# Integrated, Personalized Care for Older People

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#### Abstract

Medical science has made magnificent advances by dividing complex problems into their component parts. The strength of clinical trials, and the resulting evidence-based clinical guidelines, is that they isolate a particular phenomenon or therapy from its context to assess its effect without the confounding of diverse contextual factors. However, the health and health care of whole people, and particularly older people who often live with multiple chronic conditions, is context-dependent. Older people are not well served

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by the current fragmented medical knowledge and organization of health care, which is impersonal, often ineffective, and dangerous. More helpful approaches to health care for older people begin with the whole of the person in their family and community circumstance, and then examine the parts of people (including individual strengths, as well as diseases and disabilities) in context.

We interpret three case studies in light of research on what patients and primary care clinicians say matters in health care. What matters are 11 domains of care: accessibility, a comprehensive, whole-person focus; integrating care across acute and chronic illness, prevention, mental health, and life events; coordinating care in a fragmented system; knowing the patient as a person; developing a relationship through key life events; advocacy; providing care in a family context; providing care in a community context; goal-oriented care; and disease, illness, and prevention management.

The health and health care of older people requires contextualized knowledge and personal knowing, supported by integrated systems that treat health care not as a commodity, but as a relationship.

*Keywords:* health services for the elderly, primary care, care integration

# Atención Integral y Personalizada a Personas Mayores

#### Resumen

La ciencia médica ha hecho magníficos avances al dividir problemas complejos en sus componentes. La fortaleza de los ensayos clínicos y las guías clínicas basadas en evidencia resultantes es que aíslan un fenómeno o terapia en particular de su contexto para evaluar su efecto sin la confusión de diversos factores contextuales. Sin embargo, la salud y el cuidado de la salud de las personas, y en particular de las personas mayores que a menudo viven con múltiples afecciones crónicas, depende del contexto. Las personas mayores no están bien atendidas por el actual conocimiento médico fragmentado y la organización de la atención de la salud, que es impersonal, a menudo ineficaz y peligrosa. Los enfoques más útiles para la atención de la salud de las personas mayores comienzan con la persona en su totalidad en su familia y circunstancias comunitarias, y luego examinan las partes de las personas (incluidas las fortalezas individuales, así como las enfermedades y discapacidades) en contexto.

Interpretamos tres estudios de casos a la luz de la investigación sobre lo que los pacientes y los médicos de atención primaria dicen que importa en la atención médica. Lo que importa son 11 dominios de atención: accesibilidad, un enfoque integral de la persona en su totalidad; integración de la atención en enfermedades agudas y crónicas, prevención, salud mental y eventos de la vida; coordinar la atención en un sistema fragmentado; conocer al paciente como persona; desarrollar una relación a través de eventos clave de la vida; Abogacía; brindar cuidados en un contexto familiar; brindar atención en un contexto comunitario; atención orientada a objetivos; y gestión de enfermedades, dolencias y prevención.

La salud y el cuidado de la salud de las personas mayores requiere conocimiento contextualizado y conocimiento personal, respaldado por sistemas integrados que traten el cuidado de la salud no como una mercancía, sino como una relación.

*Palabras clave:* servicios de salud para la tercera edad, atención primaria, integración asistencial

# 为老年人提供综合的个性化护理

#### 摘要

医学通过将复杂的问题分解成不同的组成部分,进而取得了 巨大的进步。临床试验以及由此产生的循证临床指南的优势 在于,它们将特定现象或疗法从情境中分离出来,以评估其 效果,并且不会混淆各种情境因素。不过,全民的健康和卫 生保健取决于具体情况,这对经常患有多种慢性病的老年人 而言尤为如此。当前碎片化的医学知识和对医疗的组织无法 很好地为老年人提供服务,这种对医疗的组织缺乏人情味, 通常效率低且危险。更有帮助的老年医疗保健方法从家庭成 员和社区环境开始,然后在情境中分析人的各个部分(包括 个人优势、疾病和残疾)。

根据有关"患者和初级保健临床医生认为的重要医疗保健问题"的研究,我们解释了三个案例研究。重要的11 个保健领域包括:可及性、详尽的全人关注、急性和慢性疾病、预防、心理健康和生活事件的护理一体化、在分散的系统中协调护理、从人的角度看待患者、通过重要的生活事件发展关

系、倡导、在家庭情境中提供照护、在社区情境中提供照 护、目标导向的护理、以及疾病和预防管理。

老年人的健康和医疗保健需要情境化的知识和个人关怀,并 得到综合系统的支持,这些系统将医疗保健视为一种关系, 而不是商品。

关键词:老年人健康服务,初级保健,护理一体化

#### Introduction

ealthcare in the U.S. is increasingly fragmented and impersonal (Bergman et al., 2020; Cebul et al., 2008; Hu et al., 2022; Hughes et al., 2020; Stange, 2009a; Stange, 2021). To be sick and old and in need of care often feels lonely and scary (Bayliss et al., 2014; Boult & Wieland, 2010; Kim & Rich, 2016). Amidst flashes of technically brilliant procedures and sparks of personal humanism, the U.S. healthcare is a system designed to deliver commodities rather than to develop relationships (Heath, 2006; Knai et al., 2018; Loxterkamp, 2016; Stange, 2016). The fragmented, frustrating, and depersonalizing aspects of U.S. health care pertain to both those in need of care and those trying to provide it (Horwitz et al., 2013; Rotenstein et al., 2018; Shippee et al., 2018). At the macro level, the U.S. system is the most expensive in the world, while producing a population of below average healthiness and unconscionable inequities (Ellner & Phillips, 2017; Starfield, 2011; Woolf & Schoomaker, 2019).

Moreover, there is a growing sense that many of our efforts at improvement are making things worse (Bujold, 2015; Casalino, 1999; Fisher & Welch, 1999; Ganz et al., 2007; Goodson, 2007; Harrison et al., 2007; Mc-Donagh & Hurwitz, 2003; McDonald & Roland, 2009; Milstein & Shortell, 2012; Wachter & Shojania, 2000; Weyer et al., 2008). Over the past four decades, the U.S. system has moved away from a base of largely independent, small, local care, organized around relationships, reputation, and place. These local systems often were paternalistic, lacked transparency and had no centralized means for knowing about the quality of care. But they have been replaced by consolidated vertically integrated healthcare systems organized around administrative and technological accountability, "productivity," and pay-for-performance metrics, characterized by rising patient dissatisfaction and workforce moral distress and burnout, with the personal paternalism of the individual physician replaced by the impersonal paternalism of administrators and algorithms (Miller, 2021). The worship of technology and

specialism has led to fragmentation and unsustainable costs. The Chronic Care Model (Coleman et al., 2009; Wagner, Austin, et al., 2001; Wagner, Glasgow, et al., 2001) and systematic evidence of the power of prevention (Glasgow et al., 2001) have fostered a "proactive" approach (Bensken et al., 2021; Glasgow et al., 2001) to delivering commodities of care that measures and incentivizes quality of care one-disease-at-a-time, and leaves little time or space for patients' and families' lived experience (Bayliss et al., 2014; Heath et al., 2009).

Into this hurried space, an aging population with multiple chronic and acute illnesses, preventive opportunities, family needs, and social context, faces a growing need for integrated, personalized care amidst a declining sense of being known as a person (Aungst et al., 2019). A recent cross-sector initiative examining the needs of people living with multiple chronic conditions identified the importance of attending to multilevel contextual factors to generate and act on the new knowledge needed to provide personalized, integrated care (Bayliss et al., 2014).

In this paper, we explore opportunities for integrating and personalizing care for older people. We begin with three stories from the authors' personal experience. Then we examine relationship-centered care based on new research from the perspective of clinicians and patients. We close with a discussion of policy possibilities for creating a health system environment in which being known and cared for as a person is a regular possibility.

## **Case Stories**

# Serving as an Entrée Point and a Buffer (Anne Gaglioti)

For many years, I took care of my patient Mr. P, whom I met at the community correctional facility where I had developed a program that provided care and aided in the transition out of prison. I continued to care for him once he was back in the community, at my clinic at the University Hospital. He was a complex person-not just because of a laundry list of medical and mental health problems: chronic kidney disease, bilateral below the knee amputations, coronary disease, tobacco use, antisocial personality disorder, insulin dependent diabetes, but also because he tended to get admitted to the hospital a lot and caused trouble when he was there. He wanted to go out to smoke on the telemetry unit; he would trash his hospital room; he would threaten the nurses. Mr. P had burned bridges with his friends and family. Eventually, even the relationship with his mother became eroded. He would still come to see me, though, and I would see him when he came.

One of the residents asked me once how I managed to be his doctor without becoming frustrated. I told her I did become frustrated, but I figured if he was showing up, then I would show up, too, and offer a clean slate of possibilities each time. I told her I suspected I was his most stable relationship and knowing someone was there for you is very good for your health. I remember being in one of many meetings in a hospital conference room with a nurse manager and the psychiatry team about his behavior, the psychiatrist, who I respected, got frustrated with me and said, "You know, he doesn't care at all about you." I was puzzled, because to me, it wasn't my business whether he cared about me or not. We showed up for each other; he came to see me, and I came to be his doctor. I moved out of state and handed off his care to a truly open-hearted colleague and friend; the transition went well. About a year later she called to tell me he had died. I cried and wondered out loud to her if anyone else grieved his death. "I thought you would want to know," she said. I did.

This story highlights a few aspects of primary care that allow clinicians, patients, and communities to thrive. The first aspects are knowing and autonomy. I knew that this barrier existed to care for people in my community, and I had a belief I could help to build a path to care where there wasn't one before. Another aspect is connecting and boundary spanning to work across sectors. I knew I couldn't build that path alone, and we convened and built connections with those who were needed to get the job done. A third aspect is continuity of relationships over time. The continuity that led to trust with community partners was foundational to the success of the effort, and the continuity of care with the individual patients was transformative both for me and for them. It laid the foundation for meaning, healing, and safety to take place (Lynch, 2021). Lastly, this story illustrates the power of abiding, the ability to be and to stay with woundedness

(Scott et al., 2008). I think this is the most powerful of these aspects because it is anathema to the existing health care paradigm, and requires a letting go of our ego as physicians. But, when we can do it, it is worth it—surrendering to abiding is transformational for the clinician and the patient. Sometimes, when we let go of the need to fix or control and allow ourselves and our patients time to be with what is, we find the spark of healing.

# A Geriatric Physician Assistant Steps in (James Bindas)

My father, a veteran of the Korean Conflict, age 89, and my mother, age 92, lived in the same home for 60 years. They were determined to age-inplace. I lived in the same city, worked full-time, and wanted to honor their wishes. However, I was challenged trying to manage their care. In particular, the growing physical and psychosocial needs of my father.

As my father's unpaid caregiver and having worked in an administrative capacity in several healthcare organizations, I thought I knew what to expect: attendance at doctor's appointments, making sure he took the right meds at the right time, and fulfilling transportation needs. I did not realize how much more was involved, from helping to manage multiple medical conditions and multiple medications with adverse side effects. My father's growing cognitive impairment forced us to revoke driving privileges, pursue guardianship, and deal with other safety and legal issues.

My father's healthcare provider of choice was our local Veterans Affairs Medical Center (VAMC). As with most large healthcare systems, I had come to expect delays: delays in obtaining appointments, delays in accessing in receiving ancillary services and specialty care. The only thing that seemed timely, with these and other systems, were the bills. Adding in the additional complexities of a government system led me to wonder if my father would receive the timely care he needed in a coordinated fashion to have the desired effect on his wellbeing and quality of life.

I realized I was clearly in over my head.

That is until I met TW, a geriatric physician assistant associated with the VAMC, whom I found to be my father's strongest advocate.

During each clinic visit, I observed the rising number of sick patients, strained resources, and lack of support personnel. Overworked and under-supported, TW nevertheless was always pleasant, personable, and professional, despite my father's bigoted attitude and disdain at being treated by a female practitioner. TW never wavered in her focus on treating my father as a whole person, acting as a true advocate-coordinating needed specialty care even, when at my request, the care was delivered outside the VAMC system. At every visit, TW took the time to ask how my mother was doing, to ask how I was doing as a caregiver. She made me feel as though she understood what I was going through and related her own personal experience with her

mother. This personal sharing anchored me as my father's condition deteriorated. She even went as far as to provide me with a mini exam (and notes to share with my personal physician) when she could tell I was struggling with some of my own chronic health issues. She was a beacon in a storm, guiding me through a process I was not yet ready to acknowledge-becoming a trusted confidant and a powerhouse of knowledge, gently "forcing" me to recognize what was becoming inevitable. What astonished me was that she did all of this while working for a largely bureaucratic organization. I expected to experience a hierarchy, with processes based on policy, procedure, and specifically defined responsibilities. What I got was a professional who was flexible, adapted her thinking, by bringing innovation and creativity into play, to meet my father's individual needs.

TW's focus was on improving the quality of care delivered. She set goals, helped develop actions for meeting those goals, and connected and collaborated with other organizations. TW provided access to care by giving me her cell phone number. She engaged my father and our family and guided us through the complex healthcare system. As an active participant in my father's care, I was involved decision making and felt free to share information, express opinions about different treatment methods, and accept TW's recommendations.

It has been just over a year since my father passed away. We had a complex relationship for most of my adult life. TW revealed life-changing insights that made my father's final journey peaceful-we were able to talk about how much we loved each other. Through her lived experience, TW provided wisdom on how to approach the ever changing physical and cognitive needs of my father-wisdom gained from her personal struggles as she cared for an aging parent, as well as caring for many patients. TW took the time to listen, to help me understand my own fears and provided me the support I needed to make some difficulty decisions. Most importantly TW reminded me that we are all human and encouraged me to talk to my father from the heart and not let my own baggage get in the way.

Taking a step back and looking at our healthcare landscape, I realized our immense population, complete with a large aging sector, is facing increasingly complex chronic diseases, comorbidities, and social determinants of health that cause healthcare delivery to look different than it did in the recent past. Healthcare professionals need to work inter-professionally, rely on the strengths of advanced practice providers, and allow those who have earned the credential to practice at the top of their license and ability. I found myself acknowledging the special skills of those who practice geriatric medicine. I also came to realize that geriatric medicine is multi-faceted due to the complexities of chronic health conditions, frailty, dementia, changing psychosocial conditions and serious illnesses that lead to frequent hospitalizations. Geriatric patients need, and deserve, clear and compassionate communication, coordination, and teamwork not only from their medical providers, but from family and other caregivers.

As I reflect on the last year of my father's life, I have come to realize that TW's actions can be part of the sustainable solution to "fix" our broken healthcare system. People feel lost in today's healthcare system. TW's approach fostered connection and shed a new light on the broken healthcare processes that stand between providers and patient care. To me, her words and actions acknowledged that being a physician assistant, obtaining the training and having the opportunity to transform her patients' lives, is a privilege. She acknowledged how much she learned from me, and from her other patients and their families, and how that made her a better person (and clinician).

My father's end of life care, and my ability to provide the support he and mother both needed, would not have had the same impact had it not been for the guidance and support of TW. Her compassion and caring are powerful tools. She touches the souls of her patients, and their families—a gift she gives to all who entrust her with their lives.

# Being There (and not) (Kurt Stange)

I cared for two eponymous retirees, Jim and Doris Bauer for many years, providing routine care (Kurt C. Stange, 2009). For Jim this consisted of managing his high blood pressure, nagging him about his cigar smoking, and caring for various musculoskeletal complaints from his work on his boats and his garden. For Doris, it included helping her to get on with walking their dog or playing bridge while she dealt with her diabetes, hypertension, hypothyroidism, and arthritis; for both, looking for teachable moments to work a little more regular physical activity into their routines, and more veggies and less animal fat and sugar and calories in their eating.

Sometimes seeing people over time, the familiarity can allow the doctor and patient to know when to let things go. Sometimes it can breed complacency. Other times, it provides a sense of when something that appears routine is not quite right and is worthy of looking into a bit more. But just as often, this duet of knowing and being known can provide hunches on both sides of when it is important to pay particular attention.

Jim had a good story about a new onset of pain in his upper back that started after overworking in the garden. But after two weeks of ice packs, daily ibuprofen and two physical therapy appointments, it was no better. When he came in for follow up, I could feel the spasm in the muscle between his spine and his shoulder blade. Jim had laid off yard work and even stopped puttering around on his beloved boat, so I knew this pain was really irritating him.

There are a lot of organs in that area—muscles, shoulder, spine, nerves, heart, lungs, and esophagus. Each organ has its own specialist who would be happy to see if their organ of interest was the culprit. But getting the answer "not my table," if I chose wrongly, didn't seem like a good option. It still looked like a muscle spasm, but something didn't seem quite right.

I gave Jim a few more stretching exercises to try, and gave Doris instructions to call to schedule Jim a CT scan of the chest and back. A week later, the radiologist paged me to say we "got our money's worth from the CT scan." I called Jim's house to ask if I could bring over the pictures after supper. I took my time walking up the front path, as Jim and Doris watched me through the screen door.

I showed Jim and Doris the cross-sectional picture on the CT scan, and pointed to a round, white blob an enlargement of the aorta carrying blood from the heart to the body. Jim's aorta measured 7 centimeters in diameter—already larger than the usual 6-centimeter threshold for operating to prevent a catastrophic rupture.

Somehow, Jim knew to ask if there was anything else.

Yes, there is a lump on the left kidney, about 3 centimeters in diameter. This was found by accident, but most likely was a cancer of the kidney. I doubted this had anything to do with the back pain, but the kidney needed to come out. (You can live fine with just one kidney.)

Shaking, Doris asked "What do we need to do?"

"There is something more," I ventured, pointing to a poorly defined grey area. "A thickening of the esophagus, in the right location to be causing the back pain." "What is it?" Jim asked.

"Possibly another cancer."

Now Jim sat down. Doris moved her chair close and held his calloused hand. "What do we need to do?" she asked again, but the shaking in her voice and hands had gone.

I reviewed the situation. "First, we need more information. We have found two things that could be causing the back pain. I still think the pain is from muscle spasms. But rather than being caused by overworking in the yard, the spasm may be caused by the aortic aneurysm or the esophageal thickening. We need to find out what the thickening is."

"Okay" said Jim and Doris together.

I arranged for a visit to a gastroenterologist to take a biopsy of the esophagus, and a chest surgeon for advice about the aneurysm, and coordinated with them and the physical therapist.

The biopsy showed esophageal cancer, and I arranged for an oncologist to do chemotherapy before the chest surgeon removed the tumor. Together, Jim, Doris, the chest surgeon, and I weighed the pros and cons of operating on the aneurysm and decided to hold off on an operation that could kill Jim or leave him paralyzed from disrupting the blood vessels that go to the spinal cord. After his recovery from chemotherapy and chest surgery, I arranged for Jim to see a urologist, who removed his cancerous kidney. I'd tried to get him to do it at the same time as Jim was under anesthesia for the esophageal surgery, but the surgical approaches were so different it didn't make sense.

Over the next three years, to minimize the risk of the aneurysm rupturing, I used multiple medications to lower Jim's blood pressure until he started to feel dizzy, then backed off, keeping the pressure as low as he could tolerate. Twice I hospitalized him for urgent blood pressure control when his back pain ominously returned, consulting the surgeon to confirm that an operation wasn't needed.

Sometimes, Jim had problems swallowing when the scar thickened where the surgeon hooked Jim's stomach up to the back of his throat after removing the esophagus. When this happened, I asked Jim to see the gastroenterologist for a dilation procedure. Not surprisingly, Jim had horrible acid reflux. When nothing else helped, I work with Jim's son, who lived in Canada, to get a new drug recommended by the gastroenterologist but not yet available in the U.S. It helped.

I helped Jim formulate his wishes in a living will and cared for the effect of his illness on Doris, integrating care of her anxiety and insomnia with management of her diabetes, hypertension, hypothyroidism, and arthritis. I tried to make one medication work for her anxiety, insomnia, and arthritis pain, rather than using a different medication for each, and encouraged lifestyle change over medication when possible. When Jim's blood pressure gradually increased, it served as a malleable moment to encourage positive changes in Doris. They began daily walks, which helped their high blood pressure and arthritis, and reduced Doris' medication needs. It also gave Doris and Jim quiet moments to try to find meaning from Jim's illness and from a long life together that now seemed more finite.

Then, early one morning when I was out of the country on a research trip, Doris awakened to find Jim shuddering, then unmoving and unconscious next to her in bed. She called my house. My wife told her to call 911. Even today, I wonder if I had been there, if we would have been able to say that this is the end and avoid what followed. However, in my absence, Jim's chest was compressed, and his lungs ventilated. Because of his dire condition, the ambulance crew was required to take him to the nearest hospital where the physician covering for me was not on staff, and where Jim was not known.

After anticipating for years that an event like this would be caused by the aneurysm rupturing, a CT scan showed no leakage. The aneurysm was fine, but Jim was not. The intensive care specialist called in a neurologist who declared Jim brain dead. Surrounded by strangers, Doris and their children allowed Jim's life support to be turned off, and he died.

### What Care Do Older People Need?

Geriatrician Amasa "Buzz" Ford, MD, one of the originators of the widely-used Activities of Daily Living (ADL) measure of function (Katz et al., 1963), was a big proponent of primary care. When asked about this, he said, "Older people need what family doctors do."

The stories above give a sense of what is involved in the generalist approach embodied in primary care (Gunn et al., 2008; Kurt C. Stange, 2009). It begins with a comprehensive focus on the whole person in their family and community context, then uses that broad focus to provide the majority of care, selectively involving those with narrower expertise when that is likely to be helpful, and coordinating multiple sources of care (Donaldson et al., 1996; Starfield, 1998). It is based on treating health care as a relationship (Colwill et al., 2016; Green & Puffer, 2016; Miller, 2016; Rudebeck, 2019; Scott et al., 2008; Soubhi et al., 2010), not just as a commodity (Heath, 2006; Lown, 2007; Stange, 2016; Sturmberg & Cilliers, 2009)-getting to know people over time (Bazemore et al., 2018; Ford-Gilboe et al., 2018; Olaisen et al., 2020; Team, 2017), and by being available during critical life events (Mainous et al., 2004). That knowledge of the person in context allows them to help the older person and family to prioritize the most important aspects of care, taking a life course perspective and integrating care across multiple chronic illnesses, acute concerns, preventive opportunities, mental health, and family care (Stange, 2009b). Ideally it involves communication, rather than diffusion of responsibility, among health care teams (Balasubramanian et al., 2010; Bolen & Stange, 2017; Chesluk & Holmboe, 2010; Cohen et al., 2020; Friedman, 2021; Hoff et al., 2021; Jabbarpour, 2016; Pany et al., 2021; Rodriguez et al., 2007; Sinsky et al., 2010).

## What Matters in Health Care?

To try to understand what matters in health care, we went to the source, and asked hundreds of people receiving and providing care, and a smaller number (about 80) of people paying for care. We asked, "What matters? What is important in health care? How do you know good care when you see it?" Each respondent generated about a dozen ideas, and a multidisciplinary team carefully analyzed the responses to identify themes (Starfield III Summit, October 4-6, 2017). The identified attributes of what matters then were vetted and interpreted in a 21/2 day workshop among 70 national and international health system leaders with diverse perspectives. In this Starfield III Summit, participants shared personal, research and policy experiences, surfacing multifaceted mechanisms by which primary care can foster personal and population health, healing, and systemic value (Starfield III Summit, October 4-6, 2017).

In analysis of responses from the surveys and of the work by the Starfield III Summit participants, we identified eleven domains of care that represent the essence of high-quality primary care, from the perspective of those receiving or providing care. We developed an 11-item patient reported measure and assessed its validity and reliability. The resulting patient reported Person-Centered Primary Care Measure (PCPCM) has been translated into 28 languages (Larry A. Green Center for the Advancement of Primary Health Care for the Public Good; Tse et al., 2020; Zyzanski et al., 2021). It is freely available (Etz et al., 2019; Larry A. Green Center for the Advancement of Primary Health Care for the Public Good), and recently was endorsed by the National Quality Forum and by the Center for Medicare and Medicaid Services for use in measuring high value primary care in quality performance programs.

The headings below identify these 11 domains, followed by the *italicized actual question* from the Person-Centered Primary Care Measure. Below each heading, we consider the role each of these interacting domains in providing integrated, personalized care for older people.

# Accessibility

*The practice makes it easy for me to get care.* 

One of the great needs of older people is to be seen at early, undifferentiated stages of illness when interventions often are most effective (Donner-Banzhoff, 2018; Lin et al., 1999). Even when the diagnosis is not readily apparent, time and therapeutic trials may be used until things become clear (Donner-Banzhoff & Hertwig, 2014; Heath, 1995).

One of the problems with the shortage of primary care in the U.S. (Cohen, 2022; Steinbrook, 2009) and the imbalance of generalist to specialist clinicians (Kindig, 1991; Starfield, 2006; Starfield, Lemke, et al., 2005), is that it often takes weeks to get an appointment, and this fundamental advantage of primary care is lost. In addition, as the Chronic Care Model gained dominance (Coleman et al., 2009; Wagner, Austin, et al., 2001; Wagner et al., 1996a, 1996b), and care became more and more organized around helping people to manage their chronic diseases (Bensken et al., 2021), the idea that primary care should be available to people during their acute illnesses has fallen by the wayside in how health care is organized, with people being told to go to urgent care or the emergency department (Bensken et al., 2021; Johansen et al., 2016).

The decisions that health care systems make regarding accessibility show the trade-offs among these 11 domains of care that matters. Often heath care systems prioritize accessibility to any clinician over continuity of care with someone who knows the patient (Day et al., 2013). Thus, even if accessibility is good according to the metrics that systems use to assess it, that accessibility means being able to see a nurse practitioner or physician assistant or urgent care physician who doesn't have the needed relationship and context to provide personalized care, and often orders additional tests that someone who knows the patient wouldn't (Kahana et al., 1997).

In the second case story, TW enhanced Mr. Bindas' access to care by being personable and professional, even when her patient was off-putting. She gave his son her mobile phone number which allowed him to get advice that averted crises, avoided unnecessary visits, and led to earlier visits when she was able to identify a problem by phone.

# A Comprehensive, Whole-Person Focus

This practice is able to provide most of my care.

Primary care can take care of approximately 90% of what brings people in for health care (Stange, Zyzanski, et al., 1998). The advantage is not only efficiency, but the ability to see each part of a person's care as an aspect of a larger whole (Stange, 2002, 2010b). This enables many of the other domains of high value care described below.

As care has become more and more specialized, and as even generalists' scope of care has diminished (Jetty et al., 2019; Kraus & DuBois, 2017; Loxterkamp, 2019; Peabody et al., 2018; Russell et al., 2021), this ability to see and act on the whole has been hampered, along with the trust and relationship development engendered by beginning care with the broadest possible question – What is wrong and what can I do to help? (Jonas, 2020; Lee et al., 2019) vs. Do you have what is in my scope to treat? (Bayliss et al., 2014).

A recent study (Gray et al., 2022) found that the large majority of newly trained general internal medicine physicians are becoming hospitalists, and the majority of general internal medicine physicians who are not hospitalists see only outpatients. The ability to have a single physician who knows the patient and provides care in both the inpatient and outpatient setting is rapidly becoming a thing of the past, with obvious consequences for the efficiency and effectiveness of care (Jetty et al., 2019). The comprehensive care provided in all three of the case stories both avoided unnecessary emergency department and specialist visits and fostered early care of serious illness. More subtly, a comprehensive scope of practice allowed the clinicians to focus on meeting the needs of the whole person, and engendered trust by being trustworthy.

# Integrating Care Across Acute & Chronic Illness, Prevention, Mental Health, & Life Events

# *In caring for me, my doctor considers all of the factors that affect my health.*

Evidence-based guidelines, on which clinicians are evaluated for their quality of care, are based on scientific evidence from clinical trials that typically exclude people with co-morbid conditions (Fortin et al., 2006). And yet, most older people, and most people coming in for primary care, are living with multiple chronic conditions (Fortin et al., 2005; Hu et al., 2022). Optimizing care for one disease at a time is one of the major reasons for older people taking many drugs, leading them to experience exponentially growing possibilities for adverse interactions, and unsustainable cost and complexity (Burt et al., 2018; Doherty et al., 2021; McCarthy et al., 2017; Muth et al., 2019; Sasseville et al., 2019; Wehling, 2011).

Primary care clinicians look for a single medication that can help with multiple diseases, and they look for behavioral and other cross-cutting therapies effective in preventing and treating multiple conditions (Sturmberg et al., 2021). They use acute illness care as an opportunity to identify teachable moments for health behavior change that prevents or treats multiple illnesses (Cohen et al., 2011; Flocke et al., 2021; Flocke et al., 2012; Flocke, Clark, et al., 2014; Flocke & Stange, 2004; Lawson & Flocke, 2009), and they are alert for the mental health and psychosocial causes of illness and opportunities for prevention (Flocke & Stange, 2004; Lawson & Flocke, 2009).

For example, we saw that Mrs. Bauer's doctor prescribed a single drug for which the main effect or side effects helped her anxiety, insomnia, diabetic neuropathy, and arthritis pain. And by encouraging Mr. and Mrs. Bauer to walk, he prescribed a behavior change that reduced both of their needs for medication, as well as having a positive social effect on their interactions. Mr. P's and Mr. Bindas' care, by considering their sometimes-challenging personalities, helped to smooth both care and care transitions that otherwise would have been fraught.

# Coordinating Care in a Fragmented System

# *My practice coordinates the care I get from multiple places.*

Being seriously ill in the current U.S. health care system can be a lonely, dangerous experience, as each specialist provides advice or treatment for their condition of interest, but no quarterback coordinates that game plan.(Haggerty et al., 2012; Kathol & Kathol, 2010; McDonald et al., 2013; Panagioti et al., 2015; Press, 2014) Care coordination protects people from the dangers of overtreatment (Franks et al., 1992; Steel et al., 2014), iatrogenesis (Ecks, 2020), and decontextualized care (Weiner, 2004; Weiner, 2021; Weiner et al., 2010; Weiner et al., 2007).

TW coordinated complex care needs for Mr. Bindas, taking a large burden off his son, and helping him get what he needed in a complex and bureaucratic system. Mr. Bauer's doctor provided most of his care, diagnosed a complex set of new illnesses, and then got the needed specialists to provide their expertise at the moments when it could be most helpful, making the specialists more effective and protecting Mr. Bauer from the potential harms of over- or under-treatment.

# Knowing the Patient as a Person

### *My doctor or practice know me as a person.*

Being known improves diagnosis (Donner-Banzhoff, 2018; Donner-Banzhoff & Hertwig, 2014). It leads to more tailored treatment (McWhinney, 1975; Parchman et al., 2002). Being known as a person is healing in itself (Scott et al., 2008; Scott et al., 2009; Scott et al., 2017). As we increasingly conceptualize health care as a commodity, rather than as a relationship (Beach & Inui, 2006; Frankel, 2004; Safran et al., 2006), it is easy to develop systems that unintentionally make it more and more difficult to get to know people who provide the life context that is so vital for good care of older people (and all people). Being

known not only optimizes care, it is vital for helping to decide when it is time to back off on health care to provide end-of-life caring (Shippee et al., 2018; Stange, 1999).

Mr. P's care was greatly enhanced by a physician who took an interest in him as a person. This personal connection may have been healing in itself (Scott et al., 2008; Scott et al., 2009; Scott et al., 2017), and by allowing his personality, difficulty with relationships, and challenging background to be considered, enabled him to get care that otherwise would have been put off by the difficulties of others in dealing with him. Similarly, by investing in the relationship, TW was able to develop trust with a patient who tended to drive others away. For Mr. Bauer, knowledge developed over time helped his doctor to intuit that a common symptom might represent something serious, and that knowledge and the resulting trust helped him to orchestrate complicated and effective care.

# *Developing a Relationship through Key Life Events*

# *My doctor and I have been through a lot together.*

In a prior study, we found two pathways toward people valuing the relationship with their family physician (Mainous et al., 2004). One is simply being together over a long period of time—during care for multiple small illnesses that develop trust and a sense of being known that serve as an interest-bearing account that can be drawn upon when the chips are down. The other pathway, indepen-

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dent of being together for a long time, is the degree to which the family physician is available to people for critical life and health events. This doesn't necessarily require being physically present but does involve knowing about key events and being engaged in witnessing and trying to help. When both longitudinality and availability during key events are present, patients will do nearly anything to stick with their physician, and vice versa (Mainous et al., 2004; Nutting et al., 2003).

All three of the patients in the case presentations likely would have strongly endorsed this item in the PCP-CM. For Mr. P, his doctor was one of the few people with personal knowledge of his experiences in prison and the community. Mr. and Mrs. Bauer had major diagnoses, treatments contextualized understanding developed over time as a basis for developing a trusting bond, with that bond strained by a missed end-of-life event. TW made herself available for multiple medical events for the patient and his son and helped them through his ever-changing needs.

# Advocacy

### My doctor or practice stands up for me.

Advocacy for patients involves using the three kinds of medical power charismatic (personal), social, and Aesculapian (based on medical knowledge) (Brody, 1992)—to work to advance the health and wellbeing of the patient (Stange, 2010a). In the commodified and fragmented U.S. health care system that is designed to maximize revenue for health care providers and systems, it is vital to have an advocate. Often this is family and friends. But having an advocate inside the system—a primary care clinician who knows the person and their needs and is willing to stand up for them—is vital.

Mr. P's doctor's advocacy went beyond his individual care to setting up health screening sessions in prison and transportation system and a dedicated clinic for people coming out of prison. Mr. P's doctor enabled him to remain in the care system by serving as an outlet for them to share their own frustrating interactions with the patient. TW advocated for Mr. Bindas in a bureaucratic system. Mr. Bauer's doctor found a way to get a helpful drug that wasn't available in the U.S. In a system in which it often feels like every care provider is just doing the minimum to get through their overwhelming number of patients, this sort of personal advocacy reduces the system's danger and patients' and families' sense of aloneness. As the primary care system increasingly is overwhelmed, their ability to swim upstream in this advocacy role is diminished.

# *Providing Care in a Family Context*

*The care I get takes into account knowledge of my family.* 

All of us, but particularly older people, gain or lose health in the family context. Knowing the family is vital to personalizing care for familial illness and for all the health solutions that are best if family is engaged (Medalie, 1978). This is easiest when all members of a family see the same primary care clinician, but it is a vital aspect of primary care to know the family context for each individual patient (Medalie et al., 2000; Medalie et al., 1998).

Mrs. and Mrs. Bauer had the advantage of being cared for by a physician who knew them both as patients, and who could look for cross-cutting strategies to help both of them. Even though Mr. Bindas' son wasn't explicitly her patient, TW recognized how important he was to the health of her patient, and she provided him with care and advice when needed. The family context for Mr. P's care was more subtle, with his doctor using some of her knowledge of the patient and his estranged family relationships to compensate by using some of her social capital to arrange connections for a person who tended to destroy the connections in his life.

Interestingly, in a direct observation study of 4,454 patient visits to 138 family physicians, we found that the family was discussed in approximately half of new patient visits and a quarter of visits by established patients, and the presence and involvement of family members was most common in the youngest and oldest age groups (Medalie et al., 2000; Medalie et al., 1998). In 18% of visits, care was provided to another family member than the identified patient for the visit. Half the time, that patient wasn't even present in the exam room for the visit (Flocke, Goodwin, et al., 1998; Orzano et al., 2001).

# *Providing Care in a Community Context*

# *The care I get in this practice is informed by knowledge of my community.*

A vital aspect of providing culturally sensitive care and for taking advantage of local resources for health is knowing a person's community context (Geiger, 2002; Gruß et al., 2020; Hughes et al., 2016; Longlett et al., 2001; Martin et al., 2004; Mullan & Epstein, 2002; Nutting, 1986; Plescia & Groblewski, 2004; Sweeney et al., 2012).

Mr. P's doctor worked to understand the unique community of the prison system, the community factors that led people to be imprisoned, and the connections necessary to re-engage in society. For marginalized groups, this sort of understanding and contextualization of care can be lifesaving. TW used her knowledge of the community of veterans' and their experiences to be open and sensitive to how this experience might affect her patient's interpersonal interactions, including those with her. The Bauer's doctor lived in the same community as they did, so had lived knowledge of the community context and provided care for the family in the home.

# **Goal-oriented** Care

# *Over time, this practice helps me to meet my goals.*

Goal-oriented care is focused on what is important to the patient (Mold et al., 1991). What is important changes over the life course, and so a goal-oriented

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approach may be particularly important for older people who may, for example, value functional or quality of life outcomes more than the biomarker and disease outcomes that often are the focus of medical care (Mold, 2017; 2020; 2022).

Mold and Green contrast goaloriented care with the more common problem-oriented care, noting that goal-oriented care encourages patients to articulate what health means for them. It encourages dialogue and relationship development with health care providers and fosters a focus on strengths and resources (Mold et al., 1991). Reuben and Tinetti espouse three advantages of goal-oriented care that are particularly important for older patients-it tailors care to the individual rather than to the average effects that are the target of evidence-based care; it simplifies decision making for people with multiple chronic conditions by focusing on outcomes that are important to the patient, and it prompts patients to focus on what is important, and thus informs the often overlooked prioritizing function in health care (Reuben & Tinetti, 2012). Goal-oriented care may protect people from the over-treatment that is so common in the U.S. (Franks et al., 1992), particularly at the end of life (Shippee et al., 2018), but also can offer protection from undertreatment that happens when health care professionals make ageist assumptions (Henke et al., 2009; Miles, 2007; Parchman et al., 2007; Phillips et al., 2001).

TW worked with Mr. Bindas and his son to develop evolving goals as

the scope of what was possible for his health changed over time. Mr. P and his doctor established a tacit goal of showing up for each other. The Bauer's doctor helped them to develop a living will and explicit end of life care preferences, which probably were helpful when his actual end of life needed to be negotiated with doctors who didn't know him.

## Disease, Illness, and Prevention Management

# Over time, my practice helps me to stay healthy.

Seeing the whole person over time provides multiple opportunities to prevent illness, to make subtle changes in illness management that over time can make a big difference (Freeman & McWhinney, 2016; Stewart et al., 2013). In the direct observation study of 4,454 visits to 138 family physicians, we found that preventive services were delivered during 1/3 of visits for illness (Stange, Flocke, et al., 1998). Many of these preventive services were linked to opportunities to improve care of chronic illnesses, or used an acute illness as a teachable moment for improving health behaviors (Cooper et al., 2001; Flocke, Stange, et al., 1998; Stange et al., 1994).

In all three cases, the clinicians wove prevention into the course of caring for the patients' illnesses and concerns—sometimes as explicit preventive services, more looking for teachable moments for health behavior change (Cohen et al., 2011; Flocke et al., 2021; Flocke et al., 2012; Flocke, Clark, et al., 2014; Flocke & Stange, 2004; Flocke, Step, et al., 2014; Lawson & Flocke, 2009; McBride et al., 2003).

# Eleven Domains that Together Form a Complex Whole

The multiple domains of primary care work together in an integrated way enabled by a comprehensive focus on the whole person in context and investment in relationships over time (Heath, 1995; Heath et al., 2009; Heath & Sweeney, 2005; Sweeney & Heath, 2006). Different ways of knowing and doing represent tradeoffs, and the right decision among competing demands and opportunities requires local knowledge on-the-ground and in-the-moment (Kringos et al., 2010; Sturmberg & Schattner, 2001).

The diverse attributes of the Person-Centered Primary Care Measure, as assessed by the patient, all factor analyze into a single factor (Etz et al., 2019)—showing that there is strong conceptual coherence to the comprehensiveness of a person-focused approach to health care (Etz et al., 2019; Ronis et al., 2020; Tse et al., 2020; Tse et al., 2021).

During the Starfield III Summit, participants struggled to fit the interrelated complexities of the generalist approach and primary care into the usual reductionist classification and measurement systems that assume that the whole is merely the sum of its parts. The complexity of primary care was well captured in stories, and participants were able to begin to identify the mechanisms by which those com-

plex ways of knowing and doing could be described. But in trying to operationalize measurement of these ways of knowing and doing, they became quite anxious that a measure of any individual function could be misused. They emphasized that the individual facets of primary care must be understood, acted upon, and supported as a whole (Etz, 2016; Jonas, 2020; Lynch, Dowrick, et al., 2021; Lynch, van Driel, et al., 2021b; Thomas et al., 2018). This whole is much more than the sum of the parts (Stange, 2002), and efforts to measure and incentivize only the individual components risk damaging the integrative force of primary care for personalizing the care of the individual and for advancing the health of the population (Stange et al., 2014; Stange et al., 2010).

# Simple Rules to Understand the Craft of Generalism & the Complementary Specialist Function

n interesting attribute of complex system (Sweeney, 2006; Sweeney & Griffiths, 2002), such as the systems required to provide integrated care for older people (Adams et al., 2002; Boult & Wieland, 2010; Buja et al., 2018; Donaldson et al., 1996; Koroukian et al., 2007), is that their emergent behavior often can be described and understood by simple rules (Institute of Medicine: Committee on Quality of Health Care in America, 2001; Plsek & Greenhalgh, 2001; Trochim et al., 2006). When we used this idea to conduct further analyses of our crowd-sourced data and the Starfield III Summit, we uncovered three simple rules that, when actualized together by patients, clinicians, and practices, and supported by systems, describe the generalist approach from which the beneficial personalized care and population health outcomes of primary care emerge (Etz et al., 2021). These analyses also reveal complementary simple rules for the more narrowly focused specialist function (Etz et al., 2021).

When clinicians act as specialists, their behavior can be explained by three simple rules that represent the dominant approach to health care organization and quality measurement (Etz et al., 2021):

- 1) **Identify** and classify disease for management;
- 2) **Interpret through specialized** knowledge;
- 3) **Generate** and carry out a management plan.

However, when clinicians act as generalists (Kurt C. Stange, 2009), their thoughts and actions invoke three simple rules that are focused not only on single disease elements, but on the whole person (Etz et al., 2021). They consider the person in their larger context (Weiner, 2004; Weiner, 2021). They:

- 1) **Recognize** a broad range of problems/opportunities/capacities;
- 2) **Prioritize** attention and action with the intent of promoting *health*, *healing*, and *connection*;

3) **Personalize** care based on the particulars of the individual or family in their local context.

These rules work together to focus care on what is most important for each patient at a given time, and over time through a life course perspective.

*Recognizing* requires foraging for salient information (Donner-Banzhoff, 2018) based on a comprehensive generalist perspective—watching for teachable moments (Heath, 1995), clues, risks and opportunities (Cohen et al., 2011; Flocke, Clark, et al., 2014; Foucault, 1975; Lawson & Flocke, 2009; Kurt C. Stange, 2009).

*Prioritizing* begins with the broad, inclusive generalist perspective, and then sorts, ranks, and negotiates what is most important, to identify what action has the greatest potential to advance *health*, *healing, and connection* (O'Connor et al., 2017; Stange, 2009; Stange, 2009b; Stange et al., 2014).

*Personalizing* care moves from the statistical generalities of evidence-based medicine to the nitty-gritty of this person or family in their moment, place, and context. Over time, there are many particular moments (Bazemore et al., 2018; Henbest & Stewart, 1990; Stange et al., 2014; Stange, 2009; Stewart et al., 2000; Stewart et al., 2003), and attending to these develops knowledge of the person, trust, and trustworthiness (McWhinney, 1989).

The generalist rules interact and operate in an iterative fashion (Leopold et al., 1996; Ronis et al., 2019; Scott et al., 2008; Wilson et al., 1995): 1) as new information reframes problems and opportunities; 2) as what is most important continually evolves; and 3) as hypotheses are tried out with the intent of promoting some combination of health, healing, and/or connection. The cumulative effect of actualizing these rules is an investment in a relationship bank that can be drawn upon with interest during challenging moments in the health and lives of individuals, families, and communities (Bergman et al., 2020; Stange, 2009b).

Balanced with the right mix of specialist approaches, and connected with functional social systems, the generalist approach serves as an integrating and personalizing force in systems that otherwise tend to be fragmented (Lynch, 2021; Lynch, van Driel, et al., 2021a).

Focusing comprehensively on the needs of the whole person, over time, in relationship, combined with selective use of more narrow expertise, results in care that is personalized, integrated, and prioritized (Stange, 2009b; Stange, Jaén, et al., 1998). That approach fosters healthy individuals, families, and communities, and can contribute to a more fair, effective, and sustainable health care system (Starfield, 1992; Starfield, Shi, et al., 2005).

# Policy Implications for Integrated, Personalized Care for Older People

# A New NASEM Report

A recent report from the National Academies of Science, Engineering and Medicine (NASEM) calls for supporting primary health care as a common good, so that it can serve as a force for integration in our currently fragmented system (National Academies of Sciences, 2021). These policy changes to support the integrating, personalizing functions of primary care that are so essential to the care of older people. They recommend a multilevel implementation strategy, and emphasize:

- Paying for primary care teams to care for people, not doctors to deliver services;
- 2) Ensuring that high-quality primary care is available to every individual and family in every community;
- 3) Training primary care teams where people live and work;
- Designing information technology that serves the patient, family, and interprofessional care team;
- 5) Ensuring that high-quality primary care is implemented in the US.

The report stresses the importance of increasing the proportion of health care spending toward primary care, and payment models that support integrated care and sustained relationships, particularly "hybrid" models that move from fee-for-service toward capitation. The report highlights the importance of relevant research, coordinated leadership, more helpful digital support, and policies that enable locally tailored care. The recommendation that the US Department of Health and Human Services establish a Secretary's Council on Primary Care to coordinate across multiple government entities, already has been implemented (Grumbach et al., 2021).

An interesting historical analysis commissioned in support of the NASEM report shows the unintended fragmenting and depersonalizing consequences of four decades of care organization improvement initiatives, and highlights the need for business models that support and promote this generalist, whole person, relational care over time, in contrast to current models that add administrative burden by carving care into billable pieces and performance of reductionist outcomes (Miller, 2021).

Another analysis commissioned for the NASEM report (Stange, 2021), and an article in a previous issue of this journal (Gullett, 2021), highlight how the pandemic has uncovered the disastrous effects of decades of disinvestment in primary care and overspending on healthcare infrastructure that fragments care, reduces its accessibility for the most vulnerable, and reduces the resilience of people and systems attempting to integrate care for whole people.

# Relationship-centered Models for Organizing Care

urrent U.S. health care invests in technology, bureaucracy, and commodified service delivery (Heath, 2006; Hoff, 2022; Knai et al., 2018; Lown, 2007; National Academies of Sciences, 2018; Stange, 2016; Weiner et al., 2004). In order to provide integrated, personalized care for older people, it is vital to invest in supporting relationships (Hoff, 2017; Hoff, 2019). Relationship-centered care (Beach & Inui, 2006) provides the opportunity to focus on what matters to older people (Wasson, Ho, et al., 2018; Wasson, Soloway, et al., 2018), rather than providing services for which the system can maximize payment. Relationship-centered care is a cornerstone of the healing process (Scott et al., 2008; Scott et al., 2009; Scott et al., 2017), and provides a platform to providing and coordinating needed care (Sturmberg et al., 2012). Investing in relationships, particularly for older people, generates of bank of knowledge and trust that can be drawn on with interest when the chips are down-such as a new illness, a sudden loss of function, a critical life event, or nearing the end of life (Mainous et al., 2004; Nutting et al., 2003; Olaisen et al., 2020; Stange, 2016).

People who provide primary care went into the healing professions to provide this kind of relationship-centered care (Colwill et al., 2016; Griswold, 2016; Loxterkamp, 2018). But the current fragmented system has nearly destroyed their ability to provide this kind of care (Bujold, 2015, 2017). The moral distress of seeing what kind of help could be provided, but being unable to accomplish it (Frezza Md, 2019; Heston & Pahang, 2019), has led to rampant burnout (Bodenheimer & Sinsky, 2014; Dyrbye et al., 2017; Puffer et al., 2017; Rotenstein et al., 2018; Shanafelt et al., 2012).

Current health care systems emphasize vertical integration—organizing care around disease pathways, focused in a top-down fashion on managing named disease conditions or risk factors for ill health (Orszag & Rekhi, 2020).

Vertical integration connects people with defined needs with specialized services across multiple levels of the system (Baker et al., 2014). This can be helpful for managing individual diseases that fall neatly into named categories. Vertical integration can be very helpful once problems have been characterized and is a viable way to organize multiple specialized systems around a well-defined need. But if the only integrating organization is around well-characterized problems, complex multifactorial, undifferentiated, and unexplained problems get short shrift (Sturmberg et al., 2021).

Most older people have multiple chronic and acute conditions and surrounding social and family needs that don't fit neatly into boxes that can be vertically integrated. Older people need care that also is horizontally integrated—organized around whole people with complex needs in their family and community context. Horizontal integration involves broad-based collaboration to improve overall health (De Maeseneer et al., 2008). The dynamic processes of horizontal integration require flexible systems that iteratively link on-the-ground experience with efforts to grasp the larger contexts in which they operate. Primary care for older people can serve as a force for horizontal integration that make the vertically integrated systems more efficient and effective (Stange, 2021).

Comprehensive, whole systems integration includes a balance of both vertical and horizontal integration (Thomas et al., 2008). However, in the U.S., we have conceptualized and organized primary care and public health solely as part of top-down vertically integrated systems focused on problems rather than on people and communities, resulting in diminished effectiveness (Chan, 2008; De Maeseneer et al., 2008; Lawn et al., 2008; McPake & Mensah, 2008; Miller, 2021).

Local adaptation of the generalist function to specific individuals, families and communities is also reflected in the wide adaptability of the primary care function at the sociopolitical and population level. The particular needs of older people, and the high cost of their care and the care of multiple chronic conditions, have spawned some interesting practice innovations.

"Slow medicine" (Hill, 2021; Kerrigan, 2017; Marx & Kahn, 2021) that emphasizes using time and relationship as allies (Boult & Wieland, 2010; Sturmberg & Cilliers, 2009), guided care (Aliotta et al., 2008; Boyd et al., 2007) that supports integrated care of individuals and care coordination across multiple providers and settings; and multiple innovative practice models, particularly (Casalino et al., 2016; Casalino et al., 2018) in the Medicare Advantage space, appear worthy of initial support and further evaluation (ChenMed; Howe, 2017; Oak Street Health). While not focused specifically on older people, Direct Primary Care models that involve practices with small panel sizes and low-overhead from eschewing insurance and providing inclusive primary care for a small monthly fee, are revitalizing a primary care workforce energized by the ability to spend time with patients (Brekke et al., 2021; Brusch et al., 2020; Direct Primary Care Coalition; DPC Alliance; Wu et al., 2010).

The specter of venture capital looking for short-term, large return on investment is a concern (Braun et al., 2021; Brown et al., 2020; Casalino, 2020; Casalino et al., 2019; La Forgia et al., 2022), as is the current zeitgeist of bureaucratic government and not-forprofit health care systems that act like for-profit entities, both requiring stifling top-down, reductionist documentation burdens that distort the whole-person focus of frontline care of older people. But if these corrupting influences can be minimized, it is promising to invest in and evaluate creative approaches to support the time and resources needed to integrate care for whole people.

In the plurality of the U.S. health care system, there will not be one way to optimally organize care for older

people. In the diversity of older people, there will not be one way to optimally care for individuals in their family and community context. What is important, is to recognize that the knowledge needed to personalize and integrate care for older people lies at the very local level of the person, family, and primary care practitioners (Heath, 1995; Loxterkamp, 2001; Loxterkamp, 2016; Loxterkamp, 2018; Miller et al., 2010; Ventres et al., 2017; Ventres & Frankel, 2015). What is needed are systems that support investment in relationship at this local level.

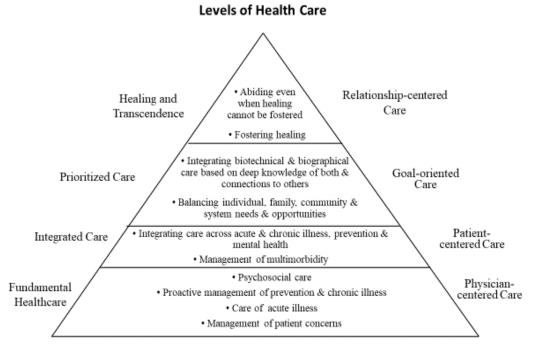
# Integrating Conceptualizations, Language, and Measurement

n the current Zeitgeist, we conceptualize that understanding comes from focusing narrowly (Diez Roux, 2011; Lynch, Dowrick, et al., 2021; Lynch, van Driel, et al., 2021a; Martin & Félix-Bortolotti, 2010; Vogt et al., 2016). In this view, the best scientific evidence comes from experimental designs in which randomization allows us to ignore messy contextual factors (Davis & Taylor-Vaisey, 1997; Gabbay & May, 2004; Genuis, 2005; Graham et al., 2000; Grol, 1993; Hayward et al., 1995; Hrobjartsson et al., 1998; Inouye et al., 1998; James et al., 1997; Lichtenfeld, 1993; Tinetti et al., 2004; Woolf, 1990; Woolf, 1993). Quality comes from narrowly-focused specialization, assessed as the sum of adherence to one-diseaseat-a-time clinical guidelines (Okeowo et al., 2018). This whole as the sum of the parts understanding works well for

simple or even complicated, well-defined problems (Heath et al., 2009). But it doesn't fit with the complexity of the care of older people (Sturmberg et al., 2021). It leads to problem definitions and top-down solutions that blames the individual for systemics problems and that don't support the bottom-up solutions needed to care for older people (Love, 2012).

The results of reductionist understanding, however, is an increasingly fragmented, impersonal, expensive, and often ineffective system that doesn't work for either the providers or recipients of care (Stange, 2009a). Our resulting efforts to improve care have added administrative burdens that have become intolerable for providers and patients/families alike (Bujold, 2015, 2017; Martin, 2017; Sinsky et al., 2021).

In order to begin to develop the needed new systems, we need to broaden our understanding of health and health care as a complex system (Lynch, Dowrick, et al., 2021; Martin & Félix-Bortolotti, 2010). Such understanding helps us to understand that there are multiple levels of care (Stange, 2009b). As shown in the figure below, basic care involves the diagnosis and treatment of individual acute diseases and problems of living, management of individual chronic conditions, support of disease prevention through healthy behaviors, early detection of treatable diseases, immunizations, and preventive medications. Currently, this basic care is all our scientific evidence can inform. Basic primary care also includes care of families.



From: Stange KC. A Science of Connectedness. Ann Fam Med. 2009;7(5):387-395.

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There is a higher level of care. Integrated care raises the gaze from individual problems and opportunities to look at the large whole of the person in context. It requires iteration between the parts and the whole, between general scientific evidence and the particulars of the person, family, and community. It involves integrating care across chronic illness, acute concerns, preventive opportunities, mental health, and family care. Our current one-disease-at-atime evidence-based clinical guidelines are blind to this integrated care. In fact, providing integrated care often flies in the face of individual disease specific guidelines, and thus integrated care is punished in quality reporting metrics and in pay-for-performance schemes that reward only compliance with disease-specific metrics.

A higher level of care still is prioritized care—focusing on what is most important in the moment, or ideally in many moments over time. Prioritized care is based on, and benefits from, knowing the person over time. It helps people and creates efficiency and effectiveness at the system level.

Prioritizing and integrating care are not supported by current information technology or reward systems, but they set up the highest level of care which involves healing and transcendence—providing cure when possible, palliation and support always, and sticking with people even when neither are possible (Jonas, 2018). Investment in the lower levels of care sets up this higher level of care which is vital near the end of life, but also for helping people with their health needs that don't fit neatly into the boxes of our currently commodified care systems.

As indicated in the figure, fundamental care often can be seen as physician-centered. Integrated care is patient-centered. Prioritized care is goal-oriented. Healing and transcendent care is relationship-centered.

# Generating New Knowledge Relevant for Integrating and Personalizing Care of Whole People

largely disease-focused National Institutes of Health (NIH) has made tremendous strides in advancing basic and disease-specific knowledge. But this siloed approach has fragmented knowledge and resulted in fragmented clinical care guidelines that fly in the face of efforts to integrate care for whole people. The National Institute on Aging has the potential to focus on the care of whole older people across the lifespan, and does so to some extent, but also is subject to the same reductionist pressures and conceptualizations that are dominant in the larger research environment. A more holistic, integrated, whole person focus is needed.

A reductionist research lens, peer review process, and funding structure limits the kind of questions that can be asked. Questions that have to do with whole people, with illnesses or preventive opportunities that transcend individual diseases, or how care can be integrated and prioritized, don't have a funding home or even a way to be seen as legitimate targets for inquiry (Miller et al., 2003). As a result, the research that we have excludes people with multiple or difficult to define conditions. It specifically excludes the contextual factors that are so important with understanding illness and health processes in older people, and the integrative solutions to advancing health (Sturmberg et al., 2021).

Integrative cross-cutting conceptualizations of health and illness are needed that take into account contextual factors across multiple levels: historic context, structural systems of bias and advantage, public policy, place, community, health care systems, family, and person, as well as the cellular and molecular levels where most research currently is focused (Balasubramanian et al., 2015; Peek et al., 2014; Stange et al., 2014; Stange & Glasgow, 2013; Tomoaia-Cotisel et al., 2013). New knowledge is needed that moves from a disease focus toward a person-driven, goal-directed emphasis (Mold et al., 1991). Non-reductionist research methods are needed that are participatory, flexible, multilevel, quantitative

and qualitative, conducive to longitudinal dynamic measurement from diverse data sources, sufficiently detailed to consider what works for whom in which situation, and generative of ongoing communities of learning, living and practice. Rigorous, integrated, participatory, multimethod approaches to generate new knowledge and diverse partnerships are needed to increase the relevance of research to make health care of older people more sustainable, safe, equitable and effective, to reduce suffering, and to improve quality of life (Bayliss et al., 2014; Miller et al., 2003; Stange, 2010b; Stange et al., 2001).

## Conclusion

The health and health care of older people requires contextualized knowledge, personal knowing, and systems that support horizontal as well as vertical integration. Such systems require understanding and supporting health care as a relationship. Focusing, measuring, and supporting whole-person care provides hope for integrated, personalized care of older people.

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