenterol Nutr 2016 May;62(5):687-91. DOI: https://doi.org/10.1097/mpg.0000000000001174.
47. Gregory SG, Anthopolos R, Osgood CE, Grotegut CA, Miranda ML. Association of autism with induced or augmented childbirth in North Carolina Birth Record (1990-1998) and Education Research (1997-2007) databases. JAMA Pediatr 2013 Oct;167(10):959-66. DOI: https://doi.org/10.1097/01.ogx.0000442814.50107.fa.
48. Kolevzon A, Gross R, Reichenberg A. Prenatal and perinatal risk factors for autism: A review and integration of findings. Arch Pediatr Adolesc Med 2007 Apr;161(4):326-33. DOI: https://doi.org/10.1001/archpedi.161.4.326.
49. Cawthorpe D, Davidson M. Temporal comorbidity of mental disorder and ulcerative colitis. Perm J 2015 Winter;19(1):52-7. DOI: https://doi.org/10-7812/TPP/14-120.
50. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. Am J Prev Med 1998 May;14(4):245-58. DOI: https://doi.org/10.1016/s0749-3797(98)00017-8.
51. Felitti VJ, Anda RF. The lifelong effects of adverse childhood experiences. In: Chadwick DL, Giardino AP, Alexander R, Thackeray JD, Esernio-Jenssen D, editors. Chadwick's child maltreatment: Sexual abuse and psychological maltreatment. Vol 2. 4th ed. Florissant, MO: STM Learning, Inc; 2014. p 203-15.
52. Anda RF, Fleisher VI, Felitti VJ, et al. Childhood abuse, household dysfunction, and indicators of impaired worker performance in adulthood. Perm J 2004 Winter;8(1):30-8. DOI: https://doi.org/10.7812/TPP/03-089.

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## A Neurological Disorder

Autism is a neurological disorder. It's not caused by bad parenting. It's caused by, you know, abnormal development in the brain. The emotional circuits in the brain are abnormal. And there also are differences in the white matter, which is the brain's computer cables that hook up the different brain departments.

— Temple Grandin, PhD, b 1947, author of *The Autistic Brain: Thinking Across the Spectrum* and autism spokesperson; American professor of animal science, consultant to the livestock industry on animal behavior

ORIGINAL RESEARCH & CONTRIBUTIONS

# Collaborative Management of Neurocognitive Disorders in Primary Care: Explorations of an Attempt at Culture Change

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## ABSTRACT

**Introduction:** Minor neurocognitive disorder (MiND; previously mild cognitive impairment) is a transitional zone between normal cognitive function and early stages of major neurocognitive disorder (previously called dementia). Of people with MiND, 5% to 10% progress to major neurocognitive disorder. Simple interventions such as memory activities, balance exercises, and anti-inflammatory diets have been shown to improve cognitive ability. Also, education and support in group settings have proved beneficial for patients with MiND.

**Design:** Survey evaluation of outcomes of geriatric consultation and prospective educational study.

**Main Outcome Measures:** We collaborated with an academic training program to introduce into primary care the ideas of educational activities and participation in group medical care for people with MiND. Educational programs were developed and presented to family medicine residents and practicing physicians, and their knowledge was assessed before and after education.

**Results:** Two group programs were implemented: one at our hospital and one at a local skilled nursing facility. These were initially envisioned as time-limited, but participants insisted on their continuance. Thirty-two different patients attended the groups for at least six sessions. Participants enthusiastically reported positive change on qualitative interviews and showed improvement in cognition, balance, and self-esteem. Family medicine residents and practicing physicians both shifted toward lifestyle medicine and significantly changed their views on the efficacy of treatments. Despite these activities, community physicians making referrals for geriatric consultations did not change their discussions with patients and families about exercise, diet, cognitive enhancement, and socialization for MiND.

**Conclusion:** Group visits that emphasized support for increased exercise, improved diet, more movement and balance, and cognitive enhancement appear to please and benefit patients with MiND. Physicians are more open to these approaches with training after initial skepticism. A struggle exists to convince the profession that lifestyle change may be beneficial in MiND.

## INTRODUCTION

Minor neurocognitive disorder (MiND; previously called mild cognitive impairment) is a transitional zone between normal cognitive function and early stages of major neurocognitive disorder (MaND; previously called dementia).[a] A diagnosis of MiND is made[1] when

- there is a decline in memory and cognition over time, confirmed by a family member or close friend
- there is objective evidence of memory impairment or another mental function for age
- general cognitive functions are sufficiently normal that no substantial interference with work or other social activities exists and all activities of daily life (ADL) can be performed
- the patient does not have a diagnosis of MaND
- the patient has no other medical conditions that might contribute to his/her cognitive status.

A 2009 meta-analysis found that MiND progresses to MaND in 5% to 10% of cases.[2] Currently there is no pharmacologic treatment approved to treat MiND. However, for those living with MiND and mild to moderate MaND, intervention has been shown to be beneficial. Almost 30% of caregivers of patients with MiND report clinically significant burden[3] and were found to have similar needs for social services to patients with MaND.[4]

Multiple methods of preventing or slowing the progression of cognitive decline have been proposed.[5] The ACTIVE (Advanced Cognitive Training for Independent and Vital Elderly) study showed that intervention aimed at memory, inductive reasoning, and speed of processing improved cognitive ability.[6] Exercise training was helpful for both MiND and MaND in physical and cognitive outcomes.[7] Tai chi improved cognitive outcomes, especially for visual attention.[8] Diets rich in fruits, vegetables, fish, and omega-3 fatty acids decreased the risk of developing MaND,[9] and foods high in antioxidants may enhance cognitive functions in aging adults.[10]

## Interventions

### Cognitive Stimulation

A 2012 Cochrane article[11] reviewed cognitive stimulation offered to people with mild to moderate MaND. The intervention "involves a wide range of activities that aim to stimulate thinking and memory generally, including discussion of past and present events and topics of interest, word games, puzzles, music and practical activities such as baking or indoor gardening."[11p2] This review and other meta-analyses found that although there are no large, well-designed randomized controlled trials clearly showing that cognitive stimulation prevents progression of MiND to MaND,

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results of small studies suggest benefits of cognitive stimulation, particularly in maintaining ADL; results of more recent studies suggest that if cognitive stimulation is ongoing, the benefits can be sustained.[12] A 2014 follow-up to the ACTIVE study reporting on 2832 participants similarly found that cognitive stimulation provided lasting benefits for continued reasoning ability and maintenance of ADL.[13]

### Exercise

A 2004 meta-analysis found that exercise benefited people with cognitive impairments, improving physical function, cognitive function, and prosocial behavior.[7] Exercise 3 times per week was associated with a significantly decreased rate of MaND in a group of 1740 adults,[14] and the 2004 Nurses' Health Study of 18,766 women found that those who walked a minimum of 1.5 hours a week at an easy pace had a 20% lower measure of cognitive decline.[15] A 2012 Cochrane review found that exercise can benefit cognitive functioning and performance of ADL.[15] In another study of 389 people with a diagnosis of MiND (amnestic) or early-stage MaND, Chinese Qi Gong-style exercises proved slightly more beneficial than stretching exercises in the improvement of cognitive functioning.[16]

### Socialization

A 2007 study found that women with wider social networks had a lower incidence of MaND than did their less well-connected sisters.[17]

### Diet and Nutrition

A Mayo Clinic researcher published a 2012 study that determined that a high-sugar and high-carbohydrate diet was implicated in the progression to MaND.[18] High caloric intake (more than 2100 kcal/d) is associated with MiND,[19] and the Mediterranean diet is associated with a lower incidence of MiND.[20]

An impressive body of evidence supports the beneficial role of balanced nutrition in lowering the risk of MaND.[21] Suboptimal micronutrient status is an early feature in the onset of Alzheimer disease.[22,23] Four cohort studies have been conducted in the past decade that collectively suggest an inverse relation between risk of MaND and vegetable and fruit consumption.[24-27] According to the National Institutes of Health, the Three-City Cohort Study[28] showed a risk reduction in MaND by about 30% in daily consumers of fruits and vegetables compared with subjects rarely consuming fruits and vegetables. In the Esprit study, consumption of fewer than 2 portions of fruits and vegetables per day was associated with a significantly higher risk of MiND and MaND compared with subjects consuming more than 2 portions.[29]

Omega-3 polyunsaturated fatty acids are a main component of the Mediterranean diet, which is inversely related to the risk of developing Alzheimer disease.[30-32] The Mediterranean diet is characterized by high intake of fish, vegetables, legumes, fruits, cereals, and unsaturated fatty acids mostly in the form of olive oil; low intake of dairy products, meat, and saturated fatty acids; and regular but moderate intake of alcohol. The total fat in this diet is 25% to 35% of daily caloric allowance with saturated fat at 8% or less of daily calorie allowance.[33] Adherence to this diet is associated with risk reduction for MiND[31] and Alzheimer disease,[30] independent of physical exercise.[32] In a meta-analysis of 8 prospective studies, the Mediterranean diet was strongly associated with a risk reduction of 13% for Alzheimer disease.[34] A review of 34 studies in the areas of dietary restriction, antioxidants, and Mediterranean diet provided evidence that nutritional interventions against MaND and Alzheimer disease have great potential for influencing MaND development.[35] A large number of studies have demonstrated protective activity of the Mediterranean diet against MiND and Alzheimer disease (systematically reviewed and meta-analyzed).[36,37]

Some studies suggest positive effects of multivitamin and mineral supplementation on cognitive function.[38,39] Ames proposes a role for comprehensive, high-dose, high-potency micronutrient supplements in MiND and Alzheimer disease, although this has not been studied, to our knowledge.[22] A low-dose, low-potency multivitamin (eg, Centrum Silver) was ineffective in altering the course of MiND and Alzheimer disease among already well-nourished physicians.[40]

Elevated homocysteine level has been associated with increased risk of Alzheimer disease and faster cognitive decline.[41-43] MaND has been associated with a deficiency of vitamin $B_{12}$.[44] The prevalence of vitamin $B_{12}$ deficiency has been estimated to be 15% to 44% in the elderly.[45] Lower levels of serum vitamin $B_{12}$ were predictive of cognitive decline ($p < 0.05$).[46] Low concentrations of folate and high levels of homocysteine in the blood are related to MaND, Alzheimer's disease, and poor cognitive function in older adults.[47-54] In the TREDEM (Treviso Dementia) study carried out in Treviso, Italy,[55] close associations were found between low serum folate levels and severe cortical-subcortical atrophy along with severe hippocampal atrophy measured by the width of the temporal horns of the lateral ventricles. The Nun Study[37] and the Rotterdam Scan Study[56] showed a similar correlation between low serum folate levels and high brain cortical atrophy. Published trials of supplementation with these vitamins have yielded mostly unsuccessful results.

Trials aimed at exploring the efficacy of antioxidant strategies in Alzheimer disease and in what is considered its preclinical form, MiND, have been largely unsuccessful so far.[57-62] A recent meta-analysis of 7 studies on dietary intakes of vitamin E, vitamin C, and beta carotene confirmed a relative risk for the development of Alzheimer disease of 0.76 for vitamin E, 0.83 for vitamin C, and 0.88 for beta carotene.[63] A trial of vitamin E in 341 patients with moderate to severe Alzheimer disease[64] treated with a daily dose of 2000 IU of vitamin E for 2 years showed a significant delay in Alzheimer disease progression and in nursing home placement compared with placebo.

## Group Visit Model

There is a growing body of literature supporting the efficacy of group medical visits for chronic medical conditions,[11] although mixed results have been found for the efficacy of cognitive training programs in demented[12,13] or nondemented older adults.[14] We hypothesized that group medical visits involving memory training, balance exercises, and nutrition consulting prevent cognitive decline, improve gait, and provide socialization for patients with MiND and their caregivers.

Kurz et al[65] conducted a four-week group intervention in 2008 that included cognitive training, activity planning, training in self-assertiveness, stress management, relaxation, external memory aids, and physical exercise. Troyer and colleagues[66] have used group visits for memory training and lifestyle education over six months, which have resulted in gains at a three-month posttest. Group teaching of visual memory strategies have been successful in helping people recall placement of objects in their homes.[67] Increasingly, group efforts are being implemented, including a two-week intensive program offered through the Mayo clinic, as well as "Cogs Clubs" and "Memory Cafes," both grassroots movements that meet standards for clinically relevant interventions.[68]

There is increasing literature on the benefits of socializing in groups and interpersonal learning as a mechanism of change. Interpersonal group therapy, according to Yalom and Leszcz,[69] offers 11 curative factors (see Sidebar: Interpersonal Group Therapy Curative Factors).

Groups offer much more than instruction on physical and mental exercise and nutrition. They offer a place where patients can embrace the change in their lives by finding purpose, focusing on the positive, reducing stress, enjoying uninhibited socialization and laughing; all factors that according to research may reduce the impact of symptoms of MiND and improve the daily lives of the patients.

### Minor Neurocognitive Disorder Groups

Recent literature has suggested that those with a diagnosis of MiND can benefit from multicomponent group visits to help them accommodate the changes that they experience, with a view to using cognitive stimulation to intervene in the possible progress of their illness[65] and to encourage continued facility with ADL.

Groups have been very helpful in treatment of medical conditions such as diabetes,[70] high blood pressure, and heart disease. The number of physicians who are using group visits in their primary care practice has been rising sharply since 2004, with 15% of physicians now including them as a practice model.[71] Group medical visits commonly focus on those linked through a shared diagnosis. *The American Academy of Family Physicians reports a study of group visit outcomes between 1974 and 2004, which resulted in the following*[71]

- reduced obesity
- reduced blood pressure and cholesterol levels
- improved quality of life
- improved health behaviors
- increased patient satisfaction
- improved physician-patient relationships
- improved control of mean blood glucose

### Interpersonal Group Therapy Curative Factors

1. Instillation of hope: One of the greatest worries of patients is that MiND may indicate that they will soon have a more serious illness, including Alzheimer-type MaND. Although there is no known treatment that can reverse the damage that has happened in the brain, there are therapies that may reduce some symptoms and can improve patients' daily lives today.
2. Universality: There is something powerful in knowing that you are not alone. Members of the MiND group enjoy comparing, not hiding, their problems with other members.
3. Imparting information: Whether the members are discussing a new "healthy" recipe, telling about the benefits of using a day journal to keep on schedule, or showing how they do leg exercises while washing dishes, they always are willing and eager to share information with a fellow member.
4. Altruism: There is a bond that builds in the group, including the caregivers and/or partners, that resembles more of a family than strangers with a diagnosis of MiND. Members are there for each other, offering help and support.
5. Corrective recapitulation: Although probably not what Yalom had in mind, the program offers a safe place for the members to work out problems that they are having with their families. Often, MiND changes how the family views the patient. The patient is no longer the parent who can do anything and everything, the one who has all the answers. The patient often thinks that his/her family no longer comes to visit but comes to "check up" on him/her. Members offer support and give suggestions on how the patient might handle the situation. Just being able to state the problems to the group serves as a corrective emotional experience.
6. Development of social techniques: Patients diagnosed with MiND often suffer social setbacks and find a need to develop new social techniques. Group members have admitted to feeling anxious and completely mixed up at social events with too many people in attendance. They find that they are no longer able to follow conversations. Something as simple as a trip to the store or a church supper can become a burden too big to carry. The group encourages socialization and works together on solutions.
7. Imitative behavior: Members are eager to hear how everyone else handles situations and problems. If something works for one member—a white board on the fridge for a reminder, a day planner in the purse—it might work for another.
8. Interpersonal learning: Through the process of interacting with the other members, each member is able to achieve a greater level of self-awareness. Because of the safety of the group, members are willing to express their emotions to other members. They are more able to accept who they are now and to recognize their strengths and weaknesses.
9. Cohesiveness: The cohesiveness of the group is evident by the members arriving early, giving hugs, laughing together, sharing stories (some embarrassing), attending each meeting, and leaving late. Members have said they consider the group to be "my new best friends."
10. Catharsis: Members are at and in a place, physically and mentally, where they can admit to their forgetfulness rather than hide it. This frees them to better cope with the changes and to strategize new coping mechanisms.
11. Existential factors: Members of the MiND group enjoyed their program enough that they asked to continue meeting after the study was completed. They enjoy sharing and supporting one another, and they recognize that in their personal battle against MaND, they are not alone. They voice their feelings about how they want to live their life. They do not want cognitive impairment to be their life, but through the group they want to learn how they can live life to its fullest.

- decreased emergency and urgent care visits, as well as referrals to other specialists
- decreased hemoglobin $A_{1c}$ levels
- better medication compliance and increased self-efficacy (ie, judgment of their capabilities to carry out the specific tasks necessary to achieve a desired goal).

In a group medical visit, a physician participates in the group care and can bill for services delivered, usually with the same codes as when delivered individually. Medicare currently allows individual codes to be used in a group visit.

A group medical visit also offers an invaluable opportunity to get to know patients. A physician seldom has time to listen to a patient for as long as either would like. In a group setting, the physician and staff have the opportunity to communicate with patients in a different way that may improve mutual understanding.

An ideal leadership combination for a group medical visit consists of a nurse, a behavioral therapist, and a physician or nurse practitioner with training in geriatrics. The physician's or nurse practitioner's presence encourages improved relationships with participants and provides the practitioner with invaluable insight into their progress.

**… those with a diagnosis of MiND can benefit from multicomponent group visits to help them accommodate the changes that they experience, with a view to using cognitive stimulation to intervene in the possible progress of their illness …**

Implementing group medical visits that focused on changing lifestyle proved to be much harder than we had imagined. Despite the literature we reviewed in the Introduction, our colleagues did not believe that changing lifestyle could alter the course of neurocognitive disorders. Virtually all prescribed medication and believed in the benefits of medication far more than the benefits of lifestyle change. An individual appointment model was the norm. This led us to understand that we were doing more than just implementing what we thought was an innovative, evidence-based program. We were changing culture, and changing culture is difficult. We were going against the norm by advocating frequent (as often as weekly) group medical visits emphasizing lifestyle change in which people contribute to each other's care and participate more in their own care. The emphasis was not on pharmaceutical intervention, and behavioral health was fully integrated into the group visit.

Our hypothesis was that we could change physicians' beliefs about neurocognitive disorders and that group office visits involving memory training, balance exercises, and nutrition instruction would prevent memory decline, improve gait instability, and provide socialization for patients with MiND and their caregivers.

## METHODS

We limited groups to fewer than 15 participants, men or women, including family members and caregivers. We initially limited groups to people who had a diagnosis of MiND but discovered over time that the boundary between MiND and MaND is a fluid one, and that willingness to come was more important than whether the person met the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* criteria[72] for MiND or MaND. Our first group met for 90 minutes weekly in the hospital. Our second group met for 2 hours weekly in a local skilled nursing facility. We strongly encouraged group members to practice the cognitive stimulation exercises between sessions, to adopt the information about diet and nutrition, and to exercise.

Group leaders included a behavioral health practitioner, a geriatric medical practitioner, and a nurse. Our initial group began as time-limited but became open-ended because the patients did not want to stop. An open-ended, ongoing group meant that participants had a "home" for their concerns as they worked on maintaining their cognitive function. Any health practitioner could refer people to the groups. Groups were open enrollment, meaning that anyone could join the group at any time if s/he chose. We strived to create a nonjudgmental, friendly group culture and encouraged people to attend whether or not they participated, thereby relieving them of anxiety and reassuring them that the group was intended to be an accessible, patient-friendly environment. Our initial group for people with MiND met, and continues to meet weekly, on the first floor of our hospital, requiring no stairs or elevators. Our second group involved a ramp or an elevator to reach the room. We did not charge for the hospital group but did charge insurance for the second group (but not the family members or caregivers who attended).

Follow-up calls or visits were made with 110 patients and their families who had attended 2-hour geriatric assessment visits in which recommendations to their primary care clinicians had been made for lifestyle changes. We recorded how often these changes actually occurred.

### Education for Physicians

Creating two groups for patients with MiND and their caregivers was one step toward changing the medical culture toward cognitive impairment. To create more active change, we used our experiences from the group visits to teach our family medicine residents about MiND. Each first-year resident rotated through geriatrics for four weeks. During that time, they were exposed to the MiND group or groups and were taught the current literature on MiND (as outlined in the Introduction). Residents were given pre- and posttraining assessment questionnaires on their knowledge of MiND literature.

Additionally, we prepared a lecture about MiND and group medical visits for practicing physicians in our community and others. We presented this lecture at our hospital and at two national conferences and obtained pre- and postassessments of knowledge of therapies for MiND.

We developed a pretest and a posttest for assessing knowledge, which consisted of a list of 24 potential therapies for MiND, for which physicians were instructed to rate in order of importance. Second came a list of 24 laboratory and imaging evaluations, that physicians could order as part of their MiND workup, which they were also asked to rate in order of importance. There were 3 additional questions on the pre- and posttests about their comfort level with patients with MiND and about how much information they thought they possessed to care for these patients. The posttest added 2 questions related to how much the presentation had changed their understanding of MiND and how likely it was that they would participate in group medical visits for MiND. We compared the 2 rankings using the Spearman rank correlation in SPSS Version 21 (Statistical Package for the Social Sciences, IBM Corp, Armonk, NY).

We assessed the knowledge of our family medicine residents (N = 18) using multiple-choice questions and compared pre- and posttests using the paired *t*-test procedure in SPSS. At the end of their training year, we gave the residents the same posttest that we had given to the practicing physicians. We also asked if they believed they could administer the Montreal Cognitive Assessment Scale, a screening test for MiND.

## Group Facilitation and Activities

We emphasized in training that group leaders needed to have patience, compassion, and skills in interpersonal communication. We used training resources in nonviolent communication, active listening, reflection and reframing, and nonverbal communication. We stressed to group leaders that simply listening to a participant's concerns and providing compassionate, respectful guidance through the exercises could accomplish much.

All group members arrived independently. Family caregivers who accompanied group members were welcome to remain and participate.

We aimed to keep group activities at a level that ensured success for almost everyone, sometimes making them deliberately simple. We relied on no-cost online resources for cognitive stimulation and enhancement. A check-in conversation began the group meeting, in which group members gave a brief description of their activities during the past week. These activities might have included walks in the park with their dog, visits from family, bridge games, or shopping. Members were encouraged to discuss any difficulties or obstacles they faced throughout the week as well as their successes. Group members were encouraged to collaborate on finding solutions for difficulties or obstacles.

Other group activities included developing breathing and mindfulness skills, movement and exercises, cognitive stimulation, and psychoeducation.

### Breathing and Mindfulness Skills

Qi Gong practices, mindfulness meditation, and other breathing practices were used to teach breathing and movement. Basic Qi Gong techniques can be easily found through video and are easy to learn. The important element is the flow of movement.

Basic mindfulness was considered a useful skill to reduce anxiety and depression. A common mindfulness exercise is to remind oneself to put aside worries and draw some slow deep breaths, aware of nothing more than the feeling of the breath as it travels in and out the nose. If an anxious or intrusive thought arises, one allows the thought to pass by, to be considered later. During this time, we offered group members the opportunity to take some moments in life to simply breathe.

Free resources for mindfulness and breathing can be found at www.freemindfulness.org/download, http://marc.ucla.edu/body.cfm?id=22, and www.umsystem.edu/newscentral/mindfuleating/audiovideo-recordings.

### Movement

The group leaders taught Qi Gong-based moves; they focused on movement *with the breath*, gentle movements to encourage retention of balance and range of motion. Qi Gong is an exercise form that is suited to people who may need to begin very slowly. Patients were advised to go at their own pace and to be careful not to exceed their own limitations.

Qi Gong is said to reduce stress, build stamina, and increase vitality.[73] Members were encouraged to spend at least 15 minutes a day repeating the Qi Gong and balance exercises at home.

Typical exercises included

- "Begin with a slow breath in. As you are breathing in, raise your arms. When you have stopped your 'in' breath, stop moving your arms. Begin to breathe out. As you are breathing out, move your arms down. Repeat this exercise, remembering to begin to breathe *before* you begin to move."
- "Now work with raising and lowering a leg, holding onto a table at first, if necessary. Make slow movements that are always *with* the breath."

Resources for exercises can be found online[74] and by searching with the parameter "exercise elderly."

### Cognitive Stimulation

Cognitive stimulation was offered in the form of games and work problems (eg, map reading, memory work) that used memory, inductive reasoning, and problem-solving skills. Two or three different exercises were offered each week. Participants were encouraged to practice the exercises at home.

Cognitive stimulation practiced the following skills and tasks:

- Simple problem-solving
- Pattern recognition
- Deductive reasoning skills
- Recall memory: Exercises included even simply recounting the events of the past week. Other ideas included recognizing which object had been removed from a group, memorizing a small group of objects and then recalling what they were when they were covered up, and grouping objects according to their common purpose. Telling life stories also is good memory recall work and helped to get to know the group members' needs
- Recognition memory: For these exercises, group participants can be invited to bring pictures of family members, look through magazines, photo albums, and the like. Pictures congruent with members' cultural experiences are useful, such as historical photographs of events and places, particularly ones that the participants have encountered in their own lives.

Resources for cognitive stimulation include many online worksheets for cognitive stimulation. The University of Alabama has a downloadable shareware publication that lists hundreds of activities for cognitive stimulation (www.uab.edu/medicine/tbi/uab-tbi-information-network/uab-tbims-home-based-cognitive-stimulation-activities). Although the university has directed its attention to traumatic brain injury, the exercises translate for anyone who needs to practice cognitive functioning.[75] The European Union's research fund has also produced a volume of activities for cognitive stimulation.[76]

### Psychoeducation

Psychoeducation[77] involved the following:

- We emphasized the value of practical skills for memory retention and activation—exploring ways for people to stay organized, use labels, make lists, place reminders, and more—as well as to maintain independence. Participants were encouraged to practice techniques at home and report to the group. Information sharing was encouraged, especially regarding solving the problems of operational necessities such as organizing rides, cooking, paying bills, and managing activities of daily life.
- We encouraged the augmentation of social skills. Participants were encouraged to discuss their problems and frustrations, as well as their successes
- We encouraged making lifestyle changes for healthy aging. We offered current research on the value of nutrition, diet, and exercise for a healthy mind. We encouraged people to try the Mediterranean diet, to increase their intake of vegetables, and to walk or exercise each day. We helped people work around physical limitations to find ways to engage in even limited activity. Where appropriate, we encouraged them to ask their health care clinician for a referral for physical or occupational therapy.

Group sessions ended with a general, open discussion and mention of any plans for what participants would take with them from the group for their activities until the next meeting.

## RESULTS

Group 1 consisted of 6 patients and 6 spouses or caregivers on average. Group 2 contained 4 patients and 6 caregivers on average. Patient interviews revealed that all group members thought that the group provided a useful setting for the provision of cognitive stimulation, balance, breathing exercises, and current research about the importance of nutrition and lifestyle changes. The group participants had all made changes to their nutrition, engaged in more social activities, reported improved sleep, and reported relief from some of the shame and anxiety they felt about having been diagnosed with MiND. They reported that the breathing exercises helped with focus and balance.

Group 1 met at our local hospital, and Group 2 met at the community room of one of the skilled nursing facilities that our hospital owned. Following 6 weeks of participation, half of our participants showed and maintained (over an average of 7.3 months) statistically significant improvement on the 5-word delayed recall and the 5-second 1-leg stand from their baseline testing ($p < 0.05$). One-fourth of the participants started with a perfect score on delayed recall and 5-second one-leg stand and maintained that score over time. One-fourth of the participants were trending downward from their baseline score. A total of 32 patients were assessed. None of our participants scored as depressed on the Geriatric Depression Scale developed by Yesavage et al.[78] One developed a score in the depression range during the group in relation to significant personal stressors. All participants' improved their 5-second 1-leg stand. All participants reported improved sleep. All participants reported making healthy dietary change. All of these changes were statistically significant at $p < 0.05$ using the paired *t*-test to compare pre- and posttest results.

We noticed that participants became more comfortable with each other and began encouraging one another and socializing more by the third session, suggesting that one should strongly encourage participants who feel reluctant about attendance to come at least three times before giving up. Caregivers who attended the group sessions reported similar benefits as the participants with regard to better cognition and dietary changes, though these were not measured.

### Changing the Local Culture of Care

Our goal in presenting information to physicians and our family practice trainees was to increase their understanding of the importance of exercise and physical activity, cognitive stimulation/enhancement, social support, and the Mediterranean diet in delaying onset of memory loss and preventing progression of memory loss. We developed a pre- and posttest for assessing knowledge, which consisted of a list of 24 therapies for MiND, and physicians were instructed to rate them in importance. There was a list of 24 diagnostic tests, which they could order as part of their MiND workup, which they were also asked to rate in importance. There were 3 additional questions on the pretest about comfort with patients who have MiND and about how much information the physicians and trainees thought they possessed to care for these patients. The posttest added 2 questions related to how much the presentation had changed their understanding of MiND and how likely was it that they would have group medical visits for patients with MiND.

Participants in all 3 settings (local hospital, international, national conference) in which we presented this information did not agree with us in their pretests. We gave a total of 52 pre- and posttests. Respondents almost uniformly believed in the value of "memory-preserving" medications (donepezil, memantine, rivastigmine, galantamine) for patients with MiND before the training. To determine if a change occurred in their perception, we asked them to rank interventions before their training and after their interventions. A statistically significant change occurred in their pre- and posttraining rankings for how to treat MiND ($p < 0.001$, Spearman rank correlation in SPSS). Visual inspection of their answers revealed that medications had dropped in importance to the bottom of their list, and exercise and diet had risen to the top. Cognitive stimulation was more varied in placement in their hierarchical listings. We found a statistically significant change in their understanding of the importance of exercise and physical activity, Mediterranean diet, cognitive enhancement/stimulation, and social support, all at the $p < 0.001$ level or better.

We assessed the knowledge of our 18 family medicine residents using multiple-choice questions and found a statistically significant increase in knowledge from pre- and posttests ($p < 0.001$ using paired *t*-test procedure in SPSS). At the end of their training year, we gave them the same pre- and posttests after the same hourlong lecture that we gave practicing physicians. We found no difference on pre- and posttesting with high Spearman correlation coefficients to how we rated the answers. We took this to mean that we were being effective in teaching them how to manage MiND during the course of the year. All survey respondents believed that they could administer the Montreal Cognitive Assessment Scale, a screening test for MiND.

We found ourselves advocating ongoing group medical care in an environment in which this was not the norm, despite its being widely used elsewhere. After the training, 55% of physicians said they wanted to try group medical care for patients with MiND. Thus far, we continue to provide a free group at the hospital. We have also implemented a group at our local nursing home. There, we charge for our patients and allow anyone else to come for free. However, we were unable to implement group visits at our own outpatient clinic. The reasons cited for not implementing group medical care have been as follows: 1) "no one will come," 2), "there's not enough space," 3) "we won't make enough money," 4) "it will be too much trouble for the front-office staff," and 5) "it will consume too many resources in nursing time and staff."

### Behavior Change with Conventional Geriatric Assessment

Of 110 geriatric assessments (performed in 2-hour office visits) in which some level of neurocognitive disorder was assessed, lifestyle changes were recommended, typically including increasing exercise (predominantly asking patients to take a daily walk because most were sedentary), making dietary changes (typically reducing consumption of sugar and simple carbohydrates, since most of our patients had a diet high in sugar and simple carbohydrates; and increasing intake of fruits and vegetables), cognitive stimulation (suggestions made appropriate for the individual patient), and socialization (suggestions made appropriate for the individual patient).

In keeping with national recommendations, we recommended against "memory-preserving" drugs for MiND and attempted to minimize use of benzodiazepines, opiates, and anticholinergic medications. For MaND, we presented patients and their families with the pros and cons of "memory-preserving" drugs, including an explanation of the number to treat for benefit and the number to treat for harm, and of the level of change one might expect; we then recommended treatment in accordance with the family's wishes. We conducted follow-up of these 110 assessments an average of 7.3 months later (range = 6.1 months to 10.3 months; standard deviation = 2.5 months) and found that only recommendations to start treatment with "memory-preserving" drugs were implemented. We found no cases in which recommendations were implemented to make lifestyle changes or to stop use of "memory-preserving" drugs in patients with MiND. Recommendations to stop opiate use were followed by 1 of 15 patients; to stop use of benzodiazepines, by 1 of 12 patient; and to stop use of other medications, by 12 of 34 patients.

## CONCLUSION

Patients and caregivers can benefit from a multidisciplinary approach across nursing, behavioral health, and medicine with regard to preventing cognitive decline, improving balance, making healthy dietary changes, and increasing socialization. Structured, multimodality group office visits could be an effective strategy for management of patients with MiND (formerly called mild cognitive impairment) in primary care settings. The curriculum devised in this study is reproducible, and further large-scale studies may prove this curriculum to be a potential resource for primary care physicians.

Weekly group visits have continued at the hospital at no cost to the patients and caregivers. Group medical visits continued for one year at the local skilled nursing facility and were stopped when personnel moved. A group held in a primary care physician's office can create the sense of the medical home that patients appreciate. Some physicians successfully create groups in their waiting room space, after hours.

The conventional two-hour geriatric assessment with report and referral back to the primary care physician produced no behavioral change and minimal medication change. Therefore, its utility is questionable, although its proponents were unwilling to question it at the institution where we practiced.

One important obstacle to changing the culture of medicine is the ethnocentrism of contemporary medicine. *Ethnocentrism* is the point of view that one's own way of life is to be preferred to all others.[79,80] It prevents people from understanding the other, let alone taking the other seriously. The views of others are judged by the standards of one's own culture. Van der Geest[81] described how the professions enculturate their practitioners to view and explain the world in particular ways. Biomedical treatment vs biopsychosocial prevention paradigms can be quite different.

The culture of medicine usually turns first to medications as solutions and is skeptical of other answers. The bias is against nonpharmaceutical approaches. Each time we present these ideas, we encounter the medical response—the upraised eyebrows, the rolling of the eyes, the shrug of the shoulders, the dismissal from a segment of our audience. Others, however, are interested and are willing to entertain another culture, a culture in which action can produce change, in which changing lifestyle has an impact. The challenge is one faced by anthropologists: to translate cultures to each other. Our challenge is to integrate the disciplines of medicine, nursing, behavioral health, and lifestyle or integrative medicine. However, as van der Geest says: "Interdisciplinarity is not only a long and difficult word, it is also a long and difficult road. It is more fashionable as lipservice than actual practice. … But disciplines are merely human designed (cultural) tools to study and interpret/explain reality. No discipline is all-embracing, or has the final word."[79p871]

More work remains to be done on how to change the culture of medicine in directions suggested by the empirical evidence, especially when that evidence contradicts common assumptions of the biomedical model. ❖

[a] Throughout this article, we will use the convention of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* and the International Classification of Diseases, Tenth Revision of referring to mild cognitive impairment as minor neurocognitive disorder (MiND) and calling dementia of all types major neurocognitive disorder (MaND). We still refer to the Alzheimer subtype of MaND as Alzheimer disease.

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## References

1. Petersen RC, Caracciolo B, Brayne C, Gauthier S, Jelic V, Fratiglioni L. Mild cognitive impairment: A concept in evolution. J Intern Med 2014;275(3):214-28. DOI: https://doi.org/10.1111/joim.12190.
2. Mitchell AJ, Shiri-Feshki M. Rate of progression of mild cognitive impairment to dementia—meta-analysis of 41 robust inception cohort studies. Acta Psychiatr Scand 2009 Apr;119(4):252-65. DOI: https://doi.org/10.1111/j.1600-0447.2008.01326.x.
3. Springate B, Tremont G. Caregiver burden and depression in mild cognitive impairment. J Appl Gerontol 2013 Sep;32(6):765-75. DOI: https://doi.org/10.1177/0733464811433486.
4. Ryan KA, Weldon A, Huby NM, et al. Caregiver support service needs for patients with mild cognitive impairment and Alzheimer disease. Alzheimer Dis Assoc Disord 2010 Apr-Jun;24(2):171-6. DOI: https://doi.org/10.1097/wad.0b013e3181aba90d.
5. Unverzagt FW, Smith DM, Rebok GW, et al. The Indiana Alzheimer Disease Center's Symposium on Mild Cognitive Impairment. Cognitive training in older adults: Lessons from the ACTIVE study. Curr Alzheimer Res 2009 Aug;6(4):375-83. DOI: https://doi.org/10.2174/156720509788929345.
6. Wolinsky FD, Unverzagt FW, Smith DM, Jones R, Wright E, Tennstedt SL. The effects of the ACTIVE cognitive training trial on clinically relevant declines in health-related quality of life. J Geront B Psychol Sci Soc Sci 2006 Sep;61(5):S281-7. DOI: https://doi.org/10.1093/geronb/61.5.s281.
7. Heyn P, Abreu BC, Ottenbacher KJ. The effects of exercise training on elderly persons with cognitive impairment and dementia: A meta-analysis. Arch Phys Med Rehabil 2004 Oct;85(10):1694-704. DOI: https://doi.org/10.1016/j.apmr.2004.03.019.
8. Lü J, Fu W, Liu Y. Physical activity and cognitive function among older adults in China: A systematic review. J Sport Health Sci 2016 Sep 30;5(3):287-96.
9. Knight A, Bryan J, Murphy K. Is the Mediterranean diet a feasible approach to preserving cognitive function and reducing risk of dementia for older adults in Western countries? New insights and future directions. Ageing Res Rev 2016 Jan;25:85-101. DOI: https://doi.org/10.1016/j.arr.2015.10.005.
10. Joseph JA, Shukitt-Hale B, Willis LM. Grape juice, berries, and walnuts affect brain aging and behavior. J Nutr 2009 Sep;139(9):1813S-7S. DOI: https://doi.org/10.3945/jn.109.108266.
11. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. Cochrane Database Syst Rev 2012 Feb 15;(2):CD005562. DOI: https://doi.org/10.1002/14651858.CD005562.pub2.
12. Kelly ME, Loughrey D, Lawlor BA, Robertson IH, Walsh C, Brennan S. The impact of cognitive training and mental stimulation on cognitive and everyday functioning of healthy older adults: A systematic review and meta-analysis. Ageing Res Rev 2014 May;15:28-43. DOI: https://doi.org/10.1016/j.arr.2014.02.004.
13. Rebok GW, Ball K, Guey LT, et al; ACTIVE Study Group. Ten-year effects of the advanced cognitive training for independent and vital elderly cognitive training trial on congnition and everyday functioning in older adults. J Am Geriatr Soc 2014 Jan;62(1):16-24. DOI: https://doi.org/10.1111/jgs.12607.
14. Larson EB, Wang L, Bowen JD, et al. Exercise is associated with reduced risk for incident dementia among persons 65 years of age and older. Ann Intern Med 2006 Jan 17;144(2):73-81. DOI: https://doi.org/10.7326/0003-4819-144-2-200601170-00004.
15. Weuve J, Kang JH, Manson JE, Breteler MM, Ware JH, Grodstein F. Physical activity, including walking, and cognitive function in older women. JAMA 2004 Sep 22;292(12):1454-61. DOI: https://doi.org/10.1001/jama.292.12.1454.
16. Lam LC, Chau RC, Wong BM, et al. Interim follow-up of a randomized controlled trial comparing Chinese style mind body (Tai Chi) and stretching exercises on cognitive function in subjects at risk of progressive cognitive decline. Int J Geriatr Psychiatry 2011 Jul;26(7):733-40. DOI: https:/doi.org/10.1016/j.ampr.2004.03.019.
17. Crooks VC, Lubben J, Petitti DB, Little D, Chiu V. Social network, cognitive function, and dementia incidence among elderly women. Am J Public Health 2008 Jul;98(7):1221-7. DOI: https://doi.org/10.2105/ajph.2007.115923.
18. Roberts RO, Roberts LA, Geda YE, et al. Relative intake of macronutrients impacts risk of mild cognitive impairment or dementia. J Alzheimers Dis 2012;32(2):329-39. DOI: https://doi.org/10.3233/JAD-2012-120862.
19. Geda Y, Ragossnig M, Roberts LA, et al. Caloric intake, aging, and mild cognitive impairment: A population-based study. J Alzheimers Dis 2013;34(2):501-7. DOI: https://doi.org/10.3233/JAD-121270.
20. Singh B, Parsaik AK, Mielke MM, et al. Association of Mediterranean diet with mild cognitive impairment and Alzheimer's disease: A systematic review and meta-analysis. J Alzheimers Dis 2014;39(2):271-82. DOI: https://doi.org/10.3233/JAD-130830.
21. Whalley LJ, Duthie SJ, Collins AR, et al. Homocysteine, antioxidant micronutrients and late onset dementia. Eur J Nutr 2014 Feb;53(1):277-85. DOI: https://doi.org/10.1007/s00394-013-0526-6.
22. Ames BN. Low micronutrient intake may accelerate the degenerative diseases of aging through allocation of scarce micronutrients by triage. Proc Natl Acad Sci U S A 2006 Nov 21;103(47):17589-94. DOI: https://doi.org/10.1073/pnas.0608757103.
23. Polidori MC, editor. Special issue: Biofactors and cognitive function. BioFactors 2012 Mar/Apr;38(2):77–171.
24. Dai Q, Borenstein AR, Wu Y, Jackson JC, Larson EB. Fruit and vegetable juices and Alzheimer's disease: The Kame Project. Am J Med 2006 Sep;119(9):751-9. DOI: https://doi.org/10.1016/j.amjmed.2006.03.045.
25. Morris MC, Evans DA, Tangney CC, Bienias JL, Wilson RS. Associations of vegetable and fruit consumption with age-related cognitive change. Neurology 2006 Oct 24;67(8):1370-6. DOI: https://doi.org/10.1212/01.wnl.0000240224.38978.d8.
26. Anlasik T, Sies H, Griffiths HR, Mecocci P, Stahl W, Polidori MC. Dietary habits are major determinants of the plasma antioxidant status in healthy elderly subjects. Br J Nutr 2005 Nov;94(5):639-42. DOI: https://doi.org/10.1079/bjn20051574.
27. Hughes TF, Andel R, Small BJ, et al. Midlife fruit and vegetable consumption and risk of dementia in later life in Swedish twins. Am J Geriatr Psychiatry 2010 May;18(5):413-20. DOI: https://doi.org/10.1097/jgp.0b013e3181c65250.
28. Barberger-Gateau P, Raffaitin C, Letenneur L, et al. Dietary patterns and risk of dementia: The Three-City cohort study. Neurology 2007 Nov 13;69(20):1921-30. DOI: https://doi.org/10.1212/01.wnl.0000278116.37320.52.
29. Ritchie K, Carrière I, Ritchie CW, Berr C, Artero S, Ancelin ML. Designing prevention programmes to reduce incidence of dementia: Prospective cohort study of modifiable risk factors. BMJ 2010 Aug 5;341:c3885. DOI: https://doi.org/10.1136/bmj.c3885.
30. Scarmeas N, Stern Y, Tang MX, Mayeux R, Luchsinger JA. Mediterranean diet and risk for Alzheimer's disease. Ann Neurol 2006 Jun;59(6):912-21. DOI: https://doi.org/10.1002/ana.20854.
31. Scarmeas N, Stern Y, Mayeux R, Manly JJ, Schupf N, Luchsinger JA. Mediterranean diet and mild cognitive impairment. Arch Neurol 2009 Feb;66(2):216-25. DOI: https://doi.org/10.1001/archneurol.2008.536.
32. Scarmeas N, Luchsinger JA, Schupf N, et al. Physical activity, diet, and risk of Alzheimer disease. JAMA 2009 Aug 12;302(6):627-37. DOI: https://doi.org/10.1001/jama.2009.1144.
33. Willett WC, Sacks F, Trichopoulou A, et al. Mediterranean diet pyramid: A cultural model for healthy eating. Am J Clin Nutr 1995 Jun;61(6 Suppl):1402S-1406S.
34. Sofi F, Cesari F, Abbate R, Gensini GF, Casini A. Adherence to Mediterranean diet and health status: Meta-analysis. BMJ 2008 Sep 11;337:a1344. DOI: https://doi.org/10.1136/bmj.a1344.
35. Burgener SC, Buettner L, Coen Buckwalter K, et al. Evidence supporting nutritional interventions for persons in early stage Alzheimer's disease (AD). J Nutr Health Aging 2008 Jan;12(1):18-21. DOI: https://doi.org/10.1007/bf02982159.
36. Singh B, Parsaik AK, Mielke MM, et al. Association of Mediterranean diet with mild cognitive impairment and Alzheimer's disease: A systematic review and meta-analysis. J Alzheimers Dis 2014;39(2):271-82. DOI: https://doi.org/10.3233/JAD-130830.
37. Psaltopoulou T, Sergentanis TN, Panagiotakos DB, Sergentanis IN, Kosti R, Scarmeas N. Mediterranean diet, stroke, cognitive impairment, and depression: A meta-analysis. Ann Neurol 2013 Oct;74(4):580-91. DOI: https://doi.org/10.1002/ana.23944.
38. Benton D. Micro-nutrient supplementation and the intelligence of children. Neurosci Biobehav Rev 2001 Jun;25(4):297-309. DOI: https://doi.org/10.1016/s0149-7634(01)00015-x.
39. Osendarp SJ, Baghurst KI, Bryan J, et al; NEMO Study Group. Effect of a 12-mo micronutrient intervention on learning and memory in well-nourished and marginally nourished school-aged children: 2 parallel, randomized, placebo-controlled studies in Australia and Indonesia. Am J Clin Nutr 2007 Oct;86(4):1082-93.
40. Grodstein F, O'Brien J, Kang JH, et al. Long-term multivitamin supplementation and cognitive function in men: A randomized trial. Ann Intern Med 2013 Dec 17;159(12):806-14. DOI: https://doi.org/10.7326/0003-4819-159-12-201312170-00006.
41. Agarwal R, Chhillar N, Kushwaha S, Singh NK, Tripathi CB. Role of vitamin B(12), folate, and thyroid stimulating hormone in dementia: A hospital-based study in north Indian population. Ann Indian Acad Neurol 2010 Oct;13(4):257-62. DOI: https://doi.org/10.4103/0972-2327.74193.
42. Davis SR, Quinlivan EP, Shelnutt KP, et al. The methylenetetrahydrofolate reductase 677C->T polymorphism and dietary folate restriction affect plasma one-carbon metabolites and red blood cell folate concentrations and distribution in women. J Nutr 2005 May;135(5):1040-4.
43. Zheng Z, Wang J, Yi L, et al. Correlation between behavioural and psychological symptoms of Alzheimer type dementia and plasma homocysteine concentration. BioMed Res Int 2014;2014:383494. DOI: https://doi.org/10.1155/2014/383494.

44. Malouf M, Grimley EJ, Areosa SA. Folic acid with or without vitamin B12 for cognition and dementia. Cochrane Database Syst Rev 2003;(4):CD004514. DOI: https://doi.org/10.1002/14651858.CD004514.
45. Neugroschl JA, Kolevzon A, Samuels SC, Marin DB. Dementia. In: Sadock BJ, Sadock VA, editors. Kaplan & Sadock's comprehensive textbook of psychiatry. 8th ed. Baltimore, MD: Lippincott Williams & Wilkins; 2005. p 1068-92.
46. Dahal A, Purkayastha M, Agrawal BK, Pandey R, Singh J. The status of vitamin B12 in elderly persons suffering from dementia. Indo American Journal of Pharmaceutical Research 2014;4(4):2057-63.
47. Riggs KM, Spiro A 3rd, Tucker K, Rush D. Relations of vitamin B-12, vitamin B-6, folate, and homocysteine to cognitive performance in the Normative Aging Study. Am J Clin Nutr 1996 Mar;63(3):306-14.
48. Vogel T, Dali-Youcef N, Kaltenbach G, Andrès E. Homocysteine, vitamin B12, folate and cognitive functions: A systematic and critical review of the literature. Int J Clin Pract 2009 Jul;63(7):1061-7. DOI: https://doi.org/10.1111/j.1742-1241.2009.02026.x.
49. Faux NG, Ellis KA, Porter L, et al. Homocysteine, vitamin B12, and folic acid levels in Alzheimer's disease, mild cognitive impairment, and healthy elderly: Baseline characteristics in subjects of the Australian Imaging Biomarker Lifestyle study. J Alzheimers Dis 2011;27(4):909-22. DOI: https://dx.doi.org/10.3233/JAD-2011-110752.
50. Li L, Cao D, Desmond R, et al. Cognitive performance and plasma levels of homocysteine, vitamin B12, folate and lipids in patients with Alzheimer disease. Dement Geriatr Cogn Disord 2008;26(4):384-90. DOI: https://doi.org/10.1159/000164271.
51. Gallucci M, Zanardo A, De Valentin L, Vianello A. Homocysteine in Alzheimer disease and vascular dementia. Arch Gerontol Geriatr Suppl 2004;(9):195-200. DOI: https://doi.org/10.1016/j.archger.2004.04.027.
52. Budge MM, de Jager C, Hogervorst E, SmithAD; Oxford Project To Investigate Memory and Ageing (OPTIMA). Total plasma homocysteine, age, systolic blood pressure, and cognitive performance in older people. J Am Geriatr Soc 2002 Dec;50(12):2014-8. DOI: https://doi.org/10.1046/j.1532-5415.2002.50614.x.
53. Nurk E, Refsum H, Tell GS, et al. Plasma total homocysteine and memory in the elderly: The Hordaland Homocysteine Study. Ann Neurol 2005 Dec;58(6):847-57. DOI: https://doi.org/10.1002/ana.20645.
54. Ravaglia G, Forti P, Maioli F, et al. Homocysteine and folate as risk factors for dementia and Alzheimer disease. Am J Clin Nutr 2005 Sep;82(3):636-43.
55. Gallucci M, Zanardo A, Bendini M, Di Paola F, Boldrini P, Grossi E. Serum folate, homocysteine, brain atrophy, and auto-CM system: The Treviso Dementia (TREDEM) study. J Alzheimers Dis 2014;38(3):581-7. DOI: https://doi.org/10.3233/JAD-130956.
56. den Heijer T, Vermeer SE, Clarke R, et al. Homocysteine and brain atrophy on MRI of non-demented elderly. Brain 2003 Jan;126(Pt 1):170-5. DOI: https://doi.org/10.1093/brain/awg006.
57. Mecocci P, Polidori MC. Antioxidant clinical trials in mild cognitive impairment and Alzheimer's disease. Biochim Biophys Acta 2012 May;1822(5):631-8. DOI: https://doi.org/10.1016/j.bbadis.2011.10.006.
58. Polidori MC, Nelles G. Antioxidant clinical trials in mild cognitive impairment and Alzheimer's disease—challenges and perspectives. Curr Pharm Des 2014;20(18):3083-92. DOI: https://doi.org/10.2174/13816128113196660706.
59. Zandi PP, Anthony JC, Khachaturian AS, Stone SV, et al; Cache County Study Group. Reduced risk of Alzheimer disease in users of antioxidant vitamin supplements: The Cache County Study. Arch Neurol 2004 Jan;61(1):82-8. DOI: https://doi.org/10.1001/archneur.61.1.82.
60. Dumont M, Lin MT, Beal MF. Mitochondria and antioxidant targeted therapeutic strategies for Alzheimer's disease. J Alzheimers Dis 2010;20 Suppl 2:S633-43. DOI: https://doi.org/10.3233/JAD-2010-100507.
61. Yaffe K, Clemons TE, McBee WL, Lindblad AS; Age-Related Eye Disease Study Research Group. Impact of antioxidants, zinc, and copper on cognition in the elderly: A randomized, controlled trial. Neurology 2004 Nov;63(9):1705-7. DOI: https://doi.org/10.1212/01.wnl.0000142969.19465.8f.
62. Polidori MC, Schulz RJ. Nutritional contributions to dementia prevention: Main issues on antioxidant micronutrients. Genes Nutr 2014 Mar;9(2):382-94. DOI: https://doi.org/10.1007/s12263-013-0382-2.
63. Li FJ, Shen L, Ji HF. Dietary intakes of vitamin E, vitamin C, and β-carotene and risk of Alzheimer's disease: A meta-analysis. J Alzheimer's Dis 2012;31(2):253-8. DOI: https://doi.org/10.3233/JAD-2012-120349.
64. Sano M, Ernesto C, Thomas RG, et al. A controlled trial of selegiline, alpha-tocopherol, or both as treatment for Alzheimer's disease. The Alzheimer's Disease Cooperative Study. N Engl J Med 1997 Apr 24;336(17):1216-22. DOI: https://doi.org/10.1056/nejm199704243361704.
65. Kurz A, Pohl C, Ramsenthaler M, Sorg C. Cognitive rehabilitation in patients with mild cognitive impairment. Int J Geriatr Psychiatry 2009 Feb;24(2):163-8. DOI: https://doi.org/10.1002/gps.2086.
66. Troyer AK, Murphy KJ, Anderson ND, Moscovitch M, Craik FI. Changing everyday memory behaviour in amnestic mild cognitive impairment: A randomised controlled trial. Neuropsychol Rehabil 2008 Jan;18(1):65-88. DOI: https://doi.org/10.1080/09602010701409684.
67. Hampstead BM, Sathian K, Phillips PA, Amaraneni A, Delaune WR, Stringer AY. Mnemonic strategy training improves memory for object location associations in both healthy elderly and patients with amnestic mild cognitive impairment: A randomized, single-blind study. Neuropsychology 2012 May;26(3):385-99. DOI: https://doi.org/10.1037/a0027545.
68. Tuppen J. The benefits of groups that provide cognitive stimulation for people with dementia. Nurs Older People 2012 Dec;24(10):20-4. DOI: https://doi.org/10.7748/nop2012.12.24.10.20.c9437.
69. Yalom ID, Leszcz M. Theory and practice of group psychotherapy, 5th edition. New York, NY: Basic books. 2005
70. Sadur CN, Moline N, Costa M, et al. Diabetes management in a health maintenance organization. Efficacy of care management using cluster visits. Diabetes Care 1999 Dec;22(12):2011-7. DOI: https://doi.org/10.2337/diacare.22.12.2011.
71. Jaber R, Braksmajer A, Trilling JS. Group visits: A qualitative review of current research. J Am Board Fam Med 2006 May-Jun;19(3):276-90. DOI: https://doi.org/10.3122/jabfm.19.3.276.
72. American Psychiatric Association, editor. Diagnostic and statistical manual of mental disorders. 5th ed. Washington, DC: American Psychiatric Association; 2013. DOI: https://doi.org/10.1176/appi.books.9780890425596.
73. Pedersen BK, Saltin B. Exercise as medicine—evidence for prescribing exercise as therapy in 26 different chronic diseases. Scand J Med Sci Sports 2015 Dec 1;25(S3):1-72.
74. Exercise and physical activity [Internet]. London, England: Alzheimer's Society; 2015 Apr [cited 2016 May 31]. Available from: www.alzheimers.org.uk/factsheet/529.
75. Traumatic brain injury model system information network. Resources for cognitive stimulation for traumatic brain injury [Internet]. Birmingham, AL: University of Alabama at Birmingham School of Medicine; 2016 [cited 2016 May 31]. Available from: www.uab.edu/medicine/tbi/uab-tbi-information-network/uab-tbims-home-based-cognitive-stimulation-activities.
76. Gonzalez MF, Facal D, Buiza C, et al. D.6.1 cognitive training exercises [Internet]. Vienna, Austria: HERMES—Cognitive Care and Guidance for Active Aging; 2009 Apr 30 [cited 2016 May 31]. Available from: www.fp7-hermes.eu/uploads/media/deliverables/HERMES_D61_CognitiveTrainingExercises_final.pdf.
77. Pendergrass A, Becker C, Hautzinger M, Pfeiffer K. Dementia caregiver interventions: A systematic review of caregiver outcomes and instruments in randomized controlled trials. International Journal of Emergency Mental Health and Human Resilience 2015 Apr 16;17(2):459-68.
78. Yesavage JA, Brink TL, Rose TL, et al. Development and validation of a geriatric depression screening scale: A preliminary report. J Psychiatr Res 1982-1983;17(1):37-49. DOI: https://doi.org/10.1016/0022-3956(82)90033-4.
79. Herskovits MJ. Cultural anthropology. New York, NY: Knopf; 1965.
80. Keesing RM. Cultural anthropology: A contemporary perspective. 2nd ed. New York, NY: Holt, Rinehart & Winston; 1981.
81. van der Geest S. Overcoming ethnocentrism: How social science and medicine relate and should relate to one another. Soc Sci Med 1995 Apr;40(7):869-72. DOI: https://doi.org/10.1016/0277-9536(94)00308-g.

## Strong and Clear

To keep the body in good health is a duty …
otherwise we shall not be able to keep our mind strong and clear.

— Siddhartha Gautama, the Buddha, 567-484 BC, ascetic and sage

*Special Report*

# The Grateful Aging Program: A Naturalistic Model of Transformation and Healing into the Second Half of Life

**Marilyn Schlitz, PhD**

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## ABSTRACT

**Objectives:** Understanding and managing the process of aging is a central issue in modern society. This is a critical factor given the demographic shift toward an aging population and the negative stereotypes around aging that can limit people's worldview on aging with gratitude and well-being.

**Methods:** Building on three decades of qualitative and quantitative studies on positive worldview transformation at the California-based Institute of Noetic Sciences, this article applies an empirically derived naturalistic model of transformation to aging. The Grateful Aging Program is introduced as a set of transformative steps to promote well-being and to shift fear of aging into inspiration for living well.

**Results:** Nine steps to Grateful Aging are identified: 1) answer the call to transformation, 2) cultivate curiosity, 3) formalize a Grateful Aging practice, 4) set intention for Grateful Aging, 5) pay attention to the gifts of aging, 6) build Grateful Aging habits, 7) find guidance, 8) move to acceptance, and 9) transform self and society. Educational programs are described for elderly patients and for the health care professionals who serve them.

**Conclusion:** The Grateful Aging Program is designed to expand awareness of healthy, mindful, and meaningful aging; to promote individual and social well-being; and to facilitate a supportive atmosphere for personal enrichment and shared learning.

## INTRODUCTION

We are alive at an unparalleled moment in human history. An enormous wave of change washes over us. As the demographic facts reveal, our world has an aging population—an unprecedented increase in the average age of people in the US and throughout the world. The number of people ages 65 years and older is projected to triple by midcentury, from 531 million in 2010 to 1.5 billion in 2050.[1] In the US, the population of seniors is expected to double by 2050, from 41 to 86 million, according to the Pew Research Report.[1] Between 1900 and 2010, life expectancy rose from age 47 to 78.6 years. Advances in medicine, including biological and pharmacologic developments, lead an ongoing longevity revolution.[2]

The Baby Boomers, those born between 1946 to 1964, rush toward retirement age; as of January 1, 2011, approximately 10,000 Baby Boomers reach age 65 years every day, according to the US Department of Health and Human Services Administration on Aging.[3] Many Baby Boomers, a group characterized by individualism, are looking for innovative ways to redefine their identity. As they confront their own existential issues, Baby Boomers seek new sources of meaning and purpose. Many pursue a self-reflective quest for wholeness, exploring diverse practices and approaches to forge their own truth system; some return to their faith of origin, whereas others seek a new spiritual path.[4] Members of the Baby Boomer generation typically share an expectation that old age could be better. To make it so, they are open to developing new skills and ways of aging with gratefulness and well-being. For many, an emerging spirituality combines traditional religion with individualized personal practice.[4]

Some call this demographic shift a silver tsunami.[5] Although poetic, this metaphor speaks to a cultural fear of aging. It reveals a limited worldview ripe with negative stereotypes affecting attitudes, intentions, behaviors, physical health, and personal well-being. Most importantly, it limits the ability to see the gifts of living longer and healthier than ever before.

It is time to challenge our cultural assumptions about aging. By shifting our worldviews from fear to inspiration, we can see this demographic shift—and our place in it—as an opportunity for immense personal and collective growth and transformation.[6] As each of us confronts aging—our own or that of others—we find creative ways of living and being in the world. We sense that there is more to our existence—more layers or dimensions than we comprehend in our daily lives. For some, this awakens an embrace of meaning and purpose fostering our kinship—or interconnectedness—with a greater whole. Many of us speak up for a new model of aging conceived as a great awakening.

We have a unique gift of life, yet we are all mortal, facing aging and changes that are part of our human unfolding. We all hold some model, even if not fully formed, about our entry into advanced years, and we consider our legacy.

As we contemplate our models, we can promote in ourselves—and in our collective engagement—a more compassionate and peaceful way of life that embraces its various stages. It is at the meeting place of science and spiritual wisdom that we discover a new paradigm, which sheds light on aging gratefully. Of course, to engage in our own positive transformation requires cultivating a growth-oriented mindset, which increases with age.[7]

## EXAMINING WORLDVIEWS ON AGING

The Grateful Aging Program (GAP) is based on a model developed from research conducted over several decades at the

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Institute of Noetic Sciences in Petaluma, CA, that examines positive transformations in worldviews. The program uses qualitative and quantitative research methods. The research goal was to understand the process by which people experience fundamental shifts in perception that alter how they view and interact with themselves and the world around them. In particular, a multidisciplinary team investigated factors that facilitate worldview transformations that result in an increased sense of well-being, quality of life, and prosocial behavior for participants. This work led to the development of a naturalistic model of worldview transformation.[8] Previous theories of development suggest that as people grow and interact with the world, they learn to categorize, discriminate, and generalize about what they see and feel.[8] A worldview emerges that combines beliefs, assumptions, attitudes, values, stereotypes, and ideas to construct complex conceptual frameworks that organize lived experience. Together they create a meaning system for individuals to make sense of their past, present, and future.[9]

Worldviews both affect and are affected by individual and collective goals and desires. These lenses of perception shape what people know and how they know it, both consciously and unconsciously. Worldviews inform human behavior in relationships, orchestrating individual and social actions and reactions at all times. They guide fundamental habits of self-reflection, our understanding of self and other, and the means by which people share meaning and actions in the world. Worldviews guide the questions people ask, how they learn and grow, and how they make sense of their experiences. These views are dynamic and capable of change throughout the course of life.

The research finds that shifts in worldview begin long before most people are aware of any change. Life transitions, peak experiences, and numinous or mystical moments—all are primers, even if not directly experienced as transformative, and lay the groundwork for what is to come. Even when people point to a pivotal moment in their lives, they often identify, in retrospect, a "destabilizer"—a combination of factors that set the stage.

A specific episode, period of life, or series of experiences culminate in an "aha!" moment.[10,11] Whether stunning beauty or deep pain or loss, such as the death of a loved one or diagnosis of a life-threatening disease, this aha! moment challenges people's assumptions and changes their view of the world.[8] Attempts to fit new experiences or realizations into their old perspective fail, forcing expansion of their awareness to allow the new insight. Aging and the reflection on the inevitable nature of bodily decline and death offer such opportunities to broaden and deepen our understanding of what gives us meaning and purpose in life.

Although transformative moments leading to insight redouble efforts to protect against destabilization, they also inspire an entirely new worldview that is capable of giving meaning to what happened. This leads people to explore and engage their insights; it is important for people to embark on practices to integrate insights as the transformative path unfolds. These practices may be psychological, physical, religious, or social in nature. Ultimately, they call for an embracing of our shared human experiences and interconnectedness—a call that is timely and relevant to our aging population.

## GRATEFUL AGING DEFINED

The GAP builds on a growing movement to bring greater awareness to aging and the potential for growth and transformation.[6] This is a philosophy of life and a set of transformative practices for awakening to later life.

As anthropologist Angeles Arrien[12p4] wrote, aging can be thought of as a kind of ultimate initiation. "In it, we encounter new, unexpected, unfamiliar, and unknowable moments that remind us that we are a sacred mystery made manifest."Arrien[12p4] urges us to embrace aging as "an enormous opportunity to develop and embody wisdom and character. We enjoy limitless possibilities to restore, renew, and heal ourselves. And because of our increased longevity, for the first time in history we also have the opportunity to create a map of spiritual maturity for future generations to use as they enter their own later years."

As a philosophy, the GAP embraces the fullness of life—and all its complexities. Grounded in transpersonal and humanistic psychology,[13-15] Grateful Aging helps us develop our human awareness and live fully into human potentials that emerge throughout our lifespan.[7,16] It recognizes human psychological and spiritual development as unfolding over time, although by no means a linear process.[17] Ultimately, learning to live with gratefulness is part of a continuous process of waking up to life.[18]

The GAP is an integral process that each of us has within our grasp. Aging from this perspective can be understood and experienced at multiple levels, including our individual and our shared understanding.[19-21] It includes the many dimensions that we are—our bodies, minds, and spirits—and the society in which we live. It is an invitation to live with a spirit of wonder and surprise about the mystery of life.

As well as a philosophy, the GAP is a transformative practice. Embracing our human development allows us to consciously transform our fears about aging and mortality into inspirations for living—and dying well.[22] Bringing mindfulness and awareness to our worldviews, the GAP offers new ways of considering our lived experiences, including pain and suffering, by developing gratitude and appreciation for the transformative potentials that come throughout the lifespan. It involves an intentional approach in which we seek to use our own embodiment as an inspiration for growth and well-being.

## GRATEFUL AGING AS A TRANSFORMATIVE PRACTICE

As a fundamental aspect of worldview transformation, the GAP introduces a series of steps that can be embraced every day, alone or in community, to fully engage the aging process. It invites us to cultivate our inner landscape, our consciousness, in ways that address our outer complexities. It is a call to transformation. The nine steps of the GAP offer a way to deepen our insights, cultivate our resilience, enhance our well-being, and grow in the face of challenge and uncertainty (Figure 1, Sidebar: Nine Steps to the Grateful Aging Program).

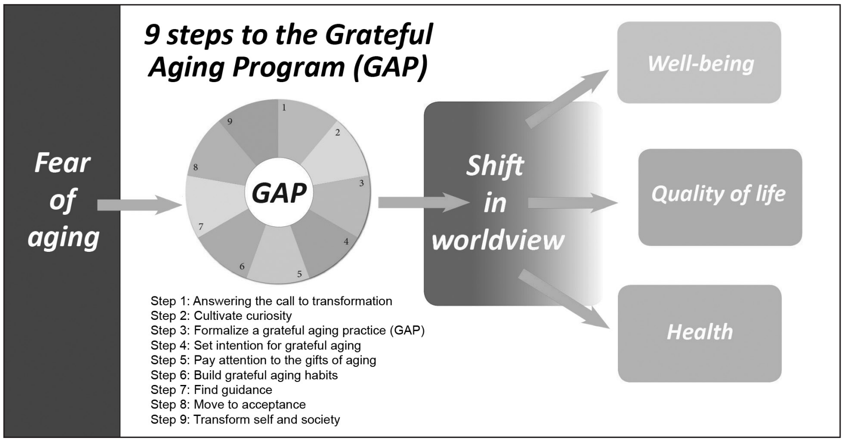

Figure 1. The Grateful Aging Program (GAP) transformation model.

### Step One:
### Answer the Call to Transformation

The first step in the GAP is to bring attention to our worldview and how it defines our experience. Worldviews function at an implicit level, under the surface of conscious awareness. Through inquiry and self-examination, people become aware of worldviews that limit or enhance their daily experience of life.[23] Gerald Jampolsky[24p13] notes in *Love is Letting Go of Fear*: "To perceive the world differently, we must be willing to change our belief system, let the past slip away, expand our sense of now, and dissolve the fear in our minds."

However, it can be hard to change our belief system. A useful way to start is to question our assumptions about aging, leading us from certainty to a kind of beginner's mind. Is the glass half-empty or half-full? Alan Alda[25] expressed so clearly in his memoir on aging, "Your assumptions are your windows on the world. Scrub them off every once in a while, or the light won't come in." As we invite in the light, we begin to plant seeds for personal growth and development. Rather than resisting change, which can be a source of suffering and discontent, we embrace possibilities from the unknown. We move from surviving to thriving in the rich soil of new possibilities.

### Step Two:
### Cultivate Curiosity

Finding surprise and wonder in life is a vital step in developing a Grateful Aging practice. Here the goal is to seek surprises, practice a beginner's mind, and learn new things about oneself and others.

This step in the GAP asks that we not take things for granted, that we instead stay open to the unknown. Brother David Steindl-Rast,[18] a Benedictine monk, described the power of surprise to awaken and experience gratefulness. In his book, *Gratefulness, the Heart of Prayer,* the insightful teacher describes a personal incident that shifted his worldview. Having grown up in Nazi-occupied Austria, he recalls a narrow escape when bombs exploded, and he was without shelter. Surviving, he stepped past the rubble and dusted off his clothes. As he ventured into the spring day, he was overwhelmed by surprise. In front of him was a small patch of grass, unscathed by the destruction. In his words, "It was as if a friend had offered me an emerald in the hollow of his hand. Never before or after have I seen grass so surprisingly green."[18p10] Noticing the surprise in something as simple as a patch of green grass opened him to a lifelong practice of gratefulness. In the midst of war, this observation served as a profound spiritual epiphany that catalyzed his transformative journey toward waking up to the gift of life.

One useful way to engage this step of the GAP is to notice one new thing each day, finding an opportunity to be surprised and to feel truly awake in the moment. As you bring curiosity and surprise into your awareness, allow inspiration to strike you. You may find treasures seeing the interdependence of life. Nourish the rumblings in you that long for greater truth, wholeness, and well-being.

**Nine Steps to the Grateful Aging Program**

1. Answering the Call
2. Curiosity
3. Practice
4. Intention
5. Gifts of Aging
6. Habits
7. Guidance
8. Acceptance
9. Self and Society

### Step Three:
### Formalize a Grateful Aging Practice

The first 2 steps are precursors that draw us toward a formal transformative practice. With the groundwork laid, we develop insights that take us deeper into our being. Commonly, however, simple awareness of our worldview is not enough to make positive shifts in perspective. Our awakening can be dulled without the scaffolding to attune to the mysteries of life. Step 3 of the GAP invites us to build a new set of intentions and habits that formalize our commitment to aging as a profound transformative practice.

Research among the world's spiritual and religious traditions reveals that transformative practices can take many forms.[8] They include inner-directed practices, such as meditation, affirmations, visualizations, mindful breathing exercises known as breathwork, and contemplative prayer, each of which can help shift our awareness to our subjective experiences (Table 1). They also include outer-directed practices to focus on our shared experiences and physical embodiment (see Table 1). Such practices include social engagement, dancing, chanting, exercising, events, and participating in authentic conversations with others.

**Table 1. Practice directions**

| Inner practices | Outer practices |
|---|---|
| Meditation | Social engagement |
| Affirmations | Dancing |
| Visualizations | Exercising |
| Mindful breathwork | Authentic communication |
| Contemplative prayer | Events |

## Step Four: Set Intention for Grateful Aging

As you feel the call to Grateful Aging, you can begin to formulate your own intention statement.[26] Where would you like to grow? What needs healing in your life and in your worldview? Are there stereotypes about aging that are limiting you from awakening to your own well-being?

Intentions involve the ways in which we bring will and purpose to our actions and reactions. By setting intentions, we chart the course toward an engagement in our own aging process. How can we move, as Rabbi Schachter-Shalomi and co-author Miller[27] suggest, from "age-ing to sage-ing," fully owning our wisdom and life experience?

Grounded in our worldviews, our intentions shape our behaviors. These include both our inner-directed intentions and our action-in-the-world intentions. Inner-directed intentions are vital as we seek truth and meaning in our lives. Looking inward and reflecting on our intuitions, insights, and revelations help us connect with what gives us deep meaning and purpose. We see the certain habits of mind that support us and other habits that limit our awakening. Setting the intention to move from fear and suffering to growth and possibility requires effort. This may include turning off the radio, finding quiet time to self-reflect, or practicing positive affirmations and focused prayer. It may also include setting a goal to engage with others in order to share in life's adventures.

## Step Five: Pay Attention to the Gifts of Aging

Training our attention to focus on what we often do not notice is one of the trickiest aspects of worldview transformation. Because much of what shapes our worldview lies below the level of our conscious awareness, we can be blinded to our own stereotypes and negative perceptions.

An important key to the GAP is the flexibility to become aware of what we are often unaware of—much that transpires around us and within us. However, we can set the intention to pay attention to those things we take for granted. Instead of operating on autopilot, we engage in mindfulness about happenings around us, right in the moment. Through meditation and self-reflection, as well as dialogue with others, we bring our awareness to limiting beliefs and actions. Actively noticing new things in the present releases us from negative thoughts and evaluations that cause upset or worry. We begin to identify assumptions, beliefs, and expectations that restrict our sense of purpose and well-being. Classic studies by Ellen Langer,[28] described in her book, *Counterclockwise: Mindful Health and the Power of Possibility,* speak to this point. She found that elderly men could improve their health by simply acting as if it were 20 years earlier. This finding reveals that our expectations about aging can shape our physical and psychological experiences.

## Step Six: Build Grateful Aging Habits

Our brains lay down neuropathways based on repetitive actions and thoughts. The more we do something, the easier and more routine it becomes. This is true of both negative and positive thoughts and behaviors. It was long thought that these pathways were fixed and would not change with maturity. However, the new science of neuroplasticity has shown that we create new neuropathways that affirm our lived experiences and help us to build new, healthy habits. Engaging in practices that support Grateful Aging make positive, healthy, and life-affirming aging our habitual way of being.

By moving and exercising our bodies, we stay healthy and alert. Building a routine for staying fit—walking, dancing, yoga, and eating well—makes us feel better and live healthier. This involves both intention to create healthy lifestyles, and attention to what we do and how we do it. We begin to trust the wisdom of our bodies to keep us moving in a positive direction.

Building mental habits is also part of the GAP. Studies reveal that through mindfulness, or being present in the moment, we feel happier and worry less. We may use affirmations to help us feel optimism and a sense of hope for how we grow and age with purpose and meaning. By finding ways to cultivate compassion for ourselves and others, we let go of troubling thoughts and feelings, choosing to live this day with peace, love, and gratitude. A simple affirmation, such as one from Jampolsky,[24] "This day I choose to spend in perfect peace," can shift our perspective.

Finding opportunities to live in positive social interactions builds positive habits. Our connections heal us, and we feel engaged rather than isolated and alone. This involves ways of being with others free from judgment, releasing grudges, and finding compassion for the lives we have all led. Cultivating forgiveness for ourselves and for others allows us to let go of hurt feelings, thoughts, and emotions that keep us from being present in the moment. Practicing active listening during meaningful conversations, while also sharing our own stories from the heart, can lead to genuine intimacy and deep caring.

**Finding ways to self-reflect and seek times of silence and contemplation can offer new insights and a feeling of peace.**

Finally, we can build habits that connect us to our spiritual nature. This may be a religious practice that provides faith-based rituals and guidelines. It may also be something more individualistic, including our own sense of connection to something greater than ourselves. Finding meaning and purpose beyond our own ego identification expands our sense of self. For some, it is a deep ecology, to connect to the natural world and feel part of an interconnected universe.[9,29]

## Step Seven: Find Guidance

Building new ways of thinking, feeling, and being in the world can come naturally for some of us. Others find guidance and inspiration from those who have been along the path. Seek out wisdom holders by attending lectures, reading books, listening to podcasts, or making new friends who have the characteristics we aspire to develop. Finding a GAP community or creating a study group offers the social networks to engage in mutual shifts in our worldviews. These sources of external guidance can offer hope and inspiration.

Just as external guidance supports us in building new habits and ways of engaging the world, it is also essential to build inner guidance as we engage in the GAP. Finding ways to self-reflect and seek times of silence and contemplation can offer new insights and a feeling of peace. Breathing practices clear our minds, bring us into the present, reduce stress and anxiety, and center our bodies. Focusing on each breath, letting go of extraneous thoughts that limit you, and following this practice every day can lead to measurable positive changes in your body and mind. This breathing can be done sitting still or walking.

### Step Eight:
### Move to Acceptance

The essence of worldview transformation is to shift our perspective on change. Resisting change can lead to anxiety and harmful stress. Most people seek stability. We want things the same, thinking we can control them. However, change is a constant in all dimensions of life. It often leads us to feel more out of control, without the inner resources to ride the tides of change.

The GAP invites us to move with the flow of change, adapting and staying open to what may lie ahead. This includes our responses to loss, grief, and suffering. Contemplating death is a vital aspect of Grateful Aging. Although it may be surrounded in fear, death is an inevitable part of transformation.[22,30] Holding a cosmology of death helps to create a frame that holds our mortality.

The fear of aging and of dying can lead people to deny the nature of our shared humanness, including our mortality. There are transformative potentials in age and death awareness that can shift fear into inspiration and action. Physician Robert Butler[31p23] pointed out: “The human desire is not to take longer to die but to live longer in good health through deferral of nonfatal as well as fatal conditions.” This is the opportunity of the GAP: live life fully and without anxiety about our mortality. Evidence points to the benefits of acceptance of our mortality. A pilot study exploring death awareness through an online training found changes in language use through journaling that indicated a reduction in anxiety and a shift in personal identification with writing about mortality.[32]

Waking each morning is an opportunity to cultivate gratitude and to nurture self-compassion. As we give up our need to control all events and life circumstances, we may find a path to forgiveness for ourselves and for others. We can change our story, embracing what unfolds with curiosity and wonder. Engaging in conversations with other GAP practitioners can clear a path for understanding and sharing that understanding. It is a great relief to consider that everything is perfect, just as it is. You can breathe into it and feel a load lifting off your shoulders.

### Step Nine:
### Transform Self and Society

As we all know, shifting our worldviews is not simple or easy. With the steps developed in this GAP model, it is possible to create a lifestyle and worldview that embraces the fullness of life in all its stages. Transformative practices are often associated with certain places or times of the season. The GAP, however, is a lifelong practice best understood in the context of our everyday life. The program is an opportunity to expand our self-understanding, through self-reflection and in the company of others who offer mutual support and encouragement. Finding sources of social support online or in social settings, such as family gatherings and senior citizen programs, offer vital ways of engaging new patterns and behaviors.

Although aging is personal and based in our individual life experiences, Grateful Aging sees the worldview shift as more than a personal quest. There are personal and social benefits as we experience the shift in focus from I to we.[29,33] In other words, the practice of Grateful Aging infuses our lives with the wish for, and active actions that speak to, the transformation of our community. Compassion and altruism emerge from our shared experiences rather than from duty or obligation.

As people move from equanimity and self-compassion in the face of life’s challenges to a daily sense of wonder and awe, most mundane aspects of life become sacred in their own way. The GAP makes personal transformation contagious. As people share their insights and experiences with others, a collective transformation emerges that stimulates more individual transformations, in an ever-widening expansion of our human potential.[6] As people engage in Grateful Aging, they bring greater awareness to the transformative process that allows a deeper experience of their life journey. Expanding wisdom allows each of us to heal, to forgive, and to experience compassion for self and others.

## DISCUSSION

Early models of human development focused on child development, and psychological maturity was considered to be largely complete by adulthood. More recent theories, grounded in empirical data, recognize that we continue to change and grow throughout our lives. The question then becomes, how can we use the challenges and opportunities of aging to cultivate wisdom and to live deeply? In the end, it is not as much about aging itself as it is about fostering our personal and shared awakening.

With the GAP, I applied a naturalistic model of worldview transformation[5,7] to the aging process. I have developed the concept of the GAP as a transformative practice that invites realizations, enhanced well-being, improved quality of life, and greater health for people as they move through developmental steps that connect body, mind, society, and spirit.

This model is now used to develop enrichment programs for seniors and for continuing education for health care professionals as they engage their aging patient population. The intention of the GAP is to bring greater awareness to our beliefs and expectations about aging in the context of a supportive community that supports well-being, growth, and awakening. When brought to almost any activity, whether explicitly personal growth-oriented or not, these nine steps to Grateful Aging make day-to-day activities, such as walking, gardening, journaling, golf, book clubs, and learning programs pathways toward positive transformation.

## CONCLUSION

As the quote on aging by an underdetermined source reminds us: “You are never too old to set another goal or to dream a new dream.” May we dream together as we move through our second half of life, both individually and as a collective force for change in the world. ❖

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## References

1. Kochhar R. 10 projections for the global population in 2050 [Internet]. Washington, DC: Pew Research Center; 2014 Feb 3 [cited 2016 Jul 6]. Available from: www.pewresearch.org/fact-tank/2014/02/03/10-projections-for-the-global-population-in-2050/.
2. Dychtwald K. Healthy aging: Challenges and solutions. Gaithersburg, MD: Aspen Publishers; 1998.
3. Ortman JM, Velkoff VA, Hogan H. An aging nation: The older population in the United States. Population estimates and projections. Current population reports. Washington DC: US Census Bureau; 2014 May
4. Ellor JW, Kimble MA. The heritage of religion and spirituality in the field of gerontology: Don Clingan, Tom Cook, and the National Interfaith Coalition on Aging. Journal of Religious Gerontology 2004;16(1-2):143-53. DOI: https://doi.org/10.1300/J078v16n01_09.
5. Celeste J. The blog: 7 ways businesses can surf the silver tsunami and survive [Internet]. New York, NY: The Huffington Post; 2015 Sep 8 [cited 2016 Jul 14]. Available from: www.huffingtonpost.com/janice-celeste/7-ways-businesses-can-surf-the-silver-tsunami-and-survive_b_8094412.html.
6. Schlitz MM, Vieten C, Erickson-Freeman K. Conscious aging and worldview transformation. The Journal of Transpersonal Psychology 2011;43(2):223-39.
7. Zenger J, Folkman J. How age and gender affect self-improvement. Harv Bus Rev [Internet] 2016 Jan 5 [cited 2016 Jul 6]. Available from: https://hbr.org/2016/01/how-age-and-gender-affect-self-improvement.
8. Schlitz M, Vieten C, Amorok T. Living deeply: The art & science of transformation in everyday life. Oakland, CA: New Harbinger Publications, Inc; 2007.
9. Schlitz M, Vieten C, Miller EM. Worldview transformation and the development of social consciousness. Journal of Consciousness Studies 2009 Dec;17(7-8):18-36.
10. Miller WR, C'de Baca J. Quantum change: When epiphanies and sudden insights transform ordinary lives. New York, NY: The Guilford Press; 2001.
11. White RA. Exceptional human experience: Background papers. Dix Hills, NY: Exceptional Human Experience Network; 1994.
12. Arrien A. The second half of life: Opening the eight gates of wisdom. Boulder, CO: Sounds True, Inc; 2007.
13. Maslow A. Toward a psychology of being. 2nd ed. Princeton, NJ: Van Nostrand Reinhold; 1968.
14. Dass R. Still here: Embracing aging, changing, and dying. New York, NY: Riverhead Books; 2000.
15. Walsh R, Vaughan F, editors. Paths beyond ego: The transpersonal vision. New York, NY: Tarcher/Putnam; 1993.
16. Tornstam L. Maturing into gerotranscendence. The Journal for Transpersonal Psychology 2011;43(2):166-80.
17. Atchley RC. Spirituality and aging. Baltimore, MD: The Johns Hopkins University Press; 2009.
18. Steindl-Rast D. Gratefulness, the heart of prayer: An approach to life in fullness. Ramsey, NJ: Paulist Press; 1984.
19. Schlitz M. The integral model: Answering the call for whole systems healthcare. Perm J 2008 Spring;12(2):61-8. DOI: https://doi.org/10.7812/tpp/07-078.
20. Schlitz M, Amorok T, Micozzi MS. Consciousness and healing: Integral approaches to mind-body medicine. St. Louis, MO: Churchill Livingstone/Elsevier; 2005.
21. Wilber K. Foreword to consciousness and healing. In: Schlitz M, Amorok T, Micozzi MS. Consciousness and healing: Integral approaches to mind-body medicine. St Louis, MO: Churchill Livingstone/Elsevier; 2005. p xv-xxxv.
22. Schlitz M. Death makes life possible: Revolutionary insights on living, dying, and the continuation of consciousness. Boulder, CO: Sounds True, Inc; 2015.
23. Schlitz MM, Vieten C, Miller E, Homer K, Petersen K, Erickson-Freeman K. The worldview literacy project: Exploring new capacities for the 21st century student. New Horizons for Learning 2011 Winter;9(1).
24. Jampolsky GG. Love is letting go of fear. New York, NY: Bantam; 1979.
25. Alda A. Never have your dog stuffed: And other things I've learned. New York, NY: Random House; 2006.
26. Erickson-Freeman K. Conscious aging: Cultivate wisdom, connect with others, celebrate life. Group process guidelines for facilitators. Petaluma, CA: Institute of Noetic Sciences; 2012.
27. Schachter-Shalomi Z, Miller RS. From age-ing to sage-ing: A profound new approach to growing older. New York, NY: Time Warner Books; 1995.
28. Langer EJ. Counterclockwise: Mindful health and the power of possibility. New York, NY: Ballantine; 2009.
29. Vieten C, Amorok T, Schlitz MM. I to we: The role of consciousness transformation in compassion and altruism. Zygon 2006 Dec;41(4):915-32. DOI: https://doi.org/10.1111/j.1467-9744.2006.00788.x.
30. Becker E. The denial of death. New York, NY: The Free Press; 1973.
31. Butler R. Revolution in longevity. In: Dychtwald K. Healthy aging: Challenges and solutions. Gaithersburg, MD: Aspen Publishers; 1998. p 19-26.
32. Schlitz M, Schooler J, Pierce A, Murphy A, Delorme A. Gaining perspective on death: Training program and language use outcomes assessment. Spiritual Clin Pract (Wash D C) 2014;1(3):169-80. DOI: https://doi.org/10.1037/scp0000030.
33. Vieten C, Estrada M, Cohen AB, Radin D, Schlitz M, Delorme A. Engagement in a community-based integral practice program enhances well-being. International Journal of Transpersonal Studies 2013 Dec;33(2):1-15.

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## A Human Skill

To get old is in the hands of God, but to stay young is a human skill.

— Croatian proverb

REVIEW ARTICLE

# Use of Improving Palliative Care in the ICU (Intensive Care Unit) Guidelines for a Palliative Care Initiative in an ICU

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## ABSTRACT

**Objective:** For improved utilization of the existing palliative care team in the intensive care unit (ICU), a process was needed to identify patients who might need a palliative care consultation in a timelier manner.

**Methods:** A systematic method to create a new program that would be compatible with our specific ICU environment and patient population was developed. A literature review revealed a fairly extensive array of reports and numerous clinical practice guidelines, which were assessed for information and strategies that would be appropriate for our unit.

**Results:** The recommendations provided by the Center to Advance Palliative Care from its Improving Palliative Care in the ICU project were used to successfully implement a new palliative care initiative in our ICU.

**Conclusion:** The guidelines provided by the Improving Palliative Care in the ICU project were an important tool to direct the development of a new palliative care ICU initiative.

## INTRODUCTION

Palliative care is medical care that enhances quality of life for patients living with serious advanced illness, by helping to align their treatment choices with their values. It is defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness.[1] This is achieved through the prevention and relief of suffering by means of early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.[1,2] A palliative care team helps to determine patient goals and align the medical care with those goals, procure resources for symptom management, assist with advanced care planning, partner with the patient to create a plan of care, ensure the patient has a safety net under him/her by using all of the available resources in the system, and educate others about the palliative care approach.[3] Despite these possible benefits of consultation with a palliative care team, palliative care traditionally has been used late in the care of patients, when all life-prolonging interventions have failed and death is imminent.[4]

In our hospital, an inpatient palliative care team had been in existence since 2010. A formal consult could be generated by either the nursing or physician staff, but there was no structure or process in place in the inpatient setting that determined when goals-of-care or end-of-life discussions should be initiated. It was only when major end-of-life issues arose that the palliative care team was brought in to assist with family and patient problems. This problem was also evident in the intensive care unit (ICU). The palliative care team was not being utilized in an appropriate manner, and the instances in which they were consulted were usually only in cases of suspected futile care. This underutilization of palliative care services in the ICU was consistent with findings from the literature in various units across the country.[2,4-8]

For improved use of the palliative care team in the ICU and improved overall awareness of basic palliative care principles, a process was needed to more quickly identify patients who required a palliative care consultation. To do this, it was necessary to use a systematic method to create a new program that would be compatible with our specific ICU environment and patient population. A team, whose members represented the physicians, nursing staff, and nursing management from both the ICU and palliative care, was formed to perform a literature search and review, develop work processes, and implement and evaluate the program.

## METHODS

### Literature Review

An electronic search was completed using PubMed, Cumulative Index to Nursing & Allied Health Literature, Cochrane, and National Quality Forum (NQF) databases. Search terms included “ICU,” “intensive care unit,” “critical care unit,” “palliative care consult,” “palliative care service,” “end-of-life care,” “palliative care,” “comfort care,” “supportive care,” “model,” “screening,” “guidelines,” “outcomes,” “measurements,” “cost,” and “metrics.” Among 63 publications from 1995 to 2014 that were examined, 23 were included in this review.

Mosby’s levels of evidence system was used to grade the level of evidence and internal validity.[9] This grading system assigned the studies to one of eight levels (Figure 1). The eighth level was designated as “Other” for evidence that was excluded from the

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previous seven categories. Clinical practice guidelines (CPGs) were added to the "Other" category because they played a major role in the formation of practice recommendations for this project. The synthesized reports, presented in Figure 2, were ranked according to the eight levels of evidence.[9]

The critiquing tools used included Mosby's Research Critique Form,[10] the Rapid Critical Appraisal of Randomized Controlled Trials by Melnyk and Fineout-Overholt,[11] and the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument for the evaluation of CPGs.[12] The AGREE II instrument was used to evaluate each CPG.[13] It uses a ranking system of an assigned grade 1 to 7, designed to assess the methodologic rigor and transparency with which a guideline was developed. The 6 different domains include: 1) scope and purpose, 2) stakeholder involvement, 3) rigor of development, 4) clarity of presentation, 5) applicability, and 6) editorial independence. The percentages assigned to each domain were averaged into 1 representative score, up to 100%.[13] The scores of the 9 CPGs used in this synthesis are presented in Table 1.

The publications focused on the various aspects of initiating a palliative care program in an ICU. These included benefits, various models, screening tools, guidelines/standards, evaluation tools, metrics, barriers, and cost. There was also a moderate quantity of data regarding the importance of family satisfaction with the end-of-life care provided for patients.[14-22]

A number of reports recommended using guidelines offered by the Center to Advance Palliative Care (CAPC). These CPGs follow the standards from the National Quality Forum (NQF) in its Framework and Preferred Practices for Palliative and Hospice Care, and from the National Consensus Project for Quality Palliative Care. These standards were operationalized by the CAPC with its Improving Palliative Care in the ICU (IPAL-ICU) project.[15,19,22-26] This project was a Web-based resource sponsored by the National Institute on Aging, the CAPC, the major critical care societies, and other nationally funded groups such as the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup. The CPGs provided by the project were designed to offer a framework, along with practical steps, for the development of a palliative care initiative in an ICU.[26-29]

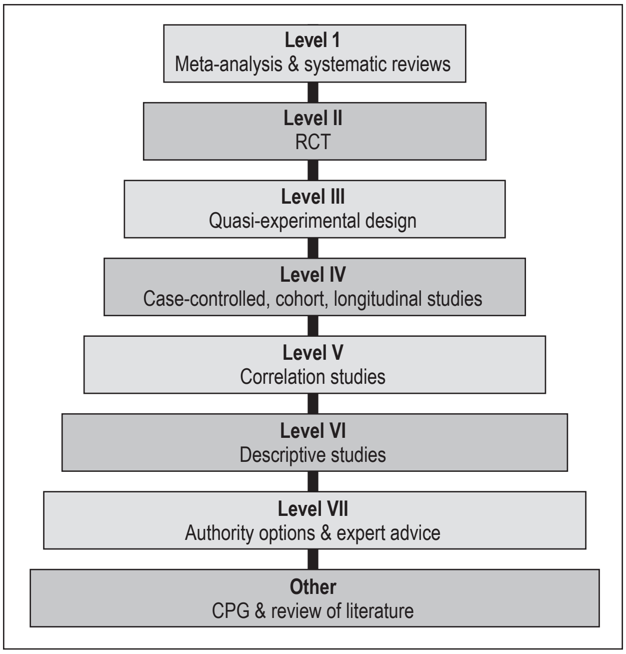

Figure 1. Mosby's levels of evidence[9]

CPG = clinical practice guidelines; RCT = randomized controlled trial.

The steps laid out by the CPGs were essential to the integration and improvement of palliative care in specific health care settings. They included convening an interdisciplinary workgroup to plan and lead the effort; assessing the needs and resources for improving palliative care in a particular ICU; developing an action plan to address existing needs in the context of available resources; and engaging the interdisciplinary ICU team to create a culture supporting palliative care improvement. The CPGs also reviewed the two major models of palliative care, along with screening and trigger criteria, guidelines and standards, and methods for program evaluation.[16-22] The guidelines were used as a road map of sorts, and most of the provided instructions were easily adapted for our initiative.

## Guideline Recommendations

### Model of Palliative Care Integration

Each ICU has an intrinsic and specific "culture" created by its history, structure, and policies and processes of care, and by the attitudes and interactions of different disciplines on the ICU team.[30] The selection of a model was considered one of the earliest steps in planning an ICU palliative care initiative.[15] The actual role of the consult service varies with local customs and culture, but the focus tends to be on issues such as goal setting, challenging care decisions regarding the use of life-sustaining treatments, withdrawal of unwanted life-prolonging therapies, do-not-resuscitate designation, conflict resolution, and transitional care planning.[15,20,31,32]

The practice guidelines all started with choosing a model for palliative care incorporation into an ICU. The literature noted two major models of palliative care: the "consultative model" and the "integrative model."[15] The "consultative model" focused on increasing the involvement and effectiveness of palliative care consultants in the care of ICU patients and families. The "integrative" model sought to embed palliative care principles and interventions in daily practice by the ICU team, for all patients and their families.[15] There were advantages and disadvantages in both models, but the "consultative model" was the most prevalent model of palliative care service delivery in acute-care hospitals. It was particularly useful in those patients identified as being at highest risk of poor outcomes and was the most feasible in institutions with preexisting palliative care teams.[15]

### Screening/Trigger Criteria

Criteria for screening then needed to be established. The CAPC IPAL-ICU consensus panel determined that identifying patients with unmet palliative care needs was important, both at the time of admission and during the hospital course. As a result, two groups published a systematic review and a set of CPGs designed to address the selection of trigger criteria. Nelson et al[31] reviewed the use of screening criteria as a mechanism for engaging palliative care consults in the ICU. They determined that the use of specific criteria

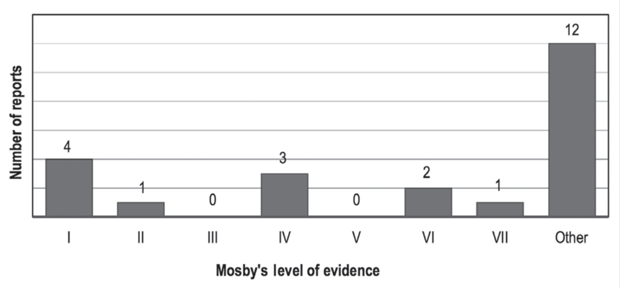

Figure 2. Reports used for literature review (N = 23) ranked according to Mosby's levels of evidence. Clinical practice guidelines are placed in "Other" category.

to prompt a proactive referral for a palliative care consultation reduced utilization of ICU resources without changing mortality rates, while increasing involvement of the palliative care specialist for patients and families in need.[31]

Weissman and Meier[20] recommended development of two checklists, divided into primary and secondary criteria, to facilitate ease of implementation. Selection of the indicators for these checklists was based on national standards, research findings, and expert opinions from the consensus panel.[20]

Screening and trigger criteria should be representative of the individual ICU. Many potential triggers have been reported, not only in the recommended CPGs but also in the literature from medical ICUs[33,34] and surgical ICUs.[2,6,35] The three main criteria fell into the domains of disease, utilization, and other criteria, following recommendations from the IPAL-ICU consensus panel and the literature.[6,15]

Mosenthal et al[30] also reviewed the use of "triggers" from the perspective of a surgical ICU, in which referral for a palliative care consultation was typically dependent on the attending surgeon. They reported that the optimal use of trigger criteria had not yet been fully demonstrated in this setting, and that the triggers might have been more successful in the surgical ICU if the criteria were applied to specific diseases.[30]

### Guideline Development and Evaluation

In several areas of ICU practice, performance improvement has been approached by grouping evidence-based processes into "bundles" of measures that are applied together, for a fuller assessment of the quality of care.[36,37] The development of care bundles is designed to bring evidence-based literature to bedside management and to create best-practice guidelines for specific disease processes common to ICU patients.

This strategy was employed by the Volunteer Hospital Association in its "Transformation of the ICU" program, a performance improvement initiative, to organize their quality measures into bundles. The resultant Care and Communication Bundle was developed to measure palliative care quality in adult ICUs and was described by Nelson et al,[36] in their report on defining standards for ICU palliative care. The bundle was designed to assist in the development of measures using a process approach for routine monitoring of, and performance feedback of, the quality of palliative care across a broad range of ICUs.[16] It also set a base in which to create a set of standards or guidelines for a new palliative care program in the ICU.[36,37] Contained in the bundle framework were identified ICU palliative care processes that are associated with desirable outcomes, a list of indicators with corresponding quality measures, a measurement guide containing specifications, definitions for the numerators and denominators of the measures, and a data tool.[36]

These recommendations provided validated measures addressing multiple domains of ICU palliative care quality, and they were consistent with standards established by the National Consensus Project for Quality Palliative Care and the NQF for palliative care across clinical settings.[16,26,37] The domains of quality are made operational as specific measures, each with a numerator and a denominator. In general, the numerator represents the number of patients receiving a care process or outcome that is to be evaluated as an indicator of quality. The denominator defines the total patient population. It is also typical to select subgroups with special risks or needs. Therefore, the population targeted by the denominator for most of the measures was to be limited to those patients in the ICU for at least 5 days, which had been determined to be a practical risk marker for poor outcomes among critically ill adults.[15,22,36] Individual care processes, which included identified advance directives, goals of care, and code status, were then to be triggered by specified days after admission to the ICU, with some processes performed by Day 1 and others by Day 3 or Day 5. This time-triggered strategy was designed to prompt timely performance of important processes for all ICU patients, while limiting the burden of data collection to patients with prolonged ICU stays.[15,38,39]

### Outcomes and Metrics

Data collection and analysis are necessary to assess the effectiveness of a program. They are essential when planning for program staffing, and to accommodate growth in demand for services as well as other types of strategic designs. They are also necessary for quality improvement and program sustainability, and to demonstrate the impact of a palliative care program on major stakeholders.[21] Weissman et al,[21] as part of the CAPC's IPAL-ICU expert panel, published the *NQF Framework for Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report,* along with the four domains for key outcome measures. These included overall and individual reports on operational, clinical, customer-satisfaction, and financial metrics.[19,21,22]

**Table 1. Clinical Practice Guideline AGREE II scores[a]**

| Reference | Score (%) |
|---|---|
| Nelson et al,[16] 2010 | 77 |
| Nelson et al,[17] 2010 | 83 |
| Nelson et al,[18] 2010 | 78 |
| Weissman & Meier,[19] 2008 | 76 |
| Weissman & Meier,[20] 2011 | 81 |
| Weissman et al,[21] 2008 | 82 |
| Weissman et al,[22] 2010 | 77 |
| Truog et al,[26] 2008 | 71 |
| Mularski et al,[28] 2006 | 82 |

[a] Clinical Practice Guideline Appraisal of Guidelines for Research and Evaluation (AGREE II) scores used a ranking grade in six domains. Percentages assigned to each domain were averaged into one representative score.

Nelson et al[17,18] reviewed the advantages and disadvantages of different quality measures and the domains for measurement of ICU palliative care quality. They showed how the domains of quality were made operational as specific measures[17] and then examined the use of data relating to mortality, utilization, and care process.[18]

The success of interventions can be determined by looking at process and outcome measures as evaluation tools. Process measures refer to interactions between the health care institution or clinician and the patient, such as charting a daily pain assessment. Outcome measures refer to a patient's subsequent health status, such as a reduction in symptom distress.[22] The differences between the two types of measures have been well described in the literature and a number of examples of validated instruments that can be used to evaluate patient, family, and clinician experiences were also provided.[40]

## Interventions

The interventions we decided on followed the guidelines offered by the IPAL-ICU program. They consisted of defining the four major recommended categories, which included the model of integration, screening and trigger criteria, guideline formation, and the process and outcome measures.

### Model of Palliative Care Integration

The consultative model was used because one of the goals was to improve the use of the existing palliative care team. However, some of the basic palliative care principles were also incorporated into the daily practice of ICU care. This was to ensure that the numbers of consultations to the palliative care team remained appropriate, while at the same time improving the level of routine palliative care management by the ICU physicians and nursing staff.

### Screening/Trigger Criteria

The physicians representing both the palliative care team and the ICU were tasked with coming to a consensus on the trigger criteria that best characterized our ICU. Although the literature suggested both an admission and daily screening tool, both with primary and secondary criteria, we concentrated on one screening tool for ease in streamlining the implementation.

### Guideline Development and Evaluation

The literature recommended obtaining the code status, advance directives, and surrogate name by Day 1 of admission to an ICU.[15] Finalization of these measures within this timeframe was questionable. At the time, the ICU social worker was responsible for the advance directives and surrogate, and the ICU physician was responsible for the code status. Because of staffing patterns, the social worker was available only on the day-shift weekdays. Although an on-call social worker was available during the days on weekends, s/he covered the entire hospital and there was no night coverage. The team members were in agreement that the nursing staff could be educated to initiate the conversations regarding the code status, advance directives, and surrogate, using the goals-of-care videos already available in the hospital television educational system.[41] In addition, guidelines were written to allow for leeway between Days 1 through 3. Identification, but not necessarily completion, of surrogate, advance directives, and code status were to be noted in the progress notes and could be carried out by any clinical staff, including registered nurses, physicians, and social workers. This would then trigger the need for a social worker consult on off-hours, which was traditionally left until a Monday morning, when the ICU social worker brought herself up to date.

The literature recommendation of a proactive, palliative care consultation by Day 3[15] raised the concern that this could generate potentially unnecessary numbers of consultations for the palliative care team. Therefore, a proactive family meeting by Day 3 was deemed possible, but was facilitated instead by the ICU team. Then, if still needed, a multidisciplinary, palliative care family meeting could be initiated by Day 5. At the time, informal family meetings conducted by the ICU team were inconsistent and based on physician availability and perceived need by the registered nurse. This also was dependent on the overall experience and knowledge of palliative care by the registered nurse, which was not necessarily consistent.

Every patient who was admitted and/or transferred into the ICU was screened daily, using the predetermined trigger criteria. Once a patient met the criteria, a social-worker consult was generated, and the charge nurse and physician were notified. The staff was to direct families to the goals-of-care videos,[41] on the Education on Demand Kaiser Permanente Webinar, and to document any questions or discussions in the electronic medical record. The social worker was responsible for completion of the advance directives and the surrogate designation if necessary. The physician was responsible for addressing code status and the patient's goals of care. Their documentation was to reflect the proactive ICU family meeting that was to be performed by Day 3 of meeting the trigger criteria. Should the need for a palliative care consultation be identified within this timeframe, a formal request for consultation was generated by the intensivist, and the staff was to offer the family the preexisting palliative care brochure. The nursing staff was to participate in the family meetings, as allowed by staffing and workload. The finalized guidelines culminated in a flowchart, demonstrated in Figure 3, that was available to all staff at all times.

### Outcomes and Metrics

The metrics and benchmarks were predetermined and approved by the Quality-Improvement Committee before the implementation of the project. Outcome measures involved operational data such as the patient age, sex, ethnicity, admitting diagnosis, comorbidities, and disposition. Process measures looked at identification of numbers of patients meeting the trigger criteria; key component identification such as surrogate, advance directives, code status, and/or goals of care by Day 3 of meeting the trigger criteria; numbers of ICU family and/or palliative care consults; and changes in code status or treatment after either the ICU or the palliative care family meeting, or both. Clinical measures looked at the number of days of intubation. Financial metrics involved the length of stay in the ICU and the hospital. Customer data were obtained from both family satisfaction and nursing surveys.

## RESULTS

The review of literature demonstrated a mix of Evidence Levels 1 through 7, but in the 23 reports chosen, the substantial number of CPGs weighted the level of evidence in the "Other" category. Although ICU culture and the incorporation of palliative care have changed considerably within the last 10 to 15 years, the numbers of randomized controlled trials in this arena remained somewhat limited, and therefore, meta-analysis was not an option.[42] Vulnerable groups are usually excluded from randomized controlled trials; therefore, true randomization of a palliative care service is difficult.[43] Methodologic and ethical concerns regarding withholding a potentially beneficial service to those in need often preclude randomization, and long-term outcome monitoring may not actually be in the best interests of the patient.[44]

The CPGs that were available to provide assistance in the initiation of a palliative care program were all based on nationally set standards and met most of the domains set in the AGREE II instrument. They fell short on procedures for updating the guidelines, clarity of strengths and limitations, and resource implications. The identified shortcomings were in part due to an evaluation of the individual CPG rather than as part of an established set of reports.

Most CPGs were published in 2010 to 2011, and the publications since then were, for the most part, literature reviews and expert opinions. Nelson et al[31] followed up on earlier reports and recommendations from the IPAL-ICU project. They published a subsequent systematic review to look at the use of recommended screening criteria as a mechanism for engaging palliative care consultants, to assist with care of critically ill patients and their families in the ICU. They concluded that the data and resources that can be used in developing such criteria should be tailored for a specific ICU, implemented through an organized process involving key stakeholders, and evaluated by appropriate measures.[31]

## DISCUSSION

Palliative care is increasingly accepted as an essential component of comprehensive care for critically ill patients, regardless of diagnosis or prognosis, from the time of admission to the ICU.[45] Hospital palliative care consultation programs have been associated with reductions in patient symptoms and higher family satisfaction with overall care.[14] The underutilization of our existing palliative care team, and the need to improve overall understanding of palliative care and its principles, prompted a literature search for a method in which to initiate a new palliative care program in our unit.

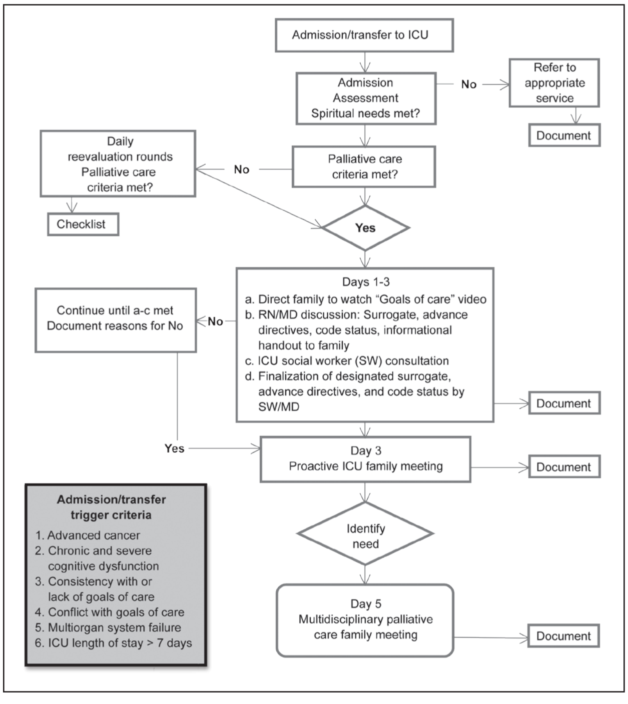

Figure 3. Flowchart: Final workflow that incorporated guidelines from Improving Palliative Care in the ICU (IPAL-ICU) project.

ICU = intensive care unit; MD = physician; RN = registered nurse.

The quantity of literature was extensive, with a considerable number of reports on issues related to the need for improved identification of goals of care and end-of-life care. The publications focused on the various aspects of initiating a palliative care program in an ICU. These included benefits, various models, screening tools, guidelines/standards, evaluation tools, metrics, barriers, and cost. There was also a moderate quantity of data regarding the importance of family satisfaction with the end-of-life care provided for patients.[14-22]

A large number of CPGs were noteworthy. Most of these were representative of the standards adopted by the NQF in its Framework and Preferred Practices for Palliative and Hospice Care and were put into operation by the CAPC IPAL-ICU Project.[15-19,22,23] The IPAL-ICU Project is a Web-based resource sponsored by the National Institute on Aging, the CAPC, and the major critical care societies and other nationally funded groups such as the Robert Wood Johnson Foundation Critical Care End-of-life Peer Workgroup. It was designed to offer a framework, along with practical steps, for the development of a palliative care initiative in an ICU.[26-29] In addition, the Care and Communication Bundle from the transformation of the ICU program provided validated measures addressing multiple domains of ICU palliative care quality. Together, these resources enable initiatives to be based on the ICU's individual needs, and customized to their specific environment.

## CONCLUSION

Despite the numerous resources available, the IPAL-ICU project guidelines were an effective tool and provided specific tailored recommendations toward initiating a palliative care program in an ICU. The successful use of these guidelines resulted in the integration of palliative care standards and the incorporation of basic palliative care principles into the daily routine in our ICU. ❖

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**Disclosure Statement**

*The authors have no conflicts of interest to disclose.*

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**References**

1. WHO definition of palliative care [Internet]. Geneva, Switzerland: World Health Organization; c2016 [cited 2016 June 16]. Available from: www.who.int/cancer/palliative/definition/en/.
2. Mirel M, Hartjes T. Bringing palliative care to the surgical intensive care unit. Crit Care Nurse 2013 Feb;33(1):71-4. DOI: https://doi.org/10.4037/ccn2013124.

3. Palliative Care Hawaii Region [Intranet]. Honolulu, HI: Kaiser Permanente Medical Center; 2010 [cited 2016 Jun 27]. Available from: https://sites.sp.kp.org/teams/hawaii/Pages/home-v6.aspx. [Password protected.]
4. Norton SA, Hogan LA, Holloway RG, Temkin-Greener H, Buckley MJ, Quill TE. Proactive palliative care in the medical intensive care unit: Effects on length of stay for selected high-risk patients. Crit Care Med 2007 Jun;35(6):1530-5. DOI: https://doi.org/10.1097/01.ccm.0000266533.06543.0c.
5. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. JAMA 2009 Aug 19;302(7):741-9. DOI: https://doi.org/10.1001/jama.2009.1198.
6. Bradley CT, Brasel KJ. Developing guidelines that identify patients who would benefit from palliative care services in the surgical intensive care unit. Crit Care Med 2009 Mar;37(3):946-50. DOI: https://doi.org/10.1097/ccm.0b013e3181968f68.
7. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. Chest 2003 Jan;123(1):266-71. DOI: https://doi.org/10.1378/chest.123.1.266.
8. Jox RJ, Schaider A, Marckmann G, Borasio GD. Medical futility at the end of life: The perspectives of intensive care and palliative care clinicians. J Med Ethics 2012 Sep;38(9):540-5. DOI: https://doi.org/10.1136/medethics-2011-100479.
9. Melnyk BM. A focus on adult acute and critical care. Worldviews Evid Based Nurs 2004 Sep;1(3):194-7. DOI: https://doi.org/10.1111/j.1524-475x.2004.04061.x.
10. Melnyk BM, Fineout-Overholt E. Adapted from: Evidence-based practice in nursing & healthcare. A guide to best practice. Philadelphia, PA: Lippincott Williams & Wilkins; 2005.
11. Melnyk BM, Fineout-Overholt E. Rapid critical appraisal of randomized controlled trials (RCTs): An essential skill for evidence-based practice (EBP). Pediatr Nurs 2005 Jan-Feb;31(1):50-2.
12. Brouwers MC, Kho ME, Browman GP, et al; AGREE Next Steps Consortium. AGREE II: Advancing guideline development, reporting and evaluation in health care. CMAJ 2010 Dec 14;182(18):E839-42. DOI: https://doi.org/10.1503/cmaj.090449.
13. Practice guidelines [Internet]. Hamilton, Ontario, Canada: AGREE Enterprise; 2013 [cited 2016 Jun 17]. Available from: www.agreetrust.org/resource-centre/practice-guidelines/.
14. Morrison RS, Penrod JD, Cassel JB, et al; Palliative Care Leadership Centers' Outcomes Group. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med 2008 Sep 8;168(16):1783-90. DOI: https://doi.org/10.1001/archinte.168.16.1783.
15. Nelson JE, Bassett R, Boss RD, et al; Improve Palliative Care in the Intensive Care Unit Project. Models for structuring a clinical initiative to enhance palliative care in the intensive care unit: A report from the IPAL-ICU Project (Improving Palliative Care in the ICU). Crit Care Med 2010 Sep;38(9):1765-72. DOI: https://doi.org/10.1097/ccm.0b013e3181e8ad23.
16. Nelson JE, Boss RD, Brasel KJ, et al. Defining standards for ICU palliative care: A brief review from the IPAL-ICU project [Internet]. New York, NY: Center to Advance Palliative Care; 2010 [cited 2016 Jun 17]. Available from: http://ipal.capc.org/downloads/ipal-icu-defining-standards-for-icu-palliative-care.pdf. [Password protected.]
17. Nelson JE, Brasel KJ, Campbell ML, et al. Evaluation of ICU palliative care quality: a technical assistance monograph from the IPAL-ICU project [Internet]. New York, NY: Center to Advance Palliative Care; 2010 [cited 2016 Jun 17]. Available from: www.capc.org/ipal/. [Password protected.]
18. Nelson JE, Campbell ML, Cortez TB, et al. Organizing an ICU palliative care initiative: A technical assistance monograph from the IPAL-ICU project [Internet]. New York, NY: Center to Advance Palliative Care; 2010 [cited 2016 Jun 17]. Available from: www.capc.org/ipal/. [Password protected.]
19. Weissman DE, Meier DE. Operational features for hospital palliative care programs: Consensus recommendations. J Palliat Med 2008 Nov;11(9):1189-94. https://doi.org/10.1089/jpm.2008.0149.
20. Weissman DE, Meier DE. Identifying patients in need of a palliative care assessment in the hospital setting: A consensus report from the Center to Advance Palliative Care. J Palliat Med 2011 Jan;14(1):17-23. DOI: https://doi.org/10.1089/jpm.2010.0347.
21. Weissman DE, Meier DE, Spragens LH. Center to Advance Palliative Care palliative care consultation service metrics: Consensus recommendations. J Palliat Med 2008 Dec;11(10):1294-8. DOI: https://doi.org/10.1089/jpm.2008.0178.
22. Weissman DE, Morrison RS, Meier DE. Center to Advance Palliative Care palliative care clinical care and çustomer satisfaction metrics consensus recommendations. J Palliat Med 2010 Feb;13(2):179-84. DOI: https://doi.org/10.1089/jpm.2009.0270.
23. Ferrell B, Connor SR, Cordes A, et al; National Consensus Project for Quality Palliative Care Task Force Members. The national agenda for quality palliative care: The National Consensus Project and the National Quality Forum. J Pain Symptom Manage 2007 Jun;33(6):737-44. DOI: https://doi.org/10.1016/j.jpainsymman.2007.02.024.
24. Lanken PN, Terry PB, Delisser HM, et al. An official American Thoracic Society clinical policy statement: Palliative care for patients with respiratory diseases and critical illnesses. Am J Respir Crit Care Med 2008 Apr 15;177(8):912-27. DOI: https://doi.org/10.1164/rccm.200605-587st.
25. Mularski RA. Defining and measuring quality palliative and end-of-life care in the intensive care unit. Crit Care Med 2006 Nov;34(11 Suppl):S309-16. DOI: https://doi.org/10.1097/01.ccm.0000241067.84361.46.
26. Truog RD, Campbell ML, Curtis JR, et al; American Academy of Critical Care Medicine. Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine. Crit Care Med 2008 Mar;36(3):953-63. DOI: https://doi.org/10.1097/ccm.0b013e3181659096. Erratum in: Crit Care Med 2008 May;36(5):1699. DOI: https://doi.org/10.1097/CCM.0b013e31817c3d1e.
27. CAPC IPAL-ICU: Improving Palliative Care in the ICU [Internet]. New York, NY: Center to Advance Palliative Care; 2013 [cited 2016 Jun 20]. Available from: www.capc.org/ipal/ipal-icu. [Password protected.]
28. Mularski RA, Curtis JR, Billings JA, et al. Proposed quality measures for palliative care in the critically ill: A consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. Crit Care Med 2006 Nov;34(11 Suppl):S404-11. DOI: https://doi.org/10.1097/01.ccm.0000242910.00801.53.
29. Wiedermann CJ, Lehner GF, Joannidis M. From persistence to palliation: Limiting active treatment in the ICU. Curr Opin Crit Care 2012 Dec;18(6):693-9. DOI: https://doi.org/10.1097/mcc.0b013e328358d417.
30. Mosenthal AC, Weissman DE, Curtis JR, et al. Integrating palliative care in the surgical and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Care Unit (IPAL-ICU) Project Advisory Board and the Center to Advance Palliative Care. Crit Care Med 2012 Apr;40(4):1199-206. DOI: https://doi.org/10.1097/ccm.0b013e31823bc8e7.
31. Nelson JE, Curtis JR, Mulkerin C, et al; Improving Palliative Care in the ICU (IPAL-ICU) Project Advisory Board. Choosing and using screening criteria for palliative care consultation in the ICU: A report from the Improving Palliative Care in the ICU (IPAL-ICU) Advisory Board. Crit Care Med 2013 Oct;41(10):2318-27. DOI: https://doi.org/10.1097/ccm.0b013e31828cf12c.
32. Smith TJ, Coyne PJ, Cassel JB. Practical guidelines for developing new palliative care services: Resource management. Ann Oncol 2012 Apr;23 Suppl 3:70-5. DOI: https://doi.org/10.1093/annonc/mds092.
33. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. Chest 2003 Jan;123(1):266-71. DOI: https://doi.org/10.1378/chest.123.1.266.
34. Lustbader D, Pekmezaris R, Frankenthaler M, et al. Palliative medicine consultation impacts DNR designation and length of stay for terminal medical MICU patients. Palliat Support Care 2011 Dec;9(4):401-6. DOI: https://doi.org/10.1017/s1478951511000423.
35. Sihra L, Harris M, O'Reardon C. Using the improving palliative care in the intensive care unit (IPAL-ICU) project to promote palliative care consultation. J Pain Symptom Manage 2011 Nov;42(5):672-5. DOI: https://doi.org/10.1016/j.jpainsymman.2011.08.002.
36. Nelson JE, Mulkerin CM, Adams LL, Pronovost PJ. Improving comfort and communication in the ICU: A practical new tool for palliative care performance measurement and feedback. Qual Saf Health Care 2006 Aug;15(4):264-71. DOI: https://doi.org/10.1136/qshc.2005.017707.
37. Penrod JD, Pronovost PJ, Livote EE, et al. Meeting standards of high-quality intensive care unit palliative care: Clinical performance and predictors. Crit Care Med 2012 Apr;40(4):1105-12. DOI: https://doi.org/10.1097/ccm.0b013e3182374a50.
38. Campbell ML. Palliative care consultation in the intensive care unit. Crit Care Med 2006 Nov;34(11 suppl):S355-8. DOI: https://doi.org/10.1097/01.ccm.0000237248.16818.e5.
39. Transformation of the ICU (TICU)-Care and Communication Quality Measures at the National Quality Measures Clearinghouse [Internet]. Rockville, MD: Agency for Healthcare Research and Quality, National Quality Measures Clearinghouse; 2013 [cited 2016 Jun 27]. Available from: www.qualitymeasures.ahrq.gov/browse/by-organization-indiv.aspx?objid=25944.
40. Curtis JR, Engelberg RA. Measuring success of interventions to improve the quality of end-of-life care in the intensive care unit. Crit Care Med 2006 Nov;34(11 Suppl):S341-7. DOI: https://doi.org/10.1097/01.ccm.0000237048.30032.29.
41. Volandes AE, Lehmann LS, Cook EF, Shaykevich S, Abbo ED, Gillick MR. Using video images of dementia in advance care planning. Arch Intern Med 2007 Apr 23;167(8):828-33. DOI: https://doi.org/10.1001/archinte.167.8.828. Erratum in: Arch Intern Med 2008 May 12;168(9):995. DOI: https://doi.org/10.1001/archinte.168.9.995.
42. Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: A systematic review. Chest 2011 Mar;139(3):543-54. DOI: https://doi.org/10.1378/chest.10-0595.
43. Curtis JR, Nielsen EL, Treece PD, et al. Effect of a quality-improvement intervention on end-of-life care in the intensive care unit: A randomized trial. Am J Respir Crit Care Med 2011 Feb 1;183(3):348-55. DOI: https://doi.org/10.1164/rccm.201006-1004oc.
44. Dunning T, Savage S, Duggan N, Martin P. Developing clinical guidelines for end-of-life care: Blending evidence and consensus. Int J Palliat Nurs 2012 Aug;18(8):397-405. DOI: https://doi.org/10.12968/ijpn.2012.18.8.397.
45. Aslakson RA, Curtis JR, Nelson JE. The changing role of palliative care in the ICU. Crit Care Med 2014 Nov;42(11):2418-28. DOI: https://doi.org/10.1097/ccm.0000000000000573.

# Consideration of Personal Adverse Childhood Experiences during Implementation of Trauma-Informed Care Curriculum in Graduate Health Programs

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## ABSTRACT

**Context:** Scientific findings of adverse childhood experiences (ACEs) and their lifelong graded relationship with leading causes of death are well established. Many health care practitioners, however, have yet to implement ACEs screening in clinical practice. Furthermore, ACEs screening and trauma-informed care (TIC) are not part of standard graduate-level training.

**Objective:** To 1) implement trauma-informed curriculum for multiple graduate health programs, 2) determine student understanding of and willingness to address ACEs, and 3) assess the relationship between students voluntarily evaluating their individual ACE Score and their attitude toward ACEs and TIC.

**Design:** Prospective study with pre- and postcurricular surveys (12-question digital survey administered before and after the curriculum) for 967 graduate students from 9 health professions programs at 2 campuses who received curriculum focused on ACEs and TIC.

**Main Outcome Measures:** Students' understanding of ACEs and TIC, their awareness of personal ACEs, and their willingness to incorporate TIC in practice.

**Results:** Among students who voluntarily completed an ACE questionnaire, there was statistical significance in familiarity with clinical and scientific findings of the ACE Study ($p < 0.001$) and familiarity with TIC ($p < 0.02$). A significant intercampus difference in the students' familiarity with the scientific and clinical findings of the ACE Study ($p < 0.05$) was found.

**Conclusion:** Students and future health care practitioners who voluntarily assess their ACE Score are significantly more likely to understand scientific and clinical findings of the ACE Study as well as TIC.

## INTRODUCTION

The lifelong graded relationship between adverse childhood experiences (ACEs) and leading causes of death is well established. ACEs have been shown to be "the main determinant of the health and social well-being of the nation."[1] Starting in the mid-1990s researchers evaluated more than 17,000 upper-middle-class, college-educated adults in the Kaiser Foundation Health Plan to better understand the relationship between childhood trauma and disease in adulthood. They found that the wider the extent of exposure to 10 types of childhood abuse, neglect, and household dysfunction, the higher the individual's risk of maladaptive behaviors, chronic health conditions, and early death.[2] Many health care practitioners, however, have yet to consider ACEs in clinical practice. Furthermore, ACEs screening and trauma-informed care (TIC) are not part of standard health practitioner graduate-level discussions.

Child maltreatment is common and pervasive in our country.[2,3] Most victims of maltreatment carry scars, sometimes unrecognized, throughout their lives. Scientific evidence shows that the consequences of childhood trauma and the excessive amount of toxic stress consequent to it are directly linked to addiction, mental health disorders, lack of impulse control, and other conditions such as chronic obstructive pulmonary disease, certain types of cancer, diabetes, coronary artery disease, liver disease, and even early death.[2]

Despite evidence clearly demonstrating significant consequences of ACEs, many health care practitioners have yet to learn about and be trained in TIC. Nadine Burke Harris, MD,[3] from the Center for Youth Wellness in San Francisco, CA, explained in a TED (Technology, Entertainment and Design) conference in 2014 that even though practitioners equipped with the knowledge of ACEs can better address childhood trauma and more effectively provide health care to their patients, there seems to be a lack of enthusiasm among physicians and other health care practitioners to consider the lifelong impact of child maltreatment. Burke Harris[3] suggested it is more than simply bringing up the difficult issue of unresolved childhood trauma, asking the ACE Score questions, and knowing what to do with the results. She proposed that it is the practitioners' lack of willingness to consider their own childhood trauma and how it has affected their lives and even their performance in their profession.

### Adverse Childhood Experiences and Trauma-Informed Care

Organizations throughout the US are implementing TIC, in which all efforts are coordinated to prevent, to treat, and to heal the lifelong consequences of child abuse.[3-7] The trauma-informed practitioner recognizes the vast consequences of trauma in the developing years and throughout a person's lifespan. A trauma-informed practitioner is better equipped to understand why their patients' current state of health is not based on their addiction, maladaptive behavior, or mental illness as much as it is

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a consequence of the body's physiologic and psychologic response to toxic stress in the developing years. After gathering results of a patient's ACE Score questionnaire[8] by mail, in person, or electronically, health care practitioners can formulate an appropriate therapeutic approach.

An intervention can begin simply by asking, "Tell me how that has affected you later in your life," or "How would you feel if you learned that a child you care about was growing up exactly as you did?"[4] Once practitioners understand that a behavior or health condition is related to a patient's ACEs, they are better equipped to see the problem as the patient's adaptation. For example, smoking can be an anxiolytic and/or antidepressant, or obesity can be a mechanism to avert unwanted sexual advances. Working with such perspective conveys acceptance and compassion.[4]

> Patients can be reassured that 'the ACEs were not your fault,' 'It is not all in your head,' and 'You are experiencing a normal response to abnormal life experiences in childhood. Help exists for that.' … Attending to the root problem and not to the patient's adaptation to the problem allows providers to address the 'fire' rather than merely the 'smoke.' In addition, the higher-quality clinician-patient relationship arising from this approach is itself therapeutic.[4]

Sometimes starting the conversation is all that must happen for patients to start processing the connections of their childhood trauma to current ailments. This knowledge alone may empower patients and start them on the path to emotional and physical healing. Someday, perhaps all practitioners can echo these profound words: "Gradually, we came to see that asking, listening, and enabling a patient to go home feeling still accepted, is in itself a major intervention. The clinical practice of asking, listening, and accepting is *doing*."[9]

## Implementation of Trauma-Informed Care in Practice

Fortunately, many communities and hospital administrations are making training in ACEs and TIC available and even implementing efforts to transform various health care systems.[5-7] Without specifically implementing screening methods, some organizations choose to teach and to openly discuss the psychobiology of toxic stress and long-term health consequences of ACEs. However, as noted by the authors of the original ACE Study,[2] some practitioners make excuses for why they do not make changes in their practice, excuses that do not scratch the surface as to why there is refusal to change.

> Internist and family practice colleagues, while commonly finding the ACE study quite interesting, generally did not want to use its findings in practice, citing time factors and *lack of training* as explanations. Those in fee-for-service practice additionally cited lack of insurance coverage. While superficially plausible, we saw *these often were cover excuses for deeper resistance, sometimes related to the awakening of personal ghosts, as well as discomfort in discussing topics* we have all been taught are protected by social taboos related to sex and the privacy of family lives.[9] [Emphasis added.]

Because the awakening of these "personal ghosts" is a very important factor in the ability to connect with one's patient, this adds yet another reason to transform medical training to address ACEs and TIC. Moreover, it is important for practitioners to address the impact of their own ACEs on work performance. Researchers found a strong and graded relationship between one's ACE Score and job problems, financial problems, and absenteeism in addition to "four areas of health and well-being that employers and medical practitioners have difficulty managing (relationship problems, emotional distress, somatic symptoms, substance abuse)… ."[10]

Trauma-informed practitioners who have implemented changes in their practice have witnessed improvements in staff and organizational health, in addition to improvements in their patients' medical care.[4,7] For example, in the late 1980s and early 1990s a team of health care practitioners based in Philadelphia, PA, clearly saw the consequences of violence and trauma in their patients.[7] They worked to form a healing system for traumatized patients and began implementing patient care through a trauma-informed approach. Later called The Sanctuary Model, this method seeks to provide healing from violence and has grown to help train workers and organizations on how to create and maintain "physical, psychological, social and moral safety within a social environment."[7] Participants "become thoroughly familiar with the psychobiology of trauma and disrupted attachment and the multiple ways that [posttraumatic stress disorder] … and other trauma-related disorders present in the children, adults and families they work with."[7]

Sandra Bloom, MD,[7] founder of The Sanctuary Model, recounts positive effects of one such implementation of The Sanctuary Model in pediatric residential facilities in Pennsylvania for both patients and staff. There were five important differences in the staff:

> *Support:* how much children help and support each other; how supportive staff is toward the children; *Spontaneity:* how much the program encourages the open expression of feelings by children and staff; *Autonomy:* how self-sufficient and independent staff perceive that the children are in making their own decisions; *Personal Problem Orientation:* the extent to which children seek to understand their feelings and personal problems; *Safety:* the extent to which staff feel they: can challenge their peers and supervisors, can express opinions in staff meetings, will not be blamed for problems, and have clear guidelines … .[7]

Specifically analyzing data of service utilization from 2007 to 2009 of children discharged from residential treatment facilities (RTFs) that implemented The Sanctuary Model vs other RTFs, Dr Bloom noted: "RTF providers implementing Sanctuary had: a substantially shorter length of stay … a substantial increase in the percentage of youth discharged who received outpatient services in the three months following discharge; a lower increase in the percentage of children readmitted to RTFs in the 90 days following discharge."[7]

Citing how TIC is shown to be therapeutic for both the patient and the organization or practitioner who implements it, Dr Bloom[7] also explains that simply "[l]earning about the psychobiology of stress, toxic stress, and trauma is liberating for people." Yet many practitioners are reticent to discuss the impact of childhood trauma with their patients, remaining personally unaware of its importance. One objective of this study is to advance the understanding of graduate health students regarding ACEs and TIC, in light of their own attitudes toward discussing trauma with their patients, as well as their attitudes toward their own ACEs.

### Objectives

We designed a curriculum to help students become comfortable addressing typically uncomfortable topics, practice listening and collaborating skills, and ultimately form confidence to implement their knowledge of ACEs and TIC in clinical practice. Using a model of teamwork and collaboration, we sought to better understand future health care practitioners' consideration of the lifelong effects of trauma and violence, and ways to combat resistance to such understanding. We hypothesized that health professions students would be more confident in understanding the clinical importance of ACEs and TIC as they assessed their own history of ACEs. The objectives of this study were to 1) implement trauma-informed curriculum for multiple graduate health programs, 2) determine student understanding of and willingness to address ACEs, and 3) assess the relationship between students voluntarily evaluating their individual ACE Score and their attitude toward ACEs and TIC. Our goal was to formulate a method of instructing the next generation of health care practitioners on ways to prevent, to recognize, and to address unresolved childhood trauma and to inspire other training programs to do the same.

## METHODS

A total of 967 students from 9 health profession programs (doctor of osteopathy [DO], doctor of podiatric medicine, doctor of optometry, doctor of dental medicine, doctor of physical therapy, doctor of veterinary medicine, doctor of pharmacy, master of science in nursing-entry, and master of science in physician assistant studies) primarily in Pomona, CA, were enrolled in the study. Participating students received curriculum focused on ACEs and TIC in an interprofessional education course. The DO program was the largest, with 340 students. It consisted of 230 students on the Pomona campus and 110 students at an expansion site in Lebanon, OR. A multiquestion digital survey administered before and after the curriculum assessed students' understanding of ACEs and TIC, their awareness of personal ACEs, and their willingness to incorporate TIC in practice (see Sidebar: The Pre- and Postcurriculum Survey). Because students were not required to complete the pre- and postcurricular surveys as part of the curriculum, we sent reminder e-mails encouraging participation in the opportunity to help advance important research. The questions with the most revealing results, graded on an interval scale, are as follows:

- How familiar are you with the clinical and scientific findings of the ACE Study?
- How familiar are you with trauma-informed care?
- How likely will you be to administer and assess an ACE questionnaire on your patients?
- How confident are you in knowing what to do to help your patient after discussing his/her history of trauma?
- Have you completed a personal ACE questionnaire in the past?

In the interprofessional education course designed to promote collaboration and patient-centered care, participants work through various relevant health care cases in teams consisting of students from each health profession. Teams of at least 9 gather in small rooms with a proctor who helps facilitate the discussion. Three sessions, each of which lasts approximately 2 hours, occur 1 weeknight a week for 3 weeks. Each session is developed to prompt conversation about what one's practice will look like and how it will be better served through collaborating with other health care professionals working with the same patient. In the week between each session, students are asked to prepare and research

### The Pre- and Postcurriculum Survey

1. **How familiar are you with the clinical and scientific findings of the Adverse Childhood Experiences (ACEs) Study?**
   Unfamiliar / Somewhat Familiar / Extremely Familiar
2. **How familiar are you with Trauma-Informed Care?**
   Unfamiliar / Somewhat Familiar / Extremely Familiar
3. **How comfortable are you discussing with your patient their personal history of physical, emotional, and sexual abuse?**
   Uncomfortable / Somewhat Comfortable / Extremely Comfortable
4. **How important do you think it is for a patient's medical record to include any history of physical, emotional, and sexual abuse?**
   Not important / Somewhat Important / Extremely Important
5. **How likely will you be to administer and assess an ACEs questionnaire on your patients?**
   Unlikely / Somewhat Likely / Extremely Likely / Uncertain what this is
6. **How confident are you in knowing what to do to help your patient after discussing his/her history of trauma?**
   Not Confident / Somewhat Confident / Extremely Confident
7. **Have you completed an ACEs questionnaire in the past?**
   No / Yes
8. **If no, how likely are you to complete an ACEs questionnaire on yourself?**
   Unlikely / Somewhat Likely / Extremely Likely / Uncertain what this is
9. **If no, how comfortable are you completing an ACEs questionnaire on yourself?**
   Unlikely / Somewhat Likely / Extremely Likely / Uncertain what this is
10. **If yes, how likely are you to discuss your personal results of the questionnaire with your own physician?**
    Unlikely / Somewhat Likely / Extremely Likely
11. **If yes, how comfortable are you discussing the results of the questionnaire with your own physician?**
    Uncomfortable / Somewhat Comfortable / Extremely Comfortable
12. **What is your sex?**
    Male / Female

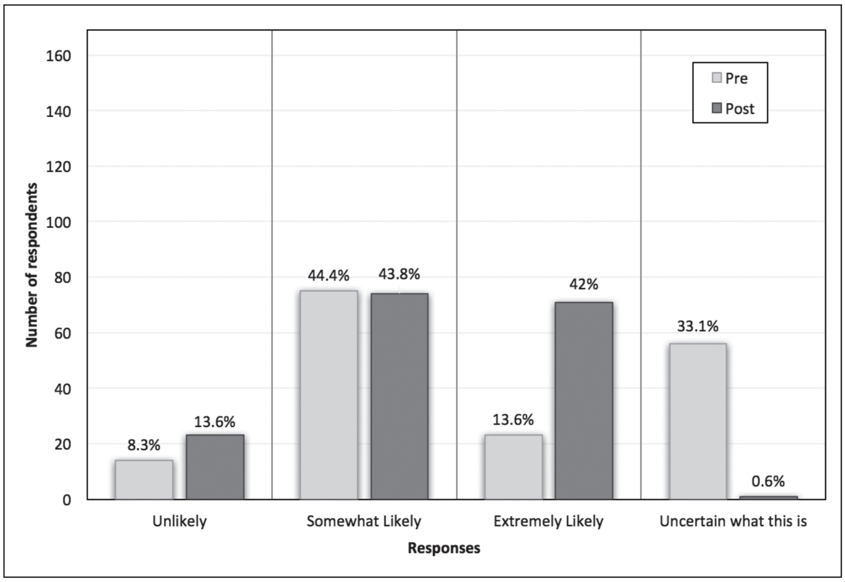

Figure 1. Precurricular (Pre) and postcurricular (Post) survey responses of health professions students to the survey question, "How likely will you be to administer and assess an ACE questionnaire for your patients?"

ACE = adverse childhood experiences.

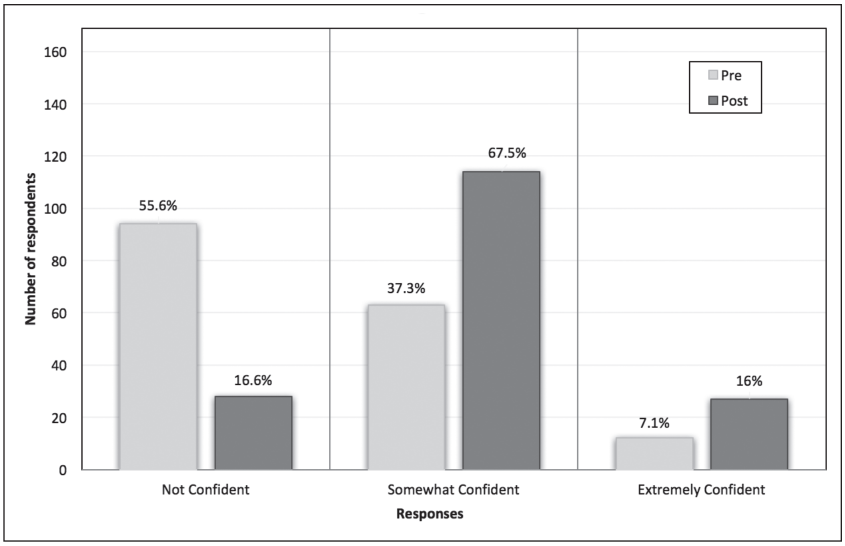

Figure 2. Precurricular (Pre) and postcurricular (Post) survey responses of health professions students to the survey question, "How confident are you in knowing what to do to help your patient after discussing his/her history of trauma?"

a topic that contributes to team-specific learning goals (questions not addressed during the prior session). In October 2015, and within this framework, we implemented a case specifically devoted to ACEs and TIC wherein the 3 sessions included the following:

Session 1: Students received instruction by trauma-informed practitioners who understand the importance of ACEs in practice. The Medical Director of a local child abuse intervention center presented a live lecture to DO students at the Lebanon, OR, campus. This was recorded and made available to all other programs involved in the curriculum if they were unable to provide a live lecturer for their own students. The purpose of this lecture was to instruct on abuse and neglect in its various forms, specifically within the scope of ACEs. Students learned the lifelong consequences of childhood trauma, how it may present in clinical practice, and reasons for practitioners to implement TIC.

Session 2: Each team watched Dr Burke Harris' TED talk "How Childhood Trauma Affects Health Across a Lifetime" and studied the Web site for Consequences of Lifetime Exposure to Violence and Abuse (http://coleva.net) with a discipline-specific approach. (Veterinary students were referred to an article linking animal abuse as a marker for child abuse.[11]) They then discussed the ACE Study and toxic stress, and practiced ways to empathetically treat patients. Students were to discuss with each other how they, in their respective professions, could better understand the health of their patients.

Session 3: Teams role-played a factual case of an adult with ACEs, alternating roles as practitioner or patient in working through a therapeutic process. Each team explored how health professions can collaborate to meet patients' needs. Finally, each team created a fact sheet intended for the general public to understand ACEs and TIC.

## RESULTS

Of the 967 students who took part in the ACEs and TIC curriculum, 267 submitted responses to the precurricular survey (response rate, 27.6%) and 422 submitted responses to the postcurricular survey (response rate, 43.6%). Of the 267 precurricular responses, 5 respondents had at one time assessed their own ACE Score, which increased to 68 respondents in the postcurricular survey. We then looked solely at the 169 anonymous students who responded to both pre- and postcurricular surveys, matching the data to more effectively assess our intervention.

There was a substantial increase in the students who were "extremely likely" to administer and assess an ACE questionnaire for their patients (13.6% of respondents precurriculum [n = 23] vs 42.0% postcurriculum [n = 71]). Of these 169 students, 1 respondent did not answer this particular question and appeared as the 0.6% "Uncertain what this is" seen in Figure 1. Among the 13.6% of respondents who answered "unlikely" to administer an ACE questionnaire for their patients in

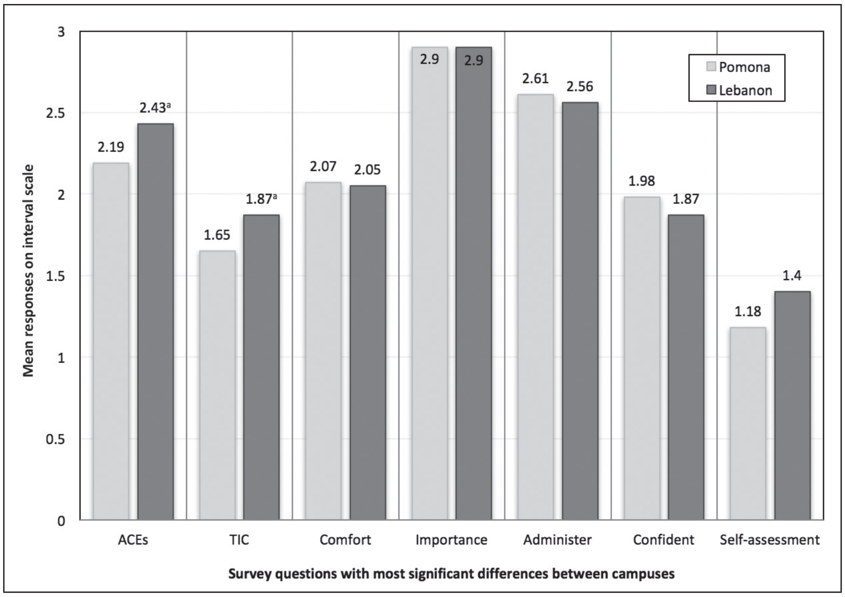

Figure 3. Comparison of responses to survey questions between osteopathic medical students from both campuses (Pomona, CA, and Lebanon, OR) who assessed their own Adverse Childhood Experiences Score, with the major difference being that Lebanon-based students received a hard copy of the Adverse Childhood Experiences and Resilience/Stress questionnaires. The X-axis represents 7 of the survey questions. The Y-axis represents the mean of responses on an interval scale of 1 = unfamiliar, uncomfortable, unlikely, etc; 2 = somewhat familiar, somewhat comfortable, somewhat likely, etc; and 3 = extremely familiar, extremely comfortable, extremely likely, etc. For the self-assessment question, 1 = no; 2 = yes.

[a] $p < 0.05$.

ACEs = How familiar are you with the clinical and scientific findings of the Adverse Childhood Experiences Study?; Administer = How likely will you be to administer and assess an Adverse Childhood Experiences questionnaire on your patients?; Comfort = How comfortable are you discussing with your patient their personal history of physical, emotional, and sexual abuse?; Confident = How confident are you in knowing what to do to help your patient after discussing their history of trauma?; Importance = How important do you think it is for a patient's medical record to include any history of physical, emotional, and sexual abuse?; Lebanon = Lebanon, OR, campus; Pomona = Pomona, CA, campus; Self-assessment = Have you completed an Adverse Childhood Experiences questionnaire in the past?; TIC = How familiar are you with Trauma-Informed Care?

the postcurricular survey, 44.0% (n = 10) were from the veterinary program; the next largest represented program was pharmacy, with 21.7% (n = 5).

Respondents' confidence levels in helping a patient with a history of trauma likewise increased (Figure 2). Those reporting feeling "somewhat confident" increased from 37.3% (n = 63) on the precurricular survey to 67.5% (n = 114) on the postcurricular survey, and there was more than twice the increase in responses to being "extremely confident"—from 7.1% (n = 12) on the precurricular survey to 16.0% (n = 27) on the postcurricular survey.

Recognizing the predictable increase in postcurricular responses regarding understanding of ACEs and TIC after our intervention, we looked closer at respondents who had voluntarily assessed their own ACE Score. We did this using a $\chi^2$ test of independence to assess postcurricular survey responses from 422 students. These 422 students were represented by all 9 health professions programs and consisted of 144 men (34.1%) and 278 women (65.9%). One hundred forty-six students were from the DO program, with 83 from the Pomona, CA, campus and 63 from the Lebanon, OR, campus. There was no significant difference in responses based on sex. Looking at the response rate from the DO program at each campus, we noted that students at the Lebanon campus were overall much more likely to participate in the postcurricular survey (63/110, 57.3%) than were Pomona students (83/230, 36.1%).

In a comparison of all postcurricular survey responses between Pomona and Lebanon DO students, a statistically significant intercampus difference in the DO students' familiarity with scientific and clinical findings of the ACE Study (degrees of freedom = 2, n = 146, $\chi^2$ = 6.422, $p < 0.05$) was found. Only 26.5% (61/230) of DO students at the Pomona campus were familiar with the clinical and scientific findings of the ACE Study, compared with a much higher 46.0% (51/110) of DO students at the Lebanon campus. Most significantly, respondents who voluntarily completed an ACE questionnaire (68/422 = 16.1%), compared with students who did not complete an ACE questionnaire, were more familiar with the clinical and scientific findings of the ACE Study (degrees of freedom = 2, n = 422, $\chi^2$ = 24.417, $p < 0.001$), and with TIC (degrees of freedom = 2, n = 422, $\chi^2$ = 8.264, $p < 0.02$). There was a higher proportion of Lebanon-based DO students who assessed their own ACE Score (25/110, 22.7%) vs Pomona-based DO students (15/230, 6.5%).

As Figure 3 depicts, the major differences between students at the two campuses were found to be 1) familiarity with the original ACE Study, 2) familiarity with TIC, and 3) self-assessment of one's own ACE Score. Responses related to comfort level and the importance of discussing childhood trauma, as well as likelihood of administering the questionnaire and confidence in knowing how to help, were similar between campuses.

## DISCUSSION

The study data (cross tabulations available online at: www.thepermanentejournal.org/files/2017/16-061.pdf) support our hypothesis that students and future health care practitioners voluntarily assessing their ACE Score are significantly more likely to understand the scientific and clinical findings of the ACE Study and TIC. Because of the surveys not being required for the course, we were pleased with what we consider a high response rate (precurricular survey, 267/967, 27.6% vs postcurricular survey, 422/967, 43.6%). From the available data, we can't explain why 354 of the postcurricular survey respondents chose not to calculate their own ACE Score or if there was any reason beyond it being voluntary (ie, lack of time, disinterest, thought to be trivial, fear of personal trauma).

A follow-up longitudinal study throughout the careers of these students might demonstrate how their approach to patients may differ from other practitioners who were not similarly trained. Measuring patient satisfaction, number of outpatient visits, and practitioner/staff health and professional attitude will help us determine the long-term effectiveness of integrating TIC into graduate programs for both practitioners and their patients. Further study is needed to assess practitioners' awareness of their own ACEs and their approach to TIC of patients, which can also include the level of trust between practitioner and patient. Added considerations would include match or mismatch between the sex of the patient and the practitioner and willingness to discuss ACEs. It would also be important to evaluate for the most compassionate and effective method that practitioners may choose to administer the questionnaire, whether it be in the clinic, mailed to patients' homes, or sent electronically.

Study limitations included a small sample size of personal ACE assessment because the institutional review board (IRB) of our institution denied assessment of students' ACE Score as part of the study. Because we were not approved to gather respondents' ACE Scores, we are unable to know if students with a higher ACE Score would be more familiar with ACEs and TIC than students with a lower ACE Score. Nor do we know the respondents' comfort level and perceived importance in discussing a patient's traumatic history, or their likelihood to administer an ACE questionnaire for their patients scaled in relation to their own ACE Score. If the IRB had approved respondents' assessment of their own ACE Score as part of the intervention, we are confident the curriculum would have had a greater impact, because more students would have probably assessed their own ACE Score and thereby acquired better understanding of ACEs and TIC.

With a substantial increase in the amount of respondents who had assessed their own ACE Score, from 5 precurriculum to 68 postcurriculum, the data show that merely assessing one's own ACE Score increases the understanding of and familiarity with ACEs and TIC. To be sure, a future study with an even larger population would include having all students self-administer an ACE questionnaire. To allay any fears or misunderstanding from the IRB, we will instruct students on the importance of building personal resiliency factors when working in health care, a field that in itself may be retraumatizing.

Furthermore, a standardization error occurred between both campuses in which students on the Pomona campus lacked a personal hard copy of the ACE and Resilience/Stress questionnaires.[8,12] This error resulted in Lebanon-based students being proportionately more likely to assess their own ACE Score, with a statistically significant intercampus difference in students' familiarity with the clinical and scientific findings of the ACE Study. In our $\chi^2$ test of independence, we should have assessed the level of significance of ACE Score self-assessment between campuses, but we chose not to in order to limit the number of comparisons being made. We are confident, however, had we included this assessment, the proportion of Lebanon students vs Pomona students would have been statistically significant because of the aforementioned standardization error. Acknowledging that people who voluntarily self-administer an ACE questionnaire are self-selecting, it is unclear whether this self-selecting population already had personal or clinical experience in assessing ACEs. However, we do know that only 5 of the 267 precurricular respondents had at one time assessed their own ACE Score.

Other major limitations of our study included controlling for variation between the programs and campuses regarding lecturers and facilitators. Compared with the other graduate programs, veterinary and pharmacy students were less likely to foresee themselves administering an ACE questionnaire, perhaps because of a perceived lack of feasible application in their fields. Future study will therefore necessitate for controlling variation in the different learners at various stages of training, by students' ages, and by their respective program of study.

Several months after the IRB denied the original proposal to assess students' ACE Scores, stating that they were "surprised [we] would even suggest" doing so, we ascertained more of the reasoning. With the remote possibility of even a minor number of the 950 students unable to process a traumatic childhood without help, the lack of mental health resources created the ultimate barrier to such a risk. What we are clearly seeing are systems-based barriers in assessing a history of ACEs for fear of retraumatization, liability, and even a personal discomfort/bias of discussing one's own history of ACEs. Protecting subjects in research that could potentially prompt overwhelming emotions is a conscientious objection on the part of the IRB. What our data show, however, is that respondents who voluntarily assessed their own ACE Score are more familiar with the science of ACEs and TIC and are more willing to assess their patients' ACE Score compared with respondents who did not voluntarily assess their ACE Score. We hope learning the psychobiology of ACEs was and has been liberating for the students in our study, as witnessed in others by Dr Bloom.[7] Perhaps allowing the Lebanon-based students to understand the importance of their own resilience, from being shown the Resilience/Stress Questionnaire, served as an important protective factor.

In a major health professions training institution, the hesitancy to ask students about a possible traumatic childhood shows a misunderstanding of reasons and of the therapeutic consequences of doing so. Patients disclose highly personal information to their health care professional in a way few others are entrusted. The nature of the physician-patient relationship holds the possibility of enkindling past trauma for both practitioner and patient. If we are to comprehensively address the health of our patients, especially regarding circumstances surrounding their developing years, we ourselves must personally do the same.

It is time we make these fundamental changes of addressing our own ACEs, becoming trauma-informed, and inspiring resilience in our patients. As exclaimed by Ginsburg,[13] health care practitioners can often work with difficult populations and revert to a model of addressing "what is wrong" with their patients, rather than attempting to understand "what happened to them." Without a TIC paradigm, practitioners can themselves become burnt out, feeling less capable of offering care for their patients. Sharing his experience in adolescent medicine in his book *Building Resilience in Children and Teens*, Ginsburg stresses the importance of recognizing the vital role of resilience for all health care practitioners, and the patients we serve:

> As a professional, being trauma-informed positions you to serve more effectively. … [and] prevents our own burnout. It allows us to learn to hold people's pain without owning their pain … it allows us to understand others' behavior in context, rather than taking their behaviors (eg, their weariness of trusting us) personally. We know what is and what is not about us. Knowing when not to personalize protects our boundaries and stems our frustration and, therefore, may increase our professional longevity.[13]

## CONCLUSION

This research study is an answer to the call of the pioneers of TIC who have opened our eyes, such as Vincent Felitti, MD; Robert Anda, MD; Sandra Bloom, MD; Nadine Burke Harris, MD; Bessel van der Kolk, MD; and others. Consideration of one's own ACEs, while learning of ACEs and TIC in the health professions setting, allows students and future health care practitioners to better understand the scientific and clinical significance of the lifelong effects of patients' traumatic histories. With refined perspective *after* better understanding the importance of ACEs, we are empowered to connect with our patients in their circumstance. The challenge we face as health care practitioners is to see our patients for who they really are—just like us—a composite of several circumstances with more than just a "chief complaint." Whether the patient is 5 or 50 years of age, the challenge is the same. ❖

### Disclosure Statement

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### References

1. Felitti VJ. [Origins of addictive behavior: evidence from a study of stressful childhood experiences]. [Article in German]. Prax Kinderpsychol Kinderpsychiatr 2003 Oct;52(8):547-59.
2. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. Am J Prev Med 1998 May;14(4):245-58. DOI: https://doi.org/10.1016/s0749-3797(98)00017-8.
3. Burke Harris N. How childhood trauma affects health across a lifetime [video]. New York, NY: TED Conferences LLC; 2014 Sep [cited 2016 Jul 27]. Available from: www.ted.com/talks/nadine_burke_harris_how_childhood_trauma_affects_health_across_a_lifetime.
4. Clarke D, Schulman E, McCollum D, Felitti V. Clinical approaches for adult ACE survivors experiencing unexplained physical symptoms and health problems [Internet]. Jacksonville, FL: Academy on Violence and Abuse; 2015 [cited 2016 Jul 27]. Available from: www.avahealth.org/aces_best_practices/clinical-approaches-for-adults.html.
5. Forstadt LA, Rains M. Working with adverse childhood experiences: Maine's history, present and future. A report for the Maine Children's Growth Council [Internet]. Augusta, ME: Maine Children's Growth Council Health Accountability Team; 2011 Dec [cited 2016 Jul 27]. Available from: http://tcmhs.org/pdfs/ACES_Report_Final.pdf.
6. Clifford Beers Clinic: help, healing, hope [Internet]. New Haven, CT: Clifford Beers Clinic; c2015 [cited 2016 Aug 2]. Available from: http://aces.cliffordbeers.org/.
7. Testimony of Sandra L Bloom, MD. Prepared for Attorney General's national task force on children exposed to violence. Defending childhood: protect, heal, thrive. Public hearing #4. Detroit, MI: Wayne State University; 2012 Apr 24.
8. Anda RF. The ACE score calculator [Internet]. San Diego, CA: Sparrow Consulting LLC; 2007 [cited 2016 Jul 27]. Available from: http://acestudy.org/the-ace-score.html.
9. Felitti VJ, Anda RF. The lifelong effects of adverse childhood experiences. In: Chadwick DL, Giardino AP, Alexander R, Thackeray JD, Esernio-Jenssen D, editors. Chadwick's child maltreatment: sexual abuse and psychological maltreatment. Vol 2. 4th ed. Florissant, MO: STM Learning, Inc; 2014. p 203-15.
10. Anda RF, Fleisher VI, Felitti VJ, et al. Childhood abuse, household dysfunction, and indicators of impaired worker performance in adulthood. Perm J 2004 Winter;8(1):30-8. DOI: https://doi.org/10.7812/TPP/03-089.
11. Arkow P. A link across the lifespan: animal abuse as a marker for traumatic experiences in child abuse, domestic violence and elder abuse [Internet]. Shakopee, MN: Academy on Violence and Abuse; 2015 [cited 2016 Jul 27]. Available from: https://avahealthorg.presencehost.net/file_download/inline/b64aff80-5461-4d9b-9cdc-cf9b47f30174.
12. Rains M, McLinn K. Resilience/stress questionnaire [Internet]. Augusta, ME: Southern Kennebec Healthy Start; updated 2003 [cited 2016 Jul 27]. Available from: www.wcasa.org/file_open.php?id=801.
13. Ginsberg KR. Building resilience in children and teens: giving kids roots and wings. 3rd ed. Elk Grove Village, IL: American Academy of Pediatrics; 2015. p 164.

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## Woe

The days of childhood are but days of woe.

— *The Retrospect,* Robert Southey, 1774-1843, English poet

**EDITORIAL**

# Mind-Body Training for At-Risk Populations: Preventive Medicine at its Best

**Charles Elder, MD, MPH, FACP**

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This article is a companion to "Transcendental meditation and reduced trauma symptoms in female inmates: A randomized controlled pilot study," available at: www.thepermanentejournal.org/issues/2017/6290-meditation.html, and on page 39 and to "Reduced trauma symptoms and perceived stress in male prison inmates through the Transcendental Meditation program: A randomized controlled trial," available at: www.thepermanentejournal.org/issues/2016/fall/6227-incarcerated-healthcare.html and in the Fall 2016 issue of *The Permanente Journal.*

Kaiser Permanente, and like-minded institutions, strongly emphasize health promotion and disease prevention in caring for our patients. We screen our population for breast cancer in an effort to achieve early detection, so appropriate curative treatment can be offered in a timely way. We promote vaccination programs to prevent outbreaks of infectious diseases. We prescribe statins for primary and secondary prevention of cardiovascular disease, expending considerable energy and resources to maximize levels of appropriate prescribing on a population-based level to reduce the incidence of cardiovascular events. We actively and systematically screen for alcohol abuse at routine primary care visits, identifying patients who might not otherwise seek intervention. These, and innumerable other such efforts, share the worthy goal of preventing the occurrence, or complications, of serious diseases.

## TWO PAPERS

In this issue and in the Fall 2016 issue of *The Permanente Journal*, Nidich and colleagues[1,2] have reported results of two clinical trials of a standardized, evidence-based mind-body intervention delivered to inmates incarcerated in three state prisons in Oregon. These projects offer insight and guidance toward advancing the scope, and paradigm, of our preventive medicine efforts.

In the article published in Fall 2016,[2] Nidich et al randomly assigned 180 male inmates in the Oregon state correction system to either Transcendental Meditation (TM) instruction or a no-intervention control group. TM is a popular mind-body technique that, from a research and therapeutics perspective, offers the important advantage of a standardized, reproducible 7-step instruction protocol. At 4-month follow-up, the intervention group showed significant reductions in total trauma symptoms and perceived stress compared with control.

The article in this issue[1] describes the same meditation intervention offered to female inmates. Twenty-two women incarcerated at an Oregon correctional facility were again randomly assigned to TM instruction or a wait-list control group. At four-month follow-up those in the meditation group showed significant improvements relative to control on the Posttraumatic Stress Checklist Civilian Version Total Trauma scale.

These 2 projects are to be contextualized within the framework of previously published literature in this area. In prison inmate populations, previously published data suggest that TM instruction may effectively reduce recidivism. In one paper,[3] a sample of 259 male felon parolees of the California Department of Corrections who had voluntarily learned the TM technique while incarcerated were compared in a retrospective analysis with matched controls and found to have significantly less recidivism at 1 year, and again at 5-6 years. In addition, stress can adversely affect a range of health conditions, including both mental health and cardiovascular outcomes.[4] Meditation instruction has been shown in multiple previous studies to favorably modify physiologic indicators of stress and to improve clinical outcomes for patients with anxiety,[5] posttraumatic stress disorder,[6] substance use disorders,[7] and cardiovascular disease.[8]

## DESIGN

The design of these studies is relatively simple, although the enterprise itself is extraordinarily bold. Walking into a prison and systematically providing TM instruction to inmates, then measuring and publishing the results, requires a certain degree of chutzpah. Solid evidence base and long history of use notwithstanding, it may not always be so easy to convince the administrators of the prison, and the relevant government officials, of the feasibility and cultural appropriateness of mind-body instruction. Of course, one must also offer an intervention that has credibility and acceptability among the inmates themselves. A principle advantage of the TM technique in this regard is a time-tested, standardized intervention protocol. That is to say, in the final analysis the instructor need only stick with the script. Indeed, the sponsor of these projects, the David Lynch Foundation, has funded programs that have successfully provided TM instruction to a range of at-risk populations, including students in low-income, inner-city schools, veterans with PTSD, victims of domestic violence, and war refugees suffering from PTSD.[9]

## IN PRISON IN PERSON

From a clinical perspective, the two papers by Nidich exemplify an approach that can expand the scope and paradigm of our current preventive medicine efforts. In the case of breast cancer screening, for example, we generally require a patient to come

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to an imaging center in a hospital or clinic to receive a procedure (mammography). In contrast, in these projects, the evidence-based intervention is taken directly to the environment where it can be best accessed by the target population. A high-risk target population is reached, in the prison environment, in a reasonably efficient way. It is difficult to imagine any other practical mechanism for delivering such an intervention to this population. Some might argue that mind-body interventions can be offered online, but again many individuals who are indigent, elderly, incarcerated, or otherwise disadvantaged may be unable or unwilling to engage in an online format. In addition, a meditation technique such as TM is both sophisticated and subtle. For instruction to be effective, the technique must be taught in person, by a trained instructor. Waiting for these inmates to come to a clinic or meditation center after they have returned to the community would, in essence, mean that they would never receive the benefits of the program.

## SELF-CARE FOR LIFE

We immunize our patients to prevent influenza. To be effective, however, the immunization must be re-administered every year. In the case of mind-body instruction, the intervention provides a self-care skill that can last a lifetime. Once taught the technique, an individual can use the skill for the duration of his or her life, as a stress management tool, providing ongoing benefits across a range of domains. We prescribe statins to reduce the incidence of heart attack and stroke. However, many patients taking statins suffer from myalgias, or otherwise find these drugs difficult to tolerate. In contrast, the mind-body intervention generally has no adverse side effects. Indeed, in addition to helping the inmate cope with the stress of incarceration, there possibly may be a range of additional "side benefits," ranging from reduced recidivism to improved cardiovascular health.

## PREVENTION

Conceptually, there are also good reasons to consider that a mind-body intervention of this type can be cost effective. Reducing recidivism can, at a societal level, save the expense of additional incarceration. There is also an additional potential economic benefit in returning the inmate to a productive role in society. Within the domain of health care, there is evidence that meditation instruction may reduce health care costs.[10]

Finally, many of our most challenging patients suffer from chronic pain, substance abuse, and multiple simultaneous medical and social challenges. The primary care physician often feels frustrated and powerless when the situation is complex, the resources are limited, and the patient's core challenges seem beyond the scope of routine biomedical practice. Mind-body interventions can provide the patient with a simple self-help tool that can effectively reduce anxiety, help treat substance abuse, reduce inmate recidivism, and help address a range of medical conditions.

In the end, prevention efforts need not, and should not, be limited to procedures and drugs. Nor must such interventions be confined to hospitals and clinics. Data suggest that we can not only prevent disease, but can also promote health and well-being with evidence-based mind-body interventions that are safe, cost-effective, and beneficial across a range of medical, psychological, and social challenges. ❖

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**References**

1. Nidich S, Seng A, Compton B, O'Connor T, Salerno JW, Nidich R. Transcendental Meditation and reduced trauma symptoms in female inmates: A randomized controlled pilot study. Perm J 2017;21:16-008. DOI: https://doi.org/10.7812/TPP/16-008.
2. Nidich S, O'Connor T, Rutledge T, et al. Reduced trauma symptoms and perceived stress in male prison inmates through the Transcendental Meditation program: A randomized controlled trial. Perm J 2016 Fall;20(4):16-007. DOI: https://doi.org/10.7812/TPP/16-007.
3. Bleick CR, Abrams AI. The Transcendental Meditation program and criminal recidivism in California. Journal of Criminal Justice 1987;15(3):211-30. DOI: https://doi.org/10.1016/0047-2352(87)90045-6.
4. Elder CR, Gullion CM, Funk KL, DeBar LL, Lindberg NM, Stevens VJ. Impact of sleep, screen time, depression and stress on weight change in the intensive weight loss phase of the LIFE study. Int J Obes (Lond) 2012 Jan;36(1),86-92. DOI: https://doi.org/10.1038/ijo.2011.60.
5. Orme-Johnson DW, Barnes VA. Effects of the Transcendental Meditation technique on trait anxiety: A meta-analysis of randomized controlled trials. J Altern Complement Med 2014 May;20(5):330-41. DOI: https://doi.org/10.1089/acm.2013.0204.
6. Brooks JS, Scarano T. Transcendental Meditation in the treatment of post-Vietnam adjustment. J Couns Dev 1986 Nov;64(3):212-5. DOI: https://doi.org/10.1002/j.1556-6676.1985.tb01078.x.
7. Aron EN, Aron A. The patterns of reduction of drug and alcohol use among Transcendental Meditation participants. Bulletin of the Society of Psychologists in Addictive Behaviors 1983;2:28-33.
8. Schneider RH, Alexander CN, Staggers F, et al. A randomized controlled trial of stress reduction in African Americans treated for hypertension for over one year. Am J Hypertens 2005 Jan;18(1):88-98. DOI: https://doi.org/10.1016/j.amjhyper.2004.08.027.
9. Healing traumatic stress and raising performance in at-risk populations [Internet]. New York, NY: David Lynch Foundation; 2016 [cited 2016 Nov 6]. Available from: www.davidlynchfoundation.org.
10. Herron RE. Changes in physician costs among high-cost Transcendental Meditation practitioners compared with high-cost nonpractitioners over 5 years. Am J Health Promot 2011 Sep-Oct;26(1):56-60. DOI: https://doi.org/10.4278/ajhp.100729-ARB-258.

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## The Ideal

The aim of medicine is to prevent disease and prolong life;
the ideal of medicine is to eliminate the need of a physician.

— William J Mayo, MD, 1861-1939, American physician and surgeon, cofounder of the Mayo Clinic

## NARRATIVE MEDICINE

# On The Shoulders of Giants

**Tom Paluch, MD**

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"In 20 f…ing years of doing this," he growled, seemingly seething as he clutched the gown at my chest drawing me across the open abdomen between us, "no one has EVER asked me that question."

Dumbstruck, terrified, fearing my career had just seen its end by simply asking "How do you DO that?" he followed softly, "Lemme show you." I breathed. "Come over here." I stepped slowly around the foot of the table until I was nestled between him and the patient's thigh, thrust up in stirrups. He reached around me, pressing his chest to my back and cradling my smaller, now trembling hand in his. He slapped the scissors into my grasp, then smothered my hand in his. "It feels like this …"

His hand was at once strong and comforting. He bade me cut. I snipped at the tissue in the pelvis. "CUT!" he softly thundered. I snipped ever-so-slightly more. "Now, like this …" He guided my hand through a series of back and forth movements, the scissors gliding through the soft areolar tissue on either side of the rectum, whispering, "You see how easily it separates? Do you see how it feels?" The scissors were long, the long Metzenbaum scissors he and he alone used for this; the scissors I would use forever after. Once, twice, thrice we swept them back and forth until … lo and behold, the "stalks," bundles of blood vessels that fed the lowest segment of the alimentary tract were laid bare.

"Clip," he seemingly commanded, but only stated, and the device appeared in my hand. This at least, I knew how to do: halfway through my surgical residency, I'd learned a thing or two. So clip I did: twice on the side staying in, once on the side coming out. I needed no command to cut between the clips. He let loose my hand and simply watched as I did the same on the contralateral side. After the "cut" came a mumbled "come back around."

I watched as he cut out, "resected" in our sterile language, the segment of colon containing the cancer and sewed the two open ends of the colon back together. To this day I'll never forget the fascination with which I watched how men like him could take two circles and sew them together. Sometimes still, I wonder how I do it. The case wound to its close, but before he left me to close the incision he again grabbed my gown. "I want you to scrub with me from here on out. I'll tell Charlie." Charlie, being my chief resident, the person responsible for my case assignments. The one individual, until that moment, to whom I had to prove myself adequate enough to garner an assignment with Irwin, an assignment at once a privilege, for Irwin was the unquestioned master technician, and a curse, for Irwin NEVER let the resident do ANYTHING.

## I WANT YOU TO SCRUB WITH ME FROM HERE ON OUT

I was at once baffled and flattered. I had scrubbed on many of Irwin's cases and marveled at his mastery of technique, the fluidity with which he passed instruments through seemingly impenetrable layers of human tissue to either dissect or "dig out" and display the anatomy one needed to see to conduct the operation. And all the while his easy grace and gentle wit, politically incorrect by today's standards, but never unkind even then, brought a light and a mood to the room that made those assigned to other cases envious.

Irwin let me do EVERYTHING. Always his hand was there to guide, to assure that I could FEEL what it was that he did and wanted me to do. His blue eyes sparkled and glared over his half-glasses. His moods were not subtle, his passion not bridled, his criticism clear and never cruel, his support beyond question. I came to see then as I absolutely know now, he sought to give me all he knew, all that he could do. Was he a mentor? Was he a father? Is there a difference??

## THE MAN WHO TAUGHT ME HOW TO OPERATE

It was only years later that I remembered when I had first met Irwin—it was he who reminded me of our first meeting. While a medical student, I was visiting surgery programs in which I was interested. I was assigned an intern, who in turn was assigned to "hold hooks," ie, watch while holding retractors, for one of his less-complicated cases. Irwin was uncharacteristically (or perhaps presciently) interested in this interloper and badgered me with questions, barbs, and jokes, challenging me to share with him a joke that he didn't know. From somewhere I dug up some lame pun that to this day I cannot remember. He was stumped, and quite surprised by that fact, and "harumphed" at its punchline. A decade later he shared with me his consternation that I had confounded him, and how it created in him an interest, an interest that grew into what we eventually shared.

A mentor is defined in Webster's as a trusted counselor or guide.[1] Irwin was, and ever will be, my dearest and most influential mentor. He is the man who taught me how to operate, what it meant to be a surgeon, and, most importantly, how it *felt* to be a surgeon; for without the feeling, a surgeon *is* a mere technician: a manipulator of human flesh. With feeling a surgeon can find transcendence, a special, powerful intimacy with another human being in this most unique of human relations.

## A MAN WHO PLAYED MOZART ON THE PIANO

It's not that I haven't had other mentors. In Medical School I met Jack, a surgeon of diminutive stature but towering talent, a man who played Mozart on the piano and similar symphonies in the operating room. He was a man who, on the first day of the rotation, stated without equivocation that we would learn about surgery, but *he* was

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here to (I swear this is verbatim), "… send you out in the quest of bullsh… ," by which he meant to have us follow evidence, not opinion, a journey, a quest that continues until today. It was Jack's example, guidance, and influence that led to my interest, and ultimately my career, in surgery. As a curious closure to the early circle of my career, it was Jack whom I sat before for my Board examination.

Later in my career, after I had finished a residency and became an attending surgeon, essentially a young buck with more attitude than aptitude, I was blessed with Emilio, an elegant man of Mexican aristocratic heritage, with technical talents I envied and a carriage and compassion I've striven to emulate. Emilio was my last mentor: the final brick in the edifice of this surgeon's career. He was the finish, the polish; he gave me the last few pieces I didn't even know I was missing. Little did I know how much he cherished the role. It was only at his recent funeral that I learned of this from his son, who in the receiving line at the funeral Mass said to me, "I want you to know how much he loved working with you." I was speechless; smitten that in this moment of grief, Emilio's son felt the need to acknowledge our relationship.

**I came to see then as I absolutely know now, he sought to give me all he knew, all that he could do.**

Such is the mentor-mentee relationship when at its best. It is symbiotic, giving as much as receiving in both directions. Few relationships rival it; only a good marriage surpasses it. It offers growth and support while providing an example of the end-product. Rarely are we as physicians afforded the opportunity to find it. I have been so very blessed.

In the two remaining years of my residency, I spent but four months with Irwin. But in those months he gave me all that he had. He was *that* master technician, a surgical impresario. One needn't know the details of the techniques of surgery to marvel at the grace of his movement, the elegance of his carriage, the economy of motion, the tenderness with which he cleaved living human flesh and brought it back together again. One needn't be a composer to listen in awe of Mozart. One needn't paint to appreciate DaVinci. *That* is what I thought, felt, saw, when I watched Irwin operate. *That* and all of the rest of him is what he gave so freely to me. All because I told him a joke he didn't know, and asked him humbly, almost awestruck, "How do you DO that?"

Although, until his great and giving heart finally failed, we would meet and correspond as my career progressed, I will NEVER forget the moment that marked the end of my residency, my "graduation" as it were. We sat down for lunch and chatted. I was off to fulfill an obligation to the Navy, all brash and confident, yet painlessly unaware of how much more I needed to learn. After that, the future was unknown. I harbored quiet hopes of coming back and perhaps working with him again (what son doesn't secretly hope that he can be his father's best friend, his greatest hope, forever?). That day, I didn't want to leave his company, his comfort. The time came to leave. We both stood up. Once again, he grabbed me by the clothes on my chest and drew me across the table. "Don't f… up," he said. I knew *exactly* what he meant: my success would be his legacy. He had given me all he could and I *knew* he hoped I would pass it on. I pray I have. ❖

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**Reference**

1. Morse JM, executive editor. Merriam-Webster's collegiate dictionary, 10th ed. Springfield, MA: Merriam-Webster, Inc; 2000.

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## On Mentoring

Mentoring is a widespread but largely unexamined phenomenon in biomedicine. It is a multifaceted and complex relationship between senior and junior professionals which, when successful, serves to fortify and extend within the younger person characteristics and qualities integral to professional development.

— Barondess JA. On mentoring. Journal of the Royal Society of Medicine 1997 Jun;90(6):347-9.

# Practicing Healing—Cleaning the Back of an Elderly Tibetan Woman

**James Lake, MD**

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Among dozens of patients I evaluated and treated when volunteering at a Tibetan hospital in August 2015, a remarkable encounter with an elderly woman shall always remain a vivid memory. In some sense this unnamed woman has become an icon of Tibetan stoicism in the face of suffering. On that particular morning our team of 8 "foreign doctors" was busy caring for a steady flow of patients who seemed to have materialized from unknown hamlets and nomadic encampments in the high plains surrounding the town of Malo. At one point I was asked to do a procedure called "dry cupping"[a] followed by "hot needles."[b] My patient was a woman who complained of chronic back and hip pain. She was bent over as she waited by the clinic door to be seen so it was difficult to estimate her height. Had she been able to stand upright she would have probably measured less than 5 feet in height. I think she was in her 70s though it was impossible to guess her actual age; 50, even 40 years of daily physical toil in the extreme conditions of the high Tibetan plateau may have accelerated aging, engraving deep, thin lines at the edges of her eyes and on her cheeks and bowing her spine into a sinuous arc.

## THE TINY WOMAN SITTING ON A WOODEN STOOL

Because an interpreter was not available, I did not have a detailed history. I approached the tiny woman sitting on a wooden stool crouching over elbows that brushed her knees. We communicated using gestures and a few Tibetan phrases. "O Koga?" (as I touched points on her back and neck). "Is this painful?" After these preliminaries I had the impression of diffuse back pain. I proceeded to palpate her spine through her thin cotton blouse starting at her neck and continuing down to her lumbosacral vertebrae. When I reached her lower spine she bent over and—without speaking—pulled her blouse to the rims of her shoulder blades exposing her back. Standing in a blue protective paper gown spotted with blood stains from procedures on other patients over the past week, I wasn't sure what I was seeing. Her skin was mottled in brown and orange from the back of her neck to the waist sash that held her skirt in place and had the tarnished appearance of weathered copper. I recall another "foreign doctor" gently touching my arm motioning me to a box of latex gloves on a dirty window sill "first wash the skin before using needles." In that moment I realized I had been staring transfixed at the woman's back not knowing how to proceed. The risk of a Staph infection caused by inserting acupuncture needles into dirty skin had not occurred to me. I snapped on blue latex gloves and started to identify the anatomical landmarks that would guide me in placing dry cups and hot needles indicated for her chronic pain condition.

## I WIPED HER SKIN WITH COTTON BALLS

As if in a trance, I wiped her skin with cotton balls soaked in isopropyl alcohol. After a few minutes I realized that gentle pressure was ineffective. I rubbed more firmly and the cotton ball absorbed what I can only assume was the accumulated grime of months. I do not remember how many cotton balls I eventually used or how long this process lasted. At one point I found myself staring at blue encapsulated fingers grasping discolored cotton and realized they were *my* hands. I had lost track of time—I had become absorbed in a ritual act of cleaning the back of an unknown woman and I had lost my "self." In the moments that followed I was aware of my psychiatrist's mind reaching for explanations—what was taking place inside me; what transpired inside the soul of this woman and in the sacred silence we shared? Did the woman regard me as a "foreign doctor" who had come to this remote place to learn about the nature of suffering? Did she feel shame at the knowledge that her poverty had been revealed to another human being? Or—and I think this is most likely—after years of meditation was this woman capable of "letting go of attachment to self" and "sitting with suffering" in a state of equanimity?

## SHE VOICELESSLY REPEATED A MANTRA

The skin of the woman's back gradually emerged as white, shiny, and pliable under my gloved fingers now covered with a sticky coat of brownish-yellow grime. Realizing that I needed to preserve my gloves for future patients I took a few steps to a small metal sink, scrubbed the plastic gloves with soapy water then rinsed them with isopropyl before patting them dry with coarse brown paper available for this purpose. I returned to the woman, sat on a wooden stool at her side and began the process of systematically applying six small brass cups to her upper, middle and last, her lower back. This proved challenging as the woman had severe scoliosis and the indentations of her ribs were palpable. After several minutes I managed to apply the first copper cup to a patch of skin just below her left shoulder blade. I resumed palpating her back seeking a smooth area of skin over the tender points she had identified earlier and I was eventually able to secure all six cups. Throughout this time the woman did not move from her crouched posture. It was then that I noticed, concealed in a fold in her skirt her right hand delicately touching a mala[c] as she voicelessly repeated a mantra. I observed her lips moving but there was no sound and I realized that performing this ritual had permitted the woman to remain immobile and alert during a lengthy procedure that could have easily caused a great deal of stress.

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I continued on to the next procedure and started to insert acupuncture needles in her lower back along a line from the iliac crest through the upper lumbar area indicated for treatment of the lower back pain she had complained of. After twirling the needles for the best energetic effect I applied a glowing moxa stick to the needles 7 times in slow repetition, each time using my right thumb to "press" the heat into a point close to where each needle entered the skin. The woman remained absolutely still. Trying to observe without her awareness, I briefly stood back from her, tested the seals of all 6 cups on her back, and saw her gently touching her mala while silently voicing a mantra. From the faint movement of her lips my impression was that she was repeating "om mana padme hum" though she did not give voice to the words. After 20 minutes it was time to break the suction of the brass cups and soon after remove and discard the needles. As I went through these steps the woman began to rock gently back and forth—absorbed in reciting a mantra to sustain her focus—perhaps distract herself from anxiety she was experiencing in response to being treated by an unknown "foreign doctor."

**I had lost track of time—I had become absorbed in a ritual act of cleaning the back of an unknown woman and I had lost my "self."**

## SHE NODDED HER HEAD AND SMILED

I stepped to her side and told the woman the procedure was finished and had gone well, that she could expect to feel less pain now. All the steps beginning with the ritual "cleansing" of her back, continuing with the placement of hot cups and then "hot needles" may have taken an hour, perhaps a bit more. I was aware of a feeling of deep stillness, and there was a sense of reverence as though I had just shared in silent prayer. The woman pulled her blouse down over her back, wrapped her traditional Tibetan gown around her waist and slowly rose from the wooden bench. Facing me she looked into my eyes for a few very long seconds, nodded her head and smiled. Ever so slowly and soundlessly she then walked down the clinic steps, crossed the courtyard and disappeared from sight among people and sheep gathered on a deeply pitted road strewn with trash adjacent to the clinic. I imagined that in the hours that followed the woman gradually re-entered the society of nomads in the wide open spaces of the high plains surrounding Malo—perhaps starting out on a bus, then finding a lift on a motorized cart or a horse, and in the final kilometers journeying back to her yurt by foot. As I tried to visualize her journey home I recalled her silence and the profound simplicity of her practice—and I realized I was smiling.

## A PLACE OF PROFOUND STILLNESS

Reflecting on this encounter while walking back from the hospital later that day it occurred to me that I had been caught up in a meditative reverie the entire time. As I was "treating" this woman using the ancient techniques of Tibetan medicine, her spirit was "entering" me and imbuing me with peace. The spaciousness of the silence created by prayer had "brought me" to a place of profound stillness in the absence of language, gestures and, I assume—though cannot know—in the absence of any conscious intention. Through prayer a nomad woman had created a sacred "space" between us in which I experienced the peace of *her* mind. As I reflected on the deeper meanings and teaching, it became clear that the act of reciting a mantra when there is fear or other forms of suffering probably sustain this woman—and millions of others who are invisible and unknown to Western eyes—through hardships I cannot imagine. As the sun faded in a hazy late August sky I felt deeply humbled by the realization that I had participated in a sacred space with a patient—and I felt *awake*. I found myself contemplating how many "exchanges" of spirit I had missed during the weeks in Tibet, how many encounters between one sentient being and another might have taken place had I paid closer attention and taken more time to be present with an open heart while doing the hard work of healing. Months later, as I remember and reflect on these impressions I know that the full "teaching" is not yet clear to me. I know I will return to my memories throughout my life to seek deeper meanings in the journey ahead. Finally, as a physician I am bound by an oath I took decades ago to bring the insights and humility learned from a Tibetan nomad who became my unexpected teacher into my practice. ❖

[a] Dry cupping: A technique used in both Chinese medicine and Tibetan medicine in which a vacuum is used to apply cups made of brass or glass to the skin with the goal of increasing local blood flow and restoring healthy energetic balance to the affected area. Cupping is used to treat a broad range of medical and psychosomatic conditions and is often used in combination with acupuncture and herbal medications.

[b] Hot needles: A technique used in Chinese and Tibetan acupuncture in which acupuncture needles are warmed by moxa applied to the needle itself or at its point of insertion to remove excess "wind" or other humoral energy and restore healthy energetic balance.

[c] Mala: A string of beads used by Buddhists and Hindus for keeping count while reciting, chanting, or mentally repeating a mantra or the name of a deity.

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## The Quiet Art

It was his part to learn the powers of medicine and the practice of healing,
and careless of time, to exercise the quiet art.

— Publius Vergillus Maro (Virgil), 70 BC-19 BC, Roman poet of the Augustan era

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## Section A.

**Article 1. (page 10) Morbidity in Pregnant Women Associated with Unverified Penicillin Allergies, Antibiotic Use, and Group B Streptococcus Infections**

All of the following are true about unverified penicillin allergy except:

☐ a. it is associated with higher hospital utilization
☐ b. it is associated with additional morbidity
☐ c. in pregnant women with group B streptococcus infections, testing is risky and may lead to additional morbidity
☐ d. in pregnant women with group B streptococcus infections, penicillin testing may reduce need for exposure to other antibiotics

This study found that an unverified history of penicillin allergy in group B streptococcus-positive women was associated with:

☐ a. higher risk of anaphylaxis in those cases where penicillin was utilized anyway
☐ b. higher rate of cesarean section
☐ c. fewer adverse drug reactions when using alternate antibiotics
☐ d. higher incidence of Clostridium difficile infection

**Article 2. (page 56) End-Stage Renal Disease Outcomes among the Kaiser Permanente Southern California Creatinine Safety Program (Creatinine SureNet): Opportunities to Reflect and Improve**

Which of the following tests actually measure glomerular filtration rate/kidney function?

☐ a. Modification of Diet in Renal Disease equation
☐ b. Chronic Kidney Disease Epidemiology Collaboration equation
☐ c. Cockcroft Gault equation
☐ d. Iothalamate scan

Which statement is inaccurate? Proteinuria:

☐ a. is one of the best prognosticators for poor renal outcomes including end-stage renal disease
☐ b. is a marker for glomerular damage and can be used to define and identify someone as having chronic renal disease
☐ c. should not be used to guide management of chronic renal disease
☐ d. was tested for in less than 50% of the Kaiser Permanente Southern California Creatinine SureNet population with chronic kidney disease which is also consistent with worldwide testing patterns

**Article 3. (page 73) Implementation and Evaluation of the Safety Net Specialty Care Program in the Denver Metropolitan Area**

Which of the following statements about the Safety Net Specialty Care Program is false?

☐ a. in a review of electronic exchanges between safety-net clinicians and Kaiser Permanente specialists, conducted in the final 2 months of 2014, the primary reasons for initiating an electronic consult were: treatment recommendations, confirmation of diagnosis, and advice about further evaluation
☐ b. the specialty department with the greatest number of electronic consultations in the first 20 months of the program was gastroenterology
☐ c. a menu of face-to-face services addresses selected conditions that can be resolved within the Kaiser Permanente Colorado system and focuses on treatments that can improve a patient's health within approximately 90 days
☐ d. during the first 20 months of the program, 25% of primary care clinicians from the 3 participating safety-net organizations initiated an electronic consultation with a Kaiser Permanente specialist

Which departments saw the greatest number of patients for face-to-face visits during the first 20 months of the Safety Net Specialty Care Program?

☐ a. gastroenterology, cardiology, and ophthalmology
☐ b. neurology and rheumatology
☐ c. endocrinology, pulmonology, and dermatology
☐ d. primary care and dermatology

**Article 4. (page 82) Reducing Unnecessary Postoperative Complete Blood Count Testing in the Pediatric Intensive Care Unit**

Blood transfusions within the pediatric intensive care unit are associated with all of the following except:

☐ a. greater number of days of mechanical ventilation
☐ b. long-term developmental delay
☐ c. increased mortality
☐ d. longer length of stay in the pediatric intensive care unit

The authors use which of the following to decrease unnecessary laboratory data:

☐ a. education based upon historical information
☐ b. restrictions on indications for testing
☐ c. pathway development
☐ d. display of cost information

## Section B.

**Referring to the CME articles, how likely is it that you will implement this learning to improve your practice within the next 3 months?**

**Key**
5 = highly likely
4 = likely
3 = unsure
2 = unlikely
1 = highly unlikely
0 = I already did this

| | **Objective 1**<br>Integrate learned knowledge and increase competence/ confidence to support improvement and change in specific practices, behaviors, and performance. | **Objective 2**<br>Lead in further developing "Patient-Centered Care" activities by acquiring new skills and methods to overcome barriers, improve physician/patient relationships, better identify diagnosis and treatment of clinical conditions, as well as, efficiently stratify health needs of varying patient populations. | **Objective 3**<br>Implement changes and apply updates in services and practice/policy guidelines, incorporate systems and quality improvements, and effectively utilize evidence-based medicine to produce better patient outcomes. |
|---|---|---|---|
| **Article 1** | 5 4 3 2 1 0 | 5 4 3 2 1 0 | 5 4 3 2 1 0 |
| **Article 2** | 5 4 3 2 1 0 | 5 4 3 2 1 0 | 5 4 3 2 1 0 |
| **Article 3** | 5 4 3 2 1 0 | 5 4 3 2 1 0 | 5 4 3 2 1 0 |
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## Section C.

**What other changes, if any, do you plan to make in your practice as a result of reading these articles?**

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**Section D.** (Please print)

Name ______________________________
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