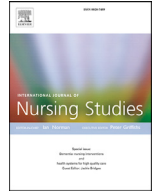




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## Self-care research: Where are we now? Where are we going?

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## ABSTRACT

**Background and objective:** The beneficial effects of self-care include improved well-being and lower morbidity, mortality, and healthcare costs. In this article we address the current state of self-care research and propose an agenda for future research based on the inaugural conference of the International Center for Self-Care Research held in Rome, Italy in June 2019. The vision of this Center is a world where self-care is prioritized by individuals, families, and communities and is the first line of approach in every health care encounter. The mission of the Center is to lead the self-care research endeavor, improving conceptual clarity and promoting interdisciplinary work informed by a shared vision addressing knowledge gaps. A focused research agenda can deepen our theoretical understanding of self-care and the mechanisms underlying self-care, which can contribute to the development of effective interventions that improve outcomes.

**Methods:** During conference discussions, we identified seven major reasons why self-care is challenging, which can be grouped into the general categories of behavior change and illness related factors. We identified six specific knowledge gaps that, if addressed, may help to address these challenges: the influence of habit formation on behavior change, resilience in the face of stressful life events that interfere with self-care, the influence of culture on self-care behavioral choices, the difficulty performing self-care with multiple chronic conditions, self-care in persons with severe mental illness, and the influence of others (care partners, family, peer supporters, and healthcare professionals) on self-care.

**Plans to achieve results:** To achieve the vision and mission of the Center, we will lead a collaborative program of research that addresses self-care knowledge gaps and improves outcomes, create a supportive international network for knowledge transfer and support of innovations in self-care research, and support and train others in self-care research. Beyond these specific short-term goals, important policy implications of this work are discussed.

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### What is already known about the topic?

- People with chronic conditions need to assume responsibility for their own health and to be actively involved in self-care.
- Investigators have revealed the complexity of self-care and illustrated that a wide variety of factors influence the decisions that individuals make about engaging in self-care.

### What this paper adds

- Self-care is challenging for reasons that can be grouped into the general categories of behavior change and illness related factors.
- Six specific knowledge gaps that may help to address these challenges include the influence of habit formation on behavior change, resilience in the face of stressful life events that interfere with self-care, the influence of culture on self-care behavioral choices, the difficulty performing self-care with multiple chronic conditions, self-care in persons with severe mental illness, and the influence of others (care partners, family, peer supporters, and healthcare professionals) on self-care.

## 1. Introduction

There is growing recognition of the need for people with chronic conditions to assume responsibility for their own health and to be actively involved in self-care. Out of 525,600 min in a year, patients spend only on average 66 min or 0.01% of the time with healthcare professionals (Racine, 2017). All other health maintenance, illness prevention, monitoring and management activities are done by persons with chronic conditions and their care partners as self-care activities (Riegel et al., 2017). A care partner can be defined as “a person who provides unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework” (<https://eurocarers.org/about-carers/>). There is also evidence and growing awareness among healthcare professionals that supporting and empowering persons with chronic conditions and their care partners and helping them to perform self-care can improve patient well-being, decrease morbidity and mortality, and reduce healthcare costs (Tol et al., 2015).

In this article, we address the current state of self-care research and propose an agenda for future research based on the inaugural conference of the International Center for Self-Care Research ([www.selfcareresearch.org](http://www.selfcareresearch.org)) held in Rome, Italy in June 2019. The vision of this Center is a world where self-care is prioritized by individuals, families, and communities and is the first line of approach in every health care encounter. The mission of the Center is to lead the self-care research endeavor, improving conceptual clarity and promoting interdisciplinary work informed by a shared vision. A focused research agenda is required to deepen our theoretical understanding of the self-care concept and mechanisms underlying self-care behaviors and to contribute to the development of efficacious and effective self-care interventions that improve patient outcomes. Without greater depth in understanding why, when, and how self-care interventions work, these interventions will be guesswork and the outcomes of self-care interventions will remain disappointing.

First, we briefly describe global achievements in self-care research to date and then reflect on challenges and anticipated developments in this area. We use these reflections as a basis for recommendations regarding next steps for self-care research.

## 2. Background

### 2.1. Where are we now?

There has been an impressive rise in the number of self-care publications over time. A search of PubMed conducted in June 2019 revealed that the first self-care publication was in 1946, with a peak in 2015 when 2457 articles were published on the topic. The term self-care was added to the Medical Subject Headings of the National Library of Medicine in 1981 and defined as caring for self when ill or positive actions and adopting behaviors to prevent illness.

Unfortunately, multiple terms are used as synonyms for self-care. Numerous related or resembling terms (such as self-management, self-monitoring, and self-help) are used, often in the same publication and it is not always clear how the term is defined. In certain conditions or research groups, specific terminology is accepted (e.g. self-management is used in diabetes). Godfrey et al. (2011) identified 139 different definitions of self-care in 2011 and little progress has been made since then to find an established uniform definition integrating related concepts (Matarese et al., 2018).

In the Middle Range Theory of Self-Care of Chronic Illness self-care is defined as a process of maintaining health through health promoting practices and managing illness (Riegel et al., 2012). In that theoretical model three concepts of self-care maintenance, self-care monitoring, and self-care management are specified. Several theoretically grounded self-report measures reflecting these theoretical concepts are available (Ausili et al., 2017; Dickson et al., 2017; Matarese et al., 2019; Riegel et al., 2019a; Vellone et al., 2013). In 2019, the Theory of Self-Care of Chronic Illness was refined to clarify how symptoms relate to the self-care process (Riegel et al., 2019b). Key areas of refinement to the theory emphasized the importance of active monitoring if bodily changes are to be detected and interpreted, without which the response to symptoms will not occur (Riegel et al., 2019b). Advances in symptom science have yielded valuable insights into how effective self-care monitoring and management are influenced by knowledge, attention, expectations, and identity (Whitaker et al., 2015).

International interest in research involving self-care is high. Many investigators across the world are studying self-care, and we anticipate that this enthusiasm will continue (Jaarsma et al., 2013). Multiple disciplines are actively studying self-care and contributing important knowledge to the topic. Clinicians have also embraced the topic and actively promoted self-care in a wide variety of settings (Mills et al., 2018). Investigators have revealed the complexity of self-care and illustrated through their research that a wide variety of factors influence the decisions that individuals make about engaging in self-care. Financial worries, financial strain, and economic hardships are sources of stress that may influence self-care (Nelson et al., 2019). Numerous studies have focused on the effects of emotions or mood states (e.g., depression, Xu et al., 2018; anxiety, Smith et al., 2016a and other forms of distress), personality traits (Skinner et al., 2014), social (Fivecoat et al., 2018) or interpersonal factors and clinical factors on self-care behaviors. Most of the evidence indicates that even low levels of depressive symptoms are associated with poor self-care (Fisher et al., 2010; Leyva et al., 2011) although some studies have found that disease-related distress is a stronger correlate or predictor of self-care (Pandit et al., 2014).

Despite these examples of progress, current challenges and opportunities include fragmented activity, lack of continuity across research initiatives, and descriptive research that ignores the mechanisms underlying self-care behavior. Without dismissing the value of replication studies, research groups may be wasting time and effort in only performing descriptive replication studies

**Table 1**  
Important reasons why people struggle to perform self-care.

Behavior change
1. Attachment to unhealthy behaviors
2. Lack of motivation to change
3. Difficulty deciding when in the lifespan to adopt a healthy lifestyle
4. Difficulty in maintaining healthy behavior over time
Illness related factors
5. Multimorbidity – difficulty integrating self-care across conditions
6. Inadequate response to symptoms, knowing the right time to seek help
7. Life events that interact with illness to interfere with healthy behavior

relevant to their local situation when there is important work to be done by contributing to an international and multidisciplinary body of knowledge.

## 2.2. Where are we going?

During the conference discussions we identified, based on evidence, experience and theory, seven major reasons why self-care is challenging, as shown in Table 1. These reasons can be grouped into the general categories of behavior change and illness related factors. The behavior change factors address habits, motivation, decision making, and the challenges of persistence. The illness related factors address specific issues that make self-care exceedingly difficult – multimorbidity, symptoms, and stressful life events.

We identified six specific knowledge gaps that, if addressed, may help to address these challenges. For example, all of the behavior change issues could be addressed to some degree with habit formation. The effect of stressful life events that interfere with self-care could be addressed somewhat by building resilience. Other issues such as the influence of culture on self-care behavioral choices, the difficulty performing self-care with multiple chronic conditions, and self-care in persons with severe mental illness are issues about which we know relatively little. Finally, the influence of others (care partners, family, peer supporters, and healthcare professionals) was identified as a challenge because of our growing recognition that others influence all of the reasons that people struggle with self-care. That is, people in our lives influence our behavior, lifestyle, and our responses to daily challenges such as symptoms as well as major challenges such as trauma. In some of these areas, significant research has been conducted, but the research has yet to be linked to self-care. In other areas, research is active and ongoing but major gaps remain in our knowledge. Here we expand on these themes, all of which require further study.

### 2.2.1. Influence of habit formation on self-care behavior change

Different factors influence lifestyle behaviors across the lifespan. Many unhealthy behaviors, such as food choices, are learned early in life and habits are hard to change (Miller et al., 2018). Environmental factors may discourage healthy behavior. For example, poor air quality, a lack of open spaces, and unsafe environments discourage physical exercise (Halali et al., 2016). Lack of motivation to change is powerful, but only one of many complex factors influencing behavior change (Chichirez and Purcareia, 2018). Further, even after a healthy behavior such as exercise is adopted, it is challenging to maintain the behavior over time (Kwasnicka et al., 2016).

Habits and goals interact to influence behavior (Wood and Runger, 2016). Habits provide a default response while goals energize and direct action by defining a desired state such as weight loss (Wood et al., 2014). Initially, goals influence habit formation by motivating action, but once habits form, contextual cues automatically activate the habit. Through activation or inhibition, people act on the habit and their prevailing goals. Even when goals are not carefully considered, we can often interpret our goals from observing our own behavior, inferring that a behavior must have

**Table 2**  
Promising person-centered interventions to improve self-care behavior change.

<ul style="list-style-type: none"> <li>• Motivation with human contact and empathy</li> <li>• Tailored interventions, using technology and accommodating culture</li> <li>• Support from others (care partners, family, significant others, peers, healthcare professionals)</li> <li>• Facilitated communication within the family and with healthcare professionals</li> <li>• Use of decision algorithms and tools that address core self-care elements, perhaps using technology</li> <li>• Skills-based approaches that build self-care skills</li> <li>• Policy changes that address self-care habit formation</li> </ul>
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been intended based on the frequency of its performance. For example, consistently eating vegetables may suggest to ourselves and others that weight maintenance is a goal. Self-care behaviors that are consistent with individual goals are more likely to develop into habits and be maintained over time (Grunseit et al., 2019).

Factors such as stress, mood and distraction influence these processes by reducing motivation or the ability to deliberately pursue goals and increasing reliance on habits. The field of behavioral economics has increased recognition of the natural human tendency to discount the future and value the present – future discounting (Parthasarathi et al., 2017). Future discounting often prevents people from making decisions that have an abstract future benefit, such as a lower risk for a heart attack, while causing inconveniences in the present, such as forgoing calorific foods and taking medicines with disagreeable side effects. If the perceived barriers outweigh the anticipated benefits of self-care, the likelihood of healthy behaviors will decrease (Mohebi et al., 2013).

*Implications for self-care research.* Some promising interventions to promote behavior change include education, persuasion, incentivizing through behavioral economics, training, enablement, modeling, restrictions and environmental restructuring (Michie et al., 2011). Opportunities for health education and implementation of proven self-care interventions are often missed by busy clinicians (Greaves and Campbell, 2007). Research using behavior change theories and methods will be crucial for deepening our knowledge of contextual influences on the success of self-care interventions with a focus on why, when and how interventions are best tested, implemented, and sustained (Herber et al., 2018). One important line of research is the development and testing of intervention approaches that address habits with stable, cue-based routines with potential for generating lasting behavior change. Some interventions discussed during the conference as particularly relevant for self-care are shown in Table 2. This list is anticipated to grow and evolve as further progress is made.

In addition to these person-centered approaches, there are high expectations that the use of Information and Communication Technology, also called eHealth or Digital health and care, will support and empower behavior change, helping individuals to perform self-care as well as simplifying and increasing access to and efficacy of health and social care. Positive effects of eHealth have been found in chronically ill populations with extensive need for self-care (Gee et al., 2015). The Global Observatory for eHealth survey showed that 125 of the 194 World Health Organization Member States had national policies and strategies in place related to eHealth (World Health Organization, 2016).

eHealth tools such as applications and websites can be used to support self-care behaviors and maintain chronic illness stability. These interventions have tremendous potential to promote patient engagement (Barello et al., 2015) and eHealth interventions have been found to improve care, self-care, self-efficacy, healthy behavior (quality of sleep, diet, physical activity mental health) and medication adherence (Changizi and Kaveh, 2017). eHealth has also

been found to support the process of observing oneself for changes in signs, symptoms, and healthy behaviors. In several chronic diseases (e.g., chronic lung disease, diabetes, heart failure, and depression), devices that help patients to monitor their symptoms are being developed and tested and appear to be promising, although the optimal way of monitoring and the right approach to optimally involve patients in managing their disease remains a challenge (Inglis et al., 2017).

### 2.2.2. Resilience in the face of stressful life events and social contexts that interfere with self-care

Resilience is the ability to adapt, to recover, to “bounce back” from adversity and difficult experiences (Foster et al., 2019). In this context, resilience is the process of adapting well when life events interfere with our ability to perform self-care. These life events may include trauma, tragedy, and stressful situations such as the loss of a job or the new diagnosis of a serious illness. Resilience relies on the person's inner strengths and protective factors such as high self-awareness, self-esteem, cognitive and social skills, optimism, and sense of humor (Kim et al., 2019). Inner strength may decrease due to poor health literacy, distressing symptoms including cognitive dysfunction, and psychological factors that can affect the ability to perform self-care (Zizolfi et al., 2019). Resilience may also rely on social context, for example social support, cultural factors, social norms, the health system itself, and a multiplicity of stakeholders with differing perceptions about self-care (Kim et al., 2019).

*Implications for self-care research.* Most of the self-care research addresses ways to build resilience in professional staff so we know little about how resilience is associated with and influences self-care in ill populations. In one study, resilience moderated the effects of depressive symptoms through self-care confidence on self-care maintenance in heart failure patients (Chang et al., 2017). The investigators advocated that self-care might be improved by targeting depressive symptoms after considering self-care confidence in patients with moderate to high levels of resilience (Chang et al., 2017). Identifying how resilience is developed or nurtured has proven elusive, although one interesting study used social media to promote resilience during attacks in Norway (Kaufmann, 2015). More research is needed to use and adapt the research available on ways to develop resilience in future self-care interventions.

### 2.2.3. Culture and self-care

Every country has its own cultural characteristics, ideas, customs, and social behaviors, both nationally and within particular groups or communities. This applies as much to self-care beliefs and practices as to any other aspect of life (Gallant et al., 2010). Although the broad elements of self-care (e.g., physical activity, healthy eating, and good hygiene) are universal, the particularities differ. For example, consulting a physician for a minor condition may be discouraged in some societies and welcomed in others. Some of these practices reflect differences in remuneration but in other countries, the differences reflect deeply and historically entrenched beliefs and values (Arnault, 2018).

Some cultural traditions are reductionist, analytical, object-oriented and intervention-focused, leading to treatment of a malfunctioning body part. Other cultural traditions are holistic with a view of health as complex and contextual, leading to a focus on balance, prevention and collective harmony (Nisbett et al., 2001). People who undertake self-care as an expression of collective harmony may be avoiding being a burden on their families, their communities and society (Cho et al., 2018).

An important implication of these cultural differences is the effect on self-care behavior. Societies in which individuals perceive ‘rights’ to health, healthcare products and services may undermine

the sense of responsibility for one's own health and discourage self-care behavior – ignoring that rights and duties are inextricably linked. When there is less emphasis on individual rights and a view of the self as part of a greater whole and consideration of an individual's share of the entire community's rights, there is less dependency on the health system and a stronger basis for personal efforts in disease prevention and self-care. Individual effort may be particularly necessary where healthcare systems are less developed.

*Implications for self-care research.* The deep cultural differences between countries illustrate the need for research examining the influences of culture on self-care (Ory, 2008). Geographic differences in self-care have not been well-studied. Lim et al. (2017) compared self-care barriers in heart failure patients managed at tertiary centers in an Eastern (Singapore) versus a Western (US) nation and reported that the Western patients perceived more barriers to self-care after adjusting for demographics and comorbid conditions. A cross-cultural validation study of the Self-Care of Diabetes Inventory demonstrated that persons in the US and Italy hold comparable views of terms used to describe self-care of diabetes (Ausili et al., 2019). In spite of this early work, we know relatively little about how cultural norms influence interpretation of bodily changes such as symptoms, although there is some evidence of concealment or overexpression of symptoms based on what is perceived to be culturally acceptable (Alonzo, 1979).

### 2.2.4. Difficulty performing self-care with multiple chronic conditions

For those who have already developed a chronic condition, additional conditions add challenges. One group that is particularly burdened in terms of self-care is those with multiple chronic conditions. Multimorbidity is associated with poor clinical outcomes including high mortality, increased frailty and disability, worse quality of life, reduced functional ability, and higher health care resource use including costs for multiple medications, hospitalizations, emergency department and provider visits (Forman et al., 2018; McPhail, 2016). The prevalence of multimorbidity is increasing as our populations age. Trials often exclude these patients, so there is much to be learned about how multiple chronic conditions influence self-care.

The presence of multimorbidity can alter, diminish, add complexity or expand self-care ability and self-efficacy. That is, effects may be synergistic or subtractive, depending on the conditions present. For example, studies of hypertensive medication-taking adherence and number of comorbidities have shown no relationship (Li et al., 2016), a negative relationship (Solomon et al., 2015), and a positive relationship between adherence and number of comorbid conditions (Spikes et al., 2019). Clinical depression and depressive symptoms are common comorbidities that typically increase complexity and interfere with healthy self-care behaviors (Birk et al., 2019). Dementia and cognitive dysfunction are particularly problematic because of the increasing prevalence of these conditions in older adults (Hugo and Ganguli, 2014).

Specific challenges for those with multiple chronic conditions include poor access to health care and fragmented care, polypharmacy, functional and psychological limitations, diet complexity, complex lifestyle changes, lack of confidence in the ability to integrate several self-care recommendations that may conflict, and an inability to cope with the burden of multimorbidity (Boyd and Kent, 2014; Garin et al., 2016). Additionally, multiple symptoms of different conditions may occur simultaneously, making symptom monitoring, interpretation and management confusing. Selecting which symptoms to report and which provider to contact can be perplexing when symptoms are misunderstood. As the self-care demand increases in difficulty, self-care self-efficacy declines



(Dickson et al., 2013). At this point we know little about optimal self-care interventions in patients with multimorbidity (Smith et al., 2016b).

*Implications for self-care research.* The study of self-care in persons with multimorbidity needs to be patient-centered rather than disease focused. That is, presumably someone with three different illnesses experiences issues with self-care, regardless of what those conditions are (Palmer et al., 2018). Further, a consistent approach to categorizing multimorbidity is needed to allow eventual comparisons of research (Kenning et al., 2014). Counting diseases or conditions limits understanding of the true effect of multiple chronic conditions on variables of interest. For example, obesity may be categorized as a disease or a risk factor. “Comorbidity” implies a defined index condition with other conditions co-occurring (Meghani et al., 2013). Other approaches conceptualize chronic conditions as concordant or discordant (Piette and Kerr, 2006) or malignant versus benign phenotypes (Chen et al., 2019). These examples underscore the need to find a consistent approach to categorizing conditions if the research is to be integrated in the future. Integrating self-care research will facilitate inclusion of multimorbidity in clinical practice guidelines, which are frequently disease specific (Boyd et al., 2019).

#### 2.2.5. Self-care in persons with severe mental illness

There are known associations between chronic physical and psychiatric conditions (Scott et al., 2016). Psychiatric conditions such as major depression and schizophrenia increase functional impairment and accentuate the risk of adverse outcomes in those with chronic physical conditions (Druss et al., 2009). Self-care is important in persons with mental illness and conversely there is good reason to expect that psychiatric comorbidities may have a profound effect on self-care. The Theory of Self-Care of Chronic Illness does not specify how to apply the theory in persons with mental illness; however, a study exploring the prerequisites for a healthy lifestyle as described by individuals diagnosed with psychosis, discussed implications of the theory in this population (Ward et al., 2013).

There has been limited research on self-care of persons with severe mental illness. Most of the research conducted has been limited to a small number of mental-physical disease comorbidities. For example, there have been studies of the effects of major depression and anxiety disorders on glycemic control in diabetes mellitus (Whitworth et al., 2016) and on the effects of post-traumatic stress disorder on treatment adherence (Zhang et al., 2017). There is also a body of literature on blood pressure self-management, glycemic control, and adherence to diabetes self-management regimens in individuals with schizophrenia (McBain et al., 2016).

*Implications for self-care research.* Further research is needed on the self-care implications of a wider range of psychiatric conditions. Interventions designed to promote self-care in this population are greatly needed as are studies exploring the effects of severe mental illness on symptom awareness and insight. Technology could play a key role in supporting self-care in this population by fostering engagement with the health care system, helping patients to monitor and interpret symptoms, guiding treatment choices, reinforcing adherence to prescribed treatments, and motivating lifestyle changes (Depp et al., 2016). This topic should be considered a high priority for self-care research.

#### 2.2.6. The influence of others on self-care

Although our efforts address self-care, we are fully aware that a variety of persons contribute to self-care - care partners, family, peer supporters, healthcare professionals, home care workers, etc.

Clearly, these partners participate in important ways to self-care efforts, although the way they participate varies widely. Results of a qualitative systematic review identified two major roles used by others to support self-care of chronic conditions: (1) co-creating a context for the self-care by creating social interaction, performing day-to-day tasks, advocating for the patient, sharing responsibilities, and maintaining a balance; and (2) co-creating ways to self-care, with direct and indirect contributions to self-care (Whitehead et al., 2018).

There is increasing scientific interest in studying care partners. Studies currently in process include studies designed to explore and better understand the “caregiver world” and variables associated with caregiving (Lanning et al., 2019; Moreno et al., 2017), studies focused on training care partners to manage the condition (Ali et al., 2018; Kavanaugh et al., 2018), studies designed to improve patient self-care and caregiver contributions to self-care (Valenta et al., 2018; Wells et al., 2018), and studies designed to improve self-care of caregivers (Riegel et al., under review).

*Implications for self-care research.* Effort is needed to standardize the terminology used in reference to these carers. The term “caregiver” suggests a linear relationship from a carer to a patient, but in many dyads, illness management is performed as an interdependent team. We suggest “care partners” to reflect the fact that dyads appraise illness as a unit and this appraisal influences how they engage in behaviors to manage an illness (Lee et al., 2018; Lyons and Lee, 2018). The processes used in long-standing relationships are recursive, involving repeating, iterative processes that influence dyadic health.

Research is needed to better understand the process and impact of caregiving on both care partners. Theory-based interventions need to be tested. Technology could be used to support the care partners contributing to self-care. Technology may help with day-to-day caregiving (Karunanithi and Zhang, 2018). Wearable technologies can be used to monitor health conditions and to connect carers and providers working as a team in providing care (The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute, 2015).

### 3. Future directions

To achieve the vision and mission of the Center, we have three specific goals. First, we will lead a collaborative program of research that addresses self-care knowledge gaps and improves outcomes. Second, we will create a supportive international network for knowledge transfer and support of innovations in self-care research. Third, we will support and train others in self-care research that promotes primordial prevention, health maintenance in individuals at risk for chronic illness, and improves clinical outcomes in those who already have a chronic condition.

Beyond these specific short-term goals, there are important policy implications of this work. Drivers of policy development and change include: (1) evidence for successful policies and programs from other countries or different jurisdictional levels, (2) public opinion and media interest, and (3) enthusiastic politicians, senior health officials and policy advisers who are champions for self-care (Dickerson et al., 2019). We intend to work with organizations addressing environmental, systemic and personal barriers to self-care to integrate our visions and support progress in self-care research.

Given the many existing challenges to our vision, it is essential to further raise the profile of, and articulate the case for, self-care as a vital element in health and healthcare. A definitive statement of the benefits and reasons for encouraging self-care and making it part of official government policies remains to be made. Many countries have incorporated aspects of self-care into policies and promoted some innovative and notable practices. However, all

countries are a long way from implementing robust and holistic policy prescriptions designed to promote individual and population self-care capabilities, shift professional practices, or reorient healthcare systems towards a prevention, self-care ethos. There is much remaining work to do.

### Declaration of Competing Interest

None.

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### Supplementary materials

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