

EDITORIAL

Shifting paradigms to build resilience among patients and families experiencing multiple chronic conditions

1 | INTRODUCTION

Worldwide, one of three people lives with multiple chronic conditions (Hajat & Stein, 2018), increasing odds of disability, healthcare utilisation and death (Tinetti, Fried, & Boyd, 2012). Developing feasible, effective and scalable interventions to reduce risk among people with multiple chronic conditions is increasingly urgent as the population ages. However, education and research gaps hinder intervention development. For example, most clinicians were educated in disease-specific siloes without considering co-occurring chronic conditions, functional limitations, family caregivers' perspectives or contextual factors that define social determinants of health (Blaum et al., 2017; Havranek et al., 2015; Tinetti et al., 2012). In addition, available interventions commonly focus on deficits rather than strengths and informal caregivers—who provide the backbone for much of the chronic care received by older adults (Wolff, Spillman, Freedman, & Kasper, 2016)—have rarely been involved in intervention development. These limitations are compounded by a failure of practitioners to communicate with people experiencing multiple chronic conditions about their goals, values and preferences (National Institute of Nursing Research, 2016). In this editorial, we develop the case for why this is important and how we can address in nursing research, education and policy change.

The science of multiple chronic conditions is hampered by siloed care, lack of family inclusion, inadequate attention to the social determinants of health and failure to include outcomes that are relevant and meaningful to patients and their families. Not only are chronic conditions treated in isolation but also management is often implemented as though the healthcare provider has the answers and the “patient” must comply. To date, the comprehensive management of chronic conditions has been hampered by the focus on one condition with inadequate consideration of multimorbidity, age-related events (Bayliss et al., 2014), social determinants of health, including poverty, inadequate housing, traumatic life events and the persons' own goals. As a special case, mental health conditions often exacerbate and/or are exacerbated by chronic physical health conditions but are also siloed from physical health conditions in specialty care, research and education. Developing new models of care requires team science including community engagement through all phases

of research and across the care continuum (“Enhancing Eff. Team Sci.”, 2015; Selker & Wilkins, 2017).

Nurses are uniquely positioned to lead practice-changing and policy-relevant research addressing multiple chronic conditions. Nurses can lead interdisciplinary teams of researchers and practitioners to view the whole person in context, including home and community environment (Szanton, Leff, Wolff, Roberts, & Gitlin, 2016) and family milieu to improve health and quality of life for those with multiple chronic conditions. The need to incorporate the context of each person is characterised by a paradigm shift from “What is the matter?” to “What matters” to the person (Bayliss et al., 2014). For example, the CAPABLE programme which addresses the functional goals of older adults' living with disability decreases their disability (Szanton et al., 2019) and is associated with ten times return on investment (Ruiz et al., 2017; Szanton et al., 2017) is based on specifically what the older adult would like to be able to do, not what the clinician wants them to do.

People's values, life purpose, preferences, family needs, abilities and resources allow them to be authorities on their health. Healthcare providers are part of a team with the patient and can use their clinical knowledge and experience to support these decisions and to help patient clarify their goals and purpose (Falk et al., 2015; Kim, Strecher, & Ryff, 2014; Strecher, Devellis, Becker, & Rosenstock, 1986). The future of health interventions and care is personalised, taking into account the intersections of chronic conditions, priorities and context.

There is an increased focus on the importance of addressing not only chronic illness but also multimorbidity. For example, in the United States, recent critical work in the area of multiple chronic conditions has resulted in Department of Health and Human Services guidelines (US Department of Health & Human Services, 2010) that can stimulate ground-breaking work in the U.S. National Institute for Nursing Research's priority areas (Parekh, Goodman, Gordon, & Koh, 2011). From symptom science using personalised health strategies to promoting health and preventing illness, to self-management, and end of life care, the heart of care is helping people identify what matters to them to set priorities and make decisions to employ tailored strategies, including those recommended by health providers and others that have experienced multiple chronic conditions to improve their health and quality of life.

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2 | BUILDING RESILIENCE

Resilience is a growing topic in health literature, but consideration is mostly limited to personal strengths and capacities, such as coping strategies or optimism. While important, the individual is just one resilient system nested within a family, community and society, all of which have resilient capacities and which in turn effect genetic, cellular and physiologic systems are nested within the individual. The emerging concept of community resilience is connected to the families within the communities as well as the policy priorities of the larger society. For example, the same stressor may happen to two different people with the same biology at birth but one may have access to a family that is more nurturing and/or community with more resources or with more educational opportunities and that person may respond more resiliently, even at the cellular level because of these differences. Limiting resilience work to a whole-individual level is only part of the resilience picture.

One way to harness strength-based eco-social dynamics is to ground work in the *Society to Cells Resilience Framework* (Szanton & Gill, 2010). Resilience in this framework is defined as resistance, recovery or rebound of mental and physical health during or after challenge. Resistance is recognised as an individual's, family's and/or community's ability to reduce the potential harm of a challenge. Recovery is a return to a normal state of health, mind or strength.

Unique to the resilience framework is that individuals, families and communities can develop increased capacity through a health challenge (such as cancer, caregiving or a homicide in a community) that they can later generalise and apply in other health challenges (Szanton & Gill, 2010). This type of resilience in health is called rebound and describes individuals who have thrived or flourished in spite or because of challenges, similar to post-traumatic growth (Szanton & Gill, 2010). Just as there are particularly vulnerable periods in chronic conditions, our resilience framework posits that there are particularly resilient or "plastic" periods for individuals, families and communities. People in certain phases of life are more likely to develop new habits or take in important information, for example at cancer treatment or caring for a family member with functional limitations. Effective symptom management is dependent on accurate assessment of physical, psychological, social and spiritual needs and working with the individual to negotiate goals, build upon their strengths and provide them with strategies and resources. There may be particularly plastic periods in the setting of multiple chronic conditions building on the assets rather than deficits of the participating persons and their families in the context of their communities.

By extension, communities can become more resilient after a challenge such as a disaster or traumatic event. Pop-up rescuers and donors facilitated by new media, and apps sometimes become part of a strengthened community after a hurricane, fire or other traumatic event. Notably, this is more likely to be true after a weather event that hits all kinds of people rather than an event that impacts only low income or segregated communities. Adding greenspace is

an evidence-based mental health intervention for communities that have experienced trauma (Beyer et al., 2014; South, Hohl, Kondo, MacDonald, & Branas, 2018). Also important, evidence shows that communities with high levels of social connectedness (or social capital) display resilience that allows them to better connect to critical resources and mobilise to overcome problems during a crisis, highlighting the importance of building robust social networks in order to promote a culture of health resilience (Adeola & Picou, 2012; Aldrich & Sawada, 2015).

2.1 | Moving forward in building resilience into research, education, practice and policy

Identifying these "plastic periods" and interventions will require a shift from provider-centric, disease-specific biomedical approaches to person-centred, resilience-based, community-engaged methods through generating and applying innovative intervention strategies to promote the effectiveness of interdisciplinary interventions targeting vulnerable populations experiencing multiple chronic conditions. Achieving these goals will require expanding from traditional methods and techniques such as using co-design (Lindblad et al., 2017). These techniques will make the research questions, methods and interventions more robust and propel science addressing multiple chronic conditions to sustainable solutions that better meet the needs of communities.

2.2 | Research implications

One of the ways to build from strength and involve patients, families and communities as partners is to employ human-centred design (HCD). This is a design specialisation that engages the end users of a product or service throughout the research process to tailor interventions to their needs, behaviours and preferences. Related to but not the same as participatory research, human-centred design is a series of tools and perspectives for humans of all abilities to be able to test small examples (prototypes) prior to formal piloting of set interventions. Human-centred design is explicitly based on the premise that lived experience is a valuable form of expertise, and therefore, people who have direct experience with a disability or health condition and its broader impact on daily life should play a decision-making role in the design of services, products and approaches to improve their health and well-being. HCD is often used with populations who may benefit from a relationships-based, collaborative approach to research (for instance, if they would not feel as comfortable in traditional research setting), such as young people, older adults and any group that has historically been marginalised by harmful power dynamics in research.

Human-centred design methods are designed with accessibility and approachability in mind. For example, designers may include the use of visual aids, interactive games and mapping during interviews

to prompt thinking and encourage reflection. The designer on the research team can incorporate HCD with a social justice lens, ensuring that the process elevates the leadership of people most impacted by interventions (such as people with disabilities and their caregivers or families that have experienced significant trauma from violence in their community) and seeks equity in research power dynamics and decision-making. Using an HCD approach also unlocks the specialised skill sets of designers, graphic designers, digital designers and others to create physical, digital and experiential interventions.

Human-centred design is a key step to creating interventions that are delightful to engage with. Because they are built by engaging key stakeholders, sustainability is built into the outputs. New research methods such as human-centred design will make the research questions, methods and interventions more robust and propel science addressing multiple chronic conditions to sustainable solutions.

2.3 | Education and practice implications

It will also be important to prepare nurses in strengths-based collaborative approaches (such as building social capital to promote resilience) to patients, families and communities. Not just identifying their strengths but also helping patients, families and communities think through their backup systems which define resilient systems similar to a backup generator or the collateral routes in cardiovascular circulation when the preferred route is blocked. One example of this is using community's traumatic regrowth to highlight community resilience in educational experiences. These may include facilitated service learning experiences that embed the course in community partnerships to work on community-identified projects (Gerstenblatt & Gilbert, 2014).

2.4 | Policy implications

Aligning healthcare delivery with what matters to people has policy implications as well. Globally, although many countries have universal coverage, they may not be centred on patient-reported needs and outcomes. In the United States, as healthcare payment models move from paying for procedures and visits to paying for value and outcomes, resilience thinking should decrease barriers to addressing the social determinants of health that can drive health outcomes. Using resilience thinking is one of the ways to address these determinants while not diminishing the need for adequate food, transportation, income and social engagement.


3 | CONCLUSION

New breakthroughs in understanding the bio-behavioural impact and the importance of tailored interventions are important in addressing multiple chronic conditions. Innovative models of nursing

research are critical in addressing the needs of the growing numbers of individuals worldwide suffering with high symptom burden and social isolation.

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