



# PRIMARY CARE

INTERPROFESSIONAL COLLABORATIVE PRACTICE

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BUTTARO: PRIMARY CARE: INTERPROFESSIONAL COLLABORATIVE

PRACTICE, SIXTH EDITION

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ISBN: 978-0-323-57015-2

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Library of Congress Control Number: 2019953331

Executive Content Strategist: Lee Henderson Senior Content Development Specialist: Heather Bays Publishing Services Manager: Julie Eddy Senior Project Manager: Cindy Thoms Design Direction: Renee Duenow

Printed in China

Last digit is the print number: 9 8 7 6 5 4 3 2 1



#### A Special Tribute

To JoAnn Trybulski, a teacher, a mentor, a colleague, a friend. We miss her laughter, her generosity, and her willingness to give everyone the benefit of the doubt. Mainly we miss her!





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#### **Preface**

Since the first edition of *Primary Care: A Collaborative Practice*, our vision has been to emphasize the value of professionals working together to improve patient care and well-being. In the past twenty years, hundreds of healthcare professionals from a wide geographic range have shared that vision and worked jointly with us and others in this intellectual endeavor. We are now acknowledging this work by changing the title of the book to *Primary Care: Interprofessional Collaborative Practice* to clearly state our commitment to collaborative practice.

We, as editors, work together respecting one another's unique talents and strengths, solving problems together, just as healthcare professionals do each day. In the clinical setting collaboration is the essence of interprofessional care, and team-based care is a fundamental component of complex care management. Most important, though, is the collaborative partnership between patient and provider. These relationships are the foundation of high-performing primary care practices.

#### **NEW CHAPTERS**

In the sixth edition of this text we have added new chapters and expanded on others. In Chapter 1, we address the challenges and opportunities of interprofessional collaboration in a turbulent health care environment. Patient-centered care, quality care objectives, and the changing landscape of primary care are explored. Chapter 2, Translating Research into Clinical Practice, addresses the relationship of primary care to research initiatives and how research translates and impacts clinical practice. The increasing incidence of chronic illness and the growing responsibilities of caring for patients across the continuum of care are discussed in Chapter 4, Coordinated Chronic Care. Our hope in providing this chapter is that understanding the challenges that patients and families face when entering or leaving a healthcare facility will aid in preventing adverse events, stress, and re-hospitalizations. In chapter 5, Introduction to Health Literacy, Health Care Disparities, and Culturally Responsive Primary Care, the disparities in care experienced by specific at risk populations and other factors impacting patient health are explored.

Other new chapters are included in the sixth edition. Each of these chapters recognizes aspects of clinical practice that are fundamental yet at times perhaps not fully considered. Because many of our patients prefer a more holistic approach to health and well-being, we have added a Wellness Chapter that explores the scope of wellness and recommended interventions. This edition also recognizes the serious issues associated with human trafficking (Chapter 12) and some of the health issues that are associated with this hidden, criminal and exploitive trend. Information about alternative therapies in which many patients and caregivers are interested are mentioned in the individual clinical chapters enabling nurse practitioners and other primary care providers to more fully understand the risks and benefits of the supplements and alternative approaches that patients are using. *Risk Management*, Chapter 8, identifies

the attitudes and relationship skills in healthcare settings that can positively or negatively impact the patient's perceptions of the patient-provider relationship. The chapter author addresses the legal risks inherent in practice and recommends strategies to improve care, patient satisfaction, and risk management. LGBTQ Patient Care reflects the editors' concern about disparities in healthcare, with the hope that the information in this chapter will aid all of us in improving care for all patients.

#### **FORMAT**

The format of the sixth edition of Primary Care: Interprofessional Collaborative Practice is purposefully similar to the systematic approach used in primary care practice and is designed and organized to promote improved clinical reasoning skills. Each section is an important building block in the assessment and diagnosis of each patient's presentation. Understanding the Epidemiology and Pathophysiology of illness is integral to understanding a patient's symptoms and the consideration of possible causes. The Clinical Presentation and Physical Examination sections in each chapter address the cognitive, physical, or psychosocial features and physical exam findings that can be associated with the patient's complaint. Attention to the patient's concerns and detection of pertinent positive and negative findings are the clues that create the list of possible Differential Diagnoses. The Differential Diagnosis requires clinical reasoning, a decision-making process that considers the "do not miss" differentials, and helps determine the most likely diagnosis and necessary Diagnostics. To aid in this process, the Differential Diagnosis sections discuss the possible differentials, and the Diagnostics boxes list the appropriate essential tests that should be considered. These include initial tests (tests that may be performed in the office setting, such as peak flow measurement or pulse oximetry), laboratory tests, imaging studies (radiographic, ultrasound, nuclear, or magnetic resonance imaging), or other miscellaneous studies that may be necessary in the evaluation of the disorder (such as EEGs or biopsies). Because the clinical presentation differs with each patient, not all diagnostic tests listed may be necessary in each circumstance. An asterisk is placed beside those tests that may be indicated by clinical presentation and physical examination findings. For more detailed information, the reader should refer to the "Diagnostics" and "Differential Diagnosis" sections included with each disorder.

The Management section of each chapter addresses goals of treatment and therapeutic interventions based on current evidence and guidelines. Pharmacologic agents are included, as are recommendations for non-pharmacologic therapies. The management sections make every attempt to incorporate the research contributions that create an evidence base for practice. Authoritative management guidelines, as well as current ongoing research findings, are incorporated whenever available. As with any evolving science, recommendations can be in a state of flux. Management recommendations may change, and

new recommendations for practice supersede the management recommendations presented in this textbook. In addition, the reader is directed to check drug indications, dosages, and potential drug-drug interactions in medication product information before prescribing or administering any medication.

Complications associated with the disease and treatments are described, and clear recommendations for Patient and Family Education are included throughout the textbook. This information is crucial in promoting health literacy and assisting healthcare providers in interpreting information about the illness and management to patients and caregivers.

This edition continues to provide clear guidelines for referrals, and the Emergency and Physician Referral Icons highlight conditions that may require immediate consultation. The reader should be aware that more comprehensive referral or consultation criteria are contained in the text of the chapters that contain these special icons. The reader should also realize that the emergency icons might not represent all of the conditions requiring emergency referral. The editors are also aware that experienced providers may not require consultation for all the specified circumstances. In addition, state practice regulations may mandate referral under certain circumstances; these regulations supersede any consultation recommendations detailed in this text.

The sixth edition again provides a collection of Instructor Resources on an Evolve website (http://evolve.elsevier.com/Buttaro), available via your Elsevier Education Solutions Consultant for programs adopting classroom quantities of the book. The Instructor Resources consist of a Test Bank, Power-Point Collection, and Image Collection. The Test Bank includes approximately 685 test items delivered in Evolve Assessment Manager for easy exam construction and administration. The Power-Point Collection consists of approximately 685 slides for classroom or online instruction. The Image Collection includes all original images from the textbook. We trust that these frequently requested resources will help to facilitate high-quality instruction of Nurse Practitioner students.

#### THE FUTURE

It is evident that an aging population, globalization, science, and technology continue to impact healthcare and clinical practice. An aging population with multiple co-morbidities has already impacted healthcare expenditures and unless we are able to identify and control these diseases earlier and effectively, morbidity, mortality, and healthcare costs will continue to rise. Global travel and an increase in transnational businesses have increased the risk of disease spread and the importance of vigilant awareness of global threats to the public health. Every day, scientific breakthroughs affect disease management, healthcare quality, and health information management. It is clear that to meet the healthcare needs of the future, innovative technology will be needed to relieve the cognitive burden created by these new discoveries. It is the editors' hope that Primary Care: Interprofessional Collaborative Practice, will provide a solid foundation on which tomorrow's primary care providers can help patients to lead increasingly healthy lives.

#### **ACKNOWLEDGMENTS**

This textbook represents a strong collaborative effort. We remain indebted to our contributors, past and present. They generously provided their time and expertise to make this textbook the trusted resource that it is. We welcome and are appreciative of the contributions made by our patients, students, and colleagues. We continue to try to incorporate their suggestions to make this book a useful one for students and practicing clinicians alike.

We greatly appreciate the support of everyone at Elsevier. Still, we are particularly thankful for the guidance of Heather Bays throughout the editing and production process, and for Lee Henderson, who encouraged us through the fourth, fifth, and now the sixth edition.

Finally, our families, friends, and colleagues deserve our eternal thanks. Their patience and understanding throughout this endeavor is greatly appreciated!

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### Introduction

CHAPTER

# INTERPROFESSIONAL COLLABORATIVE PRACTICE: WHERE WE ARE TODAY

Terry Mahan Buttaro • Joanne Sandberg-Cook

We continue to live and work in a world of volatility, uncertainty, complexity, and ambiguity (VUCA). Based on theories developed by Warren Bennis and Burt Nanus to characterize the world at large, VUCA is certainly applicable to the current state of interprofessional collaborative practice and primary care.1 Primary care practice with well-defined rules and roles, time for each patient, fewer documentation requirements, and lower costs has been replaced by new rules, complicated insurance, and new types of health care professionals. There is unchallenged recognition of the importance of an evidence base for practice decisions, disease prevention, health promotion, maintenance of well-being, involvement of patients in their health decisions, and coordination of care given by a team of health care providers. Interprofessional collaboration throughout the continuum of care is essential for successful, cost-effective care. However, the American health care system is increasingly challenged by (1) an aging population with multiple chronic conditions that often require several (expensive) medications, (2) inadequate financial and social resources, and (3) health care providers pressed for time and resources. The medical workforce is also aging and retiring, leaving gaps in the provision of service and increased demands on those remaining practitioners. Provisions of the Affordable Care Act are constantly challenged, with a resultant decrease in coverage for many people who initially benefited. This is especially true in states that refused to expand Medicaid, those states that instituted new requirements for work in order to qualify for Medicaid benefits, or in those that have removed the preexisting condition clause.<sup>2</sup> The type of insurance and policy level carried by a patient and family can determine the health care providers and hospitals where a patient or family member can receive covered care, diagnostics, medications, and other prescribed treatments. The current landscape of primary care is in a constant state of chaos with patients at the center.

### CURRENT FORCES SHAPING THE PRIMARY CARE LANDSCAPE

#### **Evidence-Based Practice**

The evidence-based practice (EBP) movement is especially relevant for primary care providers (PCPs). Research findings

inform health care practice across the transitions of care. In primary care, clinical practice guidelines, best practice, and the accessibility of information technology (IT) at our fingertips promote a culture of EBP providing resources to improve patient outcomes. Guidelines are also increasingly updated more frequently contributing to standardized evidence-based care. Insurers use this information to create reimbursement structures, driving providers and patients to treatments that have been found to be efficacious and cost effective, based on available evidence as opposed to those that provide no benefit. See Chapter 2, Translating Research into Clinical Practice, for background on how clinical evidence is created, evaluated, and disseminated.

#### **Value-Based Purchasing**

Value-based purchasing (VBP)<sup>3</sup> is a Centers for Medicare and Medicaid Services (CMS) initiative that affects all providers who practice in or admit Medicare patients to a hospital setting. VBP is part of the Affordable Care Act of 2009; its goal is improving care quality by linking payment by the CMS for inpatient services to successful outcome measures. VBP measures hospital performance on an approved set of measures grouped into four domain areas of care: safety, clinical care, efficiency and cost reduction, and patient- and caregiver-centered experience of care/care coordination (to be renamed person and community engagement as of fiscal year 2019). Private insurers are using similar metrics when negotiating contracts with institutions and PCPs. We have entered a "pay for performance" world where contracts are negotiated based on quality metrics. As a result, the field of practice analytics has arisen. There are currently sophisticated computer programs modeling financial opportunities for hospital service lines and individual health care practices based on payer mix per-case cost and contribution margin. Providers currently have a crucial opportunity along with inpatient care management to affect not only the quality of care delivered to their patients but also the financial state of organizations in which their patients receive care, as well as their own financial opportunities.

#### **Management of Care Transitions**

VBP is further shaping primary care delivery by reducing Medicare payments for all patients by a small percentage in a hospital where the unplanned readmission rate within 30 days of discharge exceeds the hospital's expected rate for patients with the selected conditions of acute MI, heart failure, coronary artery bypass graft surgery, pneumonia, chronic obstructive pulmonary disease (COPD), hip arthroplasty, and knee arthroplasty.<sup>4</sup> This program, known as Hospital Readmissions Reduction Program (HRRP), provides hospitals with a financial incentive to improve their communication and care

coordination and work more successfully with patients and caregivers on post-discharge planning.<sup>4</sup>

This new reality highlights the importance of managing care transitions, particularly the transition from inpatient care to home. Interprofessional collaboration and communication facilitates these transitions. Many institutions have created transitional care teams, others make post discharge phone calls, and some make post-discharge home visits often by nurses or nurse practitioners. See Chapter 4, Coordinated Chronic Care, for a more in-depth exploration.

#### PATIENT-CENTERED MEDICAL HOME

The Institute of Medicine (IOM) has developed a commonly accepted definition of primary care which is as follows: "Primary care is the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community." The term *integrated* in the IOM definition encompasses "the provision of comprehensive, coordinated, and continuous services that provide a seamless process of care." Using the six aims of patient-centered care as a framework gives providers easily measurable care goals resulting in improved care. Primary care should be:

- Safe: Avoiding harm to patients from the care that is intended to help them.
- Effective: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- Patient centered: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- Timely: Reducing waits and sometimes harmful delays for both those who receive and those who give care.
- Efficient: Avoiding waste, including waste of equipment, supplies, ideas, and energy.
- Equitable: Providing care that does not vary in quality because of personal characteristics such as race, gender identity, gender, sexual orientation, ethnicity, geographic location, or socioeconomic status.

The patient-centered medical home model of patient care meets each of the aforementioned aims using a team approach with continuous participation of the patient and where appropriate, the family. This model provides increased access to medical providers and coordinated care between providers. The goal of the patient-centered medical home (PCMH) is to coordinate health care for a patient, prevent possible medical situations from arising, and provide increased quality and safety of medical care by approved practitioners. The model requires considerable practice resources and is often not appropriately reimbursed.

#### **Accountable Care Organizations**

Accountable Care Organizations (ACOs) are groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high-quality care to the Medicare patients they serve. Coordinated care helps ensure that patients, especially the chronically ill, get the right care at the right time, with the goal of avoiding unnecessary duplication of services and preventing medical errors. When an ACO succeeds

in both delivering high-quality care and spending health care dollars more wisely, it will share in the savings it achieves for the Medicare program." The vision of primary care as a collaborative practice is realized with the advent of ACOs, which potentially form the centerpiece of health care reform efforts. There are multiple models for ACOs, including one that defines an ACO as a group of patient-centered medical homes (see earlier) resulting in a medical "neighborhood." There are three levels, or tiers, of an ACO, each with its distinct requirements for organizational structure, performance measures, IT requirements, and payment models.

Level 1 ACOs have the least amount of financial risk and fewest requirements. The organization's structure may be just a legal entity, and the ACO may have the IT capability to track a limited number of performance measures. Level 1 ACOs receive shared savings bonuses based on achievement of benchmarks for quality measures and expenditures.<sup>9</sup>

Level 2 ACOs have the potential to capture a greater portion of below-target spending amounts but have accountability for above-budget spending. The level 2 ACO has an evolved infrastructure, with advanced IT systems and care coordination for chronic diseases such as asthma, diabetes, and heart failure. Performance measures are linked to outcomes for chronic diseases and reduction in health risks. These organizations must make financial projections and have minimum cash reserve standards.<sup>9</sup>

Level 3 ACOs offer a full range of services and have the infrastructure to provide comprehensive health care services. They have electronic medical records (EMRs) linking all components and report on health-related outcomes, care experiences, and quality of life in multiple patient populations in the system. Level 3 ACOs have strict requirements for financial reporting and maintain larger cash reserves.<sup>9</sup>

High-quality primary care is essential to the success of ACOs. In addition, there must be sufficient technical capability and support, innovation in payment and reimbursement systems (bundled payments), and establishment of performance measures using practice analytics that reflect improved health state in patients, all of which can be a financial burden for smaller practices. In an ACO, there are care navigators to assist patients with care access and sophisticated technology to communicate with and monitor patients. Nurses have various roles—system administrators, service line managers, practice managers, case managers, PCPs, educators, and home health providers. Recent studies have demonstrated shorter hospital stays, decreased readmission rates, and decreased Medicare spending when patients are a part of an ACO.10 The downside may be that many community practices do not have the financial resources or enough patients to statistically reflect improvement in care and cost savings. When smaller practices join together to form a super ACO the patient numbers increase and cost savings become measurable.11

The super ACO alliance is created to expand the reach of the smaller systems in the alliance to create initiatives that enhance the care experience for patients and providers, control costs, and maximize reimbursement potential.<sup>12</sup>

#### **NEW LOOK OF PRIMARY CARE**

In a 2014 survey conducted by the Advisory Board Company, 4000 consumers were asked questions about primary care preferences. Patients' preferences for low-acuity complaints in primary care included 24/7 access to care, a walk-in setting

with the ability to be seen within 30 minutes, and close proximity to home.<sup>13</sup> The retail health movement, with urgent care walk-in clinics associated with pharmacy chains and department stores, is currently an accepted component of the health care delivery system and is part of the new look of primary care. Retail clinics have expanded services beyond minor acute emergencies and currently include several components of primary care (e.g., annual physicals, some chronic disease management, and medispa services) in response to documented patient preferences for close proximity to home and readily accessible primary care. 13 Primary care practices are responding to this emerging trend by opening urgent care centers, some in and near retail locations that are linked to the primary care practices, providing needed care continuity while meeting patient preferences. Other previously traditional primary care practices have converted to direct primary care or concierge practices, where patients pay an additional yearly fee directly to the practice for 24/7 rapid access to the PCP and house calls.

The new look of primary care has spawned new collaborative health care partner roles. As older physicians retire, primary care will be increasingly delivered by nurse practitioners and physician assistants. Many health care systems have community health resource specialists, sometimes called community workers, who assist patients with obtaining a variety services, care navigators who help patients with coordinating care appointments and services, and practice-based clinical pharmacists who assist both providers and patients with medication regimens. Community and parish nurses provide care coordination and education especially helpful during care transitions and provide primary care coordination to frail elders and others in need of support. Emergency medical services (EMS) providers in some communities now participate in the delivery of primary care and preventive services such as falls risk home evaluations and basic health monitoring. Community nurses, community workers, and community first responders not only monitor patients identified as high risk by hospitals and medical practices but also provide valuable community and individual social and demographic information to referring institutions.

### CHALLENGES AND OPPORTUNITIES Opioid Crisis

The opioid crisis in America continues to escalate, with 72,000 overdose deaths (200/day) in 2017. This number of deaths is more than the number who died in the Vietnam and Iraq wars combined. The escalating crisis can be partially blamed on poor access to addiction treatment, with only approximately 20% of those who would benefit actually getting the care. The number of overdose deaths is currently so high that for the first time since the 1960s the average age of death has decreased.<sup>14</sup>

PCPs including NPs and PAs are in the perfect position to relieve the crisis, but there are barriers and myths to overcome. Currently federal law requires time-consuming training and limited PCP access to medications that are proven to reduce overdose deaths (e.g., buprenorphine, methadone, and naltrexone). Other barriers which may prevent more PCPs from in-office addiction care include the erroneous belief that drugs such as methadone and buprenorphine substitute one addiction for another, that detox and rehab work are more successful options, that reducing the number of opioid prescriptions written will reduce overdoses (patients turn to the illicit market increasing the risk), and that in-office addiction treatment is

time consuming and burdensome (protocols are the likely solution to this concern).<sup>15</sup>

Enlisting PCPs and relaxing access to training and life-saving addiction medications will be a straightforward and achievable first step in addressing the crisis and reducing overdose deaths.

### Advanced Practice Registered Nurse Compact License Movement

In May 2015, the National Council of State Boards of Nursing (NCSBN) took an unprecedented step forward in potentially shaping the landscape of primary care. The NCSBN created rules and a model for the advanced practice registered nurse (APRN) Compact legislation, modeled after the successful nurse compact model, currently in effect in 25 states. 16 The purpose of the APRN Compact is to allow APRNs within the compact states who meet the compact requirements to obtain a multistate license, thereby expanding advanced nursing practice and mobility for APRNs, fostering the use of technologies to monitor and communicate with patients, and increasing the safety of and access to health care. The proposed legislation under the compact mode includes provisions for independent APRN practice and prescriptive authority for controlled substances but can be implemented only when 10 states have enacted this legislation. 16 There is ongoing discussion about a similar compact model for medical licenses. PCPs interested in fostering collaborative efforts to increase access to high-quality health care should advocate for legislation to make the APRN Compact license a reality.

#### Building Interprofessional Collaborative Practice Initiatives

Interprofessional collaboration is a crucial element in the current changing health care landscape. Collaboration is a requirement for funding in research and program support. Collaborative research is exponentially productive because it combines resources, expertise, and thinking in the creation of knowledge for practice and should include a focus on patient outcomes. Collaborative leadership of health care initiatives allows more individuals to participate, and the outcome derives from a collective of minds. Collaboration in clinical practice offers improved quality of care for patients and significant others as professionals share expertise.

The Interprofessional Education Collaborative (IPEC), composed of representatives from the major care delivery disciplines in health care, models collaboration that is advancing the practice.<sup>17</sup> An IPEC expert panel produced guidelines for collaborative practice core competencies that begin with interprofessional education to enable collaboration and improve outcomes. The IPEC report advocates for components of professional education of the various disciples to occur together, in interprofessional teams, to build the core collaboration competencies of values and ethics needed for interprofessional practice, roles and responsibilities in collaborative practice, interprofessional team communication, and knowledge of teams and teamwork. 17 The interprofessional educational efforts should instill the core competencies by following guiding principles of being patient centered; having a community or population focus; emphasizing relationships and processes; containing developmentally appropriate activities and assessments; and being outcome driven.<sup>18</sup>

A recent study with results published in 2015 explored the experiences of collaboration among physicians, nurses, and

unlicensed assistive personnel.19 Findings from this qualitative exploration indicate that we have much work to do in the area of collaboration. Most participants in this study indicated that they experienced a hierarchical feel to communication and decision-making. When there was collaboration between physicians and nurses, they failed to solicit input from unlicensed assistive personnel. 19 We also know that longer shifts, increasingly mandated by hospitals, negatively affect collaboration.<sup>20</sup> Patient care involves activities apportioned among physicians, nurses, and unlicensed assistive personnel; seamless coordination is required to prevent errors and a siloed experience for the patients and their families. Creating a model without a hierarchical structure requires that members of the team (1) understand the roles and expected contributions of each member, (2) encourage one another to meet team expectations, and (3) make the outcomes desired for patients and families the center of focus.19

#### **CONCLUSION**

The landscape of the health care system is ever changing. PCPs are delivering care in new venues with new technologies, with new types of collaborators, and in new kinds of health care systems. Health care reform continues to evolve and shape the vision for primary care. Health promotion and wellness is currently and will be an integral component of health care for all our patients and families. The current focus on wellness and primary care continues to provide opportunities for physician assistants and nurse practitioners to improve patient access to care and impact the direction and structure of health care delivery systems.

The vision of primary care as a collaborative practice remains timely and important. Although there are challenges, interprofessional collaborative practice represents the commitment that a team of expert clinicians from a variety of disciplines will offer patients and families optimal primary care even as primary care models continue to evolve.

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#### CHAPTER 2

### TRANSLATING RESEARCH INTO CLINICAL PRACTICE

Jill Walsh • Patrick LaRose

#### INTRODUCTION

Primary care providers are at the forefront of identifying practice problems and are pivotal in translating research recommendations into practice, bringing innovation from "bench to bedside." In the true spirit of interprofessional practice, the identification and solving of practice problems are a group effort, requiring the expertise of all members of the health care team.

### Nursing Research as an Exemplar for the Evolution of Knowledge Development in Health Care Professions

Over the years, nursing research has had multiple evolutions in terms of what role nurses play in the discovery of empirical research-driven information and, most notably, how nurses should use this information to rightfully impact practice, the provisions of care, and patient outcomes. To truly understand the role of nurses in relationship to research, one needs to go back in history and review the role of Florence Nightingale. Often considered the first nurse researcher, Nightingale was one of the first nurses to actually use evidence, from her practice, to make clinically relevant decisions based on the care of patients.1 In her book Notes on Nursing, published in 1859, Nightingale discusses the importance of cleanliness, warmth, clean air, and personal hygiene as a means of improving outcomes for patients. Much of what Nightingale did during this time was groundbreaking. Sadly, her efforts to use evidence as a means to influence practice would not be recognized until many years after her death. However, much of what Nightingale

did during her professional career as a nurse served as a foundation for the research nurses currently do.

Medical research is focused on the discovery of information and evidence used to help patient outcomes or serves to provide the foundation for practice changes that improve clinical care guidelines, enhance practice in public health, or provide evidence to serve the larger population in our country. Medical care providers currently look to evidence-based guidelines to help frame their practice as they work to improve the health and safety of clients (patients) within their communities.<sup>1</sup> Evidence-based guidelines are most often derived from systemic reviews of random clinical trials where the evidence of this research is compiled statistically to bring meaning to the large amount of data available on the clinical subject being studied. The Agency for Healthcare Quality and Research (AHRQ)<sup>2</sup> identifies clinical guidelines as the synthesis of empirical studies where the clinical guidelines, recommendations, and empirical information from random clinical trials can be brought together as cohesive evidence on best practice for care. The AHRQ publications clearing house closed in the fall of 2018, but publications and resources will continue to be available online at: https://www.ahrq.gov/research/publication/ index.html. These guidelines serve to help nurse practitioners, physician assistants, physicians, and other primary care providers provide patients with clinical care that is evidence based and consistent with best practice across the country.

**Evidence-Based Practice.** Evidence-based practice (EBP) is an approach to practice that uses a problem-solving approach in which individual patient care decisions are made using best available evidence. The evidence-based practice movement began in the 1970s and 1980s, partly in response to observations made by Archibald Cochrane, considered to be the father of evidence-based medicine (EBM), that treatment decisions used in medicine were being made without evidence to demonstrate the effectiveness of interventions.<sup>3</sup> In 1992, the EBM movement was launched with the breakthrough article in the Journal of the American Medical Association (JAMA) from the EBM Working Group. They stated that EBM "de-emphasises intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research." As EBP evolved, the definition has been broadened to include a life-long problem-solving approach to how health care is delivered that integrates the best evidence from high-quality studies with a clinician's expertise and also a patient's preferences and values.<sup>5</sup>

Congruent with the use of evidence to drive clinical outcomes, evidence is also used to promote changes to clinical practice. Years ago, much of nursing practice was governed by traditions, textbook, and the guidance from clinical specialists/ experts where a more experienced nurse would hand down the practice standards to newer nurses entering the profession. There was little room for newer nurses to question practice standards during this time. However, as nursing research began to take shape and more nurses were conducting empirical studies and adding to the scientific body of nursing knowledge, this information would trickle down to clinical practice. Although EBP was not the standard at this time, nurses who were forward thinking and progressive would read articles, often generated from medical research that described best practice, and would secretly implement these standards into their own clinical practice.1

Advancements in medical care and the use of technology continued to propel the use of evidence as a means to define best practice into the late 20th century. These changes, coupled with increasing educational standards of many health care professions, led to a paradigm shift in the way nurses thought about nursing practice and how this practice should look into the future.

#### **Translational Research for Practice Change**

New knowledge from research is being generated at an accelerated rate. In fact, some research articles would even say there has been an explosion of new medical knowledge. The true challenge is how to move this knowledge from the bench to bedside through translational research.<sup>6</sup> Translational research simply means moving empirically based understanding into clinical practice.<sup>7</sup> Although the concept of moving empirically based information into clinical practice may sound simple, it does require a skill set that allows the PCP to understand how to translate evidence through a system of grading and critique to determine the validity of the evidence, the scope in which the evidence is applicable to a specific practice change, and the practicality of the intervention for the practice environment.<sup>7</sup>

**Defining Practice Change and Appraising the Evidence.** The first step for the utilization of translational research is defining what needs to be changed. For PCPs, this step is often generated by a single provider asking a question of why a policy or procedure is done a certain way. In the past, policies and procedures were developed by clinical experts where tradition framed the practice policy. Currently, evidence from empirical research findings is used to frame or shape professional practice standards. Within the context of this understanding, translational research allows providers to develop a better understanding of the evidence and how the evidence can help change practice. Qidwai says, "Application of the latest research into clinical practice is a mandatory requirement for improving healthcare delivery." (8(9453))

Once the practice issue has been defined, the PCP will begin a search of the evidence to determine evidence-based interventions used to inform best practice standards. Searching the evidence can often be tedious and can result in many research studies that have little to do with needed information. Conducting a strong and accurate search of the literature requires a skill set where the PCP can filter through hundreds of research articles that have little to do with the needed information. This is where working with the medical science librarian or the librarian from the local university can be very helpful. Librarians have an excellent skill set for conducting scholarly searches and can provide nurses with assistance and key pointers for sifting through the large amount of information and filtering to collect studies that support the data set needed for the practice change.

Once the evidence for the practice change has been located and the research has been read and understood, it is time to determine the applicability of the research for the change and grade the evidence for strength and lack of bias. These actions are most often the biggest challenge for those who have little experience in determining the types of evidence that is appropriate for a practice change. However, there is a standard for grading the evidence that provides health care providers with a framework for helping determine evidence that is valid for the practice change and evidence that would not serve to support the practice change.

Grading evidence requires the PCP to develop an understanding of the different types of research studies that are available and determining the strength of the evidence. The first level in grading the evidence is focused on evidence that is derived from random clinical trials. This evidence is often considered the most scientific and most reliable (Table 2.1).11 A high level of confidence is provided with the strength of this evidence because it is normally evaluated based on systematic reviews. According to Cochran Collaboration, "a systematic review summarizes the results of available carefully designed healthcare studies (controlled trials) and provides a high level of evidence on the effectiveness of healthcare interventions."10(para 1) This type of information allows the PCP to determine the related strength of the evidence in support of the interventions. Systematic reviews are most often used with the development of clinical guidelines to promote a standard of care. 10

The next level of strength is cohort and case studies. These types of studies are often considered observational or analytical studies and identify the causality and effect on the

## TABLE 2.1 Canadian Task on the Periodic Health Examination's Levels of Evidence

Level	Type of Evidence
1	At least 1 RCT with proper randomization
II.1	Well-designed cohort or case-control study
II.2	Time series comparisons or dramatic results from uncontrolled studies
III	Expert opinions

From Canadian Task Force on the Periodic Health Examination. (1979). The periodic health examination. *Canadian Medical Association Journal*, 121, 1193–1254.

participants.<sup>11</sup> Cohort or case studies provide excellent empirical information and evidence that is considered as reliable as those found in random clinical trials. Level III evidence is expert opinion. Although this level of evidence is often questioned, experience of a clinician can be used to frame a practice change where this experience has provided the clinician with a reasonable opportunity to understand how the practice change may or may not positively impact the population. Furthermore, with the absence of clear evidence to support the practice change, the role of expert opinion from clinicians that are change agents can often provide sufficient experiential or qualitative data to support the practice change.12 Weighing the evidence basically informs the PCP of the strength of the research design and provides a structured and methodical approach to deciding which pieces of evidence should be considered for the literature review of support and which pieces of evidence do not have the inherent design or strength/trust to be included. The use of a systematic and logical evaluation system is helpful in the process and provides the PCP with a method and structure that can help make sense of all the data. Of course, no system of evaluation is perfect, and it is highly important for the PCP to understand the shortfalls and limitations of any system of ranking. According to Evans, "From this perspective, it acknowledges that, when evaluating an intervention, a variety of research methods can contribute valid evidence."13(p82)

One approach that provides a structure methodology is identified in Table 2.2 Within this structure, researchers can order evidence based on level of the empirical question (discovery), by purpose of the research, methodology (or research design), types of analysis, and application. "Evidence on effectiveness, appropriateness and feasibility provides a sounder base for evaluating healthcare interventions, in that it acknowledges the many factors that can have an impact on success." <sup>13(p79)</sup> For the PCP researcher, the most important aspect of this evaluation

#### TABLE 2.2 Summary of Study Parameters

Level of Question	Purpose	Methods	Analysis	Application
I. What is it?	To describe or to define a phenomenon of interest To identify pertinent variables or characteristics	Qualitative methods Structured interviews Questionnaires Surveys	Content analysis Ethnography Nonparametric statistics Measures of central tendency	May suggest assessment parameters (Do you experience?)
II. What is happening here?	To identify relationships between variables— associations and differences	Epidemiologic studies Cross-sectional studies Correlational studies Studies of group-wise differences	Correlations among variables Differences between variables or groups Mann-Whitney <i>U</i> test; analysis of variance; <i>t</i> test	Suggests avenues of further assessment (If you observe x, what is the likelihood that y will occur?)
III. What is the nature of the relationship among variables (cause-and- effect relationship)?	To determine cause-and- effect relationships among variables To explicate mechanisms mediating the phenomenon of interest	Experimental designs Quasi-experimental designs	Analysis of variance Regression analysis	Suggests underlying pathologic conditions that may be treated
IV. What is the therapeutic effect of a proposed intervention? What is the proper dose of a treatment to achieve a predictable outcome?	To determine predictability of hypothesized outcome at specific dose in selected population	Randomized clinical trial	Intent-to-treat analysis Analysis of variance Regression analysis	Demonstrates usefulness of particular treatment for patient population; with sufficient replication, clinician may be reasonably sure that treatment will be effective

may relate to applicability of the evidence. In this case, weighing the ability to operationalize the recommended interventions may be the primary purpose of this evaluation. If the evidence or recommendations are challenging or difficult to operationalize (perhaps related to cost, structure, or availability of resources), this would preclude the provider from including this evidence in the supportive literature. Conversely, evidence that had strong applicability and could be easily implemented might rise to the top of the ranking based on the weight of this review and the ease of applicability.

Primary care providers who use an evidence ranking system such as the one in Table 2.2 can better understand how the evidence can be used to support practice change, inform policy development or revision, and best influence patient outcomes.

**Grading the Evidence.** Once the evidence has been appraised for applicability and the strength of the evidence has been reviewed, the PCP can apply this knowledge to the grade of the evidence. Table 2.3 provides a summary of grading which is a standardized nomenclature for the applicability of the evidence for the practice change.<sup>14</sup>

Grading the evidence provides the PCP with the opportunity to declare confidence in the strength and reliability of the evidence collected. For the high category, the PCP has full confidence in the research and believes the evidence gained is sufficient to promote the practice change. From here the PCP does not believe there is a need for additional support. Each level of the grading tool demonstrates the PCP's overall confidence with the evidence and the applicability of the evidence for use in the practice change with the lowest level being insufficient; where there is no evidence to support a change.

Within the context of appraising and grading evidence, the PCP demonstrates his or her knowledge and understanding

### TABLE 2.3 Strength of Evidence Grades and Definitions

Grade	Definition
High	We are very confident that the estimate of effect lies close to the true effect for this outcome. The body of evidence has few or no deficiencies. We believe that the findings are stable (i.e., another study would not change the conclusions).
Moderate	We are moderately confident that the estimate of effect lies close to the true effect for this outcome. The body of evidence has some deficiencies. We believe that the findings are likely to be stable, but some doubt remains.
Low	We have limited confidence that the estimate of effect lies close to the true effect for this outcome. The body of evidence has major or numerous deficiencies (or both). We believe that additional evidence is needed before concluding either that the findings are stable or that the estimate of effect is close to the true effect.
Insufficient	We have no evidence, we are unable to estimate an effect, or we have no confidence in the estimate of effect for this outcome. No evidence is available or the body of evidence has unacceptable deficiencies, precluding reaching a conclusion.

From Berkman, N. D., Lohr, K. N., Ansari, M. T., Balk, E., Kane, R., McDonagh, M. S., et al. (2015). Grading the strength of a body of evidence when assessing health care interventions: An EPC update. *Journal of Clinical Epidemiology*, 68(11), 1312–1324.

of the need for change and the empirical support that can be located to support change. Once empirical support is located within the evidence, a framework for theoretical change can be established. This includes providing a theoretical context to the change by assigning a model that represents either a nursing grand theory or a mid-range theory and the theory for change.

### THEORIES OF CHANGE AND ADOPTION OF INNOVATIONS

Planned change is a common thread that runs throughout health care and is necessary for many reasons, but it can be challenging to implement. Primary care providers and change agents therefore must have knowledge of change theories in order to implement planned change in nursing. It is important also to understand how an innovation (i.e., new idea, practice, or object) gains momentum over time, diffuses (or spreads), and is adopted by a culture.

As early as the 1940s, Kurt Lewin originated the term planned change to distinguish the process from accidental or imposed change<sup>15</sup> Lewin's theory is a time-tested easy-touse change theory that is applicable for individual, group, and organizational change. Lewin considered behavior to be a dynamic balance of forces working in opposing directions that can affect change, which he called force-field analysis. He assumed that there are both driving and restraining forces that influence change. Successful organizational change is achieved by either strengthening the driving forces (facilitators) in the desired direction or weakening the restraining forces (barriers) that impede change. Therefore, to shift the balance in the direction of the planned change, the forces need to be first analyzed and understood. Lewin's change theory consists of a three-step model of change: unfreezing, movement, and refreezing. The first step is the unfreezing of the old pattern of doing things. Unfreezing is then replaced with the moving phase of change, followed by refreezing as people adjust to the new ways of doing things (Box 2.1).

In health care, there are many evidence-based innovations; however, knowledge disseminates slowly. The diffusion of innovation (DOI) theory developed by E. M. Rogers in 1962 is a classic theory that seeks to explain how, why, and at what rate new ideas and technology spread through a specific population or social system. Rogers<sup>16</sup> proposed four fundamental elements of the diffusion process that affect the spread of a new idea: the innovation (an idea, practice, or object perceived as new by an individual), communication channels (the process for

#### B O X **2.1**

#### **Lewin's Change Theory**

#### Unfreezing

- Recognize need for change
- Prepare the desired change
- Identify and increase driving forces for change
- Identify and decrease resisting forces against change

#### **Moving or Changing**

- Develop new attitudes or behaviors
- Implement the desired change

#### Refreezing

- Reinforce and stabilize change to make permanent
- Solidify the desired change
- Hardwire the desired change through new norms and operating procedures

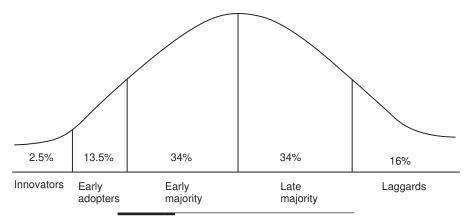


FIG. 2.1 Roger's diffusion of innovation theory.

messages to travel from one individual to another), time (time it takes for individuals to get used to an idea and the rate of adoption), and the social system (groups that join together to solve problems for a common goal).

Rogers modified and expanded Lewin's change theory and described five stages through which individuals (or larger decision-making groups) pass during the adoption of a new idea—the "innovation-decision" process. The five stages include knowledge, persuasion, decision, implementation, and confirmation. Knowledge is the process whereby the individual is exposed to a new idea and has some information about how the innovation works. Persuasion is the process in which the individual is interested in the idea and develops an attitude about the innovation. In the decision phase, the individual decides to either adopt or reject the innovation. In the implementation phase, the individual puts the innovation into use and may seek out additional evidence. Lastly, the confirmation phase is when the individual evaluates the results of the innovation and decides to continue the innovation.

Rogers proposed that there are also personal characteristics that influence how rapidly people adopt an innovation. He identified five categories of adopters: innovators, early adopters, early majority, late majority, and laggards (Fig. 2.1). Innovators are people who are willing to take risks and are the first to adopt. Early adopters are likely to be opinion leaders who embrace change opportunities and are comfortable adopting new ideas. The majority of the population or the critical mass is in the early majority and late majority categories. The early majority adopt new ideas slower than the previous groups, will adopt if practical, and are rarely leaders. The late majority adopt an innovation after it has been proven and often not by choice but rather out of necessity. Lastly, the laggards are change averse, very conservative, and very skeptical of change.

Rogers identified attributes of innovations that help decrease uncertainty about the innovation and influence decisions to adopt or reject. Rogers asserted that individual's perceptions about the five characteristics of innovations: relative advantage, compatibility, complexity, trialability, and observability predict the rate of adoption of innovations.

### USE OF THEORETICAL APPROACHES IN IMPLEMENTATION SCIENCE

Use of a framework, theory, or model to systematize and guide the planning, implementation, and evaluation of practice change projects supports successful implementation of EBP. There are many models for implementation of EBP available for use in clinical settings. However, selection is dependent on the setting and type of practice change proposed.

Nilsen<sup>17</sup> identified five categories of theoretical approaches used in implementation science. Process models are used to describe and/or guide the research-to-practice process. Determinant frameworks, classic theories, and implementation theories aim to understand and or explain what influences implementation outcomes. Evaluation frameworks provide a structure to evaluate implementation efforts.

Four commonly used process models that focus on the implementation process from both the practitioner and organizational perspectives will be presented, including: (1) the Iowa Model of Evidence-Based Practice to Promote Quality Care, <sup>18</sup> (2) the ACE Star Model of Knowledge Transformation, <sup>19</sup> (3) the Johns Hopkins Nursing Evidence-Based Practice Model (JHNEBP), <sup>20</sup> and the (4) the Stetler Model of Evidence-Based Practice. <sup>21</sup>

The Iowa Model of Evidence-Based Practice to Promote Quality Care<sup>18</sup> is a widely used, very practical model for the systematic implementation of EBP. The Iowa model is applicable in diverse settings, including academic settings and health care institutions, and is intended for nurses and other clinicians at the point of care.

The Iowa model consists of a flowchart to guide decisionmaking that includes problem-solving steps and feedback loops to guide the change process. The first step in the Iowa model is determining if the topic is a problem-based or knowledge-based trigger and if it is a priority for the organization. A team of stakeholders with consideration of interprofessional involvement is then formed to develop, implement, and evaluate the practice change. The team first searches, critiques, and synthesizes the literature to determine if the research evidence is sufficient. At this decision point, if the research evidence is not sufficient, the team can recommend conducting more research or using lower levels of evidence. If sufficient evidence is found, a pilot of the practice change is initiated. The team then evaluates the pilot for feasibility and effectiveness and decides whether to adopt the change in practice. Ongoing monitoring and dissemination of results are further elements of the model.

The Iowa Model Collaborative convened in 2012 to review and revise the Iowa model based on changes in health care and feedback from users. The Iowa Model-Revised: Evidence-Based

Practice to Promote Excellence in Health Care was validated and made available in 2015. Important additions to the revised model include the explicit inclusion of patient and family values and preferences, more detail based on user feedback about the "design and pilot the change" step, and the "integrate and sustain the practice change" step (Fig. 2.2). 18

The ACE Star Model of Knowledge Transformation<sup>19</sup> was developed in 2004 and revised in 2012 and is another process model created from the nursing-led field of research use/utilization to guide change. The Star model is useful as a simple yet comprehensive framework to translate evidence into practice. The model has been used in both educational and clinical practice and can be used by both individual practitioners and organizations to guide practice change in a variety of settings. The major focus of the Star model is knowledge transformation.

The five stages of the Star model depict the stages of knowledge transformation as research evidence is incorporated into practice. The five stages include: (1) discovery research, (2) evidence summary, (3) translation to guidelines, (4) practice integration, and (5) process, outcome evaluation. In the first stage, discovery, the literature is searched using databases such as CINAHL for primary research studies. The next stage is evidence summary in which the large amount of available evidence is synthesized and integrated in summary forms (e.g., evidence synthesis and systematic reviews) so that the review of available evidence is more manageable. The third stage is translation into action where the evidence is translated into a practice document or tool that guides practice, such as an evidence-based clinical practice guideline. Practice integration is the fourth stage and is where the evidence is implemented and there is a change in practice. The final stage, evaluation, is the stage in which the impact of the practice change on outcomes is evaluated (Fig. 2.3).

The ACE Star Model of Knowledge Transformation provides an organized and practical framework for implementing best evidence into clinical practice. As new knowledge is transformed through the five stages, the final outcome is evidence-based quality improvement of health care. <sup>19</sup>

The JHNEBP<sup>20</sup> was developed jointly by a collaborative group of leaders in nursing education and practice at Johns Hopkins Hospital and the Johns Hopkins University School of Nursing and implemented in 2004 to address the identified need for a process to implement EBP in the hospital setting. The model was updated in 2013 and again in 2017. The JHNEBP model is a process model specifically designed as a practical guide for clinicians to use for implementation of best evidence for care decisions. The three-step model called PET is composed of three components: (1) the practice question, (2) evidence, and (3) translation.

The aim of the JHNEBP model is to assist clinicians to rapidly and appropriately incorporate the latest research findings and best practices into patient care. The 2017 revised model reflects a change to the conceptual model itself and offers updated tools for question development, rating the evidence and appraising research and nonresearch evidence. New tools include a stakeholder analysis tool, action-planning tool, and dissemination tool.

The revised conceptual model currently has "inquiry" as the starting point. Individuals or teams raise the question as to whether the current practice reflects evidence-based best practice. Inquiry as the starting point ignites a dynamic, interactive process for practice change, creating an ongoing cycle of inquiry, practice, and learning (Fig. 2.4).

The Stetler Model of Evidence-Based Practice<sup>21</sup> was first developed in 1976, refined in 1994, and updated in 2001. The Stetler model is a process model that is practitioner oriented and emphasizes the critical thinking process. The model links research use, as a first step, with evidence-informed practice and promotes use of both internal and external sources of evidence. Stetler's model consists of five phases: (1) preparation, (2) validation, (3) comparative evaluation/decision-making, (4) translation/application, and (5) evaluation. Each phase is designed to facilitate critical thinking about the practical application of research findings and related evidence; result in the use of evidence in the context of daily practice; and mitigate some of the human errors made in decision-making.<sup>22</sup> The last two versions of this model consist of two parts: five phases of research/evidence use and clarifying information and options for each phase (Figs. 2.5 and 2.6).

The Promoting Action on Research Implementation in Health Services (PARIHS) framework, <sup>23</sup> originally developed in 1998, is a determinant framework that is useful for clinicians and researchers to understand the nature of complex interventions and how new knowledge moves into practice. The PARIHS framework is a multidimensional conceptual framework that proposes that key factors and the interplay and interdependence of these factors influence successful implementation of EBPs. This framework presents successful implementation as a function of the quality and type of evidence; the characteristics of the setting or context; and the way in which the evidence was introduced or facilitated into practice.

The PARIHS framework was refined in 2015 and is currently called the integrated-PARIHS (i-PARIHS) framework.<sup>24</sup> In the revised framework, the core constructs are facilitation, innovation, recipients, and context (Fig. 2.7). In this approach, facilitation is the active element that promotes successful implementation of new knowledge in the clinical setting active element through assessing, aligning, and integrating the other three constructs. The framework identifies three core facilitation roles—the beginner or novice facilitator, experienced facilitator, and expert facilitator—and provides structured interventions they need to undertake as they move out to different layers of context.

The Advancing Research & Clinical Practice through Close Collaboration (ARCC) model: A Model for System Wide Implementation and Sustainability of EBP<sup>25</sup> is an organized conceptual framework that provides health care institutions with a guide for system-wide implementation of EBP to achieve quality outcomes. The model was developed using nurse input about the barriers and facilitators of using EBP and is based in control theory and cognitive behavioral theory. A considerable amount of research exists to support the ARCC model.<sup>24</sup>

The central constructs of the model include: (1) assessment of organizational culture and readiness for EBP, (2) identification of strengths and barriers to EBP, (3) development and use of EBP mentors, (4) EBP implementation, and (5) outcome evaluation (Fig. 2.8). Research findings showed that a key strategy to sustain EBP is the presence of an EBP mentor and that having a mentor leads to stronger beliefs and greater implementation of evidence-based care by nurses.<sup>26</sup>

The ARCC model emphasizes organizational environment and factors that support EBP. This model includes several scales to measure organizational culture and measurement

## The Iowa Model Revised: Evidence-Based Practice to Promote Excellence in Health Care



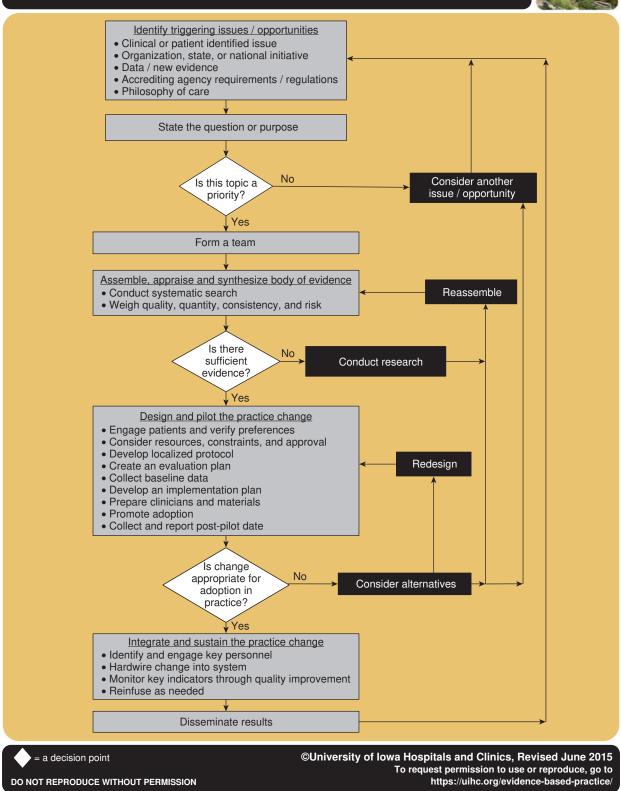


FIG. 2.2 The Iowa Model Revised: Evidence-based Practice to Promote Excellence in Health Care (2017). (From Iowa Model Collaborative. [2017]. Iowa model of evidence-based practice: Revisions and validation. Worldviews on Evidence-Based Nursing, 14[3], 175–182. Used/reprinted with permission from the University of Iowa Hospitals and Clinics, copyright 2015. For permission to use or reproduce, please contact the University of Iowa Hospitals and Clinics at 319-384-9098.)

of effectiveness of EBP in practice. These include the EBP beliefs (EBPB) scale, Organizational Culture and Readiness for System-Wide Implementation of EBP (OCRSIEP), EBP Knowledge Assessment Questionnaire (EBP-KAQ), and the EBP implementation (EBPI) scale.

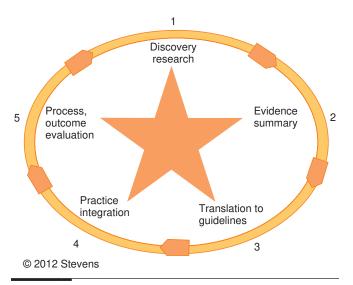


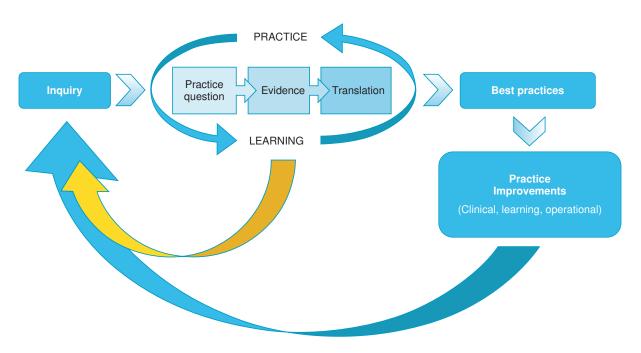
FIG. 2.3 The ACE star model of knowledge transformation. (From Stevens, K. R. [2012]. Star Model of EBP: Knowledge Transformation. Academic Center for Evidence-Based Practice. The University of Texas Health Science Center at San Antonio.)

### Developing an Evidence-Based Practice Change—the Final Piece

It is widely acknowledged that EBP improves the quality and reliability of health care, improves patient outcomes, and reduces variations in care and costs.<sup>27</sup> Primary care providers are leading, implementing, and evaluating practice change projects and quality improvement (QI) initiatives with a goal of improving patient outcomes and organizational effectiveness.

The Plan-Do-Study-Act (PDSA) cycle is an improvement-science model commonly used for testing a change. The steps include: "P" Plan—plan a change or test of how something works; "D" Do—carry out the plan or test; "S" Study—observe and learn from the consequences and analyze the data; and "A" Act—decide what actions should be taken to improve. The model is summarized in three simple questions: (1) What are we trying to accomplish? (2) How will we know that a change is an improvement? (3) What changes can we make that will result in improvement?<sup>28</sup>

It can sometimes be challenging to identify whether an activity involving human participants and data collection falls in the realm of QI or human subjects research due to subtle differences and frequent overlap. The Department of Health and Human Services (DHHS) definition of research (from 45 CFR 46.102) is: "A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. Activities that meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program that is considered research for other purposes. For example, some demonstration and service programs



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FIG. 2.4 The Johns Hopkins Nursing Evidence-Based Practice Model (JHNEBP) (2017). (© The Johns Hopkins Hospital/The Johns Hopkins University School of Nursing.)

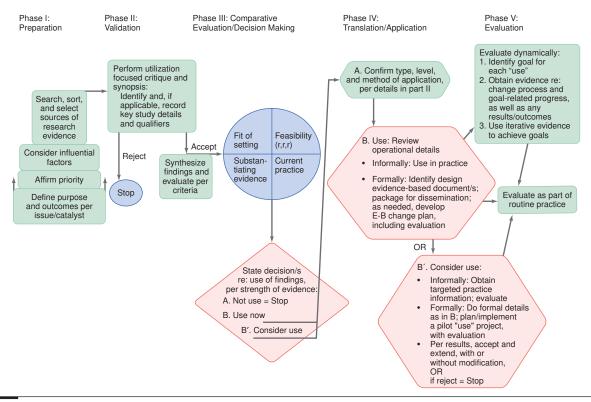


FIG. 2.5 Steller model, Part I. Shown are the steps of research utilization to facilitate evidence-based practice. (From Steller, C. B. [2001]. Updating the Steller model of research utilization to facilitate evidence-based practice. *Nursing Outlook*, 49[6], 276.)

may include research activities."<sup>29</sup> Important in this definition are the words "designed to contribute to generalizable knowledge." To be considered "generalizable knowledge," the activity would include the following concepts: knowledge contributes to a theoretical framework of an established body of knowledge; results are expected to be generalized to a larger population beyond the site of data collection or population studied; and results are intended to be replicated in other settings.

Many health care institutions have developed policies that describe the key differences between QI activities versus research and provide guidance for determining whether a project constitutes human subjects research (and subsequently requires IRB review). Whether the QI activity is human subject research or not, it is vital that it be conducted in a manner that is ethical and respects the rights and welfare of the human participants.

### DISSEMINATING KNOWLEDGE: CHANGING PRACTICE

APNs and their interprofessional colleagues are publishing findings of studies or practice change projects that use evidence to improve either practice or patient outcomes that contribute to the body of medical and nursing knowledge.<sup>30</sup>

Chronic diseases and conditions such as heart disease, stroke, cancer, type 2 diabetes, obesity, and arthritis are among the most common, costly, and preventable of all health problems.<sup>31</sup> The management of chronic diseases and health problems is rapidly becoming the major component of primary care. The use of evidence-based guidelines to manage these conditions has become standard practice. Primary care providers can

influence the closing of the research–evidence–practice gap by implementing clinical practice guidelines within their own practice setting and disseminating information about guideline implementation strategies for other organizations.

### PARTNERSHIPS AND COLLABORATION

Research has shown that interprofessional collaboration improves coordination and communication resulting in improved quality and safety of patient care. Interprofessional collaboration is defined as "when multiple health workers from different professional backgrounds work together with patients, families, caregivers, and communities to deliver the highest quality of care." 32

There are many benefits to interprofessional collaboration. Patient outcomes, quality of care, safety, and cost of care delivery are improved when disciplines work together and approach patient care from a team-based perspective with a shared goal that focuses on the patient. Primary care providers must take responsibility to gain the knowledge and develop the skills to lead interprofessional teams in the implementation of EBP to improve patient, organizational, and system outcomes.

#### **SUMMARY**

Translational research is the movement of research from the bench to practice with the understanding of how the research supports the practice change to improve outcomes. Advancements in technology and health care research are changing the way nurses practice. Although large amounts of research evidence are continually being produced, it sometimes takes more than a decade to implement research into clinical practice.

Phase 1: Preparation	Phase II: Validation	Phase III: Comparative Evaluation/Decision Making	Phase IV: Translation/Application	Phase V: Evaluation
Purpose, Context, & Sources of Research Evidence	Credibility of Findings & Potential for/Detailed Qualifiers of Application	Synthesis & Decisions/ Recommendations per Criteria of Applicability	Operational Definition of Use/Actions for Change	Alternative Types of Evaluation
Potential Issues/ Catalysts = a problem, including unexplained variations or less-thanbest practice; or routine update of knowledge: or validation/routine revision of procedure, policy, etc.; or innovative program goal  Affirm perceived problems, with internal evidence  Focus on high priority issues  Decide if need to form a team or involve formal "structures"/ key stakeholders  Consider other influential internal and external factors, such as beliefs, resources, or timeliness  Define desired, measurable outcomes  Seek out systematic reviews  Determine need for an explicit type of research evidence, if relevant  Select research sources with conceptual fit	individual sources  Rate the level & quality of each evidence source per a "table of evidence"  Differentiate statistical and clinical significance Eliminate non-credible sources End the process of there is no evidence or there is clearly insufficient credible research evidence that meets your need	Synthesize the cumulative findings:  Dogically organize & display the similarities and differences across multiple findings, per common aspects or sub-elements of the topic under review  Evaluate degree of substantiation of each aspect/sub-element; reinforce any qualifying conditions  Evaluate degree & nature of the other criteria: feasibility (r,r,r = risk, resources, readiness); pragmatic fit; & current practice  Make a decision whether/what to use:  Can be personal practitioner-level decision or a recommendation to others  Judge the strength of this decision; and indicate if primarily "research-based" or per use of supplemental information, "evidence-based", qualify the related level of strength of decision/recommendations per related table  For formal recommendations, determine degree of stakeholder consensus  If decision = "Not use" research findings:  May conduct own research or delay use all additional research done by others  If still decide to act now, e.g. on evidence of consensus or another basis for practice, STOP use of model but consider need for planned change and evaluation  If decision = "Use/Consider Use", can mean a recommendation for or against a specific practice	<ul> <li>Types = cognitive, symbolic &amp;/or instrumental</li> <li>Methods = informal or formal; direct or indirect</li> <li>Levels = individuals, group or department/organization</li> <li>Direct instrumental use: change individual behavior (vis-à-vis assessment; plan/intervention options; implementation details; &amp;/or evaluation) or change policy, procedure, protocol, algorithm, program components, etc.</li> <li>Cognitive Use: validate current practice: change personal way of thinking: increase awareness: better understand or appreciate conditions or experiences</li> <li>Symbolic use: develop position paper or proposal for change; or persuade others regarding a way of thinking</li> <li>CAUTION: Assess whether translation/product or use goes beyond actual findings/evidence: <ul> <li>Research evidence may or may not provide various details for a complete policy; procedure, etc.; indicate this fact to users, and note differential levels of evidence therein</li> </ul> </li> <li>Formal dissemination &amp; change strategies should be planned per relevant research: <ul> <li>Simple, passive education is rarely effective as an isolated strategy. Consider multiple strategies, e.g., interactive education, opinion leaders, educational research, etc.</li> <li>Consider need for appropriate, reasoned variation</li> <li>WITH B' where made a decision to use in the setting: <ul> <li>With formal use, may need a dynamic evaluation to effectively implement &amp; continuously improve/refine use of best available evidence</li> <li>WITH B' where made a decision to consider use &amp; thus obtain additional, pragmatic information before a final decision</li> <li>With formal consideration, need a pilot project</li> <li>With a pilot project, must assess if need IRB review, per relevant institutional criteria</li> </ul> </li> </ul></li></ul>	Evaluation can be formal or informal; individual or institutional     Consider cost-benefit of various evaluation efforts     Use RU-as-process to enhance credibility of evaluation data     For both dynamic pilot evaluations; include two types of evaluative information:         o formative, regarding actual implementation & goal progress         o summative, regarding Phase I outcomes and goal results

NOTE: Model applies to all forms of practice, i.e. educational, clinical, managerial, or other See Stetler, C., Morsi, D., Rucki, S., Broughton, S., Corrigan, B., Fitzgerald, J., Giuliano, K., Havener, P., & Sheridan E.A. (1998). Utilization-focused integrated reviews in a nursing service, *Applied Nursing Research*, 11 (4), 195-206 for noted tables, reviews, and synthesis process.

FIG. 2.6 Stetler Model, Part II: Additional, per phase details. (From Stetler, C. B. [2001]. Updating the Stetler model of research utilization to facilitate evidence-based practice. *Nursing Outlook*, 49[6], 276.)

Primary care providers need to have an understanding of empirical evidence and how to use this evidence to improve patient and systems outcomes. Knowledge of appraisal and grading of the evidence is needed to determine the strength and confidence in the evidence for use with a practice change.

Use of a framework, theory, or model to systematize and guide the planning, implementation, and evaluation of practice change projects supports successful implementation of EBP. There are many models for implementation of EBP available for use in clinical settings; however, selection is dependent on the setting and type of practice change proposed.

Primary care providers can influence the closing of the research-evidence-practice gap by gaining the knowledge and developing the skills to lead interprofessional teams in the implementation of EBP to improve patient, organizational, and system outcomes.

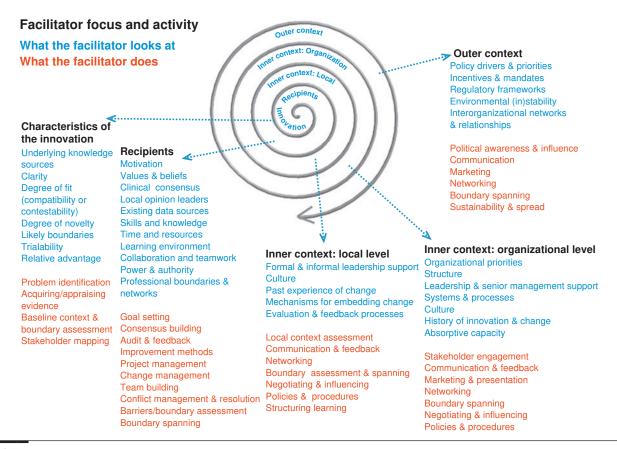
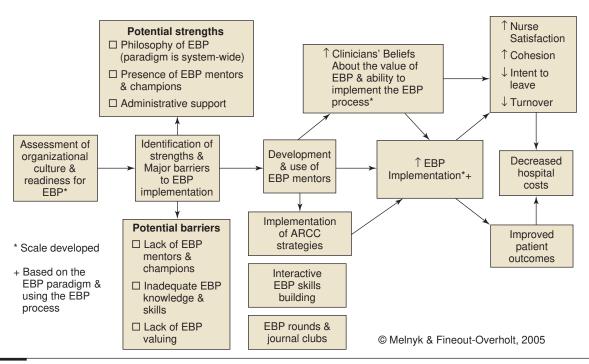


FIG. 2.7 The integrated Promoting Action on Research Implementation in Health Services framework. (From *Implementing evidence-based practice in healthcare: A facilitation guide, G. Harvey & A. Kitson. Copyright* [© 2015] and Routledge. Reproduced by permission of Taylor & Francis Books, United Kingdom.)



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### CHAPTER 3

### EMPOWERING PATIENTS AS COLLABORATIVE PARTNERS: A NEW MODEL FOR PRIMARY CARE

Marcia Potter

### **CURRENT CHALLENGES**

The past decade has produced a sea change of health care regulations, access to care, patient satisfaction, and reimbursement issues. Coupled with decreasing numbers of physicians entering primary care, increased numbers of physicians leaving primary care, the aging population, and growing disease burden, many Americans remain underserved by the US health care system. <sup>1,2</sup> Although the implementation of the Affordable Care Act in 2010 increased the number of Americans with access to insurance, gaining access to care services has been more elusive. <sup>3</sup> Significantly, the cost of care continues to impose a major burden on individuals and the US economy, reaching more than \$3 trillion in 2015, equating to nearly \$10K per person in the United States. <sup>1,4</sup>

## SOLUTIONS FOR CURRENT CHALLENGES: ANY SUCCESSFUL SOLUTION MUST EMPOWER PATIENTS

To reverse the current health care crisis, policy experts across multiple domains within the health care system have advocated for primary care transformation. <sup>1,5,6</sup> Based on the broad goals of the Quadruple Aim and set within the Institute of Medicine's definition of high-quality health care, paradigms for transformation have gained traction in primary care. <sup>7-9</sup> The Quadruple Aim is an expansion of the Institute for Health Care Improvement's Triple Aim, adding the fourth aim, to improve patient care team (or clinician's) experience to the previous three aims: (1) improve patient satisfaction with health care, (2) reduce per capita costs, and (3) improve population health. <sup>7</sup> All of these are important contributors of high-quality

health care: safe, patient centered, efficient, effective, timely, and equitable.<sup>9</sup> However, none of these initiatives can reach optimal success without the inclusion and empowerment of the most important member of the health care team, the patient. Designing care processes around the patient has been referred to as patient-centered care, but even this perspective falls short of the full partnership and empowerment required of patients.<sup>1,10</sup>

As health care transforms, the awareness of the need to personalize health care to individuals became the rallying cry for many, including Congress. Patient-centered care sought to put patients at the center of their health care, include them in all decision-making, cocreate shared goals, and improve health outcomes. Unfortunately, this has remained an elusive goal, partly because even in patient-centeredness, human beings are constrained by the medicalization of their perception of their own health; this does not foster the patient empowerment that is needed to make care truly patient centered.<sup>10</sup>

What is emerging is the idea that patients are persons throughout their experience of their health state. Indeed, because people cannot be separated from their health state, their wishes, goals, and desires should account for more than simply the navigation of a particular condition—it should reflect respect for the holistic needs and life force of each human being. For these reasons, empowering patients to be full participants in their health care is integral to improving their health and the health of the health system. The goal of health care is to create high-quality health capability for patients. In turn, this capability creates capacity to live a high-quality life, to liberate energy allowing people to pursue their goals and desires, and to enable personal freedom. In professional practice, the shift to person-centered caring also encompasses the professional development of each team member. As health care is transforming, so must health care team members transform their perspective about their work, their patients, and themselves. 1,10

Two concepts are integral to the perspective of personcentered care and empowering patients: activation and engagement. Activation is the belief that a particular choice is important; engagement is the belief that choice can be carried out, even in adverse circumstances. 11,12 Although activation and engagement for the patient empowerment and collaboration is key, so is the activation and engagement of the health care staff. After all, one cannot expect full partnership without full participation of each partner. But how is this partnership created? What structures, processes, and outcomes should be included to optimize this concept? What framework provides the foundation to guide decision-making?

One of the most studied and well-supported paradigms for transforming the health care team from patient centered to person centered is the Chronic Care Model (CCM). Of course, paradigms alone will not transform a complex adaptive system such as health care. To optimize the potential of a paradigm, evidence must provide the foundation and theory should guide decision-making. Health care providers are uniquely educated and situated to both transform practice and influence health policy using multiple levels of evidence applied across all levels of the health system. Therefore it is imperative to apply theory as the foundation for practice transformation.

So why is it important to begin with a theory? Theory not only guides practice; it frames how we view the world, our professions, and our decision-making and supports practice situates within health care at all levels. When choosing a theory to guide practice, the unique needs of all stakeholders within the health system must be addressed. Bureaucratic Caring Theory (BCT), a grounded, phenomenological theory, seeks synthesis between the thesis of caring and the antithesis of bureaucracy, essentially seeking to humanize an inherently bureaucratic system, such as health care systems (Fig. 3.1).<sup>15</sup> This humanization is key to the transformation of health care delivery models from a productivity-driven business model to one of human caring and relationship-building that empowers patients as partners in their care.

### **Bureaucratic Caring Theory**

Originally developed by Dr. Marilyn Ray in 1989, the BCT seeks to synthesize the inherently humanistic and bureaucratic needs within health care organizations. Because health care is situated within systems, the health of the system must be balanced with the needs of the individuals who cocreate the system. Health care, as a complex adaptive system, changes and evolves at decision points, leading to increasing order or disorder. As a complex adaptive system, health care organizations reside at these bifurcation points in nearly every domain of existence. BCT is composed of eight domains of caring (Table 3.1). It is important to know that it is not a choice of whether or not to care but how caring is accomplished. 17

### **Expanded Chronic Care Model**

Originally developed by Edward Wagner, Director at the MacColl Institute for Healthcare Innovation, Group Health Cooperative of Puget Sound, Washington, the CCM was designed to meet the health care needs of patients and populations with complex chronic conditions.<sup>18</sup> The CCM focuses on longitudinal needs of the patient's health condition, rather than fragmented, episodic visits. Evidence strongly supported four interventions that led to the greatest improvement in health outcomes: use all staff at the top of their skillset levels; educate and support patients; planned, proactive, team-based care; and better use of registry-based information.<sup>18</sup> The CCM, in use for two decades, has robust evidence to support its effectiveness in improving care and health outcomes at all levels of the health care system. 18,19 In 2003, the CCM was expanded to include the components of preventive care and renamed the Expanded Chronic Care Model (ECCM).<sup>20</sup> This focus on prevention as well as chronic condition management is more aligned to the nursing perspective of holistic nursing care: reducing pain and suffering and preventing disability. Six components comprise the ECCM: organizational support, clinical information systems, delivery system design, decision support, self-management support, and community resources. We can build a new model for primary care that empowers patients by leveraging the caring domains that relate to the components of the ECCM.

# BUILDING PATIENT EMPOWERMENT BY USING COMPONENTS OF THE EXPANDED CHRONIC CARE MODEL AND CARING DOMAINS OF THE BUREAUCRATIC CARING THEORY

### **Organizational Support**

With any process improvement, optimization occurs when leaders at all levels of the organization cocreate a culture that supports evidence-based practice (EBP). For these improvements to come to fruition, leaders must value not just

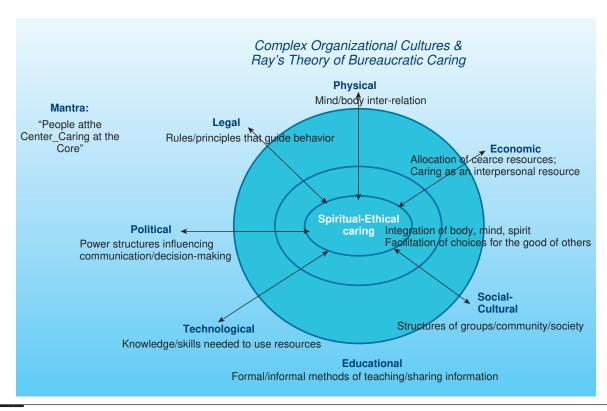


FIG. 3.1 Bureaucratic Caring Theory. (From Ray, M., & Turkel, M. [2015]. Marilyn Ann Ray's theory of bureaucratic caring. In M. Smith & M. Parker [Eds.], Nursing theories and nursing practice [4th ed.]. Philadelphia: F. A. Davis Company, with permission.)

TABLE 3.1 Bureaucratic Caring Theory Caring Domains <sup>15</sup>				
Spiritual-ethical caring	Facilitating choices of good for others. It is the domain of body-mind-spirit, viewing human as spiritual beings and founded in the ethical principles of autonomy, beneficence, and nonmaleficence.			
Physical caring	Physical and mental well-being of humans. Encompasses all of the physical ways in which caring is expressed to another, as well as biologic and mental patterns.			
Legal caring	Caring through justice and fairness. All of the laws and regulations we follow in our profession.			
Technological caring	The nonhuman ways in which caring is expressed. Includes information technology, information technology systems, medications, and care delivery processes and procedures. Encompasses the knowledge and skills to use those resources.			
Political caring	Power and the use of legitimate authority to convey caring. Political caring is the process for and outcomes of policy decisions, workplace relations, and lines of authority.			
Economic caring	Monetary and fiscal health of organizations. The economic ability to provide care for patients as well as funds for health care resources and decisions on coverage inclusions/exclusions/limits			
Educational caring	How we teach patients, what we teach. Includes the essential knowledge and skills needed to provide health care services.			
Social-cultural caring	Relationships forged as individuals, teams, and organizations cocreate bonds, affiliations, and partnerships with one another and in the wider community. All of the social relationships as well as the expression and meaning of health to the individual.			

From Ray, M., & Turkel, M. (2015). Marilyn Ann Ray's theory of bureaucratic caring. In M. Smith & M. Parker (Eds.), *Nursing theories and nursing practice* (4th ed.). Philadelphia: F. A. Davis Company, with permission.

outcomes but the process of innovation and change, and they must provide resources needed for this change. For the implementation and success of the ECCM, this will also include the resource of time.<sup>19</sup> In the design and implementation of any process improvement, we encourage empowerment by ensuring the initiatives reflect the caring domains of political,

social-cultural, spiritual-ethical, economic, technological, legal, physical, and educational caring.

### **Clinical Information Systems**

Clinical information systems bridge the gap between data creation and storage to high-quality health services. Without

these systems, gathering information about individual patients, aggregates, and populations is not possible. These systems also serve as tools for practice management, demand forecasting, outcome comparison, and resource use. Although electronic medical records are integral to this, expansion of this capability to the macro system level includes the use of population health and disease management registries, secure messaging, access to electronic data by the patient (patient-facing portal), tracking and reminders for preventive care services, and risk stratification of patients. As personal electronic medical tracking devices, such as fitness and nutrition tracking, become more prevalent, the expectation is for that data to also be communicated from the patient to the clinical team. Futuristic views include medications that communicate to the health care team when they have been ingested or injected.<sup>21</sup> Key functions of any clinical information system should empower patients by enhancing their access to personal health care information, providing a platform for patient communication concerning questions and requests, tracking health-related patient activities/data, guiding patients' abilities to make optimum health choices, and acting as a vehicle to remind patients of recommended activities. Domains of caring to reflect for success with this component are technological, educational, legal, political, spiritual-ethical, and physical.

### **Delivery System Design**

The roles and tasks of each team member, including the patient, how they interact, how visits are structured, and how follow-up is managed, comprise delivery system design. New initiatives focus on engaging patients in delivery system design, emphasizing the need for their voice in cocreating a system that will meet their needs. In this component, each team member performs to the top of their skills and training, works collaboratively, and is respected for their knowledge. Hallmarks are frequent communication, ongoing training, and strong leadership. In each encounter, the team is both patient focused and practice focused, ensuring the right care is delivered to the right person at the right time.

In the traditional model of care, the physician may not engage with the physician assistant, nurse practitioner, nurse, or other support team members except in complex cases. In the ECCM, each member of the team is needed to provide care services in some capacity for each patient. In complex cases, there is often a need to engage nurses, medical assistants, health coaches, and administrative staff to provide planned outreach to patients in between office visits. Using staff resources in this way facilitates improved access to care, health outcomes, and patient and staff satisfaction, while decreasing the overall cost of care. <sup>19</sup>

The structure of the health care visit is integral to delivery system design. Planned visits for the management of chronic health conditions and for preventive visits should be separate from acute care visits. Although this may seem counterintuitive, evidence supports that adults retain only approximately 30% of what they have heard.<sup>22</sup> Trying to address too many issues in a single visit leads to increased fragmentation, frustration, and poorer outcomes in all caring domains.<sup>13</sup> Although in-person appointments remain the majority of encounters, virtual visits, group visits, and secure messaging (asynchronous visits) are becoming more prevalent.<sup>21</sup> The goal must be to build empowerment patients by ensuring that care delivery system designs

reflect the caring domains of technological, educational, political, spiritual-ethical, and economic caring.

### **Decision Support**

We live in a digital age of almost instantaneous access to information—this same information is also accessible to patients. Although accessible, information is not always easily interpretable, and patients may not know what applies to them. As part of shared decision-making and patient empowerment, patients need the special expertise of their health care team members. There are a number of resources available for decision support tools for shared decision-making with patients (e.g., the Agency for Healthcare Research and Quality and HealthDecision.org). 23,24 These sites are readily available and offer tools and algorithms to help patients and clinicians determine a course of care relevant and tailored to the patient. Use of decision aids has been shown to improve use of health care resources, communication and relationship building, and satisfaction.<sup>24</sup> When designing and implementing initiatives for patient decision-making, create designs that are in concert with the following domains of caring: economic, spiritual-ethical, legal, technological, and social-cultural.

### **Self-Management Support**

Although decision support aids assist in making choices about testing and interventions, self-management support aids assist the patient to navigate the experiences of their health condition, foster activation and engagement, and enable personal freedom. Self-management is founded on the idea of self-efficacy and the ability to complete tasks and reach goals. <sup>11,12</sup> A patient's self-efficacy is subject to change over time and can be highly influenced by the health care team's support and engagement with the patient. Building patient empowerment in this component uses the spiritual-ethical, technological, political, social-cultural, educational, and economic caring domains.

### **Community Resources**

Patients and health care teams do not exist in vacuums but are part of a larger community system. This system of resources enables or impedes patient self-efficacy, health outcomes, and health care team effectiveness. Health care systems often develop outreach programs within the communities they serve, to project the effectiveness of the clinical encounter into the patient's social environment. This is important for a variety of reasons: access to health services, ongoing support to improve health, and improvement of population health. Although a discussion of this is beyond the limits of this chapter, community resources are integrally linked with community and population health efforts, needs, and outcomes. Incorporate information from the caring domains of spiritual-ethical, economic, political, social-cultural, and physical when establishing the network of community resources.

### INCORPORATING BUREAUCRATIC CARING THEORY AND THE ENHANCED CHRONIC CARE MODEL TO EMPOWER PATIENTS AS COLLABORATORS IN A NEW MODEL FOR PRIMARY CARE

Theory-guided, EBP underpins the health of the health system and ensures that patients and their health care team

### TABLE 3.2 Solutions to Practice Design Problems

Problem	Solutions	Key Stakeholders
Engaging Patients and Team members	Build trust by respect, reliability, and relational caring in every encounter. Prior experience with the organization affects trust.	Patients, team members, organization leaders
Patients nonadherent to care	Use social-culture domain of caring to respect patient's values. Explore reasons for nonadherence.	Patients, team members
Leading health care delivery	Treat as a complex adaptive system. Understand the interplay in any organization of the BCT domains of caring. Identify sources of resistance; engage stakeholders in seeking a better way. Frame daily work using the ECCM. Communicate linkages of ECCM to Caring Domains. Engage team members in authentic dialogue about their perspective of how the ECCM affects and reflects their practice. Be open to their observations and discoveries. Coach them in best practices of caring behaviors. Remember that change can begin with only small number that grows.	Team members, organization leaders
Frustration with Requirements for Mentoring/ Professional Development (peer review, performance reports and administrative)	Expand the view of what nursing is as a profession and what are professional obligations. As practitioners of a profession, we have an obligation to educate and insure adherence to ethical standards. Peer Review is a method to ensure quality care, fulfilling professional as well as legal requirements for monitoring safety and quality of nursing services. Performance reports are a critical component of professional development, mentoring and leadership development. Monitoring a person's quality performance should lead to authentic feedback about their goals, potential, and actual capabilities. People are integral to a human system, so we want to be sure we provide them the caring they need. In these tasks we see the expression of caring in the educational, legal, technological, social-cultural, and spiritual-ethical domains.	

Grounded in BCT from the Take Your Theorist to Lunch series developed by the author and based on work by Melrose. BCT, Bureaucratic Caring Theory.

Data from Melrose, S. (2006). Lunch with the theorists: A clinical learning assignment. Nurse Educator, 31(4), 147-148.

partners cocreate the circumstances for optimal health outcomes. Although health care organizations are complex adaptive systems, so are people. Patients and health care team members are all human; the potential for complexity multiplies exponentially. Each decision point in creation of health initiatives has the potential to lead to increasing order or disorder, improved health, or increased disability. Using the BCT to frame practice system designs and quality improvement initiatives humanizes health care system designs, leverages knowledge about the effects domains of caring have on the health care system, clinical teams, and patients, and provides a roadmap for successful care delivery modes that empowers patients as collaborators. Table 3.2 addresses the application of the BCT to some current challenges in primary care practices, with possible solutions in critical areas of patient care, practice leadership, and mentoring and by imagining a conversation over lunch with the Dr. Marilyn Ray, the BCT theorist, to energize ideas for solutions to primary care practice issues.<sup>25</sup> Framing primary care model decisions within the BCT enables caring to flourish in all domains without compromising any particular domain, empowering patients and creating individualized practice-based solutions for providers. Incorporating the ECCM into a primary care practice creates a model that empowers patients and health care team members to collaborate, engage, and grow in capability and capacity.

A new model for primary care that empowers patients as collaborators starts with the delivery system design. Overarching characteristics of the delivery system in the new model has each team member's understanding that they cocreate the patient experience in every interaction each of them has with a patient. Team members have a commitment to enabling

planned, caring, proactive patient visits and practice to the full extent of their education and training. Leaders in the new model ensure there are adequate human, financial, technological (includes analytics), physical, and educational resources. Leaders act to hold team members accountable for performance of their assigned duties, the quality of their patient communication, response times within patient visits, and response times to patient requests. The structure of the health care visit is integral to delivery system design. Begin by restructuring practice templates and schedules to allot 30 minutes for well and established appointments and 15 minutes for acute and routine appointments. Institute team huddles at the beginning of each day to discuss what is needed for each patient from team members. There are critical activities for the NP, RN, and medical technician and administrative staff for each patient visit: previsit, at the time of visit, and post visit. (Table 3.3).

As both team leaders and team members, practitioners are uniquely positioned to shape the design and delivery of health care as we progress in health care reform. Using the BCT and the ECCM in a new model for primary care, practitioners cocreate innovative, person-centered systems to improve the health of individuals, populations, and the health system. Understanding how each of our patients experience their health states differently reflects the holistic view of patient as person. Framing practice as person centered empowers patients as collaborators and offers the opportunity to embrace the beautiful mural of human experiences and interactions, cocreating relationship-based care and moving beyond the medical to the humanistic. This is a new model for primary care that will truly reform our current health care system.

### TABLE 3.3 Planned Visit Protocol in the New Model for Primary Care

Stage	Team Member	Critical Activities
Previsit	Registered nurse	Consult chronic disease/preventive services registries for patient's record  Assess: How is the patient tolerating medications; exercise type/frequency; dietary measures; barriers to self-management: social, physical, psychological, spiritual; successes with self-management: social, physical, psychological, spiritual  Plan: Labs, supply refills, bridge medication refills, appointment with primary care; consults to specialty clinics per standing orders; prevention needs: immunizations: flu, shingles, pneumonia; general: mammogram, pap smear, colorectal cancer screening, sexually transmitted infection screening lmplement: Order needed labs, supplies, bridge medications per standing orders; enter consult requests per standing orders; reinforce lifestyle measures; remind patient to bring all medications to planned visit Evaluate: Patient's understanding of plan; patient's acceptance of plan; patient's follow-up with scheduled/ recommended interventions
	Medical technician	Document in patient's electronic health record Reviews clinician schedule 4 weeks in advance Assess: Are labs completed and in the record? Has patient picked up medication (if needed)? Is patient enrolled in patient portal? Are primary prevention services completed or scheduled? Plan: Ensure labs transferred to electronic health record encounter; ensure any primary preventive services updated in EHR encounter Implement: For any services not completed, contact patient to remind them to complete services Document in patient's electronic health record.
At the Visit	Primary care provider  Administrative staff	Assess: Review all lab data, nursing information, screening data with patient Conduct needed physical exam Plan: Medication or lifestyle adjustments; community resources that may be required Implement: Tailor plan of care to patient's needs based on: Nursing evaluation; primary care provider evaluation and judgment; patient-identified goals and desires; decision aids and shared decision-making Enter/sign appropriate orders Enter any further consults needed Provide information on community resources Create checkout sheet for patient (discharge instructions) Evaluate: Patient's understanding and agreement with cocreated plan of care Ensure patient knows: When to follow-up; how to follow-up (appointment, virtual visit, secure messaging); how to engage in community resources; clarify any questions patient has before visit ends Document in patient's electronic health record Assess: Review checkout sheet with patients
		Plan/Implement: Schedule patient for follow-up as directed by clinician (face to face, virtual, telephone); review patient demographics; ensure patient signed up for patient portal Evaluate: Does the patient have any questions prior to leaving?
Post visit	All team members	Team huddle to debrief any issues with specific patients or processes as needed  Ensure team members aware of any community resources needed and how to engage patient with these  Ensure all orders signed

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### CHAPTER $oldsymbol{4}$

### COORDINATED CHRONIC CARE

Laura Reed

A chronic disease or illness is defined as diagnosed illness, functional limitation, or cognitive impairment that lasts at least a year, places limits on a person's daily activities, and requires regular attention and medical care. The Centers for Disease Control and Prevention (CDC) states that chronic diseases and conditions such as asthma, heart disease, stroke, cancer, type 2 diabetes, obesity, HIV/AIDS, and arthritis are among the most common and costly of all health problems. As of 2012, approximately half of all adults in the United States—117 million people—had one or more chronic conditions. One in four adults had two or more chronic health conditions<sup>2</sup> Seven of the top 10 causes of death in 2015 were from chronic diseases. Heart disease and cancer together accounted for almost 46% of all deaths.<sup>2</sup>

Chronic diseases impact lives in many ways. Many people with chronic illnesses experience a reduced quality of life and limitations in the activities of daily living. People with chronic illnesses have increased numbers of hospitalizations and emergency room visits and higher medical expenses compared with those who do not have a chronic illness. In the United States, 86% of the nation's \$2.7 trillion annual health care expenditures are for people with chronic physical and mental health conditions. Decreasing the incidence of chronic illnesses can reduce these costs.

Cardiovascular disease, diabetes, arthritis, and obesity are chronic conditions that may be prevented or delayed by life style changes such as increased exercise, improved nutrition, tobacco cessation, and reduced alcohol intake.<sup>2</sup> Risky health behaviors and health disparity issues, such as income, education, community resources, and access to health care, contribute to higher rates of chronic illness, poorer health outcomes, and increased medical costs among minority communities.

The prevalence of chronic diseases is steadily increasing, and it is estimated that by 2030 the number of adults living with one chronic illness will be in excess of 171 million. In clinical practice, chronic illness management must include effective communication between team members and coordination of care across different health care settings to improve the overall care of the chronically ill.<sup>3</sup>

### COMPREHENSIVE CARE COORDINATION

As the incidence of chronic illnesses continues to rise internationally, strategies have been developed to address the optimal care of these patients. Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the delivery of health care services. This involves the gathering of personnel and other resources needed and communication between all parties involved including the patient. The Chronic Care Model (CCM) was originally developed by Edward Wagner to organize the care of the chronically ill. This model incorporated six key components necessary to ensure improved clinical and functional outcomes. These six areas are: community resources, health system support, self-management support, delivery system support, decision support, and clinical information systems. The model was developed when the focus of care was the hospitalized patient. More recently, the focus of illness care is moving from hospital-based to community-based care, and the need for integration of health promotion into the prevention and treatment of chronic diseases model is obvious. The Expanded Chronic Care Model (ECCM), developed in 2003,5 includes a community portion to address the influence of social determinants of health on the prevention and management of individuals with chronic diseases. It is believed that the combination of population health promotion and improved disease management as described in the ECCM will be a game-changer in addressing the burden of chronic disease on the health care system.5

Primary care offices and clinics are the gateway to coordinated care for many individuals with complex mental health disorders and substance use issues, as well as a variety of chronic health illnesses. Often patients do not seek early treatment because of the challenges associated with their medical needs, the complexity of the health care system, and financial and transportation challenges. To address these needs, integrated health care programs have been developed often as part of a population health initiative.

Over the past few decades, there have been many attempts to establish a health care system that could effectively care for patients with chronic illnesses. Because the majority of these patients are insured by Medicare and Medicaid, the Centers for Medicare and Medicaid Services (CMS) has worked diligently to find a health care system that will address all the needs of these patients while reducing hospitalizations, emergency room visits, and cost.

Several models of care are worth mentioning. These models can be organized in several different ways: by diagnosis, population served, age of population served, type of provider offering services, and payment sources. All models, regardless of structure, will benefit from assigning an "integrater" to each patient.

Berwick and associates identified the need for an "integrater" as a critical component of any CCM—one individual who would formulate a care plan with the patient and all those involved in his care, guide the patient through the technological nightmare of acute care, advocate for the patient and family, and interpret complex instructions and systems.<sup>6</sup>

### **MODELS OF CARE**

Several models of care have been established, including Patient-Centered Medical Homes (PCMHs), self-management programs, house call or home-based primary care programs, and distance chronic disease programs (telehealth), to address the care of those with chronic illnesses who live in rural areas or are homebound. PCMH are based on the CCM and provide comprehensive primary care using a team approach to deliver patient-centered coordinated care.<sup>6,7</sup>

Self-management programs were designed to encourage the patient as an active participant in his or her own care. These programs initially started in rehabilitation settings but are currently being used in the primary care setting to include the patient as a partner in the management of his or her chronic illnesses. Distance chronic disease programs were designed to allow patients who live in rural areas access to care via internet or telephone to address their chronic disease processes.

House call programs are gaining in popularity and are available in many communities. The Veterans Health Administration (VHA) has a long-established home-based primary care programs using MDs, NPs, and PAs to deliver primary care to older or homebound veterans using house calls and phone calls.

First introduced at the Massachusetts General Hospital in 2006 as a Medicare demonstration project, the Integrated Care Management Program (iCMP) matches high-risk patients with a nurse care manager who works closely with patients and their families to develop a customized health care plan that addresses the specific health care needs of the patient. The care is individualized and relationship based and includes biopsychosocial care planning, multidisciplinary case rounds, outcomes accountability, and a standardized electronic health information platform. This program focuses on early identification and aggressive management of the most complex, highest-risk patients to control costs and improve the quality of care and quality of life of the individual. These programs are guided by an interdisciplinary team of professionals including primary care providers, mental health providers, nurses, licensed clinical social workers, and an array of other key personnel. Each patient is assigned a case manager who works with other team members to ensure all areas of care coordination are addressed. Outcomes have been impressive: lower costs, lower readmission rates, and lower mortality. Although the initial investment is high, subsequent cost reductions have resulted in savings https://www.partners.org/Innovation-And-Leadership/ Population-Health-Management/Current-Activities/Integrated -Care-Management-Program.aspx).

Several small communities in rural New Hampshire and Vermont have established community nurses or are recognizing the work of parish nurses working from local churches. These registered nurses, often recently retired or no longer working full time, are practicing as care coordinators for frail older adults in their towns. The nurse functions in the "integrator" role as an educator, advocate, and coordinator of care. There is no charge for services, and services are delivered in patient's homes. The nurse is paid by a creative system of small town and private grants and donations, thereby keeping insurers and government payers completely out of the loop. The goals are similar to all community-delivered health services: keep people out of the emergency room and hospital, reduce medication errors and cost, improve patient confidence and satisfaction with care, and promote aging with dignity. See https://www.uvcnp.org.

The explosion in availability of personal electronic monitoring devices is potentially useful to many patients with chronic disease and others hoping to maintain good health. Millions of Americans currently use devices to monitor their health and fitness. These include scales, activity monitors (Fitbit, Apple Watch, Microsoft Band, with more being developed every day), heart rate, anticoagulant monitoring, and blood sugar monitors that do not require finger sticks, and more. Data are recorded and can help people have more control over their health and lifestyle. It can also help health care providers keep track of their patients' health status, because information from these devices can be uploaded into apps and electronic health records. These devices are becoming more affordable and some are covered by Medicare. Coupled with telehealth, e-mail or other electronic communication with health care providers allow patient problems to be recognized early and lives and dollars saved.

### **TELEHEALTH MEDICINE**

Telehealth/telemedicine use is rapidly increasing in the United States. This use of technology allows increased access to care for patients who live in rural areas with limited health care access or those who are homebound. Telehealth or telemedicine is the use of electronic communication, ideally an interactive audio-video communication system, to provide medical services and monitoring to patients without them having to travel to the health care facility. Telehealth services are further divided into two categories: synchronous and asynchronous.

Synchronous or real-time telehealth requires the presence of both parties at the same time and a communication link between them that allows a real-time interaction to take place. Videoconferencing equipment is one of the most common forms of technologies used in synchronous telehealth. There are also peripheral devices that can be attached to computers or the videoconferencing equipment, which can aid in an interactive examination.

Asynchronous telehealth involves acquiring medical data (e.g., medical images, biosignals, voice recordings) and then transmitting these data to a doctor or medical specialist at a convenient time for assessment offline. It does not require the presence of both parties at the same time.

These services are being used effectively to monitor patients with diabetes, heart failure, and chronic obstructive lung disease, as well as dermatologic conditions. Telemedicine is also providing consulting services to intensive care unit ICU patients and staff in small hospitals and remote locations that may not have access to highly trained intensivists. The ability to provide care to a chronically or acutely ill

patient from a distance can have a positive influence on the patient's overall health status and quality of life. Telehealth/telemedicine programs are currently available in all 50 states and the VA and are increasing in popularity across the United States as the technology becomes more available and less expensive.

The VHA has one of the largest telehealth programs in the United States. This program coordinates care for more than 490,000 veterans with chronic illnesses across the country. The goal of the program is to increase access to care and improve patient outcomes of those living with chronic diseases. Each participant has a home health device that collects the data and transmits it to the VHA electronic record system. This system allows health care providers to manage chronic diseases such as diabetes, congestive heart failure, depression, and chronic lung disease. The VHA also has a telehealth in the primary care clinic that allows rural outreach clinic to connect with specialists at larger VHA medical centers. Researchers at the VHA investigated the long-term effect of home telehealth on hospitalization rates. The study showed that there was statistically significant reduction in hospitalizations in the patients who participated in the telehealth program.8

There are issues with training patients to use equipment, meeting patient expectations of 24-hour care, understanding which health markers are most helpful in monitoring to prevent exacerbation of disease, and maintaining equipment. Studies are mixed regarding cost effectiveness, but the potential impact is considerable.

CMS restricts reimbursement of telehealth services to patients who reside in either a health provider shortage area (HPSA) or a US census-defined micro statistical area (MSA). These services are being reevaluated by CMS currently, and new guidelines have been published in 2018. See https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/TelehealthSrvcsfctsht.pdf.

In 2015, CMS recognized chronic care management as a critical component of primary care. CPT codes were assigned, and Medicare currently reimburses clinicians, including MDs, NPs, and PAs, for 20 to 60 minutes of time devoted to the coordination of care of medically complex individual patients with two or more chronic conditions that place the patient at risk of death, decompensation, or functional decline.

The use of integrated care programs has increased nation-wide with the Affordable Care Act of 2010, especially in the Medicare/Medicaid-eligible patient population, although these services are still scarce and resources supporting them are also sparce.<sup>9</sup>

### **CHRONIC CARE CONDITIONS**

Adolescents and children with medical complexity (CMC) are defined as a group with chronic medical conditions or neuro-developmental impairments in need of complex coordinated care. Although these individuals make up 0.4% to 0.7% of all US children (approximately 320,000 to 560,000 children), their health care costs account for 15%–30% of pediatric health care costs. <sup>10,11</sup> These children require comprehensive complex care that most primary care clinicians or community pediatricians have limited experience in providing. Specialist pediatricians are scarce and usually practice in large children's hospitals that are often located at great distance from families. Other barriers to caring for CMC include decreased time to spend with the patient and his or her family in settings that

require high patient volumes, limited resources including staff, and poor reimbursements.

Care of CMC requires care coordination between primary care and specialty providers and health care agencies, as well as addressing the developmental, educational, dental, social, and family financial concerns. Frequent communication with the family allows for early identification of any illness, social, or financial issue that, if not addressed, could result in complications and/or hospitalization. All aspects of care, including caregiver needs, should be addressed to ensure optimal health of the CMC and the family. 1,3,10

Care coordination for CMC is integral to the long-term outcomes. Close cooperation with the school and development of an individualized education plan (IEP) should be a part of the overall plan of care. The care plan should also include addressing physical, social, and psychological aspects of the child's life, including the family's psychological support system and financial status. When care coordination is instituted in the primary care setting, the family of CMC report increased patient satisfaction, improved quality of life, and decreased health care costs. <sup>10</sup>

NPs and physician assistants have the skills and competencies to effectively manage the health care needs for CMC. Pediatric NPs in particular can provide comprehensive care in schools and various health care settings. Research has shown that care provided by NPs and PAs as part of a multidisciplinary team results in better health outcomes and patient/family satisfaction.<sup>12</sup>

### TRANSITIONAL CARE

Transitional care is defined as a set of activities that ensures coordination and continuity of care of patients as they move from one level of care to another or one setting to another.<sup>13</sup> Transitional points include: home or nursing home to emergency room to inpatient settings, hospital discharge to a rehab facility, nursing home, or care transferred from primary care providers to specialists, hospitalists or home care agencies and back. These transition periods are associated with increased rates of adverse events (AEs) and rehospitalizations that can be avoided if risks are properly identified and anticipatory measures taken. Some common AEs include unnoticed laboratory abnormalities or outstanding lab tests at the time of discharge, adverse drug effects, infections, falls with injuries, and surgical complications. Older patients and patients with complex medical conditions are at the highest risk for transitional complications or an AE (Box 4.1). Transitional care, including care coordination with primary care providers, communication with home care agencies, and careful written and verbal discharge directions, in a language understood by the patient and family, should be in place for all patients with complex medical or surgical conditions. Provider ambiguity has been identified as an impediment to patient safety during transitions, particularly in the immediate posthospital discharge period. Conflicting instructions from specialists and the primary care provider can be confusing and lead to a variety of AEs.

There are penalties associated with inadequate care transitions that result in complications and rehospitalizations. The component of the Affordable Care Act that resulted in the Readmissions Reduction Program requires that CMS reduce payments to Acute Care Hospital Inpatient Prospective Payment System (IPPS) hospitals for readmissions to the

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### **Potential Risks for Adverse Events**

- Use of high-risk medication (antibiotics, glucocorticoids, anticoagulants, narcotics, antiepileptic medications, antipsychotics, antidepressants, and hypoglycemic agents)
- Polypharmacy
- More than six chronic conditions
- Cognitive impairment
- Physical frailty
- Prior hospitalization within the last 6-12 months
- Older age
- Sociocultural disadvantage
- Low health literacy
- Reduced social network indicators (e.g., being alone most of the day with limited or no family or friend contact by phone or in person)
- · Lower socioeconomic status
- Hospital discharge against medical advice

same or another IPPS-associated hospital within 30 days of discharge.

Multiple research studies have shown that transitional care provided by advanced practice nurses (APNs) or registered nurses improves patient outcomes and reduces health care expenditures. Hirschman and colleagues conducted a randomized study with high-risk older adults that revealed transitional care provided by APNs decreased cost and readmission rates. In this study, transitional care was initiated with hospital discharge planning and continued at home after discharge. Patients were first visited in the hospital within 48 hours of admission. After discharge, two home visits were conducted. The first one was conducted within the first 48 hours after discharge and the second was with in the first 7 to 10 days. The APNs were available 7 days a week by telephone and called the patients at least weekly.<sup>14</sup> Coleman et al. conducted a study that used transitional coaches who were APNs, specifically master's degree-prepared geriatric NPs who performed home visits within the first 24 to 72 hours after discharge. The APNs performed medication management and reconciliation, evaluation or worsening symptoms, and communicated with health care providers regarding the patient's condition. 14,15 APNs and PAs are both qualified providers for these services because of their knowledge of medications and medication management, their ability to assist the patient in transitioning from the hospital to home, and an awareness of self-management tools needed by the patient and families to adapt to their new daily routines at home.

Any time a patient moves from one setting to another, the risk for an AE is raised, especially when caring for older adults and/or the medically complex patient. The most common reason for the AE is poor communication, both verbal and written. Many of these events can be avoided with detailed patient and family education before discharge from a health care setting or between health care settings and careful monitoring after discharge. Clear communication between providers, including the primary care provider and other specialists participating in the care of the chronically ill patient, should also include all members of the care team such as nursing, physical therapy, home health services, and social work.

Communication is most effective when there are verbal interactions between care team members, as well as written forms such as discharge summaries and medicine reconciliation sheets. When electronic records are not transferable from one setting to the next, printed copies can be sent with the patient or faxed to the receiving facility. Ideally, discharge summaries and written instructions arrive at the same time as the patient.

Polypharmacy is responsible for many of the issues that arise after discharge, especially if new medications have been prescribed without adequate education. In older adults, high-risk medications such as insulin, warfarin, oral antiplatelet agents, and oral hypoglycemic medications, as well as benzodiazepines and opioids, are the most likely culprits for an AE and/or readmission.<sup>16</sup>

Primary care providers play a crucial role in transitional care. The recently discharged complex patient should be seen within 48 to 72 hours of discharge to review the discharge plan and evaluate the patient's medication list to ensure all changes are in writing and that the patient and family understand the medication instructions. Ideally, a house call is made for this purpose. Studies have shown that care coordination by a nurse, communication with the primary care providers upon discharge, and a nurse home visit within 3 days significantly reduced readmission rates.<sup>17</sup> A written list of the current medications and instructions using large print at a third-grade reading level should be given to the patient at the end of the appointment. Patients should be reminded that medications taken before hospitalization may no longer be on the current list or be listed at a different dosage. A discussion of polypharmacy can be found in Chapter 13.

Other impediments to successful transitions between levels of care are cognitive impairment, depression, physical frailty, and delirium that developed as a result of the hospitalization. Care coordinators should establish the patient's cognitive and physical baseline before the current illness by interviewing family or caregivers in order that the most appropriate discharge plan is established.

Healthy People 2020 defines social determinants of health as "conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."18 These conditions can be social, economic, and/ or physical. People in lower socioeconomic brackets and/ or who have lower educational levels are at higher risk for chronic illnesses because of lack of insurance, limited access to health care, or language barriers. Health care providers need to incorporate awareness of health disparities when planning the transition of care. These health disparities all influence the chronically ill patient's access to primary care, ability to follow a prescribed care plan, and make these patients more likely to experience AEs. Acknowledging a patient's health beliefs and incorporating those beliefs into the care plan are elements of cultural competent care and an important part of successful transitional care planning.

Several models of care proposed over the past decade were designed to avoid hospital readmission. Most include a pre-discharge interview with a nurse or social worker, a home visit within 72 hours, and periodic home visits and phone calls to monitor medications and functional status. Basic primary care services delivered at home as well as restorative services such as physical, occupational, and speech therapy can be features of a successful transition model. House call programs, parish

nurses, and community nurses are becoming more popular as communities look for better ways to care for homebound residents. Assisting patients to navigate the complex medical system reduces confusion and likely improves compliance with the medical plan, hopefully resulting in fewer health crises and hospital admissions.

Concerns about patient safety mandate improved health literacy assessment, uncomplicated medication instructions, and safer transitions for patients from hospital to home. Improved medication reconciliation and more expedient follow-up after hospitalizations may promote successful transitions.

### CARE OF THE PATIENT WITH END OF LIFE ISSUES

As the population ages, the number of people dealing chronic health problems is rapidly rising. Chronic and eventually terminal health issues such as heart disease, cancer, chronic respiratory disease, and dementia can have prolonged courses with a gradual decline and long periods of disability. These patients can benefit from palliative care in collaboration with regular medical care.

Palliative care is defined as patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. Patients with chronic medical conditions such as heart disease, cancer, stroke, diabetes, renal disease, and Alzheimer disease can be treated with palliative care. Research has shown that patients who received early palliative care had less depression, better quality of life, and increased survival time (see Chapter 14 for an in-depth discussion of Palliative Care and End of Life discussions).

The care of the chronically ill patient is complex, time consuming, and expensive. It requires the coordination of multiple providers, health care systems, and reimbursement systems. This care is constantly challenged by the high cost of care and medications, lack of public transportation to office visits, unstable living situations, food insecurity, poor communication between health care providers, and myriad other social issues without clear solutions. As the population of the United States continues to age, there will continue to be an increase in the number of patients with complex medical conditions who need these services making the need for universally applied models imperative.

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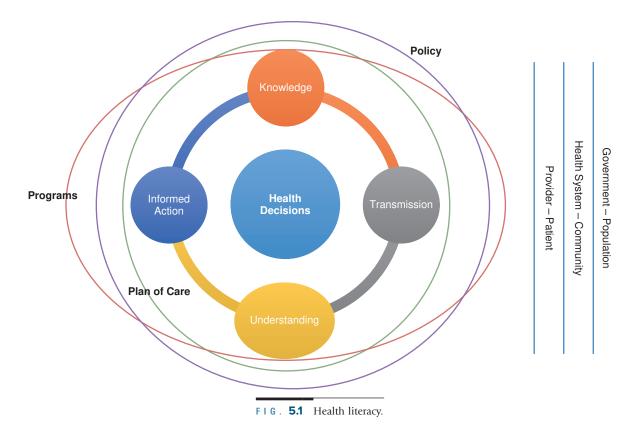
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### CHAPTER 5

### AN INTRODUCTION TO HEALTH CARE DISPARITIES AND CULTURALLY RESPONSIVE PRIMARY CARE

Catherine Gaines Ling

he Quadruple Aim is a framework for improving health at a systems level. The four areas of focus are: improving population health, decreasing cost of care, improving patient experience, and attending to the health and well-being of the care team. Social factors or determinants of health have a significant impact on all of these areas and are an increasingly critical part of primary care delivery. Social determinants of health include race, socioeconomic status, gender, education, occupation, and sexual orientation.<sup>2</sup> These factors are integral to delivery of holistic, quality, and safe care. Failure to integrate or acknowledge factors that affect health care behaviors and health care decisions creates a significant cost, both for the individual and for society as a whole. At its core, caring for another human being involves communication. For that communication to be health promoting, health literacy and an understanding and awareness of disparities and culturally relevant care delivery are essential for health care providers. This chapter provides an introduction to the topics



of health care literacy, health care disparities, and culturally responsive care.

### **HEALTH LITERACY**

Health literacy is a person's capacity to find, discuss, and comprehend health information and health systems and also to be able to use that knowledge to make informed decisions about all aspects of his or her health.<sup>3–5</sup> That ability to make informed decisions is critical for health promotion and self-monitoring. These are key skills for managing chronic diseases like diabetes and hypertension. There are several factors (knowledge, transmission, understanding, and informed action) that interact to inform health decisions that are the core of all aspects of care from the individual to the societal level (Fig. 5.1).<sup>3–9</sup>

Healthy People 2020 is the blueprint for the United States to achieve aspects of the Quadruple Aim. This blueprint has three objectives focused on improving health literacy. These objectives state that delivery systems, organizations, and providers need to:

- Increase the proportion of persons who report that their health care provider always gave them easy-to-understand instructions about what to do to take care of their illness or health condition.
- 2. Increase the proportion of persons who report that their health care provider always asked them to describe how they will follow the instructions.
- 3. Increase the proportion of persons who report that their health care providers' office always offered help in filling out a form.<sup>10</sup>

The most recent estimate of financial costs of inadequate health literacy is \$106 to \$238 billion annually. The Health Literacy of America's Adults report from the National Assessment of Adult Literacy survey (NAAL) stated that only 12% of

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### Risks Associated With Low Health Literacy

Delays in accessing care

Higher emergency department use

Higher hospitalization and re-hospitalization rates

Limited knowledge about personal health conditions

Limited self-management

Limited use of preventive health measures, including screenings and immunizations

Misunderstanding of follow-up recommendations

Misunderstanding of treatment options and medications

Misunderstood forms

Poor/limited or no follow-up care

Americans had a proficient level of health literacy, with 53% having an intermediate level. <sup>12</sup> This leaves approximately 88 million Americans with a basic or below-basic level of health literacy. Factors associated with high health literacy included being female, having an education beyond high school, and speaking primarily English, whereas low health literacy was associated with belonging to a minority, living in poverty, and being older than age 65. <sup>12,13</sup>

### HEALTH LITERACY AND HEALTH CARE OUTCOMES

Individuals with low health literacy are at risk for myriad poor health outcomes that impose increased fiscal and societal costs (Box 5.1). These poor outcomes start in childhood. Children with parents who have low health literacy are more prone

to be seen in the emergency department, have increased severity of conditions (e.g., asthma), and are less likely to be fully immunized. 16,18-20 Adolescents have not been as thoroughly studied as some other populations, but it stands to reason that this dynamic stage in life presents an opportunity to improve health literacy. It is posited that poor health literacy contributes to increased mortality, as noted in suicide and untreated depression.<sup>21,22</sup> During adulthood, low health literacy is related to inadequately treated conditions (e.g., hypertension, influenza, HIV, heart failure, and mental health issues), which, in turn, lead to increased morbidity. 14,15,23-25 Systematic reviews found that low health literacy is associated with increased emergency department use and hospitalizations, inappropriate use of medications, misunderstanding of follow-up instructions, and decreased use of preventative services such as mammograms. 14,15 Older adults are particularly vulnerable to poor health outcomes related to low health literacy and have a higher risk of all-cause mortality even when lower cognition is not a consideration.14

### HEALTH LITERACY—FROM MODEL TO ACTIONABLE COMPONENTS

Health literacy does not refer solely to the general ability to read and write. However, those with low general literacy rates will often have low health literacy rates. Knowledge refers to the baseline understanding of how the body and disease processes work. While this ability to understand physiology and pathology are facets of health literacy, even patients who are highly literate and educated can have low health literacy. Transmission and understanding refer to the delivery and receipt of key pieces of information. These data can be given verbally (requires adequate hearing and language comprehension), in written format (requires adequate eyesight and reading comprehension, including numeracy), or via technology (requires ability to use and understand technology). Successful understanding leads to informed action, often defined by providers as self-management. 7,24 For more information, see Chapter 6. Identifying strategies for improving communication with patients can have a positive impact on health outcomes.

### Strategies to Improve Oral Communication

Oral communication (sending and receiving) is the cornerstone of health care delivery. Conversations with patients with low literacy can be affected by four different qualities: (1) use of medical terminology, (2) complex speech content, (3) abstract context, and (4) dense, rapid discussion. 6.26.27 Providers need to use plain speech and avoid cramming multiple abstract and complex concepts into a fast-paced discussion. Additionally, they need to check with the patient and see what message was received. One method for accomplishing this is known as teach-back. 28,29 Teach-back will be discussed in more detail in a subsequent section.

### **Strategies to Improve Written Communication**

Every handout, prescription, or written referral is provided with the assumption of a certain level of patient reading comprehension. The average American has an eighth-grade reading level; however, the suggested reading level for health information is fifth grade.<sup>30</sup> There are several tools for determining the reading level expectation of written material. Two that are integrated into Microsoft Word are the Flesch Reading Ease test and the Flesch Kincaid Reading Ease level. The Centers for Medicare

and Medicaid Services has an 11-part toolkit for gauging the reading comprehension level of a provider's written materials, along with tools and tips to clarify those materials and make them more user-friendly for patients (www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit).

### Strategies to Improve Communication Using Technology

Electronic health or eHealth materials that have successfully reached individuals with low health literacy through a number of different platforms include audio files, videos, and voiceover slides, along with read-only materials and non-internet-dependent DVDs.<sup>31</sup> It is critical to gauge the patient's technologic literacy as a component of their health care literacy in using the various technology programs and platforms as electronic health records, self-monitoring applications, and communication via smart phones and computers become more integrated into health care delivery.<sup>7,32,33</sup> Health care providers should inquire about patients' familiarity with using the various technology programs and platforms utilized by their practices.

### INTRODUCTION TO HEALTH LITERACY ASSESSMENT

The first step in addressing the needs of low-health-literacy patients is to do an assessment. Although there are a variety of tools for gauging health literacy, there are four that are readily translatable into primary care settings: (1) the Patient Education Materials Assessment Tool (PEMAT),<sup>34,35</sup> (2) Rapid Estimate of Adult Literacy in Medicine–Short Form (REALM-SF)<sup>36</sup>; (3) Ask Me 3<sup>37</sup>; and the (4) Newest Vital Sign<sup>38-40</sup> or ice cream label assessment (see Chapter 6).

### **An Overview of Health Literacy Interventions**

It is not only patients and materials that need to be assessed for health literacy. Providers need to develop the awareness, knowledge, and interventions to effectively meet the needs of patients with less-than-optimal health literacy. Patients should be routinely assessed for health literacy levels using one of the methods listed previously. Previous research has found that using images and symbols and decreasing the overall amount of text broaden the health literacy scope of materials. Teach-back is another patient-centered intervention. This method involves asking a patient to verbally relate their understanding of a plan, instructions, or a routine.

In addition, use of native language materials, diseaseor condition-specific information, and print-only alternate formats (like podcasts, videos, or infographics) can help address information needs of patients with low health literacy.<sup>4,33,42,43</sup> Box 5.2 provides measures to reduce the impact of health literacy. For further information, see Chapter 6.

### **Organization-Centered Interventions**

Organizations should systematically review materials and navigation procedures to gauge the health literacy expectation of users and then involve employees and community members in planning, implementing, and evaluating steps to address health literacy needs. 44 The Centers for Disease Control and Prevention provides health literacy toolkits emphasizing the use of plain language in all written, audio, video, and virtual materials; these toolkits can be found by accessing www.cdc.gov/healthliteracy. The Ask Me 3 website (www.npsf.org/?page=askme3) offers

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### Measures to Reduce Health Literacy Impact

- 1. Routinely assess patients for health literacy level.
- 2. Routinely assess providers for communication skills.
- 3. Use the teach-back method in patient interactions.
- Provide written patient education materials at reading level appropriate for every patient.
- Use pictographs and symbols to convey information in patient education materials.
- 6. Minimize the use of text in written materials.
- 7. Provide alternative formats of information (e.g., audio, video).

helpful resources for providers and ideas for making primary care settings more user-friendly for patients with lower health literacy (see Chapter 6).

### **HEALTH CARE DISPARITIES**

Along with health literacy, disparities in care are a key social determinant impacting health outcomes. Disparities occur when one group has barriers to the standard of care and poorer health outcomes than another group. 43 The inability to access high-quality and timely care results in increased morbidity and mortality. The direct cost of health care disparities is estimated to be over \$229 million.8 Specific populations are particularly vulnerable to disparities in accessing adequate care and resources. Patients with decreased mobility, those in lower socioeconomic strata, and minorities face existing or worsening health care disparities. 43 These care inequities also impact lesbian, gay, bisexual, and transgendered individuals and are found to be more prevalent in certain zip codes and geographic regions. 43,45-47 The Office of the Surgeon General, the Department of Health and Human Services Office of Minority Health, National Partnership for Action to End Health Disparities, and the Centers for Disease Control and Prevention are a few of the federal agencies involved in addressing health care disparities.

Although disparities in health care would seem to be a system- or organizational-level concern, it is incumbent on health care providers to know who the vulnerable populations are in their communities, identify the disparities those patients face, and implement programs to address those disparities. Examples include a traditional foods project for diabetes prevention in partnership with indigenous tribes and a community-based asthma exacerbation and prevention project. <sup>43,48</sup> The initial efforts providers make to address disparities start through self-examination for personal biases. This is essential because unintended or implicit biases in a health care professional affect clinical decision-making. <sup>49,50</sup>

### AN OVERVIEW OF CULTURALLY RESPONSIVE CARE

Like disparities and health literacy, an individual's cultural context determines how, when, and to what degree he or she will seek care and what interventions are considered acceptable. Cultural context determines what is considered to be health, what are normative treatments, and what is illness behavior. Providers must provide culturally responsive care in patient-centered environments, maximizing communication and minimizing bias.

### OBLIGATIONS IN CULTURALLY RESPONSIVE PRIMARY CARE

### Address Cultural Variations Among Diverse Patient Groups

With increases in globalization and increasing access to health care services, the diversity of patient populations in the United States has increased. Health care professionals might not be familiar with all the cultural views represented in a practice; however, this knowledge is essential to provide high-quality care. In a patient-centered environment, health care professionals inquire about beliefs regarding health, illness, and treatment; are responsive to individual preferences; and work with patients and their families to devise treatment plans that are acceptable and actionable and therefore have an increased likelihood of adherence.<sup>51</sup>

### **Create a Patient-Centered Environment**

Clinicians must always ask and not assume a patient's cultural, racial, ethnic, or gender context. A discussion of health concerns should include the patient's perspective because that perspective factors greatly into the approach to and success of the treatment plan. That plan should be negotiated within the framework of the patient's worldview. Culturally responsive patient-centered environments seek a culturally relevant understanding of health from the patient and other sources. The resources available from the AHRQ give a road map to assessing and developing culturally competent care (https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/6-strategies-for-improving/communication/strategy6kcultural competence.html).

### **Minimize Clinician Bias**

The personal views and professional and personal experiences of health care providers can also create bias and impede culturally responsive care. Recognition of bias begins in training through self-reflection, observed clinical encounters, and simulation (see Chapter 6).<sup>50</sup>

### **Overcome Patient Barriers: Language Environment**

Increasingly, health care providers deliver care to culturally diverse populations of individuals who are not native English language speakers. Only approved, professional interpreters experienced in health care interpretation should be allowed to interpret for patients. Family members or friends should *not* be used as interpreters. Use of family members or friends may create misinterpretation or misunderstanding between the clinician and the patient. Family members may not understand medical terms or may interpret only what they feel is important, or patients might feel uncomfortable divulging personal information to the person interpreting.

Every effort should be made to use a certified, professional interpreter, with bilingual staff members used as interpreters only in emergency situations. When interacting with a patient through an interpreter, clinicians should still speak directly to the patient and refrain from discussing the patient in the third person with the interpreter. The patient should feel that the clinician is directly interacting with him or her and not with the interpreter. Pausing every two or three sentences, especially in discussing or describing complex diseases or treatments, will ensure that the interpreter is able to correctly interpret all of the information discussed with the patient. Disease information,

brochures, and consent for treatment and procedures should be printed in the patient's language. Federal law regarding Medicaid and Medicare federally funded programs mandates access to linguistic services. Certified translation services are available by phone 24 hours a day from multiple vendors.

### **CONCLUSION**

In today's changing and challenging health care environment, primary care providers are called to improve health care literacy, reduce health care disparities, and deliver care to culturally diverse populations. This challenge is accomplished by assessing and improving health care literacy, delivering culturally responsive primary care, and addressing disparities. Key components of culturally responsive primary care include addressing cultural variations among diverse patient groups, creating patient-centered friendly environments, recognizing clinician bias, and overcoming patient language and social barriers.

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