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MBI Ready to Replace HICN: Is Your Organization Prepared?
Abbe Sodikoff and Kim Browning

Summary

The Medicare system is set to undergo a drastic change. Starting in the spring of 2018, all Medicare beneficiaries will be transitioning to a new identification system. As part of the Medicare Access and Children’s Health Insurance Program (CHIP) Reauthorization Act of 2015 (MACRA), this transition is designed to protect millions of Medicare beneficiaries. Through MACRA, beneficiaries will now be assigned a new Medicare Beneficiary Identifier (MBI) that will replace the problematic Social Security number (SSN)-based HICN with a more unique and secure identifier. This new number will help to prevent medical identity theft, better protect private healthcare and financial information, and safeguard federal healthcare benefits and service payments.

Key Points

• Expected to impact claims, reporting and payments for millions of individuals, this conversion will require significant changes to current healthcare systems.

THE DISCONTINUANCE OF HICN

For years, the Health Insurance Claim Number (HICN) has functioned as the backbone of the Medicare payer system. This Social Security number-based system has long served to identify Medicare beneficiaries for claims, reporting and payments. Unfortunately, the reliance on social security numbers has opened the program up to a number of potential risks including medical identity theft and fraud.

While certainly an important step forward in combatting potential program fraud and identity theft, the movement to MBIs will significantly impact healthcare providers. Currently, there are more than 150 million Medicare beneficiaries using the HICN system. This includes current beneficiaries, deceased beneficiaries and archived beneficiaries. Thanks to MACRA, these individuals will need to be transitioned to the new MBI system by January 2020.

Starting in April of 2018, new Medicare cards with MBI numbers will be mailed out to all current Medicare users. Any new enrollees after this point will also be automatically set up with an MBI. April 2018 will also mark the beginning of the transitional grace period where both HICNs and MBIs may be used within the Medicare system. Currently, the full transition is scheduled to be completed by January 2020. The Center for Medicare and Medicaid Services (CMS) will be responsible for monitoring the use of HICN and MBI during the transitional period to determine the progress of implementation.

Transitional Concerns and Implementation Strategies

The long transitional period and monumental scale of the HICN conversion project presents a number of challenges to the healthcare field. From implementation coordination and claims management to reporting and data analysis, health organizations must develop a strategic plan in order to successfully manage the change.

There are currently 60 million active Medicare beneficiaries and 90 million deceased or archived beneficiaries. Under MACRA, each of these 150 million records will need to be converted from an HICN to an MBI. Further complicating the matters, payers and providers will not be sent the updated identifier—in order to further protect against potential fraud. Instead, they will need to rely on the individual beneficiaries to bring in their updated cards. Without access to the cards, filing claims may be increasingly difficult as organizations juggle both MBIs and HICNs. There is concern that this may result in denials or delays in payment during the transitional period.

In addition, while Medicare beneficiaries are expected to receive their updated MBI cards between April 2018 and December 2019, the CMS has yet to provide clear directions on how the new cards will be rolled out. As a result, healthcare payers must be prepared to accept both MBIs and HICNs for processing and reporting throughout the entire rolling implementation period. CMS, as well, will accept both MBIs and HICNs for both incoming and outgoing data report. However, it is critical that systems are put
into place to ensure data congruence. Organizations should develop a “crosswalk” to capture data for both numbers while avoiding duplicates. New software and infrastructures may be necessary to accept dual processing of both HICNs and MBIs during the transitional period. Organizations utilizing data warehousing should ensure they are prepared to handle the movement from HICNs to MBIs in order to avoid incorrect identification and duplicate data. Risk adjustment analytics should be utilized to identify the specific interventions that are most efficient in closing any potential data gaps.

The discontinuance of HICNs is also anticipated to impact the claims process. Starting in 2020, some claims processors will be unable to process any claims that do not have an updated MBI. As a result, claims departments need to develop a proactive strategy focused on fully transitioning all claims to the new identifiers. Controls should be set in advance to ensure there is no “hiccup” in the data flow and that accuracy is assured. In addition, organizations must be prepared to address a potential increased volume of transactions.

The MBI transitional grace period is expected to have a significant impact on company operations. The extensive movement from HICNs to MBIs will drive an increase in customer service calls and result in an increasingly busy enrollment season. In order to be proactive and support a positive customer experience, organizations need to develop a comprehensive communication strategy that includes consumers and providers. It is critical that both parties are aware of the implementation timeline and potential changes. Hotlines and support resources may be necessary to answer questions and assist beneficiaries.

Companies may also want to assess vendor readiness to ensure they are prepared to address the transition. Is there a plan in place to accommodate MBIs? How will plan operations be affected? It is important that systems and processes are proactively updated to ensure seamless coordination throughout the rolling implementation.

Organizations looking to stay ahead should focus on bringing in additional staff to assist with this increased workload. Interim support solutions are great options for companies in need of an immediate response. Due to the workload influx that is all too common within the health field, specialized and tenured professionals are available to assist on a contract basis. The key in finding impactful interim hires is to partner with a talent provider who staffs a broad landscape of contract professionals—from entry level all the way to executives and subject matter experts. Partnering with a boutique firm that has access to a database of health professionals will provide organizations with highly skilled interim professionals ready to jump right in and get started.

In addition, health organizations should develop a communication strategy with their own staffs to promote internal corporate awareness. The transition will require a number of changes including updating charts to reflect the MBI, archiving HICNs and adapting electronic medical records. In addition, the rolling implementation will require coordination across multiple years and affect business segments and processes that are currently data dependent on the HICN. Communicating a clear plan of action and ensuring all necessary individuals are well informed will help ensure a smooth transition.

The key to success during HICN discontinuance is preparation. In order to weather the transition to MBIs, organizations need to prepare themselves. By developing forward-thinking strategies and bringing on additional staff to assist with an increased workload, healthcare companies will be able to navigate these critical changes to the Medicare payer system.


References:
Population Health: 
Moving from Strategy to Implementation 
Part 1: Background and Population Health Models 
Michelle R. Hawkins, DNP, MBA, MSN, RN, CCM, 
Felizitas Devine, RN, MS, MBA, CCM, CMCN, and John Socolofsky 

Summary 
As health systems move from fee-for-service to value-based care, increased focus is being placed on population health as a means to improve care outcomes and reduce costs. While many health systems have a long-range strategy to improve or implement population health programs, they may lack the structure to act on the strategy. Part 1 of this paper presents definitions and models of population health programs, to help health systems make progress toward implementation. Three models are presented, with focus placed on the Johns Hopkins HealthCare model. Part 2 will focus on practical tactics for managing a population. 

Key Points 
- Social determinants of health (SDH) such as geography and socio-economic status become predictors of health disparities and have a significant impact on health outcomes. 
- Many organizations develop a strategy or vision before beginning or improving a population health management program. 
- Using a framework such as the Johns Hopkins model or the PHA model can help ground a population health management program by providing a structure that has worked for others. 

TODAY’S HEALTH CARE ARENA IS RAPIDLY evolving. This evolution is driven by several factors, including: governmental and regulatory changes, rapidly increasing health care costs, poor health care outcomes, a surge in number of people with chronic conditions that are often preventable, tremendous growth in the aging population with multiple co-morbidities, lack of access to care, and disparities in care. Health systems continue to struggle with the patients that have complex, chronic and costly conditions. Historically, health care has focused on the care of the sick, with little attention paid to wellness and lifestyle management. Over the past few decades there has been a shift from disease management to care management. More recently, prompted by the movement from fee for service to value-based care, there is another shift taking place – this one from a focus on care of the individual toward a greater consideration of population health, which has more of a laser focus on the precipitating factors that impact health outcomes. 

Moving from Care Management to Population Health 
Although the movement toward population health has intensified in recent years, the concept goes back several decades. Population health management consists of targeted interventions for a group of similar individuals through the continuum of care. Population health is one tenet of the Institute for Healthcare Improvement (IHI) Triple Aim in healthcare: Applying integrated approaches to simultaneously improve care, improve population health, and reduce costs per capita. A focus on population health improves health outcomes for a large collection of people, and should produce long-term savings in the healthcare system. Health systems are discovering that population health can lead to improved clinical outcomes, better management of impactable chronic diseases, decreased utilization of care, and improved quality of life. 

Population Health Defined 
There are several good definitions of population health. An early and still oft-cited definition is “the health outcomes of a group of individuals, including the distribution of such outcomes within the group”. Some definitions add the concept of health influencers, such as social determinants of health. The Population Health Alliance adds the continuum of care to the definition:
The shift from care management to population health changes focus for a number of healthcare considerations:

<table>
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<th>Care Management (Current State)</th>
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“A population health management program strives to address health needs at all points along the continuum of health and well-being through participation of, engagement with and targeted interventions for the population.”

From a population health perspective, social determinants of health (SDH) are important considerations. Determinants such as geography and socio-economic status become predictors of health disparities and have a significant impact on health outcomes. For example, in Baltimore, the neighborhood where a patient lives can impact their life expectancy by as much as 20 years. Most of the mortality difference is due to treatable conditions. Understanding and measuring SDH can significantly impact the success of population health management.

Available Population Health Models

Many organizations develop a strategy or vision before beginning or improving a population health management program. A strategy typically describes the goals the organization desires to meet within a given timeframe, the governance structure around the transformation, and perhaps a cost/benefit analysis or business case. Strategies may include some level of implementation details, such as a roadmap or a high-level implementation plan. Models or frameworks can help during strategy creation in order to improve comprehensiveness and to help set direction. Before embarking on a transformation related to population health, an organization should consider adopting or creating a model to guide the approach. There are several population health models in use. Most of them share the following key elements:

- Assessment and identification of population
- Prioritization of health needs based on population groups
- Risk stratification of population
- Understanding of health determinants
- Development of targeted intervention strategies
- Coordination of care among stakeholders
- Use of technology and analytics
- Maximization of health outcomes for a group

The CMS Basic Model

Population Health models range from very simple to comprehensive. CMS offers a basic conceptual model of population health showing population health at the intersection of clinical care, community and social services, and public health (Figure 1). While this helps communicate the definition of population health management, it does little to help create or implement a strategic direction.

The Population Health Alliance Model

The Population Health Alliance (PHA) developed a conceptual framework for population health that includes more detail, and brings into the picture population monitoring and identification, health assessment, and risk stratification (Figure 2). The PHA framework also focuses on the care continuum moving from low to high risk populations and tailoring interventions according to risk. This is a patient centric model that encompasses organizational interventions (culture and environment), targeted interventions along with community resources and operational measures to impact a range of outcomes.

The Johns Hopkins Model

Johns Hopkins HealthCare developed a more detailed model to guide its own population health management programs (Figure 3). This model aligns with Johns Hopkins HealthCare’s definition of Population Health Management, which is “the process of addressing population health needs and controlling problems at the population level; strategies to address population health needs.” For the remainder of this paper, we will focus on this model.

Walking through the Johns Hopkins population health model provides a step-by-step approach to planning and implementing a
population health strategy.

1. **Identify population for intervention**

   Identifying the correct population is the basis for population health. A health system must use all available data to understand morbidity, health priorities, health risk, and targets for intervention. Effective population health management increasingly relies on data and analytics. Specific data is available from clinical systems and payer claims systems. Many health systems use predictive modeling tools to identify at-risk populations.

   Factors that contribute to health outcomes impact the understanding of morbidity and risk in a population. Typical considerations include social determinants of health, environmental, social, genetic, and biological factors. These factors play important roles in influencing a population’s needs for physical healthcare, and also social health, mental health, and lifestyle or behavioral health.

   Analytics can be developed internally or purchased in a packaged solution or as a service. Tools and algorithms can be used to stratify populations to understand morbidity and social determinants, develop risk models, and help identify populations and care options that are most likely to yield favorable results from a clinical and financial perspective.

2. **Develop and implement intervention plan**

   Based on the population analytics from the prior step, a health system should design appropriate interventions for each population segment. The intervention plans should take into account primary and secondary prevention, disease management, case management, population health, and the required supporting infrastructure. Implementation of intervention plans should extend across the continuum of care, and include health systems, community partners, social services, and public health organizations. Components supporting the care of the individual include:

   • **Transitional Care:** Transitioning between settings is a critical component of population health. Transitions between levels of care often lead to lost or mixed messages that can result in poor outcomes. It is imperative that there be coordination of care between settings and providers of care.

   • **Community Mobilization for Health Partnerships:** Health systems are recognizing that they must partner with community organizations, as patients frequently use the services of these organizations. Partnering with these organizations allows health systems to reach out to patients in their own environments.

   • **Pharmacist-led Medication Management Program:** Medication reconciliation is essential for appropriate health outcomes. Pharmacists are playing a more active role in...
Figure 3

Johns Hopkins HealthCare Population Health Management

Population Assessment
1. Interpret and Prioritize Health Needs
2. Risk Stratification and Segmentation Population According to Needs

DEVELOPMENT OF PRIMARY AND SECONDARY PREVENTION, DISEASE MANAGEMENT INTERVENTIONS AND SUPPORTING INFRASTRUCTURE TO MEET THE NEEDS OF EACH POPULATION SEGMENT

IMPLEMENTATION OF CUSTOMIZED HEALTH INTERVENTIONS

Health Systems

- Pharmacist Led Medication Management
- Community Health
- Primary Care
- Transitional Care
- Health Coaching and Self-Care Management
- Health and Social System Navigation Services
- Quality Management
- Clinical Care Management
- Outreach and Engagement Services
- Health Education
- Medical Management

Social Services

PUBLIC HEALTH

COMMUNITY PARTNERS

PROVIDER, PATIENT, AND COMMUNITY ENGAGEMENT
FINANCIAL ACCOUNTABILITY AND CONTRACTING

HEALTH OUTCOMES

Reporting for management, monitoring, and continuous quality improvement

<table>
<thead>
<tr>
<th>Analytics</th>
<th>IT Infrastructure and Support</th>
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ensure appropriate use of medications and are an integral part of the care team.

- **Clinical Case Management:** Case managers are located in various settings across the continuum of care, developing care plans and managing the longitudinal episode of care. They work closely with patients to establish care plans and set mutually agreed-upon goals. They assist with navigating the complex health system, providing coordination of care, and locating needed services.

- **Health Coaching and Self-care Management:** Health coaching offers opportunities to work individually with patients to achieve established goals and promote patient engagement, enabling the patient to engage in their own healthcare.

- **Health and Social System Navigation Services:** Many organizations exist outside of the health care arena that can assist with needed services. Navigation services help the patient to understand the options available to them and how to utilize them.

- **Health Education:** Education helps improve the patient’s understanding of their health conditions and impacts of their actions, both in a preventive and reactive manner. Patients are provided health education materials via mail or electronically. It is imperative to assess level of health literacy and assess if health education material is received and understood.

- **Outreach and Engagement Services:** Maintaining regular communication is essential to engage patients and determine if goals are being met, if barriers to care exist, and to gage the success of care management. Outreach and engagement services keep the patient involved by intentional communication, in person, over the phone, or using websites and portals.

3. **Monitor program execution**

Health systems should engage all stakeholders, monitor program implementation, and seek to continuously improve programs to maximize health outcomes. Monitoring of program clinical and financial performance depends on data and analytics, often the same elements as involved in program design in step 1. Metrics should be continuously or at least periodically monitored and compared against targets to determine if a program is meeting its goals. A management dashboard is an excellent tool to pull together the various metrics for leadership to monitor at a glance. If a program’s performance deviates from the plan, a root cause analysis can help identify the reason. If the deviation is correctable, a corrective action plan should be developed and executed. If the deviation is not correctable, stakeholders should be engaged to determine if the program should be continued with different targets, or else discontinued. Learnings from the monitoring and root cause analysis should be folded back into this and other programs, to continuously improve an organization’s approach to population health management.

Using a framework such as the Johns Hopkins model or the PHA model can help ground a population health management program by providing a structure that has worked for others. Its use can accelerate an organization’s entry into population health management and help provide confidence that important elements have not been overlooked. However, there is more to designing and implementing an effective population health management program. In a future article we will cover practical tactics for managing a population, expanding on the Johns Hopkins model in more detail.

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References:

Doing More Harm Than Good? Epidemic of Screening Burdens Nation’s Older Patients

Liz Szabo

Summary

Although screenings can extend and improve lives for healthy, younger adults, they tend to inflict more harm than good in people who are old and frail. A variety of medical specialties — from the American College of Surgeons to the Society of General Internal Medicine — have advised doctors against screening patients with limited time left. This article explains the harms of such screening, or ‘overdiagnosis’.

Key Points

- Nearly 1 in 5 women with severe cognitive impairment, including older patients, are still getting regular mammograms, according to the American Journal of Public Health — even though they’re not recommended for people with a limited life expectancy.
- 55 percent of older men with a high risk of death over the next decade still get PSA tests for prostate cancer, according to a 2014 study in JAMA Internal Medicine.
- Researchers estimate that up to two-thirds of prostate cancers are overdiagnosed, along with one-third of breast tumors.
- Although screenings can extend and improve lives for healthy, younger adults, they tend to inflict more harm than good in people who are old and frail.

ELENA ALTEMUS IS 89 AND HAS DEMENTIA. SHE often forgets her children’s names, and sometimes can’t recall whether she lives in Maryland or Italy.

Yet Elena, who entered a nursing home in November, was screened for breast cancer as recently as this summer. “If the screening is not too invasive, why not?” asked her daughter, Dorothy Altemus. “I want her to have the best quality of life possible.”

But a growing chorus of geriatricians, cancer specialists and health system analysts are coming forth with a host of reasons: Such testing in the nation’s oldest patients is highly unlikely to detect lethal disease, hugely expensive and more likely to harm than help since any follow-up testing and treatment is often invasive.

And yet such screening — some have labeled it “overdiagnosis” — is epidemic in the United States, the result of medical culture, aggressive awareness campaigns and financial incentives to doctors.

By looking for cancers in people who are unlikely to benefit, “we find something that wasn’t going to hurt the patient, and then we hurt the patient,” said Dr. Sei Lee, an associate professor of geriatrics at the University of California-San Francisco.

Nearly 1 in 5 women with severe cognitive impairment — including older patients like Elena Altemus — are still getting regular mammograms, according to the American Journal of Public Health — even though they’re not recommended for people with a limited life expectancy. And 55 percent of older men with a high risk of death over the next decade still get PSA tests for prostate cancer, according to a 2014 study in JAMA Internal Medicine.

Among people in their 70s and 80s, cancer screenings often detect slow-growing tumors that are unlikely to cause problems in patients’ lifetimes. These patients often die of something else — from dementia to heart disease or pneumonia — long before their cancers would ever have become a threat, said Dr. Deborah Korenstein, chief of general internal medicine at New York’s Memorial Sloan Kettering Cancer Center. Prostate cancers, in particular, are often harmless.

Patients with dementia, for example, rarely live longer than a few years.

“It generally takes about 10 years to see benefit from cancer screening, at least in terms of a mortality benefit,” Korenstein said.

Enthusiasm for cancer screenings runs high among patients and doctors, both of whom tend to overestimate the benefits but underappreciate the risks, medical research shows.

In some cases, women are being screened for tumors in organs they no longer have. In a study of women over 30, nearly two-thirds who had undergone a hysterectomy got at least one cervical cancer screening, including one-third who had been screened in the past year, according to a 2014 study in JAMA Internal Medicine.

Even some patients with terminal cancers continue to be
screened for other malignancies.

Nine percent of women with advanced cancers — including tumors of the lung, colon or pancreas — received a mammogram and 6 percent received a cervical cancer screen, according to a 2010 study of Medicare recipients over age 65. Among men on Medicare with incurable cancer, 15 percent were screened for prostate cancer.

Although screenings can extend and improve lives for healthy, younger adults, they tend to inflict more harm than good in people who are old and frail, Korenstein said. Testing can lead to anxiety, invasive follow-up procedures and harsh treatments.

“...”

A variety of medical specialties — from the American College of Surgeons to the Society of General Internal Medicine — have advised doctors against screening patients with limited time left. For example, the American Cancer Society recommends prostate and breast cancer screenings only in patients expected to live 10 years or more.

In November, a coalition of patient advocates, employers and others included prostate screenings in men over age 75 in its list of the top five “low-value” medical procedures. Dr. A. Mark Fendrick, co-director of the coalition, referred to the five procedures as “no-brainers,” arguing that health plans should consider refusing to pay for them.

Prostate cancer screening in men over 75 cost Medicare at least $145 million a year, according to a 2014 study in the journal Cancer. Mammograms in this age group cost the federal health plan for seniors more than $410 million a year, according to a 2013 study in JAMA Internal Medicine.

Taxpayers usually foot the bill for these tests, because most seniors are covered by Medicare.

And while cancer screenings generally aren’t expensive — a mammogram averages about $100 — they can launch a cascade of follow-up tests and treatments that add to the total cost of care.

Most spending on unnecessary medical care stems not from rare, big-ticket items, such as heart surgeries, but cheaper services that are performed much too often, according to an October study in Health Affairs.

A Hard Habit To Break

Many older patients expect to continue getting screened, said Dr. Mara Schonberg, an associate professor at Harvard Medical School and Boston’s Beth Israel Deaconess Medical Center.

“It’s jarring for someone who’s been told every year to get screened and then at age 75 you tell them to stop,” she said.

John Randall, 78, says he plans to live into his 90s. He sees no reason to skip cancer screening.

“I, for one, do not like to hear what my life expectancy is,” said Randall, who lives near Madison, Wis. He plans to have his next colonoscopy in January. He feels healthy and walks 2 miles at a stretch several days a week. “No one knows when I am going to die.”

Decades of public awareness campaigns have convinced patients that cancer screenings are essential, said Dr. Lisa Schwartz, a professor at the Dartmouth Institute for Health Policy and Clinical Practice. Her research found that many people see cancer screening as a moral obligation and can’t imagine a day when they would stop getting screened.

Such campaigns have convinced many women that “mammograms save lives.”

But those campaigns don’t mention that doctors need to screen 1,000 women for a decade in order to prevent one death from breast cancer, said Schonberg.

Yet screenings can have dire consequences. Medical complications during colonoscopies — such as intestinal tears — are almost twice as common in patients ages 75 to 79 compared with those 70 to 74, according to a study published in January in Annals of Internal Medicine.

Colonoscopies, which require extensive bowel cleansing before the procedure, also can leave many older people dehydrated and prone to fainting.

PSA tests can lead to prostate biopsies — in which doctors use needles to sample tissue — that cause infections in about 6 percent of men. These infections send about 1 in 100 men who undergo the procedure to the hospital, according to a 2014 study in the Journal of Urology.

Even removing nonfatal skin cancers can cause problems for older patients, said Dr. Eleni Linos, an associate professor at the University of California-San Francisco School of Medicine. Frail patients can struggle to care for surgical wounds and change dressings; their wounds are also less likely to heal well, Linos said. More than 1 in 4 patients with nonfatal skin cancers report a complication of treatment, Linos’ research shows.

Yet most of the 2.5 million slowest-growing skin cancers found each year are diagnosed in people over 65, according to Linos’ 2014 study. More than 100,000 of these nonfatal skin cancers are treated in patients who die within one year.

Screenings, follow-up tests and treatments can cause emotional trauma as well.

“For a woman of that generation who doesn’t have the cognitive ability to understand what’s going on, having private parts of their body exposed and pressed against a machine can be very agitating and upsetting,” Lee said.

Among older women, about 70 percent report significant stress at the time of a biopsy, Schonberg said. Simply lying on a table for a 45-minute biopsy can cause pain for women with significant arthritis, she said.

“Instead of spending time and effort on things that are hurtful and never going to help them, why not direct time and energy on things that will help them live longer and better?”

~ Dr. Louise Walter
Virtually all older women with breast cancer wind up getting surgery, which poses additional hardships, Schonberg said. Many are prescribed hormonal therapies that can cause bone pain, fatigue and increase the risk of stroke.

With prostate cancer, doctors today try to reduce the harm from overdiagnosis by offering men with early-stage disease “active surveillance” instead of immediate treatment. A study published last year in the New England Journal of Medicine found that men are just as likely to survive 10 years whether they choose to be treated or monitored.

Jay Schleifer, 74, of Wellington, Fla., was diagnosed with a low-risk prostate cancer last year. Since then, his doctor has monitored him with additional tests. He’ll be treated only if tests suggest his cancer has become more aggressive.

This less aggressive approach aims to spare Schleifer from long-term side effects.

Among men who have had prostate cancer surgery, 14 percent lose control of their bladders and 14 percent develop erectile dysfunction, according to a 2013 study in JAMA Internal Medicine.

In a study published in July in the Journal of Clinical Oncology, Dr. Richard Hoffman found 15 percent of prostate cancer survivors regretted their treatment decision. Those treated with surgery and radiation were about twice as likely to regret their choice compared with those who opted to monitor their disease.

Men are more likely to regret their prostate cancer treatment decisions if they don’t understand the risks beforehand, said Hoffman, director of general internal medicine at the University of Iowa Carver College of Medicine/Iowa City VA Medical Center.

Harold Honeyfield, 87, said he didn’t fully understand the risks when he had prostate cancer surgery 12 years ago. Although he is glad he was treated, the surgery caused irreversible erectile dysfunction, which has caused stress and sadness for him and his wife of 47 years.

“When a man has no erections, that is paralysis,” said Honeyfield, of Davis, Calif., who started a support group for other men dealing with prostate cancer. “You’ve lost the ability to be a man.”

A Tough Sell

Doctors have a number of incentives to continue ordering screening tests as people age.

“It’s a lot easier to say, ‘Fine, get your regular mammogram this year,’” than to have the much more difficult conversation that it’s not helpful when life expectancy is limited,” Gross said.

Schonberg said she tries to be diplomatic when talking to patients about halting screening.

“In patients well into their 80s, with other chronic conditions, it’s highly unlikely that they will receive any benefit from screening.”

~ Dr. Cary Gross

“It’s hard to tell people, ‘You’re not going to live long enough to benefit,’” Schonberg said. “That doesn’t go over well.”

Many physicians continue screening older people because they’re afraid they’ll be sued if they miss a cancer, Schonberg said. And she notes that some health systems award bonuses to clinicians whose patients have high screening rates.

In addition, “doing less can be perceived as a lack of caring or as ageism,” Schonberg said. “It can be uncomfortable for a physician to explain why doing less is more.”

Doctors should prioritize what they can do to help patients be healthier, said Dr. Louise Walter, chief of geriatrics at the University of California-San Francisco and a geriatrician at the San Francisco VA Medical Center. For many older patients, screening for cancer is not their most pressing need.

“Instead of spending time and effort on things that are hurtful and never going to help them, why not direct time and energy on things that will help them live longer and better?” Walter asked.

For example, Walter might tell a patient, “Right now, you have really bad heart failure and we need to get that under control,” Walter said.

Other key issues for many older people include preventing falls, treating depression and alleviating stress in their caregivers, Walter said. Gross said he urges patients to take steps shown to improve their health, such as getting a flu shot or exercising at least 15 minutes a day.

“These are things that can help them feel better very quickly,” Walter said. “Screenings can take years to have a benefit, if at all.”

KHN’s (Kaiser Health News) coverage related to aging and improving care of older adults is supported in part by The John A. Hartford Foundation.

Liz Szabo, a John A. Hartford Senior Correspondent, is an enterprise reporter focusing on acute care and end-of-life issues.

This article first appeared on the Kaiser Health News (KHN) website and is republished here under a Creative Commons license. https://khn.org/news/doing-more-harm-than-good-epidemic-of-screening-burdens-nations-older-patients/
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FOOT ULCERATION IN PATIENTS WITH DIABETES mellitus can become a major health problem for this population. Diabetic Foot Ulceration (DFU) is among the most serious of causes of morbidity for patients with diabetes, as well as contributes to a longer hospital stay.1 The Centers for Disease Control (CDC) track nontraumatic lower extremity amputation (LEA) rates occurring within the diabetic population. The number of diabetic patients discharged from hospital with a LEA increased by 24% from 1988 to 2009.3 There are estimates stating 15% to 25% of all diabetics will incur a diabetic foot ulcer (DFU) at some point in their lives.4 Practitioners who work with patients with DFU’s are well aware of the recurrent wound infections, cycles of breakdown, and patient adherence to treatment challenges, which then lead to the subsequent renegotiation of care goals, reassessment, and review of treatment plans. Obviously prevention is key, but once a person acquires a non-healing diabetic foot ulcer, patient understanding of the importance of adherence to a treatment plan becomes crucial for prevention of complications, including LEA.

Research Question
A PICO clinical question was developed using a Cochrane review: ‘Will wound care patients with diabetic foot ulcers benefit from providers experiencing an annual in-service regarding education methods to aide in patient compliance?’ The population of concern is diabetic patients with DFUs. The intervention focused on training and in-services for the healthcare providers including physicians, nurse practitioners and nurses who treat patients with DFU’s in a clinic or outpatient setting. The comparison variable is not identified in the research question, but can be assumed that the variable is current practice. Lastly, the outcome of interest is improvement of patient compliance and in turn an improved heal rate.

Method
The literature search included PubMed, CINAHL, and Cochrane Review databases. The articles were selected with inclusion and exclusion criteria. The inclusion criteria for the selection of articles were published research articles on diabetic foot ulcerations, including the research methods of RCTs, Quasi experimental studies, quantitative research, and reviews of systematic reviews, integrative reviews, and meta-analysis.

The participants were people with DFU’s. The search criteria for participants was adjusted to include all people when it was discovered limiting participants to age 18 and older narrowed from providers experiencing annual in-service regarding education methods to aide in patient compliance?’ The population of concern is diabetic patients with DFUs. The intervention focused on training and in-services for the healthcare providers including physicians, nurse practitioners and nurses who treat patients with DFU’s in a clinic or outpatient setting. The comparison variable is not identified in the research question, but can be assumed that the variable is current practice. Lastly, the outcome of interest is improvement of patient compliance and in turn an improved heal rate.

Key Points
• The literature search included PubMed, CINAHL, and Cochrane Review databases. The articles were selected with inclusion and exclusion criteria.
• The inclusion criteria for the selection of articles were published research articles on diabetic foot ulcerations, including the research methods of RCTs, Quasi experimental studies, quantitative research, and reviews of systematic reviews, integrative reviews, and meta-analysis.
• The review revealed that the health care practitioners training and knowledge on diabetic foot ulcer care including physician, nurses, and health care provider helped to improve the patient outcomes.
• There is a need for future interventional research focused on integrated health care providers training in DFU care impacting patient care outcomes that may help to improve quality care.

Summary
Diabetic Foot Ulceration is the most serious causes of morbidity and lower extremity amputations for patients with diabetes. In addition, it contributes to the longer hospital stay, increased health care cost, and decreased quality of life. The purpose of the literature review was guided by the research question ‘Will wound care patients with diabetic foot ulcers benefit from providers experiencing an annual in-service regarding education methods to aide in patient compliance?’
an already anemic search result. Study intervention included physician, provider, or practitioner, training or in-service for the purpose of improved ability to educate DFU patients. The primary outcome was decreased rate of LEA, shorter healing time, and/or improved patient compliance. There was a secondary outcome of interest which was data regarding patient behavior in terms of foot care and attempts to follow treatment plans. The search method was electronic searches conducted within CINAHL Complete and PubMed Central (PMC). The following search terms and number of articles returned are listed in the Table 1.

<table>
<thead>
<tr>
<th>Boolean search words</th>
<th>CINAHL</th>
<th>PubMed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider, training</td>
<td>1,312</td>
<td>2,775</td>
</tr>
<tr>
<td>In-service</td>
<td>0</td>
<td>704</td>
</tr>
<tr>
<td>Training, improve, outcomes</td>
<td>4,107</td>
<td>7,102</td>
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<tr>
<td>Training, wound</td>
<td>1,146</td>
<td>2,239</td>
</tr>
<tr>
<td>Training, improve, wound outcome</td>
<td>4</td>
<td>451</td>
</tr>
<tr>
<td>Provider, wound, training</td>
<td>58</td>
<td>2,420</td>
</tr>
</tbody>
</table>

This search strategy resulted in volumes of research articles, as evidenced above, but not the outcome addressed for this review. The choice of using the word provider worked as intended, most of the time, but still resulted in articles involving physical therapists, coaches, parents, and/or caregivers. The term training resulted in studies with the intent of training as an adjective, a noun, or a verb. Thus training produced thousands of articles with no connection to educational training of practicing healthcare providers. For example, training in the literature involved developing muscles, improving gait, medical resident teaching programs, sports, and other uses. Wound also proved difficult in the combinations referenced in the above table. The word wound pulled in literature regarding trauma, the military, imaging, sports medicine, stomas, and a few articles regarding International Classification of Diseases 10th revision (ICD-10). Time constraints prevented searching the titles of the thousands of articles found to find research for the problem of interest.

The Cochrane Wounds Group Specialized Register and The Cochrane Central Register of Controlled Trials were also searched, as a matter of need for search ideas, curiosity and for a future project’s needs. Although the Cochrane Library database of systematic reviews did not meet the criteria for the literature review, the database does contain meta-analyses research, controlled trials, and information regarding current trials. The Cochrane database search results are found in Table 2.

The results of the Cochrane Library search found two articles, neither of which pertained explicitly to the research problem. The articles involved patient and provider education for the prevention of DFU’s. Although of note was that Dorresteijn, et al, 2014 reported for their search for studies pertaining to patient education for prevention of DFU’s, resulted in only 12 randomized controlled trials (RCTs) that met their inclusion criteria, and only five reported the effects of patient education. Three of the studies did not demonstrate any educational effect for the prevention of DFU’s. Five out of eight RCTs with a dependent variable of patient foot care knowledge, showed an improvement in the short term. Patient self-care behavior involving foot ulcer prevention was found in seven out of nine RCTs assessing this variable, but the study results were a short term look. Dorresteijn, et al, 2014 went on to say that only one of the 12 RCTs was at a low risk for bias. The other Cochrane Review article found involved assessing for complex interventions, meaning two or more interventions, for the prevention of DFU’s. Ultimately what was found, due to the difficulties of the search and the implausibility of viewing the thousands of articles found during the search, were eight studies that could be linked to the desired outcome of the research problem of interest.

The inclusion criteria were adjusted to include articles containing physician, practitioner, and/or nurse education regarding communication for the purpose of improving a patient outcome. The outcome involved improvement of patient behavior or compliance towards self-care involving a chronic disease. Inclusion criteria also pertained to the use of only peer reviewed journals were to be searched.

**Review Results and Discussion**

The search yielded ten eligible articles, among them six articles were addressing the selected PICO question. The problem of DFU patient’s compliance with treatment plans, diabetes management, care of their other health conditions, and care of self cannot rest solely on the patient or their caregiver. There are health literacy components, financial constraints, psychosocial issues, and emotional issues that play a role in patient adherence.

Researching the effect of healthcare provider’s continuing education training impact on patient outcomes and compliance is of interest. Surprisingly few study articles are found regarding this phenomenon. Because DFUs are a major risk factor for nontraumatic lower extremity amputation, aggressive treatment is required, as well as prevention protocols, and patient adherence. An overview of the articles found to assess the effect of healthcare provider training to aid in communication of knowledge to patients for the purpose of improving patient outcomes is listed in the table below. The levels of evidence appraisal were performed

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Cochrane Library results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wounds</td>
<td>177</td>
</tr>
<tr>
<td>Diabetic foot ulcers</td>
<td>28</td>
</tr>
<tr>
<td>Diabetic foot ulcers education</td>
<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Cochrane Controlled Trials results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetic foot ulcer</td>
<td>414</td>
</tr>
<tr>
<td>Diabetic foot ulcer: Training</td>
<td>0</td>
</tr>
<tr>
<td>Diabetic foot ulcer: Provider</td>
<td>0</td>
</tr>
<tr>
<td>Diabetic foot ulcer: Education</td>
<td>0</td>
</tr>
<tr>
<td>Diabetic foot ulcer: Outcomes</td>
<td>1</td>
</tr>
<tr>
<td>Provider training diabetic foot ulcer</td>
<td>1</td>
</tr>
</tbody>
</table>
based on University of Wisconsin (2016) nursing resources.

The Major Findings of the Review:

- Foot care education significantly increased the DFU healing. Integrated self-care education program in patient care may help to improve patient outcomes.
- Impact of education for physicians on patient outcomes has been found associated with decreased number of emergency department visits, hospitalizations, and follow-up visits.
- General Practitioners Trained in Motivational Interviewing of Type 2 Diabetes patient study results revealed that the intervention group was more motivated after one year than the control group. Motivational interviewing helped to improve patient’s understanding of the disease process, beliefs regarding treatment and prevention, and motivation for changing behaviors.
- Physician Communication and Patient Adherence to Treatment: A Meta-Analysis indicated that there was positive correlation between physician communication and patient adherence; and physician training and patient adherence to the care.
- Training of physician and care providers on patient communication may improve patient compliance to the prescribed care.
- Patients’ foot care knowledge was found associated with improved patients’ self-care behavior, decreased callus and infections.
- Communication and Medication Adherence: The Diabetes Study of Northern California revealed that cardiometabolic, oral hypoglycemic and anti-hypertensive medication adherence scores decreased and correlated with poor physician communication scores.
- Basic training workshop on diabetes care for the health care provider was associated with positive outcomes of diabetic patients.
- Implementation of DFU protocol was found associated increased accountability among care providers and reduced amputations.

There is gap in literature including educational interventions of the health care providers in improving outcomes of patients with DFUs. Of concern is how few articles there are regarding research projects involving physician training geared towards educating patients in a manner that effects patient outcomes. Three of the articles found a correlation between physician communication efforts and patient adherence. The study by Ku and Kegels (2014), did not find a statistically meaningful improvement in patient outcomes and had several concerns; that patients had difficulty acquiring or little access to medications, diabetes management related equipment, and physicians. Ku and Kegels (2014), did note that of the patients who had access to resources a statistically significant improvement was noted after healthcare providers received training. There is a need for future studies focusing on physician and health care providers training on DFU patient education and patient outcomes may help to prevent morbidities among this vulnerable population.

The findings of the performed literature review did not support the annual training of providers having impact on patient care outcomes among DFUs. Given the difficulty encountered during the search for literature, the research question may be limited. Another conclusion could be that there is not enough research at this time to determine with finality that educating providers with an aim towards improving patient adherence outcomes is not a fruitful venture. The articles chosen did not give detailed accounts of the training performed with the providers. Another limitation of the review may be due to the fact that the review included only selected research methods as inclusion criteria for this paper’s purpose. Further, research is needed regarding provider training on DFU towards an outcome of improved patient adherence. Research is also needed for the purpose of developing teaching methods aimed at the research questions outcomes.

Conclusion

The review revealed that the Health care practitioners training and knowledge on DFU care including physician, nurses, and health care provider helped to improve the patient outcomes. Integrated DFU protocol and training of health care providers may help to improve self-care, compliance to the care, and may prevent morbidities and complications among patients with diabetic foot ulcers. There is a need for future interventional research focused on integrated health care providers training in DFU care impacting patient care outcomes may help to improve quality care.

Sondra Deimund, FNP, CWS is associated with Methodist North Wound Healing Center.

Annapoorna Mary, PhD, MSc (N), RN, CNE is an Assistant Professor at The University of Memphis.

References:

foot ulceration. Cochrane Database of Systematic Reviews, 2015(8), 1-42. doi:10.1002/14651858.CD007610.pub3.
Discharge planning protects patients by providing them and their caregivers with a care plan to follow after the patient’s discharge from a hospital, nursing home, or other care setting. Health care professionals, the patient, and caregivers participate in discharge planning activities.

<table>
<thead>
<tr>
<th>Provider Type and Service Provided</th>
<th>Discharge Planning Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Acute Care Hospital</strong> for acute hospital inpatient care. and <strong>Inpatient Rehabilitation Facility</strong> and <strong>Long-Term Care Hospital</strong> for post-acute care.</td>
<td>• Arrange necessary post-acute care hospital services and care, including:  o Transfer to rehabilitation facilities;  o Referral to medical equipment suppliers;  o Community resources;  o HHA; and  o Appropriate access to medications.</td>
</tr>
<tr>
<td><strong>Home Health Agency</strong> (HHA) for home health care.</td>
<td>• Include the patient’s medical, health, and medication status in their discharge summary.  • Unless required by State law or HHA policy, a physician’s order is not required to receive home health care.</td>
</tr>
<tr>
<td><strong>Inpatient Psychiatric Facility</strong> for acute psychiatric treatment.</td>
<td>• Develop a follow-up plan with the patient and all service professionals.  • Include follow-up psychiatric treatment and medication in the follow-up plan.</td>
</tr>
<tr>
<td><strong>Long-Term Care Facility</strong>, also known as a Skilled Nursing Home, for skilled nursing care and related services or rehabilitation services.</td>
<td>• Assess the resident’s continuing care needs and services.  • Consider the resident’s and caregiver’s preferences for care.  • Coordinate the needed care and caregivers.</td>
</tr>
<tr>
<td><strong>Hospice</strong> services for the management of terminal illness and related conditions.</td>
<td>• Account for the possibility of the patient’s condition stabilizing and the patient no longer being considered terminally ill.  • Plan for necessary family counseling, patient education, or other services prior to patient discharge from hospice.</td>
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</tbody>
</table>

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Caregiver Burnout: Signs, Prevention and Risk Reduction
Lakelyn Hogan, MA, MBA and LaNita Knoke, RN, BS, CMCN

Summary
Whether you are a family member or a professional, caregiving can be a very rewarding experience – but as with all experiences, there can be high and low points. The potential for caregiver burnout can be one of those low points. This article gives advice on how to identify and avoid caregiver burnout, while maintaining a fulfilling role of support.

Key Points
- 4 in 10 caregivers in the U.S. have identified themselves as being in high-burden caregiving situations, according to the Caregiving in the U.S. Report.
- 9 in 10 caregivers provide over 21 hours of care per week.
- If the caregiver fails to take care of their own health, then they won’t be any good to the person they are caring for.

According to the Caregiving in the U.S. Report, more than 43.5 million people in North America report caring for a family member on a routine basis. When you add the number of professional caregivers into that mix, you are looking at over 70 million caregivers.

Whether you are a family member or a professional, caregiving can be a very rewarding experience – but as with all experiences, there can be high and low points. The potential for caregiver burnout can be one of those low points.

This is especially true when you consider that 4 in 10 caregivers in the U.S. have identified themselves as being in high-burden caregiving situations, according to the Caregiving in the U.S. Report. The report also found that 9 in 10 caregivers provide over 21 hours of care per week (Figure 1). On average, this care lasts for a duration of 4 years. In situations such as this, families are increasingly challenged with finding a balance between their caregiving role and a life outside of those responsibilities. As a result, the risk for potential stress, burnout and health issues increase significantly.

The Caregiving in the U.S. Report also found that more family caregivers are taking on complex caregiving tasks. About 46% of caregivers handle medical or nursing tasks for the care recipient and 57% of those indicate there is little choice as to whether or not they handle the tasks. The little choice is due to either a lack of insurance coverage for outside assistance or there is no one else available to assist. Of that same group of individuals, 96% of them also report assisting with all activities of daily living (ADLs).

Along with these complex caregiving duties, caregivers also report holding significant decision-making authority over monitoring the condition and communicating with healthcare professionals. These types of decisions and responsibilities can be stressful for family members for a lot of reasons, but especially if they have no medical background or prior caregiving experience.

Caregiving primarily becomes a family responsibility but for many families the responsibility often falls to one individual. According to a recent study conducted by the Home Instead Senior Care® network, 31% of family caregivers admit they’d like more help, and 25% actually resent other family members who don’t help out more. The stress gets worse if the caregiver has other important and pressing responsibilities, such as a job, children to care for, a busy social life or some distance to travel to reach the care recipient.

Whether or not the individual is the sole caregiver, it’s important to avoid burnout and stress. If the caregiver fails to take care of their own health, then they won’t be any good to the person they are caring for.

How do you know if someone is suffering from caregiver burnout? The following are some of the common signs:
- Disturbed sleep
- Anxiety
- Depression
- Increased irritability
- Feeling isolated
- Feeling out of control
- Back, shoulder or neck pain

 ACCORDING TO THE CAREGIVING IN THE U.S. REPORT, 40 million people in North America report caring for a family member on a routine basis. When you add the number of professional caregivers into that mix, you are looking at over 70 million caregivers.

Whether you are a family member or a professional, caregiving can be a very rewarding experience – but as with all experiences, there can be high and low points. The potential for caregiver burnout can be one of those low points.

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Key Points
- 4 in 10 caregivers in the U.S. have identified themselves as being in high-burden caregiving situations, according to the Caregiving in the U.S. Report.
- 9 in 10 caregivers provide over 21 hours of care per week.
- If the caregiver fails to take care of their own health, then they won’t be any good to the person they are caring for.
• Headaches
• Increased use of alcohol or drugs
• Stomach and digestive problems
• Weight gain or loss
• Loss of hair
• Fatigue
• High blood pressure
• Irregular heart beat and/or palpitations
• Chest pain
• Perspiration
• Skin disorders such as hives, eczema, psoriasis, tics, or itching
• Periodontal disease
• Jaw pain
• Weakened immune system suppression

“I keep trying to help mom on my own. I think I’m doing a good job and I don’t want to burden anyone else with this, but seriously, there are times when I could really use some help…”

One of the best ways to avoid becoming overstressed is to enlist the help of other family members and friends. Caregivers should do so without feeling bad or guilty for reaching out. When family members are in these situations it may be difficult for them to ask for help. The following are suggestions to get other family members or close friends involved:

➤ Divide up the tasks. Have a specific family member who handles the medical aspects of the care (talks with doctors, medication information, etc.), while another may be responsible for groceries/meals and another handles paying the bills. By dividing up the tasks, each person becomes more involved with the details of these tasks and can keep each other abreast of changes, issues, problems, etc.

➤ Make sure to converse with other family members about the care recipient. If the caregiver fails to express their concerns (e.g., debilitating health, amount of time they spend caregiving, etc.), they can’t expect other family members to know what they are thinking and feeling.

➤ Don’t be a control freak. If the caregiver wants to control every aspect of the care, other family members may be less apt to step in, thinking they have it all under control.

➤ Look outside of the family. If the caregiver doesn’t have other family members to help out, suggest they join a local caregiver support group or involve outside friends, church members or professional caregivers to share the duties.

In addition to asking for help, it is important to make sure the caregiver takes time to care for themselves. The following are additional tips for avoiding caregiver burnout:

➤ Work out: Exercise and enjoy something (like walking, dancing, biking, running, swimming, etc.) for a minimum of 20 minutes at least three times per week. Consider stress-management exercises such as yoga or tai-chi, which teach inner balance and relaxation.

➤ Meditate: Sit still and breathe deeply to quiet the mind as much as possible when feeling like things are moving too quickly or feeling overwhelmed by their responsibilities as a caregiver.

➤ Take a break: Make arrangements for any necessary fill-in help (family, friends, volunteers or professional caregivers). Take single days or even a week’s vacation. And when away from the caregiving role, make sure to stay away. Read that book, take naps, gather with friends, whatever is relaxing and brings happiness.

➤ Eat well: Eat plenty of fresh fruits, vegetables, proteins, including nuts and beans, and whole grains. Remember that indulging in caffeine, fast food and sugar as quick “pick-me-ups” also produce a quick “let-down.”

➤ Keep your medical appointments: Make sure to get an annual check-up. Being a caregiver provides many excuses for skipping your necessary check-ups, but don’t do it. A healthy caregiver is worth more to the care recipient than a sick, weak caregiver.

➤ Indulge: Enjoy a foot massage, manicure, nice dinner out or a concert to get away from the situation and celebrate the wonderful care that is being provided. Don’t feel guilty about wanting to feel good.
Support: Find a local caregiver support group. They will help normalize caregiving feelings and experiences. This is a place to get practical advice from people who are in similar situations and to bounce off those feelings of stress, since everyone is likely to be in the same situation and can empathize.

Medical professionals constantly deal with people who are suffering from burnout from either their own medical condition or that of a loved one. It is important to remember your role is not as a therapist but as a support to the patient and family as they move through the experience. What can be done for patient’s families who appear to be suffering from burnout? Stay involved and support your patient’s families as you watch for the signs of burnout. Frequent check-ins can help give insight into what is happening in the home and if an intervention is necessary to keep the caregiver healthy and able to care for their loved one. Once you have identified potential issues it is time to act with a few simple questions and suggestions:

• Do they qualify for respite care? Can you assist them in getting respite assistance? (For dementia respite consider Hilarity for Charity)
• Can another family member support them and allow a break to the main caregiver?
• Is the patient progressing to the point that the caregiver needs more assistance in the home?
• Are they at the correct level of care?
• Encourage the caregiver to complete a Caregiver Self-Assessment
• Encourage support groups
• Encourage utilizing resources, such as the videos and companion workbook on caregiverstress.com

For more tips and resources for managing the burdens of caregiving please visit: caregiverstress.com.

Lakelyn Hogan, MA, MBA is employed as a Gerontologist for Home Instead Senior Care.
LaNita Knoke, RN, BS, CMCN is employed as a Healthcare Strategist for Home Instead Senior Care.
Can mHealth Interventions Reduce Health Disparities Among Vulnerable Populations?

Monica E. Peek, MD, MPH

Summary

Mobile health (mHealth) is a general term for the use of mobile phones and other wireless technology in medical care. The most common application of mHealth is the use of mobile phones and communication devices to educate consumers about preventive health care services. The potential for mHealth technology to improve the health of vulnerable populations can be magnified if mHealth interventions are also designed to specifically connect persons to health promoting information and resources within the communities where people live, work and play.

Key Points

• Studies that do exist of mHealth interventions within vulnerable populations show promise at engaging patients in self-management, health promotion behaviors and chronic disease management.

Disparities in healthcare and health outcomes are pervasive and pernicious. Such disparities exist between persons living in high-income countries in comparison to those in low to middle-income countries (LMICs), between whites and racial/ethnic minorities, between those with substantial differences in literacy/numeracy, between high-income and low-income persons, and between other advantaged groups compared to disadvantaged or vulnerable groups. This is particularly true for chronic diseases such as type 2 diabetes, a leading cause of morbidity and mortality in the United States and globally and a disease with significant economic and societal costs as well. For example, within the U.S., racial/ethnic minorities have 2-4 times the rate of diabetes-related microvascular complications (e.g. limb amputations, end-stage renal disease and blindness) in comparison to whites.1

Unfortunately, significant advances in medical technology, clinical treatment options and healthcare delivery methods are often slower to spread, with lower rates of utilization, within vulnerable populations, thus further exacerbating health disparities in the care and outcomes among such groups. mHealth interventions have the potential to do the same. The “e-movement” has largely consisted of white, relatively affluent voices with lower representation by racial/ethnic minorities, low-income persons and/or other vulnerable populations. Relatively few studies of mHealth interventions have included vulnerable populations or specifically tailored programmatic aspects to fit the cultural, linguistic, literacy/numeracy or other needs of marginalized groups. Thus, mHealth technologies may ultimately prove to be another mechanism for widening health disparities in the US and globally.

However, studies that do exist of mHealth interventions within vulnerable populations show promise at engaging patients in self-management, health promotion behaviors and chronic disease management.2 3 Further, because of high rates of utilization across socioeconomic groups, including low income, low literacy groups and racial/ethnic minorities, mobile technology represent a natural bridge across the digital divide to serve these traditionally “difficult-to-reach” populations. In fact, there has been a “reverse digital divide” between racial/ethnic minorities and whites in the utilization of mobile phones for a range of services, and the digital divide in smart phone use continues to narrow. Thus, mHealth represents a unique historical opportunity to potentially reduce health disparities by disproportionately improving the health and well-being of vulnerable populations. There are many reasons to believe that this is so. For example, because many of the mHealth selfmonitoring applications (e.g. physical activity, blood pressure, blood glucose, caloric intake) can assist in the management of chronic diseases (e.g. diabetes, hypertension, heart disease), which are disproportionately experienced among vulnerable populations, mHealth programs’ content often has more direct relevance to low-income racial/ethnic minorities than other populations.

A recent review of mHealth and internet interventions among disadvantaged/vulnerable persons with diabetes found high rates of satisfaction with the full range of intervention platforms.4 This may reflect a strong desire by such groups, who disproportionately report negative healthcare experiences, to feel supported and “cared for” by their health system and healthcare team. There is
increasing financial incentives to invest in mHealth programs—service to value-based models, healthcare organizations will have system payment models transition from traditional fee-for-
and internationally. Within the U.S., as physician and healthcare vulnerable populations with chronic diseases, both in the U.S.
interventions can help reduce health disparities among complex, vulnerable patients who need multiple touch points between clinic visits. mHealth also has the potential to improve quality of care by automating patient and provider reminders for tests, immunizations, clinic appointments, and other healthcare delivery aspects. mHealth interventions can potentially increase access to care, particularly in low-resource settings, by shifting tasks to lower level providers or to an automated electronic system. Implementing an automated text-message system in conjunction with a case management program, for example, may allow the program to increase patient/case manager ratios and thereby reach more patients at little marginal cost.

The potential for mHealth technology to improve the health of vulnerable populations can be magnified if mHealth interventions are also designed to specifically connect persons to healthpromoting information and resources within the communities where people live, work and play. Because racial/ethnic minorities and other vulnerable populations disproportionately live in under-resourced communities, technologies that help such populations identify, navigate and access health-promoting goods and services (e.g. low-cost options for physical activity, healthcare organizations that accept uninsured and underinsured patients) may play a powerful role in mitigating health disparities. For example, a community health worker (CHW) intervention in New York City is currently using mobile decision-support applications to help patients manage their disease. The intervention targets patients with diabetes and hypertension, and CHWs can connect their patients to a vast network of community partners (e.g. fitness centers, yoga classes, cooking demonstrations, faith-based organizations, health education classes) in “real time” through mobile support.

Thus, there are many reasons to have hoped that mHealth interventions can help reduce health disparities among vulnerable populations with chronic diseases, both in the U.S. and internationally. Within the U.S., as physician and healthcare system payment models transition from traditional fee-for-service to value-based models, healthcare organizations will have increasing financial incentives to invest in mHealth programs—particularly in socially disadvantaged, high-risk communities. Accountable care organizations (ACOs) and bundled-payment models (e.g. capitation) will inevitably reward healthcare systems for the population-based outcomes of their constituents, including vulnerable populations that have disproportionately poor health outcomes.

There are growing incentives and interest in making mHealth interventions part of the solution to reduce health disparities. Now is the time for innovative strategies and bold action that leverage mHealth to effectively connect vulnerable patients to health information, health promotion, self-care and healthcare services in ways that are scalable and sustainable. Collectively, we have the technology, financial resources, and human capital to make significant improvements in the health of the world’s residents, particularly the most vulnerable among us. We just have to act to make it happen.

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References:
Case Management and the Homeless Population: Nursing Case Managers Meeting the Challenge
Courtney Czerwin, BSN, RN, SCRN and Jamesetta Halley-Boyce, PhD, RN, FACHE

Summary

Homelessness has increasingly become a health concern in the United States. It has been well documented the involvement of the nurse case manager in the delivery of care can serve to enhance the outcomes of any patient population. A review of the literature on the homeless population confirms this assumption. The purpose of this paper is to explain the many facets of homelessness and their health issues in the United States as well as the role of the case manager for this population. The impact case management has on medical and non-medical/social outcomes for this population is discussed. With the overall number of homeless individuals in the nation increasing, it is essential we identify ways to promote health and increase health literacy to achieve prevention of some illness, to facilitate the care coordination and enhance the management of the chronic illnesses most prevalent in homeless population. Nursing case managers are well positioned to lead the charge and meet the challenge of population health for the homeless.

Key Points

- Although numerous members of the Interprofessional Team, namely social workers, physicians, nurses, psychologists, and others, significantly contribute to the care of patients who are deemed homeless, this manuscript only addresses the outcomes achieved by nurses for this population.
- “Despite a national increase between 2016 and 2017, the number of people experiencing homelessness declined in 30 states and the District of Columbia during that time period.”10 Yet increases in the homeless population in places like Los Angeles, California as recently presented in a CNN Special Report (February 26, 2018) remains discouraging.11
- A blueprint identifying strategies for effective population health for the homeless is discussed in detail.

INTRODUCTION: WHAT IS HOMELESSNESS?

During the 1980’s, the number of homeless people grew due to housing and social service cuts, a widening of income disparities as well as gentrification.44, 9 The Reagan administration did not view homelessness as a problem that required federal intervention. The first federal task force was created in 1983 to “provide information to localities on how to obtain surplus federal property; this task force did not address homelessness through programmatic or policy actions”.28 Congress passed the landmark legislation, now known as the McKinney-Vento Homeless Assistance Act, on July 22, 1987. This legislation was the first significant federal legislation to address homelessness. This legislation established distinct assistance programs for the homeless population, including emergency shelter, transitional housing, job training, primary health care, and education.29 The McKinney-Vento Act established the first national definition of homelessness: “An individual who lacks a fixed, regular, and adequate nighttime residence; or an individual who has a primary nighttime residence that is (A) a supervised or publicly operated shelter designed to provide temporary living accommodations including welfare hotels, congregate shelters, and transitional housing for the mentally ill; (B) an institution that provides a temporary residence for individuals intended to be institutionalized; or (C) a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings”.44

The 2009 Homeless Emergency and Rapid Transition to Housing Act (HEARTH), is an amendment to the McKinney-Vento Homeless Assistance Act which “modernizes the U.S. Department of Housing and Urban Development’s homelessness assistance programs”.13 This amendment provides rapid re-housing to permanent independent housing to help resolve homelessness, as well as “educational assurances requiring collaboration between
HUD-funded homeless service programs and school districts. The U.S. Department of Health and Human Services and the U.S. Department of Housing and Urban Development use two different definitions of homeless, which affects program eligibility for individuals and families at the state and local level.

There are three different types of homelessness: chronic, transitional and episodic. Those who are chronically homeless utilize the shelter system as long-term housing, rather than emergency housing. Chronically homeless individuals are usually older and suffer from disabilities and substance abuse. Those who are chronically homeless have increased rates of inpatient admissions to health care facilities. Transitional homeless individuals stay in the shelter system for shorter periods and have become homeless due to a catastrophic event. They tend to be younger individuals that are forced to spend time in a homeless shelter until able to move to permanent housing. Those who are frequently in and out of homelessness are known as episodic homeless individuals. This type of homeless individual is usually chronically unemployed and suffers from medical, mental health and/or substance abuse problems.

The National Health Care for the Homeless Council estimates approximately seventy percent of homeless people do not have health insurance. Combined with a lack of health literacy education, it is difficult for the homeless population to receive proper medical care. There is a lack of knowledge about where to go for treatment, a lack of access to transportation and without health care insurance, and the cost of treatment is too much to pay for the homeless individual.

Case management has an important role in helping the homeless population achieve positive medical outcomes as well as non-medical outcomes. Case management is an important link to ensure continuity of care and delivery of resources to this vulnerable population. “The US Department of Health and Human Service’s Health Resources and Services Administration requires all federally funded health centers to provide case management services including counseling, referrals, follow-up services, and assistance in helping patients establish eligibility for and gain access to federal, state, and local programs that provide or financially support the provision of medical, social, housing, educational, or other related services.” Additionally, Case Management for the homeless population has also been shown to improve health education. A study by Tyler, et, al found homeless individuals who received nursing case management intervention on targeted hepatitis education had a greater knowledge base about hepatitis C than those who just received targeted education.

**Homeless Demographics**

As of January 2015, there was an estimated 564,708 homeless people in the United States. Out of those, 391,440 lived in a shelter or transitional housing and 173,268 lived in places not meant for human habitation. Sixty-three percent of all homeless people are individuals, largely male; approximately eight percent are veterans and six percent are unaccompanied youth and children. The fastest growing segment of the homeless population is women and children, making up thirty seven percent of the total homeless population. African American families make up forty-three percent of the homeless family population. Homelessness is often assumed to be a largely urban phenomenon, but the rate of rural homelessness is rising. When comparing homeless people in rural areas to those in urban areas, the rural homeless are more likely to be married, white females with children and are more likely to be homeless due to domestic violence. The urban homeless population is largely made up of males, either Caucasian or African American, and over the age of twenty-four.

**Reasons for Homelessness**

A lack of affordable housing, a lack of affordable health care and an increase in poverty levels have contributed to the homeless population over the last thirty years. The quality of housing available to low-income workers, limited amount of housing assistance programs and foreclosures have increased the number of people experiencing homelessness. Maness and Khan (2014) report, “In 2009, 14.3% of individuals and 10.5% of families had incomes below the poverty level, placing approximately 46.2 million Americans at risk of homelessness if they experience a single catastrophic financial or medical event.”

Poverty and homelessness are inextricably linked. The official poverty rate in 2015 was 13.5 percent and there were 43.1 million people living in poverty. When poor individuals have to make choices between food, health care, housing and education, it is usually housing that they cannot afford due to the high cost. “Housing is difficult to access and maintain for a large swath of the American public due to a lack of affordable housing stock combined with insufficient and stagnant incomes.” There is a growing disparity between the rich and poor, combined with a lack of employment opportunities and a decline in availability of public assistance, which accounts for the increasing poverty levels.

Another cause of homelessness is poor health and a lack of health insurance. The homeless population is more likely to have multiple chronic conditions; homeless people experience the same illnesses as the general population, but at a rate of three to six times higher. Homeless people lack health care coverage, access to physicians, nutritious foods, and psychological services, leading to an exacerbation of their health issues. Additionally, living in crowded shelters exposes homeless people to diseases that are more communicable, to violence and malnutrition.

**Homeless Individuals, Families, Women and Children**

Homelessness affects a large portion of families in the United States. As of January 2016, there were reportedly 194,716 homeless people in families and 35,688 unaccompanied homeless youth. The number of homeless women and children is the largest growing segment of the homeless population. An estimated 2.5 million children in America experience homelessness in a year. It is believed, the leading cause of homelessness among women and families is domestic and sexual violence, with twenty to fifty percent of them experiencing homelessness as they attempt to flee domestic violence.

There are many health issues affecting homeless women and children further enhanced by the absence of health care, preventative care services such as prenatal care, mammograms and Pap smears, etc. Homeless women have an increased rate of unintended pregnancies as well as an increased rate of adverse birth outcomes such as preterm births and small for gestational age newborns.

Homeless women face more danger and violence than non-homeless women do. Many homeless women develop posttraumatic stress disorder due to the increased exposure to
Homelessness impacts every facet of a child’s life. The physical, emotional, cognitive, social and behavioral development of homeless children are hindered. Homeless children are sick more often than housed children, including increased rates of asthma, infectious diseases and anemia. Because homeless children witness more traumatic events than housed children, they have higher incidences of mental disorders, anxiety, depression and behavioral problems. Homeless children have decreased academic performance in math, reading, spelling and vocabulary tests.37

Homeless Veterans

Homeless veterans, predominantly single males, make up six percent of the homeless population in America. Roughly fifty-four percent of homeless veterans suffer from a mental and/or physical disability. The majority of homeless veterans served in the Vietnam War and have substantial needs due to physical injuries, psychiatric illness and substance abuse. This population has an increased rate of traumatic brain injuries and posttraumatic stress disorder due to combat-related trauma. Veterans have an increased risk of homelessness if they have a low socioeconomic status, a mental health disorder and a history of substance abuse. A lack of family and social support networks also contributes to the risk of veterans becoming homeless.38

Health Issues and the Homeless

Poor health is a common problem among the homeless population with “seventy-three percent of homeless individuals reporting at least one unmet health need, including medical, surgical, mental health, vision or dental care or unmet prescription needs”.10 The lack of access to health care leads to delayed clinical presentation, increased use of emergency services, and higher rates of hospitalizations.4 Homeless individuals suffer from the same medical conditions as the general population, but they experience long-term exposure to living without essential resources for proper health maintenance.

Common chronic cardiovascular diseases in the homeless population include uncontrolled hypertension, coronary artery disease, congestive heart failure and peripheral vascular disease. Cardiovascular disease is the leading cause of death in the homeless population between ages 45 and 64 years old.15 “Cardiovascular disease evolves from material deprivation, excessive psychological stress, anger, mental illness, the adoption of unhealthy coping behaviors such as alcohol, drug and tobacco abuse along with challenges involving ethnicity, education and employment”.19 Smoking contributes to cardiovascular disease in the homeless population. Three quarters of homeless adults smoke cigarettes. The incidence of smoking among the Homeless is four times greater than the US general population.5 The homeless population also has an increased prevalence of uncontrolled diabetes and hypercholesterolemia.20

Mental illness affects twenty to thirty percent of all homeless individuals. Thirty to fifty percent of homeless individuals suffer from substance abuse and/or mental illness. Substance abuse is a cause and result of homelessness. The most common mental illnesses include major depressive disorder, bipolar disorder and schizophrenia.20 Mental illness also contributes to an increased rate of suicide in the homeless population.

Due to crowded, unsanitary living conditions and limited access to health care, the homeless population is exposed to many infectious diseases. The most common infectious diseases among the homeless population include HIV, hepatitis B and C, active tuberculosis, scabies, and body lice. Approximately six to thirty-five percent of homeless individuals are affected by HIV; seventeen to thirty percent have hepatitis B; twelve to thirty percent have hepatitis C; one to seven percent have active tuberculosis; four to fifty-six percent have scabies; and seven to twenty-two percent have body lice.2

The homeless population is at an increased risk for dental, visual and feet problems. “Homeless adults have higher rates of vision impairment (37%), skin/leg/foot problems (36%), positive tuberculin testing (31%), and high blood pressure (14%)”.21 Homeless individuals are twelve times more likely to have dental problems than the general population. It is believed the most common dental problems homeless individuals experience includes periodontal disease, gingivitis and a complete lack of teeth. Oral disease is associated with an increased risk of cardiovascular disease, stroke and poor diabetic control. The homeless population has a higher prevalence of cataracts, glaucoma and macular degeneration.20 Due to the lack of proper foot hygiene, properly fitting shoes and unsanitary living conditions, the homeless population suffers from a variety of illnesses such as venous stasis ulcers, cellulitis, and foot abscesses.20

Case Management and Rapid Re-Housing

With the addition of The Homeless Emergency and Rapid Transition to Housing Act (HEARTH), “case management has been identified as a strategy to support rapid rehousing, especially for those with complex needs”.13 Case management is vital to the success of the rapid re-housing program. “Highly skilled and effective case management is a core component of homeless prevention and rapid-rehousing program (HPRP). Effective, strengths-based case management is essential to the success of the HPRP model”.17 Nursing Case Managers must actively engage in outreach efforts with the homeless population to build trust, engagement and determine the best plan of action for long-term housing stabilization.

In addition to the multiple health problems that the homeless population faces, a lack of a support system impedes treatment. Many homeless individuals are socially isolated and lack support, which can contribute to poor health, yet, individuals who have a high level of trust in their health care provider are more likely to seek care when medically necessary and adhere to follow-up treatment. “When trust is low, research in primary care has found that lower rates of primary care correlate with higher rates of emergency room use”.9 Many homeless individuals report feeling unwelcome, ignored and treated differently because they are homeless when interacting with a health care provider. The health care system often is not prepared to deal with the complex issues that affect the homeless population.8 Nursing Case Managers must bridge the gap for the Homeless Population.

Health Care for the Homeless Centers

The Health Care for the Homeless (HCH) model is the only federal program responsible for addressing the health needs of the homeless population. HCH is a Medical Home model established
in 1984 by two philanthropic foundations, the Robert Wood
Johnson Foundation and the Pew Charitable Trust. HCH has grown
significantly and is now funded through the Health Resources and
Services Administration at the U.S. Department of Health and
Human Services

As of 2008, HCH programs served more than 740,000
homeless people per year.\textsuperscript{10} HCH models utilizes a multidisciplinary
approach to care and coordination of services for the homeless
population. HCH projects provide dedicated services such as
emergency care, housing qualification assistance, primary health
care, medical respite care and outreach services.\textsuperscript{44} HCH models
rely heavily on case managers to help homeless individuals connect
with services, provide a continuum of care and act as advocates
for this population. “By pairing clients who are homeless with
a case manager, clients have access to the broader network of
agencies connected to the HCH site”.\textsuperscript{44} HCH programs recognize
how important case managers are to help connect the homeless
population to multiple services.

The HCH model has developed and refined the best strategies
for engaging a vulnerable population through outreach services,
providing multidisciplinary care, utilizing community resources
and incorporating patient-centered care.

**ACA and Homelessness**

The Affordable Care Act Medicaid Expansion allowed for
millions of uninsured adults to receive health care coverage,
which significantly affects the homeless population. Homeless
individuals account for a large portion of hospital admissions and
emergency services due to their complex health conditions and lack
of coverage. This has resulted in poor health outcomes, increased
mortality and increased costs. With the implementation of the
ACA, health insurance is more accessible and affordable, “giving
people greater protection from financial vulnerability that can
lead to homelessness”.\textsuperscript{44} By providing better health coverage and
connecting the homeless to needed health services, there will be
increased cost savings, improved health outcomes and hopefully,
a decrease in the rate of homeless individuals in the United States.

**Case Management Models/ Strategies to Care Giving in the
Population Health of the Homeless**

There are five case management models that have been
used to help support the homeless population: standard case
management (SCM), intensive case management (ICM), clinical
case management (CCM), assertive community treatment (ACT),
and critical time intervention (CTI). We believe the application of
these models when and where most appropriate to assure the care
needs of the Homeless are met can assist the nursing case manager
specifically with providing care even in the absence of a stable
home setting.

SCM is a coordinated approach to service delivery with the
goal being to provide continuing supportive care. SCM utilizes
the “commonly accepted functions of case management and are
characterized by a closer involvement between case manager and
client”.\textsuperscript{43} The average case load for a standard case manager is
thirty-five and they do not provide outreach services.\textsuperscript{13}

ICM is directed at homeless individuals with the greatest
service needs. The intensive case manager has an average
case load of fifteen and engages in frequent client contact and
more intensive services. The case manager is responsible for
the homeless individual’s care, providing outreach and direct
counseling services.\textsuperscript{13}

CCM is also known as rehabilitation case management and
combines “resources acquisition (case management) and clinical
or rehabilitation activities, which might include psychotherapy for
clients and their families or teaching of specific skills”.\textsuperscript{43} This is an
even smaller case load of approximately 10 cases and has frequent
client contact.\textsuperscript{13}

ACM is a multidisciplinary team approach that is accessible
around the clock. Both case manager and clinical providers work
together to provide services to the homeless population with the
greatest service needs. The average case load for the team is fifteen,
and while similar to ICM, it is even more intensive and involves
skill-building, family consultations and crisis intervention.\textsuperscript{13}

CTI is a time-limited case management approach to “enhance
continuity of care by bridging the gap between services and
strengthening client’s social and professional networks”.\textsuperscript{13} CTI is
utilized during critical moments of a homeless individual’s life,
such as transitioning from a shelter to permanent housing. The
average caseload is approximately twenty-five and aims to ensure
continuity in the delivery of care.

A literature review (2013) examined the effects of four different
delivery models of case management (SCM, ICM, ACT, and CTI)
had on specific subpopulations of homeless individuals. Overall,
ACT has shown to be the most effective in producing positive
outcomes for the homeless population. SCM has been found to be
highly effective in improving housing stability, reducing substance
use and removing employment barriers among homeless substance
users. ICM had a positive connection between the severely
mentally ill homeless individuals and housing stability. Homeless
individuals receiving ICM showed reduce use of substances and
an improvement in psychiatric symptoms. In addition, there was a
decrease in the number of days homeless, emergency department
visits and length of hospital stay.\textsuperscript{13} ACT had a positive effect on
the severely mentally ill and substance-using homeless veterans.
Among these populations, they had improved housing stability
and reduced inpatient and emergency mental health services. CTI
had a positive impact in supporting housing stability and reducing
psychiatric symptoms for the severely mentally ill homeless
population.\textsuperscript{13}

Overall, the literature displays positive outcomes case
management has on those experiencing homeless. These outcomes
include: increased housing stability, reduced use of emergency
medical services, reduced use of drugs and alcohol, increased
mental stability, and improved quality of life quite appropriate and
acceptable clinical outcomes when population health strategies are
utilized by Nursing Case Managers with the Homeless.

**Homelessness - How We Can Make It Better- Treatment
Considerations and Interventions for Nursing Case Managers**

Population Health for the Homeless is a difficult task but, as
Nurse Case Managers we can successfully lead the charge to assure
all individuals in need of care are provided the care they need.
While the homeless suffer from many different health problems, it
is difficult to provide treatment because of a multitude of factors.
A major barrier to treatment is the instability of housing; homeless
individuals cannot store medication properly while living on the
street and a lack of access to housing has been shown to decrease
adherence to treatment and increase use of emergency services.\textsuperscript{3}
Many medications are expensive, especially mental illness medications, and the side effects can interfere with the ability to protect themselves while vulnerable in a homeless situation.

In addition to the multiple health problems that the homeless population faces, a lack of a support system impedes treatment. Many homeless individuals are socially isolated and lack support, which can contribute to poor health, yet, individuals who have a high level of trust in their health care provider are more likely to seek care when medically necessary and adhere to follow-up treatment. “When trust is low, research in primary care has found that lower rates of primary care correlate with higher rates of emergency room use.” Many homeless individuals report feeling unwelcome ignored and treated differently because they are homeless when interacting with a health care provider. The health care system often is not prepared to deal with the complex issues that affect the homeless population. Nursing case managers must bridge the gap for the homeless population.

Conclusion

Homelessness in the United States is a complex problem. Case Management has been shown to have positive effects on the homeless population through increased housing stability, improved health outcomes, and a reduction in the use of emergency services. With care coordination, case managers are able to identify and prioritize issues, develop a cost-effective and feasible plan, promote understanding of the client’s health condition and treatment plan, as well as help the individual connect with other support services such as housing and transportation. The homeless population is especially vulnerable due to their complex medical problems, mental illness, and substance abuse. The case manager in the role of a navigator can facilitate care coordination both medical and social needs with the patient’s active participation in the plan of care, case management can help the homeless population achieve positive medical and non-medical outcomes through effective communication, collaboration, health education and service referrals. Although as a nation, we may never be able to eliminate homelessness but we know the two major aspects to help end homelessness are the availability of affordable housing and effective case management. Nursing case managers will lead the charge and meet the challenge to assure population health even for those negatively impacted by homelessness will receive care that is safe, compassionate, affordable and therapeutic.

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Barriers to Gender Transition-Related Healthcare: Identifying Underserved Transgender Adults in Massachusetts

Courtney Czerwin, BSN, RN, SCRN and Jamesetta Halley-Boyce, PhD, RN, FACHE

Summary

The present study sought to examine whether individual (e.g., age, gender), interpersonal (e.g., healthcare provider discrimination), and structural (e.g., lack of insurance coverage) factors are associated with access to transition-related care in a statewide sample of transgender adults. In 2013, 364 transgender residents of Massachusetts completed an electronic web-based survey online (87.1%) or in person (12.9%). A multivariable logistic regression model tested whether individual, interpersonal, and structural factors were associated with access to transition-related care.

Key Points

• Overall, 23.6% reported being unable to access transition-related care in the past 12 months. In a multivariable model, younger age, low income, low educational attainment, private insurance coverage, and healthcare discrimination were significantly associated with being unable to access transition-related care (all p<0.05).

• Despite state nondiscrimination policies and universal access to healthcare, many of the Massachusetts transgender residents sampled were unable to access transition-related care. Multilevel interventions are needed, including supportive policies and policy enforcement, to ensure that underserved transgender adults can access medically necessary transition-related care.

TRANSGENDER PEOPLE HAVE A GENDER IDENTITY or expression that differs from their assigned birth sex. It is estimated that transgender people comprise 0.6% of the United States adult population, with North Dakota (0.3%) and Iowa (0.3%) among the states with the lowest percentage of transgender adults and Massachusetts (0.6%) and Hawaii (0.8%) among the states with the highest percentage of transgender adults. Moreover, it is likely that the number of transgender people is even higher when transgender individuals under age 18 are accounted for. Like all people, transgender individuals need to access healthcare to meet their preventative and urgent medical needs. Many transgender people also access healthcare to “transition” or medically affirm their gender, which can include the use of hormone therapy and/or surgery to align one’s gender presentation with one’s gender identity. Access to transition-related care is considered medically necessary for many transgender people and is associated with reduced gender dysphoria and improved mental health and quality of life. However, many transgender people face structural- (e.g., restrictive insurance policies), interpersonal- (e.g., provider discrimination), and individual-level (e.g., education) barriers to healthcare, which can contribute to poor health. Due to having a gender expression or identity that does not conform to the socially sanctioned gender norms of their birth sex, transgender people experience widespread stigma, which can impact their access to essential resources, including employment, housing, and healthcare. Transgender stigma in healthcare can include overt enacted discrimination at the interpersonal level, such as being refused care by a healthcare provider, as well as more subtle or even inadvertent forms of stigma, such as provider’s use of nonaffirming language and/or lack of transgender health knowledge. Research suggests that healthcare discrimination can impact access to care for transgender individuals directly through healthcare refusal or indirectly through healthcare avoidance. Indeed, studies have found that transgender individuals may avoid healthcare for fear of discrimination, which can lead to otherwise preventable healthcare emergencies.

While it is not always necessary to disclose one’s transgender history to one’s healthcare provider, accessing transition-related care is unique in that providers must know a patient is transgender to offer and oversee transition-related care. Transgender individuals, who have socially transitioned or live “full time” in their identified gender, may be better able to access transition-related care.
related care than those who have not socially transitioned as those who have socially transitioned tend to have better mental health and therefore may be more capable of managing the threat of healthcare discrimination.11,12 Regardless of social transition status, visual gender conformity or the extent to which a person’s gender expression aligns with socially-sanctioned expressions of the gender binary (i.e., masculine or feminine but not both) could also potentially impact access to care. For example, being visually gender nonconforming could be a barrier to care as gender nonconformity may increase exposure to discrimination and discrimination has been linked to healthcare avoidance in transgender people.11,12 Conversely, those who are gender conforming may not experience provider discrimination based on their visible gender presentation; however, they would be required to verbally disclose their transgender history to obtain medical transition-related services, at which point they could experience discrimination, including being denied services.8 Given the potential for experiencing discrimination upon disclosing one’s transgender history, some transgender individuals may conceal their transgender history, which could further impede access to care even for those who are visually gender conforming.4,8,13

Research that concurrently examines social transition status, visual conformity, disclosure of transgender status, and experiences of discrimination in relation to access to transition-related care is needed.

Affordability and insurance coverage can also limit access to healthcare for transgender people.9 Many transgender individuals lack health insurance, which may be due, in part, to the higher prevalence of unemployment and poverty faced by transgender people relative to the general United States population, a likely product of employment discrimination.14,15 For transgender people who are insured, barriers to care can persist, as private insurers have historically excluded coverage for medical interventions related to gender transition.16 While the passage of the Affordable Care Act (ACA) made illegal for any health program, provider, or organization that receives federal funding to discriminate against an individual due to their race, color, national origin, sex, age, or disability (e.g., treat inequitably, including charging more for services and denying coverage for preexisting conditions or based on health status),17 private insurers and healthcare entities not receiving federal funds are not subject to the ruling and lack of early clarification about whether the law extended to transgender individuals and transition-related care limited the reach of the ACA.18–20 Moreover, the limited availability of transgender-competent providers21 forces some transgender people to pay out of pocket for providers outside their plan, leading to high healthcare expenditures even for the insured.22 Due to the many challenges surrounding affordable healthcare coverage for transgender people, along with the disproportionate prevalence of poverty and unemployment facing this patient population, inadequate insurance coverage and lack of financial resources remain important barriers to accessing healthcare.

While numerous studies have documented transgender people’s experience accessing general healthcare,17 access to transition-related care remains understudied, particularly in more progressive areas of the United States like Massachusetts that has had universal healthcare and transgender nondiscrimination polices since 2006 and 2011, respectively. The current study sought to assess the individual, interpersonal, and structural factors associated with being unable to access transition-related healthcare in the past 12 months among transgender adults in Massachusetts. Understanding the multilevel factors associated with being unable to access medically necessary transition-related care among transgender individuals living in one of the most socially progressive areas of the United States can inform the development of targeted interventions to increase access to care for the most vulnerable and underserved transgender individuals.

Methods

This study conducted a secondary analysis of data from 452 transgender residents of Massachusetts who completed a one-time, secure, electronic web-based survey between August and December 2013. Only participants who had sought transition-related care in the past 12 months were included in the analytic sample (n=364; 80.5%).

Participants were recruited through transgender-specific online and in-person venues. The majority (87.1%) of the analytic sample was recruited online through transgender-focused electronic listserv, e-mails, web postings, and social networking sites; 12.9% were surveyed in person through electronic tablets at transgender community events and other social programming. Eligible participants were ages 18 years or older; self-identified as transgender/gender nonconforming (e.g., had a gender identity/expression that differed from assigned sex at birth); lived in Massachusetts for at least 3 months in the last year; and had the ability to read and write in either English or Spanish. All participants provided consent before beginning the survey. Participants could opt to be entered into a community raffle for two tablet computers. All study activities were IRB approved. Additional details on the study can be found elsewhere.21

Measures

Access to Transition-Related Care (Outcome)

Participants were asked the following question used in prior national research with transgender samples:14 “I was unable to access transition-related care (hormones or surgery) in the past 12 months” (yes, no).

Demographics

Age in years was assessed continuously. Race/ethnicity captured whether participants were White non-Hispanic, Black non-Hispanic, Hispanic, Other race/ethnicity, or Multiracial. Participants were then categorized as White non-Hispanic or people of color (POC). Gender was assessed using a two-step method24 asking: (1) assigned sex at birth (female, male) and (2) current gender identity (man, woman, female-to-male (FTM)/trans man, male-to-female (MTF)/trans woman, genderqueer, gender variant, gender nonconforming, other). The two items were cross-tabulated to categorize participants according to their natal sex: FTM transmasculine spectrum, which included binary and nonbinary/gender nonconforming people assigned a female sex at birth versus MTF transfeminine spectrum, which included binary and nonbinary/gender nonconforming people assigned a male sex at birth. Educational attainment ranged from 1="high school or less” to 4=”graduate school,” using a measure from the Behavioral Risk Factor Surveillance Survey.25 Educational attainment was then dichotomized as “high school degree or less” versus “college
Participants were asked whether they were currently employed for wages (yes, no). Annual household income was assessed continuously and then categorized as earning “less than $35,000 a year,” which is 300% of the federal poverty level in 201326 vs. “$35,000 a year or more.”

Insurance Coverage
Participants were asked whether they had private, public, or no insurance. Participants were also asked to indicate whether they had insurance coverage for transition-related services (yes, no, don’t know), including for mental health services to support the transition process; hormones; breast or chest surgeries; and sex reassignment surgery.

Social and Medical Gender Transition
Social gender transition was assessed with one item previously used in research with transgender adults:27 “Do you consistently present (live “full time”) in your identified gender?” (yes, no). Participants were also asked whether they had legally changed their name (yes, no) and, if yes, the specific document where they had changed their name (license, passport, social security card, and birth certificate). In addition, participants were asked about specific types of medical transition-related care they had received in their lifetime (yes, no), including hormones (e.g., estrogen, testosterone); breast or chest surgeries (e.g., FTM chest reconstruction, MTB breast augmentation, or implants); abdominal surgeries (e.g., oophorectomy, hysterectomy); gender confirmation surgery (e.g., metoidioplasty, phalloplasty, vaginoplasty); and or another type of procedure (e.g., facial feminization, hair removal). Visual gender conformity was assessed by asking participants how often people could tell they were transgender (never to always). Participants indicating that people could never tell they were transgender were coded as yes (visually gender conforming), otherwise no (visually gender nonconforming).

Healthcare Experiences
Participants were asked about specific experiences seeking medical care in the past 12 months, including whether they had presented as transgender at one or more healthcare entity (yes, no), which could entail verbally disclosing one’s transgender identity to a provider or visually “disclosing” one’s transgender identity vis-à-vis one’s nonconforming gender expression. Participants were also asked whether they had to teach their doctor or other provider about transgender people to receive appropriate care (yes, no); whether they had been verbally harassed or physically assaulted by a healthcare provider (yes, no); and whether a healthcare provider had refused to treat them (yes, no).

Data Analysis
Statistical analyses were performed in SAS v9.4.1. Distributions of individual items were assessed, including missingness. Because missingness was differential and violated the missing completely at random assumption,29,30 data were multiply imputed.30–32 Descriptive statistics (means, frequencies) was stratified by whether participants were unable to access transition-related care in the past 12 months (yes, no). Crude unadjusted bivariate logistic regression analyses then estimated associations among demographic, insurance coverage, social and medical gender transition, healthcare experiences, and the outcome—unable to access transition-related care in the past 12 months. Variables that were statistically significantly associated with ability to access transition-related care at the bivariate level (p<0.05) were retained in a final multivariable logistic regression model, which also adjusted for survey mode (online or in person). Adjusted odds ratios and 95% confidence intervals were estimated.

Results

Distribution of Variables
As shown in Table 1, the mean age of participants was 34.0 (standard deviation=13.0; range=18–75). The majority of participants were White non-Hispanic (85.0%) and more than half (59.1%) were on the transmasculine spectrum (i.e., assigned a female sex at birth and currently identify as man, male, or another masculine gender identity). The majority of participants had a college degree or higher (54.7%), were employed for wages (53.0%), and earned <$35,000 a year (57.7%).

Nearly all participants had some form of insurance coverage (96.1%), with 60.1% having private insurance and 36.0% having public insurance (e.g., Medicare, Medicaid/MassHealth). When asked about whether they had insurance coverage for specific transition-related services, nearly half of the sample had insurance for mental healthcare to support the transition process (47.8%) and 40.1% had coverage for hormone therapy. Only 7.4% of participants had coverage for breast or chest surgeries and gender confirmation surgery. Approximately a third of participants did not know if their insurance covered specific transition-related services, including coverage for mental healthcare related to their transition-related care (36.5%), hormones (32.1%), breast or chest surgery (37.4%), and gender confirmation surgery (36.5%).

The majority of participants had socially transitioned (77.0%) and almost half had legally changed their name (49.2%). Hormone therapy was the most common transition-related intervention received (66.2%), followed by breast or chest surgeries (25.3%), abdominal surgeries (7.4%), gender confirmation surgeries (6.3%), and other services (5.2%). A quarter of the sample (25.0%) indicated that they were visually gender conforming.

The vast majority of participants (79.7%) had presented as transgender when accessing healthcare in the past 12 months. Nearly a third of participants (32.1%) reported having to teach their provider about transgender care, 25.0% had been discriminated against in healthcare, and 5.8% indicated that a provider refused to treat them in the past 12 months. Finally, nearly a quarter of the sample (23.6%) indicated that they were unable to access transition-related care in the past 12 months.

Factors Associated with Being Unable to Access Transition-Related Care
Multivariable models are shown in Table 2. In multivariable models adjusted for survey mode, younger age, being visually gender conforming, and having presented as transgender when accessing healthcare were each protective against being unable to access transition-related care in the past 12 months (all p<0.05). Factors associated with the increased odds of being unable to access transition-related care in the past 12 months included the following: having a high school degree or less; having an annual household income of <$35,000; having private insurance or no insurance; not having mental health coverage for transition-related
Table 1. Demographics of Transgender and Gender Nonconforming Adults from Massachusetts \((n=364)\) Who Accessed \((n=278)\) and Who Were Unable to Access \((n=86)\) Transition-Related Care in the Past 12 Months

<table>
<thead>
<tr>
<th>Age Range: 18–75</th>
<th>Able to access (n=278)</th>
<th>Unable to access (n=86)</th>
<th>Total (n=364)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean 33.8</td>
<td>SD 13.3</td>
<td>Mean 30.3</td>
<td>SD 11.5</td>
</tr>
<tr>
<td>%</td>
<td>(n)</td>
<td>%</td>
<td>(n)</td>
</tr>
<tr>
<td>Age Range: 18–75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>81.7</td>
<td>83.72</td>
<td>82.1</td>
</tr>
<tr>
<td>Person of color</td>
<td>18.3</td>
<td>16.3</td>
<td>17.9</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>3.2</td>
<td>2.3</td>
<td>3.0</td>
</tr>
<tr>
<td>Hispanic</td>
<td>9.0</td>
<td>5.8</td>
<td>8.2</td>
</tr>
<tr>
<td>Other race/ethnicity</td>
<td>1.4</td>
<td>3.5</td>
<td>1.9</td>
</tr>
<tr>
<td>Multiracial</td>
<td>4.7</td>
<td>4.7</td>
<td>4.7</td>
</tr>
<tr>
<td>Current gender identity</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Transmasculine spectrum</td>
<td>57.9</td>
<td>62.79</td>
<td>59.1</td>
</tr>
<tr>
<td>Female-to-male/trans man/man/male identity</td>
<td>36.3</td>
<td>37.2</td>
<td>36.5</td>
</tr>
<tr>
<td>Female assigned birth sex nonbinary gender nonconforming identity</td>
<td>21.6</td>
<td>25.6</td>
<td>22.5</td>
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<tr>
<td>Transfeminine spectrum</td>
<td>42.1</td>
<td>37.21</td>
<td>40.9</td>
</tr>
<tr>
<td>Male-to-female/trans woman/woman/female identity</td>
<td>33.1</td>
<td>30.2</td>
<td>32.4</td>
</tr>
<tr>
<td>Male assigned birth sex nonbinary gender nonconforming identity</td>
<td>9.0</td>
<td>7.0</td>
<td>8.5</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>High school degree or less</td>
<td>43.5</td>
<td>51.16</td>
<td>45.3</td>
</tr>
<tr>
<td>College degree or more</td>
<td>56.5</td>
<td>48.84</td>
<td>54.7</td>
</tr>
<tr>
<td>Employed for wages</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>47.1</td>
<td>46.51</td>
<td>47.0</td>
</tr>
<tr>
<td>Yes</td>
<td>52.9</td>
<td>53.49</td>
<td>53.0</td>
</tr>
<tr>
<td>Annual household income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$35,000</td>
<td>55.0</td>
<td>66.28</td>
<td>57.7</td>
</tr>
<tr>
<td>$35,000 or more</td>
<td>45.0</td>
<td>33.72</td>
<td>42.3</td>
</tr>
<tr>
<td>Insurance coverage—current</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4.0</td>
<td>8.1</td>
<td>4.9</td>
</tr>
<tr>
<td>Public (medicare, medicaid/masshealth)</td>
<td>35.3</td>
<td>25.6</td>
<td>33.0</td>
</tr>
<tr>
<td>Private</td>
<td>60.8</td>
<td>66.3</td>
<td>62.1</td>
</tr>
<tr>
<td>Mental health coverage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>52.9</td>
<td>31.4</td>
<td>47.8</td>
</tr>
<tr>
<td>No</td>
<td>13.3</td>
<td>23.3</td>
<td>15.7</td>
</tr>
<tr>
<td>Don't know</td>
<td>33.8</td>
<td>45.3</td>
<td>36.5</td>
</tr>
<tr>
<td>Hormone coverage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>42.8</td>
<td>31.4</td>
<td>40.1</td>
</tr>
<tr>
<td>No</td>
<td>25.5</td>
<td>34.9</td>
<td>27.7</td>
</tr>
<tr>
<td>Don't know</td>
<td>31.7</td>
<td>33.7</td>
<td>32.1</td>
</tr>
<tr>
<td>Breast or chest surgery coverage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7.6</td>
<td>7.0</td>
<td>7.4</td>
</tr>
<tr>
<td>No</td>
<td>54.7</td>
<td>57.0</td>
<td>55.2</td>
</tr>
<tr>
<td>Don't know</td>
<td>37.8</td>
<td>36.0</td>
<td>37.4</td>
</tr>
<tr>
<td>Gender confirmation surgery coverage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7.9</td>
<td>5.8</td>
<td>7.4</td>
</tr>
<tr>
<td>No</td>
<td>54.0</td>
<td>62.8</td>
<td>56.0</td>
</tr>
<tr>
<td>Don't know</td>
<td>38.1</td>
<td>31.4</td>
<td>36.5</td>
</tr>
<tr>
<td>Social and medical gender transition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socially transitioned—lifetime</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>24.1</td>
<td>19.8</td>
<td>23.0</td>
</tr>
<tr>
<td>Yes</td>
<td>75.9</td>
<td>80.2</td>
<td>77.0</td>
</tr>
</tbody>
</table>
Table 1. Demographics of Transgender and Gender Nonconforming Adults from Massachusetts (n=364) Who Accessed (n=278) and Who Were Unable to Access (n=86) Transition-Related Care in the Past 12 Months

<table>
<thead>
<tr>
<th>Age Range: 18–75</th>
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<th>Unable to access n=86</th>
<th>Total n=364</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean 33.8 SD 13.3</td>
<td>Mean 30.3 SD 11.5</td>
<td>Mean 33.0 SD 13.0</td>
</tr>
<tr>
<td></td>
<td>% n</td>
<td>% n</td>
<td>% n</td>
</tr>
</tbody>
</table>

**Legal name change**
- No: 51.1 142 50.0 43 50.8 185
- Yes: 48.9 136 50.0 43 49.2 179

- Changed on license: 46.0 128 45.3 39 45.9 167
- Changed on social security card: 45.3 126 44.2 38 45.1 164
- Changed on passport: 21.6 60 16.3 14 20.3 74
- Changed on birth certificate: 12.9 36 10.5 9 12.4 45

**Medical transition-related care accessed—lifetime**

- **Hormones**
  - No: 33.1 92 36.0 31 33.8 123
  - Yes: 66.9 186 64.0 55 66.2 241

- **Breast or chest surgeries**
  - No: 75.5 210 72.1 62 74.7 272
  - Yes: 24.5 68 27.9 24 25.3 92

- **Abdominal surgeries**
  - No: 92.8 258 91.9 79 92.6 337
  - Yes: 7.2 20 8.1 7 7.4 27

- **Gender confirmation surgery**
  - No: 92.8 258 96.5 83 93.7 341
  - Yes: 7.2 20 3.5 3 6.3 23

- **Other surgery**
  - No: 94.2 262 96.5 83 94.8 345
  - Yes: 5.8 16 3.5 3 5.2 19

- **Visually gender conforming—current**
  - No: 73.0 203 81.4 70 75.0 273
  - Yes: 27.0 52 18.6 16 25.0 91

**Healthcare experiences—past 12 months**

- **Presented as transgender when accessing healthcare**
  - No: 18.7 52 25.6 22 20.3 74
  - Yes: 81.3 226 74.4 64 79.7 290

- **Taught provider about transgender care**
  - No: 73.0 203 51.2 44 67.9 247
  - Yes: 27.0 75 48.8 42 32.1 117

- **Experienced discrimination**
  - No: 78.8 219 62.8 54 75.0 273
  - Yes: 21.2 59 37.2 32 25.0 91

- **Provider refused to treat**
  - No: 97.1 270 84.9 73 94.2 343
  - Yes: 2.9 8 15.1 13 5.8 21

- **Unable to access transition-related care**
  - No: 0.0 0 0.0 0 0 76.4 278
  - Yes: 100.0 278 100.0 86 23.6 86

*SD, standard deviation.*
care or not knowing if one has mental health coverage; having taught one’s provider about transgender care; having experienced discrimination; and having been refused care by a provider in the past 12 months (all p<0.05).

Discussion

In this statewide sample of transgender adults in Massachusetts, nearly a quarter of respondents reported being unable to access transition-related care in the past 12 months. The study also identified key individual, interpersonal, and structural factors associated with an inability to access transition-related care, including low educational attainment, low income, limited insurance coverage, and healthcare discrimination. These findings highlight the need for multilevel interventions to improve access to transition-related care for transgender adults in Massachusetts, with implications for transgender individuals across the United States.

Massachusetts pioneered the concept of universal healthcare coverage (i.e., MassHealth) and uninsurance in the state has been below 5% since passing the landmark healthcare law in 2006. However, when it comes to transition-related healthcare policies, Massachusetts did not have protections prohibiting the denial of transition-related care by insurers and medical providers until 2014 and 2016, respectively. Thus, at the time these data were collected in 2013, transgender residents of Massachusetts did not have any state-level protections against healthcare discrimination. Despite access to general healthcare coverage under MassHealth, nearly a quarter of the sample was unable to access transition-related healthcare in the past year. In addition, patients with private insurance or no insurance had 1.62 and 2.92 increased odds of being unable to access transition-related care, respectively, relative to those with public insurance (i.e., Medicare, Medicaid/MassHealth). While the ACA provided federal protections against discrimination on the basis of sex for any healthcare entity receiving federal funds, before the 2016 issuing of the final nondiscrimination rule (Section 1557), there was great uncertainty as to whether the mandate applied to transgender individuals. Furthermore, while an earlier directive issued to Massachusetts insurers in 2014 noted that the exclusion of coverage on the basis of gender identity was inherently discriminatory, both the 2014 state directive and 2016 federal ruling contain ambiguous language that likely limited coverage for transition-related services by private insurers. For example, the ACA ruling did not define “health services related to gender transition” and the state directive defined procedures in terms of their “medical necessity,” which has only been defined for public insurers under MassHealth as of 2015. In addition, the burden of policy enforcement largely relies on the reporting of violations by individual subscribers, which can be difficult, time consuming, and prohibitive for many people. As a result of delays in state and federal directives and challenges with their interpretation and enforcement, particularly for private insurers, it follows that a greater proportion of transgender individuals in our survey with private insurance were unable to access transition-related care relative to those with public insurance. Continued efforts should be made to monitor healthcare access and utilization by insurance status and type among transgender individuals in Massachusetts, as well as more conservative states where lack of state-level protections (e.g., Arizona, Alaska, Louisiana, Montana, and Tennessee) and/or current legislative efforts to remove transgender protections (e.g., Florida, South Carolina, Texas, Virginia, and Wisconsin) threaten healthcare access for transgender individuals.

When examining the specific type of healthcare services covered, transition-related mental health coverage emerged as one of the factors most strongly associated with an inability to access care. Specifically, compared to participants who had transition-related mental health coverage, those who did not have transition-related mental health coverage and those who did not know if they had coverage had more than a twofold increased odds of being unable to access transition-related care in the past 12 months. Historically, a diagnosis of gender dysphoria was required to access transition-related care for both hormones and surgeries. With the advent of informed consent models, in which patients are able to access hormones through their primary care provider after being informed of the risks and benefits of treatment, a mental health diagnosis of gender dysphoria is no longer required to receive hormone therapy. However, not all clinics or physicians utilize informed consent models and it is possible that less experienced clinicians may feel more comfortable referring transgender patients to a mental health provider who specializes in transgender care before prescribing hormones. Furthermore, most insurers still require a diagnosis of gender dysphoria to access surgical care. Consequently, transgender people who face challenges accessing mental healthcare due to lack of coverage or limited coverage (e.g., restrictions on number of visits, competent providers outside of one’s insurance network) might also report an inability to access gender affirming hormones and surgical services. Advocacy work is needed to ensure better access to mental health coverage for transition-related services and fully eliminate any mental health diagnosis requirements to access medically necessary care for transgender individual in Massachusetts and across the United States. In accordance with informed consent models, transgender patients should still be evaluated by their primary care provider to determine capacity to provide informed consent, and mental health diagnoses that may interfere with a patient’s ability to consent should be treated before receiving transition-related services.

Younger age, having a low income, and low educational attainment were also associated with increased odds of being unable to access transition-related care for transgender individuals in our sample. It is possible that younger people, those with lower incomes, and those with limited education may face challenges navigating the healthcare system, including identifying knowledgeable and gender affirming providers and understanding their healthcare coverage, which may in turn impact their ability to access gender affirmative care. Research among the general population has shown that low health literacy predicts likelihood of both being uninsured and facing difficulties accessing healthcare. Health insurance literacy may therefore be a salient mechanism to improve access-to-care for intervention efforts. High cost of services may further prevent healthcare access directly through the inability to pay for services, as well as indirectly through healthcare avoidance. In light of the healthcare insurance coverage available to low-income individuals through MassHealth (Massachusetts)/Medicaid (federal), efforts must be made to identify eligible low-income individuals to help them access healthcare insurance and successfully navigate the healthcare system to facilitate access to needed transition-related services. Future research would also benefit from examining...
Table 2. Bivariate and Multivariable Logistic Regression Analyses Examining Associations Among Demographics, Insurance Coverage, Healthcare Experiences, and Ability to Access Transition-Related Care in the Past 12 Months in a Sample of Transgender Adults in Massachusetts (n=364)

<table>
<thead>
<tr>
<th>Outcome: unable to access transition-related care—past 12 months</th>
<th>Demographics</th>
<th>Bivariate</th>
<th>Multivariable</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>OR</strong></td>
<td><strong>95% CI</strong></td>
<td><strong>p-Value</strong></td>
<td><strong>aOR</strong></td>
</tr>
<tr>
<td><strong>Demographics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.98</td>
<td>0.97–0.99</td>
<td><strong>&lt;0.001</strong></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>Ref</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Person of color</td>
<td>0.87</td>
<td>0.65–1.16</td>
<td>0.33</td>
</tr>
<tr>
<td><strong>Gender identity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfeminine spectrum</td>
<td>Ref</td>
<td>—</td>
<td>—</td>
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<td>Transmasculine spectrum</td>
<td>0.82</td>
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<td><strong>Education</strong></td>
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<td>1.36</td>
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<td>Yes</td>
<td>1.03</td>
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<td><strong>Annual household income</strong></td>
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<td>&lt;$35,000</td>
<td>1.64</td>
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<td>$35,000 or more</td>
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<tr>
<td><strong>Insurance type</strong></td>
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<td>—</td>
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<tr>
<td>Private</td>
<td>2.89</td>
<td>1.80–4.63</td>
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<td>None</td>
<td>1.54</td>
<td>1.20–1.97</td>
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<td><strong>Mental health coverage</strong></td>
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<tr>
<td>Yes</td>
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<td>—</td>
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<tr>
<td>No</td>
<td>2.94</td>
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<td><strong>&lt;0.001</strong></td>
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<td>Yes</td>
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<td>1.43–2.43</td>
<td><strong>&lt;0.001</strong></td>
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<td>1.45</td>
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<td>0.88</td>
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<td>Yes</td>
<td>Ref</td>
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<td>No</td>
<td>1.58</td>
<td>Ref, 2.50</td>
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<td>Socially transitioned—lifetime</td>
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<td>Yes</td>
<td>1.33</td>
<td>1.01–1.74</td>
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<td><strong>Medical transition-related care accessed—lifetime</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Hormones</td>
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<td></td>
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<td>Ref</td>
<td>—</td>
<td>—</td>
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<tr>
<td>Yes</td>
<td>0.96</td>
<td>0.89–1.04</td>
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<tr>
<td>Breast or chest surgeries</td>
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<td></td>
<td></td>
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<tr>
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<td>Ref</td>
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the role of health literacy in access to transition-related care for transgender patient populations.

In addition to individual- and structural-level barriers to accessing transition-related care, many participants reported recent negative interpersonal healthcare experiences. One quarter of the sample reported healthcare discrimination, 32.1% reported having to teach their provider about transgender care, and 5.8% reported that a healthcare provider had refused to treat them in the past year. Discrimination, teaching one’s provider, and care refusal were associated with a 1.69–3.69 elevated odds of being unable to access transition-related care. One possible explanation for these findings is that transgender people face mistreatment in healthcare settings, which may impact their ability to access transition-related services due to healthcare refusal or subsequent avoidance of healthcare due to anticipated healthcare discrimination. At the time the survey was conducted in 2013, no state-level healthcare protections existed for transgender people. Given the more recent passage of state-level protections, future research should assess the current prevalence of healthcare discrimination among transgender residents of Massachusetts and whether the association between discrimination and access to transition-related services persists or has decreased in magnitude. Efforts should also be made to enforce healthcare nondiscrimination policies and encourage the reporting of healthcare discrimination at the healthcare delivery level (e.g., healthcare clinics, hospitals) and governmental level (e.g., Health and Human Services office of civil rights), to improve access to quality gender affirmative care for transgender patients.

Finally, in a multivariable model, having socially transitioned (i.e., living full time) was not associated with access to care; however, being visually conforming was protective against an inability to access transition-related care relative to lower visually gender conforming transgender individuals who are less visually conforming have a higher probability of experiencing discrimination than those who are more gender conforming and that discrimination experiences are associated with avoidance of preventative and urgent healthcare.

Table 2. Bivariate and Multivariable Logistic Regression Analyses Examining Associations Among Demographics, Insurance Coverage, Healthcare Experiences, and Ability to Access Transition-Related Care in the Past 12 Months in a Sample of Transgender Adults in Massachusetts (n=364)

| Outcome: unable to access transition-related care—past 12 months | Bivariate | | | | | Multivariable |
|---|---|---|---|---|---|
| | OR | 95% CI | p-Value | aOR | 95% CI | p-Value |
| Yes | 0.99 | 0.90–1.08 | 0.81 | — | — | — |
| Abdominal surgeries | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 0.96 | 0.86–1.07 | 0.46 | — | — | — |
| Gender confirmation surgery | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 0.82 | 0.84–1.02 | 0.11 | — | — | — |
| Other surgeries or services | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 0.93 | 0.83–1.03 | 0.18 | — | — | — |
| Visual gender conforming—current | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 0.62 | 0.47–0.81 | <0.001 | 0.62 | 0.46–0.84 | 0.002 |
| Healthcare experiences and consequences—past 12 months | | | | | | |
| Presented as transgender when accessing healthcare | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 0.67 | 0.52–0.86 | 0.002 | 0.52 | 0.38–0.72 | <0.001 |
| Taught provider about transgender care | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 2.57 | 2.06–3.22 | <0.001 | 1.90 | 1.45–2.49 | <0.001 |
| Experienced discrimination | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 2.23 | 1.77–2.82 | <0.001 | 1.67 | 1.27–2.19 | <0.001 |
| Provider refused to treat | | | | | | |
| No | Ref | — | — | — | — | — |
| Yes | 6.01 | 3.99–9.06 | <0.001 | 3.69 | 2.32–5.87 | <0.001 |

*p < 0.05; Bolded text = significant at the *p* < 0.05 level.

aBlack (non-Hispanic), Hispanic, multiracial, and other.
aOR, adjusted odds ratio (adjusted for survey mode); CI, confidence interval.
conforming people likely reflects both less care refusal on the part of providers, as well as less care avoidance by patients; longitudinal data are needed to explore the ordering of these experiences and their interrelationships over time. In addition, presenting as transgender when accessing care was protective against an inability to access transition-related care. Given that nearly 80% of the sample disclosed their transgender history (either verbally or visually) when accessing healthcare, our findings suggest that transgender individuals in our sample felt comfortable presenting as transgender and/or were highly motivated to do so regardless of the risk of mistreatment. Healthcare providers play an essential role in creating safe and welcoming clinical environments for transgender individuals where they can feel comfortable disclosing their transgender history. Thus, efforts must be made to ensure providers’ cultural and clinical competence to care for transgender patients to facilitate patient disclosure of their transgender history and, ultimately, enable access to care. Future mixed-methods research would benefit from examining facilitators and barriers to presenting as transgender, and differences by gender conformity, to identify intervention targets to increase access to transition-related care for transgender individuals who desire to medically affirm their gender.

This study has several limitations. First, convenience sampling was used to identify a statewide sample of transgender residents of Massachusetts; findings may not be generalizable to all transgender adults in Massachusetts or other areas of the country. Second, this observational study utilized cross-sectional data, thus causal inferences cannot be made. Third, participants were asked whether they had “presented” as transgender when accessing care, which could entail verbally disclosing one’s transgender identity to a provider or visually disclosing one’s transgender identity vis-à-vis one’s nonconforming gender expression. In addition, transgender participants in our sample had diverse racial/ethnic backgrounds and gender identities; however, due to low prevalence of transgender people from specific racial/ethnic groups (e.g., “other race/ethnicity”) and gender identity groups (e.g., nonbinary/gender nonconforming male assigned sex at birth) in our sample, race and gender were collapsed into dichotomous variables (i.e., White Non-Hispanic vs. POC; Transmasculine Spectrum vs. Transfeminine Spectrum). These binary specifications may have obscured the unique healthcare access challenges of particular subgroups of racial and gender minorities. In addition, while the present study assessed social gender transition, participants were not asked about whether or not they had changed their name or gender marker on their insurance documents. Future research should assess verbal and visual disclosure separately, oversample racial/ethnic minorities and nonbinary individuals, and assess transition-related changes on insurance documents to better characterize multilevel risk factors for access to care challenges among transgender people. Finally, the present study utilized quantitative methods to evaluate access to care, which did not allow for nuanced exploration of the contexts shaping access to care barriers. Future research would benefit from utilizing mixed-methods approaches to characterize access to transition-related services to develop interventions that are responsive to the various healthcare barriers faced by transgender people.

This study found that approximately one quarter of the transgender individuals sampled were unable to access transition-related care in the last 12 months. Age, income, education, insurance coverage, and healthcare discrimination were identified as key factors associated with being unable to access transition-related care among transgender adults in Massachusetts. United States Healthy People 2020 aims to “improve the health, safety, and well-being of lesbian, gay, bisexual, and transgender individuals.” By identifying individual-, interpersonal-, and structural-level factors where access-to-care barriers exist and persist, this study paves the way for the development of targeted public health research, programming, and intervention efforts to reach underserved transgender individuals to promote transgender health equity.

Acknowledgments

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Jaclyn M. White Hughto, MPH and Sari L. Reisner are associated with The Fenway Institute, Fenway Health.

Adam J. Rose is associated with RAND Corporation.

John E. Pachankis is associated with the Chronic Disease Epidemiology department of Yale School of Public Health.

This article first appeared in Transgender Health by Mary Ann Liebert, Inc. and is republished here under a Creative Commons license. https://www.liebertpub.com/doi/10.1089/trgh.2017.0014

References:


8. CruzTM. Assessing access to care for transgender and gender nonconforming people: a consideration of diversity in


CMS Proposes Regulation to Alleviate State Burden
Proposed rule furthers President Trump’s commitment to “cutting the red tape” by relieving states of burdensome paperwork requirements. The Centers for Medicare & Medicaid Services (CMS) issued a notice of proposed rulemaking (NPRM) that would provide state flexibility from certain regulatory access to care requirements within the Medicaid program. Specifically, the NPRM would exempt states from requirements to analyze certain data and monitor access when the vast majority of their covered lives receive services through managed care plans. CMS regulations separately provide for access requirements in managed care programs... Read more at goo.gl/R8RF1c

Trump Administration Announces MyHealthEData Initiative to Put Patients at the Center of the US Healthcare System
Centers for Medicare & Medicaid Services (CMS) Administrator Seema Verma announced a new Trump Administration initiative – MyHealthEData – to empower patients by giving them control of their healthcare data, and allowing it to follow them through their healthcare journey. Last year President Trump issued an Executive Order to Promote Healthcare Choice and Competition Across the United States. In response the Administration is moving towards a system in which patients have control of their data and can take it with them from doctor to doctor, or to their other healthcare providers. The government-wide MyHealthEData... Read more at goo.gl/uGGsdU

CMS Finalizes Coverage of Next Generation Sequencing Tests, Ensuring Enhanced Access for Cancer Patients
The Centers for Medicare & Medicaid Services (CMS) took action to advance innovative personalized medicine for Medicare patients with cancer. CMS finalized a National Coverage Determination that covers diagnostic laboratory tests using Next Generation Sequencing (NGS) for patients with advanced cancer (i.e., recurrent, metastatic, relapsed, refractory, or stages III or IV cancer). CMS believes when these tests are used as a companion diagnostic to identify patients with certain genetic mutations that may benefit from U.S. Food and Drug Administration (FDA)-approved treatments, these tests can assist... Read more at goo.gl/rdx35x

H7N9 Influenza Vaccine Clinical Trials Begin
Two new clinical trials testing an experimental vaccine to prevent influenza caused by an H7N9 influenza virus are now enrolling volunteers at sites across the United States. The Phase 2 studies, sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH), will test different dosages of the inactivated influenza vaccine candidate (called 2017 H7N9 IIV) as well as different vaccination schedules. The studies also will evaluate whether an adjuvant boosts the immune responses of people receiving the vaccine. H7N9 is an avian (bird) influenza virus first reported in humans... Read more at goo.gl/okLcsB

FDA Authorizes First Fully Interoperable Continuous Glucose Monitoring System, Streamlines Review Pathway for Similar Devices
The U.S. Food and Drug Administration today permitted marketing of the Dexcom G6 integrated continuous glucose monitoring (iCGM) system for determining blood glucose (sugar) levels in children aged two and older and adults with diabetes. This is the first type of continuous glucose monitoring system permitted by the agency to be used as part of an integrated system with other compatible medical devices and electronic interfaces, which may include automated insulin dosing systems, insulin pumps... Read more at goo.gl/rbV4zw

FDA Approves New HIV Treatment for Patients Who Have Limited Treatment Options
Today, the U.S. Food and Drug Administration approved Trogarzo (ibalizumab-uiyk), a new type of antiretroviral medication for adult patients living with HIV who have tried multiple HIV medications in the past (heavily treatment-experienced) and whose HIV infections cannot be successfully treated with other currently available therapies (multidrug resistant HIV, or MDR HIV). Trogarzo is administered intravenously once every 14 days by a trained medical professional and used in combination with other antiretroviral medications. “While most patients living with HIV can be successfully treated using a combination of two... Read more at goo.gl/xN2mGi
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University of Rochester,
School of Nursing
Uroplasty, Inc.
Woundtech

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Amy Carson, RN, CMCN
Deborah Chambers, RN, CMCN
Jeffrey Crofoot, RN, CMCN
Pennie A. Dee, LPN, CMCN
Teresa E. Dingus, RN, CMCN
Renee C. Dover, RN, CMCN
Amanda M. Fink, RN, CMCN
Maggie Gonzales, RN, CMCN
Lori A. Howe, RN, CMCN
Leah Jacoby, RN, BSN, CMCN
Karen Johns-Smith, RN, CMCN
Lauretta S. Jones, LVN, CMCN
Riaz A. Kanji, RN, CMCN
Billie W. Lang, RN-BC, CMCN
Jennifer Lott, LPN, CMCN

Aria Magwood, LPN, CMCN
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Sherry Wainwright, LPN, CMCN
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Anita Baker, AHP
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Kellie Brown, RN
Nancy Brunner, RN
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Martha Embry, United Health Care
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**I. Original Articles**

1. Each article should clearly state a problem or challenge facing today’s healthcare environment, discussion of possible strategies for solution or implementation, and reach a conclusion. Solutions or implementation strategies are expected to be reasonable, original thoughts supported by data. All statistical data and information not public knowledge should be referenced from a reliable literary source.

2. Articles should be relevant to United States managed care, and have sound and timely references.

3. Articles can include topics of interest focusing on employee or worker-type concerns relevant to membership such as work-life balancing, reducing stress, managing personal responsibilities, avoiding burn-out, dual-role caregiving of parents and children issues, managing technologies and social medias, etc.

4. No articles that endorse services or products should be submitted.

**II. Editorial Review and Processing**

1. Peer Review: All articles submitted will be reviewed by the Editorial Review Board. Peer-reviewer identities and author identities are kept confidential during this process.

2. Rejected articles will not be returned to authors unless specifically requested by the author in advance. Original illustrations, photographs, and slides will be returned.

3. Editing: Accepted articles are copy-edited for style, grammar, clarity, and length. At the editor’s discretion, particularly if substantive changes are made, articles may be returned to author for final review. Authors are responsible for all statements made in their work, including changes made by the editors and authorized by the author.
III. Article Preparation

1. Biography: Every article should include a brief biography of the author(s) (< 50 words) including academic/corporate affiliations. The name of the author(s) should be bold face and include academic degrees as follows:
Natalie Irish, RN, MSN, CMCN (etc.)

2. Abstract: JMCN abstract style includes a one or two paragraph “Summary” followed by “Key Points,” a series of quick-read bulleted items. The total word count should be no more than 275 words.

3. Headings
“A” heads should be in bold face, flush left and initial caps.
“B” heads should be in bold/italic face, flush left and initial caps.
“C” heads should be underlined, flush left and lower case.

4. References: References should be double-spaced and consecutively numbered as they are cited in the text (the number of the reference should appear in superscript within the text). The article should be fully referenced within the text. References in incorrect format could be grounds for rejection of the article. If you need assistance in producing correct references, the editorial staff will be happy to answer any questions. References should follow the format of the AMA Manual of Style, 10th edition. Sample references are as follows:

Books


Articles


5. Exhibits: Tables and figures should be typed and consecutively numbered as they are cited in the text. Each table and figure should have a title. Title should be flush left, in bold face with initial caps. Source for the table or figure should be identified in the title with a superscript number and be listed as a reference.

Exhibit 1. Number of Inhabitants Per Region in France³

<table>
<thead>
<tr>
<th>Region</th>
<th>Male Population</th>
<th>Female Population</th>
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</thead>
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<tr>
<td>Bordeaux</td>
<td>14,000</td>
<td>15,000</td>
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<tr>
<td>Bourgogne</td>
<td>120,000</td>
<td>234,000</td>
</tr>
</tbody>
</table>
6. **Abbreviations and Acronyms:** On first reference, spell out the word and place the abbreviation or acronym in parentheses. Verify correct usage of all abbreviations and acronyms.

7. **Drug Names:** In general, use generic names for drugs. If the author wishes, the brand name may be included in parentheses when the generic name is mentioned for the first time. Drug names should be initial caps only. If the article is CE approved, the author must work with the AAMCN CE committee to complete all processes required by AAMCN and the American Nurses Credentialing Center (ANCC). Please contact us for more information.

8. **Punctuation & Miscellaneous:**
   - Use commas to separate elements in a series, and also use the serial comma before the conjunction (e.g., patients, physicians, and medical providers)
   - Indent bullet points
   - Spell out numbers under 10. Use numerals for 10 and higher (e.g., The study results indicated that six persons were salt-sensitive; out of the 120 patients studied, six were insulin-resistant).
   - Always spell out numbers at the beginning of a sentence (e.g., Twenty-five of the 30 patients enrolled suffered from hypertension).
   - Spell out the word “percent” vs. using the symbol (%) in text (e.g., 50 percent of the population) The percent symbol is acceptable in tables and figures.
   - Use initial caps vs. all caps for company names (e.g., Lederle Laboratories).
   - Do not use hyphens between numbers within the text. (e.g., 12 to 16 patients; not 12-16 patients).

**IV. Submission Checklist**

All article submissions should include the following elements:
- The author(s) short biography
- Article summary and key points
- Contact numbers (phone and fax), complete mailing address, and e-mail address for designated corresponding author. This information should appear on the title page, along with the word count for the article and any acknowledgments for research and/or project support.
- Electronic version of the article as a Word Document or Rich Text Document emailed or sent by DropBox to April Snyder at asnyder@aamcn.org.

**Journal of Managed Care Nursing**

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