Bringing Nursing Back to the Future Through People-Powered Care

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Abstract
At a time when there is a growing interest in person- and family-centred care and integrated community-based models, the unique strengths and expertise of home care nursing is a strategic lever for change across all healthcare settings. In this paper, we explore the theme of people-powered care as a universal starting point – a new approach to health and wellness that is anchored in the strengths of people, their networks and the patterns of everyday life. Leveraging key insights from home and community care, along with broader societal shifts towards personalization and empowerment, we discuss how nurses in all areas of the system can lead the way by empowering staff, patients and their families. Finally, we look at the implications for nursing leadership including how our knowledge, skills and abilities must continue to evolve to effectively impact change and enable this vital transformation to occur.

Introduction

Every day, home care nurses across Canada are invited through the door into people's homes and lives. This is a very different starting point than meeting patients who come into the system through a "healthcare" door, be it a hospital, a medical office or a health clinic. Home care nurses have the privilege of engaging with patients on their own terms, in their own territory, based on their own unique capabilities and desires. In the home, nurses sit around all kinds of kitchen tables,

on rickety wooden chairs and sleek bar stools, experiencing firsthand the diverse ways people live, care and connect. Interactions with family, friends and neighbours are generally frequent – and in some cases, noticeably absent. Pets often wander about and become a topic of conversation. Some homes are dark and quiet, while others are bright and boisterous. Some people are early adopters with all the latest smart home and mobile technologies, while others need help with the TV remote on a regular basis. Through the course of a visit, home care nurses may witness the smiles and delight of a video call with grandkids, catch the lingering scents of the last meal, hear someone's favourite music or news station playing in the background and see family photographs and artwork hanging on the wall. Each of these interactions provides an opportunity for nurses to practice person- and family-centred care, honouring each patient as an individual with a unique life story, personality and values.

As nurses, the time and attention we give to understanding people and the context of their lives help us develop deeper human connections in all areas of practice. This "soft side" of healthcare is so essential, yet often undervalued because it can be difficult to measure and manage (MacLeod 2015). We tend to focus on the hard economics of healthcare, which are easier to quantify and certainly important in a well-functioning system. However, the real key to healthcare transformation and sustainability lies within the human side. In this way, the hard side and soft side of healthcare are inextricably intertwined. When nurses and nursing leaders understand what people think, feel and need, we are able to customize care and provide more meaningful interventions that result in better health outcomes and efficiencies in the system. This opportunity of course is not limited to home care. It can and must be embraced across all care settings and in every area of nursing, from policy and research to education, leadership and clinical practice.

If we were to successfully adopt a culture of person- and family-centred care across the entire health system, we would engage in different sorts of conversations and decision-making, uncover new approaches and place a greater emphasis on user experience design. Patients and caregivers would have a greater voice. When we talk to people and families, they have a natural ability to see healthcare in its broader context – like work, family and finances, healthcare is another dimension of life. As nurses, we need to consciously work to cultivate, understand and honour this perspective. This will allow us to achieve a deeper level of integration and impact through holistic and responsive care.

People-Powered Care: A Universal Starting Point

Person- and family-centred care is a concept that is both startlingly simple, yet amazingly complex. It has been defined and practiced in diverse ways by different health professions in different care settings. In a nutshell, the philosophy of

person- and family-centred care guides us to approach each patient as an individual and *equal partner* in their care, incorporating the elements that are most important to them on their well-being journey: their families, their lifestyle, their values and their health goals. There is a growing body of evidence that indicates that this leads to positive outcomes including better quality of care (Barbosa et al. 2015; Luxford et al. 2010; McMillan et al. 2013); better relationships (Barbosa et al. 2015; Luxford et al. 2010); better patient, family and staff experiences (Barbosa et al. 2015; Healthcare Improvement Scotland 2011; Luxford et al. 2010; National Ageing Research Institute 2006; Rave et al. 2003); fewer conflicts and complaints (Healthcare Improvement Scotland 2011); and lower health system utilization and costs (Bertakis and Azari 2011; Charmel and Frampton 2008; Pelzang 2010).

Although adopting a person- and family-centred approach may seem like common sense in many respects, experts acknowledge that it is difficult to do well. In organizations, there is often a tendency to spend so much time focusing on the tactics and checklists of patient engagement that we lose sight of the large-scale cultural change we are trying to achieve. Although the tactics are clearly important, it is critical, as leaders that we keep our eye on the prize. Shifting the culture is a big undertaking, and similar to organizational performance, there is no "finish line" when it comes to person- and family-centred care. We can achieve excellence, but our work in this area will never be done. As care changes, our organizations and practice must continue to change with it. Today, there are a growing number of tested strategies and evidence-based resources such as organization assessment tools, indicators and measures to help leaders embed, evaluate and sustain person- and family-centred care across their organizations (Health Foundation 2016 ; Institute for Patient and Family-Centred Care 2011; Registered Nurses' Association of Ontario 2015; Saint Elizabeth 2016).

As we pursue health system integration and transformation, the unique insights of home care nurses can be a strategic lever for change across all care settings. As we have described, nurses working with people in the home environment have an extraordinary opportunity to observe human behaviour, family dynamics and social networks over time in a natural setting. They see how people are coping with health conditions in their everyday life – what's working and what could change. When the goal is to support people to live at home for as long as they desire, the home environment becomes a central focus and living laboratory for how we need to approach and deliver care across the entire system. In this way, home care nurses can help to inform more robust and tailored approaches to everything from effective hand-offs and care transitions, to chronic disease self-management, virtual health and supports for community living. These nursing insights are not only helpful in designing and delivering care at home, but also in hospitals, primary care, public health and long-term care. In all care settings,

we can do a better job of capitalizing on the strengths of people and finding ways to wrap care and services around their needs and lives. As we see it, people-powered care needs to become a universal starting point across the healthcare system. When looking at transformation, the starting point is critical because it shapes the entire process and end results. For example, if we design the health system from the perspective of a patient lying in a hospital bed, with their current health issues and limitations, we end up with a very different system than if we were to design it from the starting point of where the person is in their home, with the support of their network and community resources.

The Case for Change

People's needs and expectations of healthcare are evolving. As patients experience greater personalization, connectedness and empowerment in other areas of their lives such as retail, hospitality and social networks, they want these elements to be reflected in their healthcare experiences as well. Information is immediate and everywhere – with a click of a mouse, patients and caregivers can research their symptoms or condition, learn about mainstream and alternative treatment options, join a peer support group and have a medical question answered – often much more quickly than they can arrange a face-to-face service within the formal healthcare system. Clearly, the rules of engagement are changing and this means we have to work with people differently than we have in the past. Today, patients want and *expect* to be involved in their care and treatment and in the broader discussions that are shaping our health system. This is evidenced in the rise of the patient movement and organizations such as Patients Canada.

The healthcare industry is also changing. Scan the business news on any given day and it is clear the healthcare market is booming not only in Canada but worldwide. Many large companies are diversifying into healthcare, from supermarkets to consumer electronics. As new players and entrepreneurs enter the health and wellness space with low-cost models and a strong customer orientation, established health systems cannot afford to ignore disruptive innovation (Ball 2010;). One example is the growth of minute clinics and virtual monitoring devices that are changing the way healthcare is distributed, reducing the need for travel and large facility footprints. Responding to these disruptions is imperative for nursing leaders, who are well positioned to impact system transformation. For years, we have been talking about the need for change. Now we have to step up and actually make it happen. As political, economic, social and technological forces collide, we must disrupt ourselves or be disrupted.

To realize the full potential of healthcare, we need to stop looking at the system and its parts in isolation of each other and society at large. There is a growing focus on home care, which is great to see because our sector has long been an

afterthought and a poor cousin in the healthcare system. At the same time, we must be thoughtful with the vision because home care itself is primed for transformation – and in dire need of a makeover. Rather than simply scaling up existing, dated models, which are limited in scope and heavily weighted to post-acute care, we need to think bigger and broader about how we can support people to live at home for as long as possible, if that is what they want. There is no magic bullet or single solution. Instead, we must work on building integrated systems of care delivery that incorporate health and social care along a continuum (Chappell and Hollander 2011).

When it comes to providing care in the home, it is clear that the funding and service delivery model must change. The current approach of paying for services on a "per visit" or hourly basis is not designed to support holistic care (Mason et al. 2015). The allotted time nurses have with patients makes it difficult to provide care at the highest standards of professional practice, let alone supporting new needs that are identified. Care is task-based and fragmented, leading to gaps in services, duplication, challenges in communication and coordination and, ultimately, inconclusive value and higher costs. We often hear from patients and families who are not receiving the level of support they need to stay safe and healthy at home. In addition to burden and stress, they experience many pain points – from having to repeat their story many times over, to dealing with wait times, scheduling challenges, lack of continuity and communication breakdowns at the various points of transition. The consequences of this fragmented approach are felt across the healthcare system, through the overuse of emergency departments, repeat hospitalizations and early placement in long-term care. From a funding and service delivery perspective, it is critical that we shift the focus from tasks to outcomes. New models such as bundled care – where providers are paid based on the number and type of patients they care for, the quality of their services and the results they achieve – allow health professionals the freedom to work directly with people to understand their needs and provide care and support in the best way possible (Mason et al. 2015).

Back to the Future: Guiding Principles of a New Approach

It is time to reinvent not just home and community care but healthcare itself. To shift the culture towards people-powered care, we need to embrace innovation and new approaches. When we talk about innovation in healthcare, it is interesting how the discussion always gravitates towards technology. Indeed, technology is one exciting facet of innovation that is opening the door to many new possibilities in areas such as remote patient monitoring, smart homes, robotics and artificial intelligence. Yet, we work in a field that is founded on human connections and, beyond technology, there are so many other ways in which we can bring innovation to health and social care. For example, we know many groups

have unmet needs, including the frail elderly, family caregivers, Indigenous people, the homeless and vulnerably housed and those at the end of life – to name a few. In addition to the specific clinical interventions that are required, home care can also play a key role in addressing these unmet societal needs at a higher level. Consider:

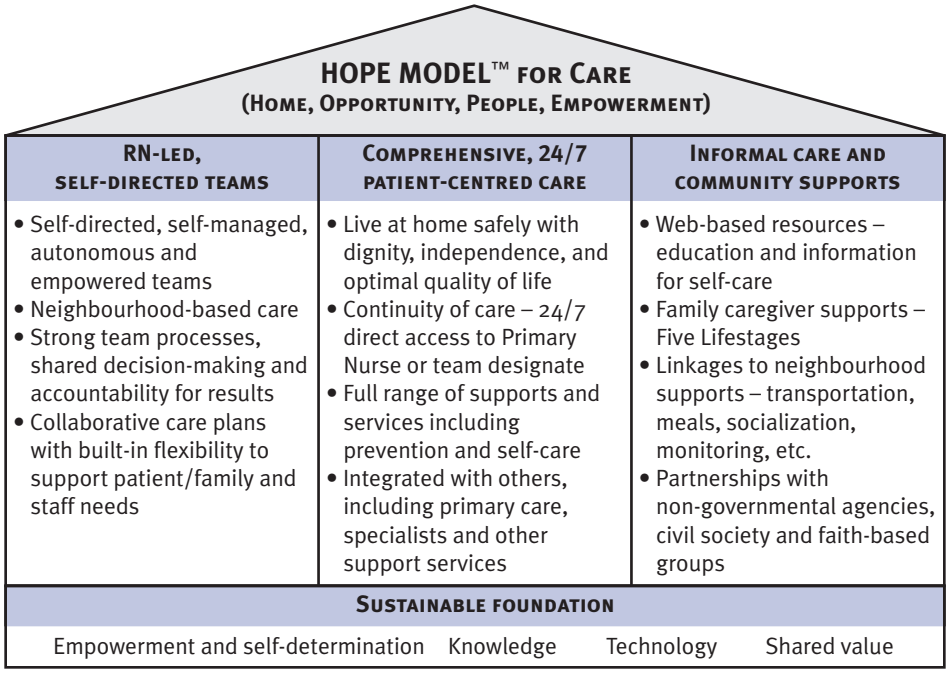
- Green care farms that offer small-scale, homelike environments and community living for people with dementia, as an alternative to traditional nursing home care.
- Models that integrate patient social needs as a standard part of quality care, giving health providers the ability to "prescribe" basic resources like food and heat, as well as transportation, health benefits and well-trained patient advocates.
- Well-being enterprises that tackle the causes of poor health and empower people and communities to take control of their own health and well-being through activities such as pet and music therapy, volunteerism, mindfulness and personalized wellness chats.

These examples begin to illustrate how we need to redesign the way nurses are functioning in home and community settings, and the significant change and benefits we could realize as a result. To engage and empower *people*, we must engage and empower *nurses*.

Within our own organization, we have been working for many years to better understand and align the relationship between nursing practice and person- and family-centred care. Based on our experience and a review of the literature and international models, we believe there is an amazing opportunity to enrich nursing practice and simplify the system by empowering nursing-led home care teams to focus on patient care and wellness. We have come up with an innovative approach that we are calling the HOPE MODEL™ (Figure 1), and we have started working with health system partners to bring it to life.

In this model, there is a focus on wellness and independence guides' clinical practice versus the number of visits conducted. The local nursing team is the first point of contact to address patient and family concerns before visiting the emergency department or using other crisis supports, and nurses are empowered to work creatively to support people to live at home. Front-line innovation can flourish based on a spirit of entrepreneurial freedom and nurses working at their full/optimal scope of practice. Reinforcing the direct interaction and accountability between the nurse and the patient and family, the nurse supports the patient across the continuum of care – communicating with primary care providers, specialists and community supports; advocating for care and finding the most relevant and innovative solutions; and supporting transitions as needed.

Figure 1. HOPE MODEL™ for care



The HOPE MODEL™ brings home care "back to the future" as it shares many similarities with visiting nursing models we have seen and used throughout our 100-year history; yet, it introduces increased autonomy and responsibility, specialized clinical skill sets and the greater use of technology to communicate and report on outcomes. Existing tools and data such as the interRAI instruments (interRAI 2016) can be used to provide a common framework for assessments, care planning and communication and performance management. HOPE nurses have access to technology supports such as remote patient monitoring to enable care for chronic or complex patients around the clock. A user-friendly electronic documentation and communication system is available to the patient and family, the home care team, the primary care physician and other professional and informal providers as necessary. With the widespread use of smartphones, tablets and a full range of apps, the technology already exists to facilitate this level of communication exchange across the system, support patients and caregivers towards self-management and virtualize care where it makes sense.

Different versions of this home care model are currently being used in many countries around the world, with very positive outcomes. For example, in The Netherlands, the Buurtzorg model created by Jos de Blok based on his own experience as a visiting nurse, has shown that care delivered is 40% less expensive,

while achieving 100% patient satisfaction. Although the average hourly cost of care is in fact higher – based on the utilization of highly skilled nurses and corresponding compensation – efficiencies are being achieved in The Netherlands through reduced overhead costs and a significant reduction in the total hours of care patients required based on a holistic approach and proactive supports for self-management. The model is also very popular with front-line nurses (Gray et al. 2015). We recently had the opportunity to visit with several nurses who are working in this model, and it was clear to see they are highly engaged in their work and deeply rooted in their communities.

Opportunities for Learning

The creativity, energy and learning that comes from engaging people and nurses in the design and delivery of healthcare is an opportunity we must all seize in the journey towards person- and family-centred care. Within our own organization, the highly dispersed and mobile nature of our work has forced us to come up with some innovative channels for patient engagement. For example, we recently had 100 of our business and clinical leaders spend a day in the field doing home visits with a front-line staff member in their local community. As a result, our entire leadership team from across the organization had the opportunity to engage directly with patients and families in their own homes and experience the wonderment of home care firsthand. The response from our non-nursing staff was so amazing, imagine if nurses working in other areas of the system were offered the same opportunity – to spend a day or two, going into people's homes and meeting them on their own terms and territory. This would allow more nurses to understand, not necessarily the mechanics of "home care," but the starting point of people's lives, their conditions and the communities they are a part of. As nurses and nursing leaders, the richness of this experience would enable us to design better solutions that intersect with people's needs and lives, regardless of where we work in the system.

Another tremendous opportunity for learning comes when we invite people to be a part of, and even drive, the process of research and design. At Saint Elizabeth, we have been using this approach for several years in our work with family caregivers. In one research study, we partnered directly with caregivers to explore their experiences and develop five promising practices and 20 indicators of effective caregiver education and support (Giosa and Holyoke 2014). Caregivers were involved in every phase of the process and had a significant influence on the study and its outcomes. Through this process of engagement, we learned that the current system of caregiver support across the healthcare system is largely medical and reactive, focusing on managing and treating caregiver burden and distress. Caregivers told us we need to, in fact, shift the focus upstream, providing more proactive supports to help them manage the demands of caregiving and prevent burnout and other adverse health effects (Giosa and Holyoke 2014).

This knowledge, together with consumer research and insights from front-line nurses and staff who work with families every day, has helped to inform a comprehensive approach to caregiver wellness, including the creation of a dedicated support service for family caregivers.

As part of our larger focus on person- and family-centred care, we are using many of the same strategies to understand people's needs, experiences and wishes at the end of life. Palliative care during the final stages of life is perhaps one of the most sensitive and critical opportunities to be deeply attuned to the needs and experiences of people and their network of support. As an example, we know that a majority of Canadians want to die at home, yet only a small fraction of people actually are able to (Collier 2011; Heyland et al. 2000). For most of us, home represents a place of comfort, familiarity, intimacy, memories, independence and control. Our research team is currently delving deeper into this topic to understand what people *really mean* when they say they want to die at home – specifically, what elements of the home environment make it so compelling, and can these elements be in fact replicated in other care settings where people often die such as hospitals and long-term care facilities? With this knowledge, we can work together to design a system where people can experience the comforts of "home" wherever they are, irrespective of their physical location.

As nursing leaders, we have an important role in defining the starting point of our work, setting the stage for our staff and ensuring that patients are meaningfully engaged in the design and delivery of healthcare. While the process of co-design can be both time- and resource-intensive, it can lead to more successful innovation, better alignment between the people who are accessing and delivering the service and higher satisfaction over the long term (Steen et al. 2011). Despite the talk and popularity of person- and family-centred approaches, we still have a great deal of work to do. No matter where in the system we work, as nursing leaders, we must be bold and courageous in crashing through the barriers to change.

Making it Happen: Implications for Nursing Leadership

Nursing leaders must be both proactive and responsive in the shift to people-powered care. Specifically, we should be *more proactive* in creating and sustaining the culture within our organizations and, at the same time, be *more responsive* to the needs, goals and desires of people. Doing both of these things well requires us to acknowledge and embrace the complexity of people and their lives and the diverse ways they intersect with the healthcare system. We must overcome our tendency to compartmentalize the health system by sector and instead shift the focus to integration. As we know, people do not live in compartments – the whole point is to blur the lines. This is where we need to trust and follow the lead of patients and families in taking a broader view and situating healthcare in the context of everyday life.

Change never happens in a vacuum. For better or worse, there is no pause button on the healthcare system. As leaders, our challenge is to experiment with new approaches "on the go," while maintaining or improving the key metrics of patient satisfaction, quality, safety and efficiency. No easy feat, but creative thinking can help propel us forward. To enable innovation, we need to let go of some of our aversion to risk-taking, messiness and failure in healthcare. While it is exciting and gratifying to learn from success, failure is also critical because it means we are learning and trying new things. Rather than shying away from it, we must learn to fail quickly and smartly. Likewise, when we try something new and it is successful, we must do a better job at sharing and scaling best practices.

Nursing leaders also have a key role to play in championing new models of healthcare and nursing practice. We must ensure we are designing and funding structures at both the organizational and systems levels that allow nurses to function differently. The learning and change process will take time, space and new skills. With more autonomy and accountability, nurses will require a high degree of situational awareness, appreciating all they need to know about a patient and family and their network of supports and resources when the full scope of care and social support is taken into account. This includes developing an in-depth knowledge of their neighbourhood and the communities within it, as well as awakening their awareness of societal trends and the strategic use of technology. In addition to having strong clinical and assessment skills, nurses must be expert communicators – listening, coaching, informing, educating and advocating for their patients. Where there is a true spirit of partnership between health professionals, patients and families – defined by mutual trust, respect and the open exchange of information and ideas – the best results can be achieved. As leaders, we can model this spirit of partnership in our own interactions with patients, staff, colleagues and partners.

We can become transformative leaders by exploring the tensions that exist between being bold and being humble, and between strong leadership and self-determination. A great example here is the concept of a "servant leader," whereby the leader shares power, puts the needs of others first and helps people develop and perform as highly as possible. Similar dichotomies exist in so many areas – consider, for example, the tensions between discipline and free thinking; between privacy and transparency; between research and innovation; between consistency and customization, and the list goes on. There is inherent value and opportunity in all of these things, and especially the sweet spot of combining them. In pursuing large-scale system change, we as nursing leaders need to look at issues from many different angles, bring in new voices and viewpoints and devise solutions that play to both ends of the spectrum.

Closing Remarks

The strengths of people, their networks and the patterns of everyday life should set the stage for how we work with patients, not only in their own homes but also across all care settings. Nursing and nursing leadership have a pivotal role to play in enabling this transformation to occur. In this article, we have outlined some of the unique insights and strengths that nursing leadership in home and community care can bring; at the same time, we look forward to continuing to listen and learn from the wisdom and experiences of those working in other areas of nursing practice. Reorienting the health system towards people-powered care requires leadership throughout – from us all – in every sector and at all levels, from the point of care to organizational governance and everywhere in between. An incredible opportunity awaits us. By combining our diverse strengths and perspectives, with our shared passion for people and high performance, we can collectively make an even bigger dent in the universe. With a healthy dose of hope and happiness, change is not only achievable but possibility is everywhere.

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