Self-care: An effective strategy to manage chronic diseases

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Abstract

The increase in life expectancy and an aging demographic have led to a surge in chronic diseases, presenting substantial challenges to healthcare systems worldwide. Chronic conditions are characterized by their long-term nature, recurrence and incurability, necessitating effective management strategies. This paper aims to explore the concept of self-care as a pivotal element in chronic disease management, examining its evolution, components and the role of caregivers in facilitating self-care practices. It also seeks to review the development of instruments for measuring self-care and discuss recent experimental research on self-care interventions. Self-care is an essential strategy for managing chronic diseases, involving maintenance, monitoring and management practices influenced by various personal and environmental factors. Caregivers play a vital role in supporting self-care, especially within certain cultural contexts. The development of reliable and valid instruments to measure self-care is crucial for assessing the effectiveness of the interventions. Recent trials, such as those focusing on motivational interviewing and virtual reality, show promise in improving self-care behaviors and patient outcomes. This paper advocates for the design of tailored, evidence-based interventions and highlights the potential of artificial intelligence in advancing self-care research. Future studies should continue to explore the dyadic dynamics between patients and caregivers and include economic evaluations to inform clinical decision-making.

Key words: chronic diseases, self-care, Orem concept

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Introduction

With the increase in life expectancy and the aging of the population, we are facing a worrying increase in the number of people affected by chronic diseases. Currently, there is no uniform definition of chronic diseases, but the general literature agrees that they share the characteristics of incurability, persistence, recurrence, and duration in terms of months or years.[1] Cardiovascular and respiratory diseases, diabetes mellitus and cancer are examples of the major and common chronic diseases highly prevalent in Western countries.[2]

The harmful effects of chronic diseases are well known to health scientists thanks to the numerous qualitative and quantitative research papers published in the field. These long-term conditions have a significant impact on all aspects of the lives of those affected. For example, chronically ill patients often suffer from physical disability, pain, distress, depression, and a poor quality of life,[3–5] which inevitably leads to an increase in healthcare utilization and mortality.[6,7] This is the reason why, over the years, self-care has become so important in the management of chronic diseases.

What is self-care?

Traditionally outlined in *Nursing* by Orem in 1959,[8] the concept of self-care has been expanded over the years, as a result of the shift from the traditional medical model to multidimensional patient-centered care. In 1979, Levin defined self-care as a broader process in which people take responsibility for health promotion, disease prevention and treatment.[9] An even more complete definition was given by the World Health Organization (WHO) in 2013, where self-care was defined as "the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider".[10]

The authors of this editorial have adopted the definition of self-care derived from the Middle-Range Theory of Self-Care of Chronic Illness, in which it is "a process of maintaining health through health-promoting practices and managing illness".[11] In this theory, self-care includes the 3 main concepts of self-care maintenance, self-care monitoring and self-care management. Self-care maintenance is a group of behaviors that patients with chronic conditions engage in to promote wellbeing and control their physical and emotional stability. Some examples include medication adherence, healthy eating and physical activity. Self-care monitoring refers to observing signs and symptoms of the disease, e.g., routinely measuring blood pressure or blood sugar. Self-care management refers to the behaviors that are put into practice whenever signs and symptoms of illness occur, such as consulting a healthcare provider or taking medication in cases of pain. The process of self-care requires making complex cognitive decisions and can be influenced by a number of factors related to knowledge, self-efficacy, functional and cognitive skills, cultural beliefs, support from others, and access to care.[11]

The role of caregivers in self-care

Many patients affected by chronic diseases face difficulties in performing self-care, particularly if they are older or belong to a culture that prioritizes familial ties over individualism. In this particular context, the caregiving role is essential. Caregivers are defined as those individuals within the family or friends' network who assume most of the responsibility for providing informal care to their loved ones. This type of care can be measured using specific tools designed in the format of a traditional questionnaire, where caregivers are asked to self-report on the frequency with which they support or substitute the patients in carrying out specific self-care tasks.

The first instrument to measure caregiver contribution to self-care was developed for heart failure,[12] but over the years, other instruments have been developed for general chronic conditions,[13] pulmonary diseases[14] and ostomies.[15] Investigators are also developing instruments to measure caregiver contribution to self-care in diabetes, cancers, inflammatory bowel diseases, and strokes. A caregiver's contribution to self-care was conceived with the identical 3 core concepts of (caregiver contribution to) self-care maintenance, self-care monitoring and self-care management, and numerous investigators have utilized this instrument as a landmark to develop their specific caregiver contribution instruments.

The items of the caregiver contribution to self-care measure the same aspects of self-care behaviors (e.g., physical activity), but the wording has been changed to be completed by caregivers. For example, while the item of the patient version of the instrument asks how often they have performed physical activity, in the caregiver version, they are asked how often they have recommended the patient to perform physical activity.

Regular assessment of caregiving contribution is particularly important in the context of chronic diseases. Caregivers often experience significant physical, emotional, social, and financial challenges while taking care of these patients. Scheduling periodic screenings can identify caregivers at risk and provide them with information and education, which are known to increase caregiving competence and promote wellbeing.[16]

Dyadic approaches to study self-care

The possibility of measuring patient self-care and caregiver contributions to self-care has stimulated researchers to investigate the self-care process using a dyadic approach.

This is because patients are uniquely linked to their caregivers, and caregivers are also dependent on the patient's behaviors and attitudes. In the context of a chronic illness, these 2 members approach the health problem as a unit and become an interdependent team, making illness management a dyadic phenomenon.[17]

The existence of the dyad in the self-care process implies that patients and caregivers influence each other. This violates the assumption of statistical independence because their scores in the questionnaires are likely to be correlated. Adopting a dyadic approach in self-care research implies that the variables of both members are used in the models. For example, if we want to understand whether depression affects the patients' self-care behavior, one would be tempted to build a regression model with only patient-level variables (i.e., patient depression and self-care). However, according to the theory of dyadic illness management, patient self-care may be influenced not only by their levels of depression (actor effect) but also by the caregivers' level of depression (partner effect). This relationship can be bidirectional, i.e., depressed caregivers can provide poor contributions to self-care as a result of their own mental state (actor effect), and that of the patients (partner effect). These partner effects should be taken into account to avoid inaccurate test statistics and the inflation or absence of statistical significance of the hypothesized relationships.

The actor-partner interdependence model (APIM) is widely utilized for analyzing dyadic data in the social and health sciences. This statistical framework allows for the estimation of both actor and partner effects, enabling the investigation of various processes occurring within the members of the dyad. Notable contributions to the field of self-care research can be found in the work by Iovino et al.,[18] who explored the dyadic predictors of self-care in individuals with multiple chronic conditions. These findings revealed that caregivers, in comparison to other groups, were more inclined to provide support to patients who had a higher formal education. Additionally, it was observed that patients were more likely to engage in health-promoting behaviors when cared for by female caregivers. Iovino et al.[19] studied dyad members in the context of ostomy care; their findings revealed that, compared to the others, caregivers of more depressed patients were more likely to stimulate the health-promoting activities of their partners. Additionally, patients with more depressed caregivers were less likely to take action in case of signs and symptoms occurrence. For interested readers, all the contributions to self-care instruments can be viewed on the following website: https://self-care-measures.com.

How to measure self-care

The authors of this editorial have devoted consistent efforts to the development and validation of theory-based instruments for measuring self-care in chronic illnesses. These measures, which are based on the middle-range theory of self-care in chronic illness, can be condition-specific, such as the Self-Care of Heart Failure Index (SCHFI)[20] or the Self-Care of Diabetes Inventory (SCODI),[21] or generic, such as the Self-Care of Chronic Illness Inventory (SC-CII).[22] For interested readers, all the self-care instruments can be viewed on https://self-care-measures.com.

Self-care is, by definition, an ensemble of complex behaviors. Therefore, to measure this construct, the instruments must assess a wide range of behaviors. An important structural characteristic of these instruments is the formulation of their questions on a 5-point Likert scale. This format is important because it helps researchers and clinicians measure how often a behavior is performed in a given period. As in this case, Likert scales measure behaviors with greater precision and nuance than simple "yes" or "no" questions. For example, the reader can come up with a question to measure medication adherence. One instrument may ask patients whether they take prescribed medicines without missing a dose, with a "yes" or "no" response, and another asks how often or routinely they take the medicines. In the latter case, of course, the patient has the opportunity to give a more specific and precise answer.

Another requirement of self-care measures (and indeed for any other instrument) is that they must be psychometrically valid and reliable and adapted to the patient's cultural context.[23] This aspect is not surprising, considering that, as mentioned above, self-care behaviors are highly sensitive to the cultural context. It may be that a certain behavior is never performed or not performed as often as in other countries. For example, De Maria et al.[24] conducted a cross-cultural validity study of the Self-Care of Chronic Illness Inventory across Italian, Swedish and American patients, and found that people in the USA used comparatively higher scores when answering the items related to physical activity and diet. This is an example of bias that must be recognized when validating a scale, as scores on the scales can be seriously inflated when different types of populations are compared. Therefore, when there is a knowledge gap, validation of an instrument in specific countries and languages is mandatory before administration.

Trials on self-care

Compared to the last decade, where the main efforts were to understand the deficits in self-care and its risk factors in chronically ill populations, we have recently approached the so-called experimental phase. This phase is about gathering evidence for the effectiveness of self-care interventions. One of these trials is the MOTIVATE-HF study, in which an intervention based on motivational interviewing demonstrated significant improvement in self-care maintenance behaviors, physical symptoms, quality of life, and mortality in patients with heart failure.[25–28]

A more recent study in the same population (the REMOTIVATE-HF trial) is currently ongoing, in which a similar but more intensive intervention is being implemented remotely via video calls.[29] Other ongoing trials are looking at the effectiveness of virtual reality on rehabilitation adherence in patients with heart failure[30] and educational interventions for patients with ostomies.[31]

Future trends for the study of self-care

We believe that the future of self-care sciences will be devoted to the design of interventions that could be highly effective for a number of important outcomes, including the quality of life of patients and their caregivers. To accomplish this, evidence is still needed to understand the power of specific behavior-change techniques; moreover, further studies should be invested in designing interventions that would adapt to the patients' and caregivers' needs. In this regard, it is important to highlight that certain populations face important barriers that impede their access to self-care interventions.[32,33] Such barriers include inherent beliefs (e.g., lack of trust in healthcare providers), psychosocial conditions (e.g., homelessness, poverty, loneliness, and migration), and structural barriers (excessive distance from the healthcare setting and a lack of transportation). Consequently, the focus of research will inevitably shift from individuals with high and medium socioeconomic status to individuals in disadvantaged and underserved communities.[32] The involvement of clinicians, researchers and policymakers is crucial in determining how these programs can be customized for disadvantaged people, whether they could help reduce the inequities, and ultimately improve their wellbeing. To accomplish this, a thorough multidimensional assessment of the patient-caregiver background is necessary to pinpoint contextual factors that may impede access and effectiveness of self-care interventions.[32]

We also foresee a step further to the evidence extracted from trials by including economic evaluations. With such information, we will help clinicians make more informed decisions about which types of interventions should be adopted to care for their patients.

An important role will be taken using artificial intelligence (AI) to study self-care. Artificial intelligence could be used to collect and analyze data collected by patients or by wearable devices and sensors, or it could be used to study how patients report their experience with chronic diseases on social media.[34] So far, there is evidence that AI-driven approaches offer substantial benefits in terms of higher frequency and duration of lifestyle choices, as well as decreased utilization of healthcare services.[35] Future studies could be performed by testing AI-powered chatbots, which can provide patients with personalized and motivated self-care guidance. Artificial intelligence algorithms can also predict potential challenges patients may face in managing specific self-care behaviors (e.g., exercise). These are the only examples in which AI can be used. Other forthcoming trends will undoubtedly be the study of patient-caregiver dyads and, specifically, how their coactive relationship during the disease process could be mutually beneficial for both members.

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