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Self-management of complex chronic conditions: Recommendations for qualitative health communication research

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ABSTRACT

Background: Chronic conditions are on the rise worldwide, urging researchers to increase efforts to develop tailored self-management interventions. Theories and findings from health communication hold great potential to inform these developments, provided that the main current challenges in the field are adequately addressed. **Aim:** To recommend targets for research in health communication, focusing on qualitative methods, in the field of self-management of (complex) chronic conditions. **Methods:** A position paper based on a selective review of literature on self-management of chronic health conditions. **Findings:** To better support the development of tailored self-management programs, health communication research should: i) consider the existential dimension of self-management behavior; ii) recognize and address the fact that we live in an information landscape characterized by information overload and infodemic, and iii) apply qualitative methods to ensure that individuals' perspectives are fully taken into account. **Discussion and conclusion:** Gaining in-depth qualitative insights into the adjustment process for (complex) chronic health conditions is of mainstream importance for developing tailored communication interventions that can assist newly diagnosed individuals in integrating multiple self-management behaviors in their lives. This holds great potential to improve health outcomes for individuals and to reduce costs for society.

KEYWORDS

Chronic disease, existential perspective, infodemic, qualitative research, self-management

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Introduction

Chronic conditions are on the rise worldwide, with important implications for individuals and societies. Promoting health self-management is increasingly recognized as a valuable strategy, as it holds the potential to improve quality of life and reduce healthcare costs. As communication is one of the main determinants of self-management, much health communication research has been conducted in recent years in this field. In this conceptual paper, we show how, despite its achievements, there are still areas of potential improvement. In particular, through a selective review of literature, we aim at making the point for the need for health communication research in the field of self-management of chronic diseases to i) consider the existential dimension of self-management behavior, which we define as the process through which individuals concretely adapt to the new situation and integrate a multiplicity of different self-management requirements into sustainable behaviors in the context of their lives; ii) recognize and address the fact that we live in an information landscape characterized by information overload and infodemic and that this has important implications for the success of self-management interventions; and iii) put more emphasis on qualitative methods to ensure to fully take into account the individuals' perspectives in the design of tailored self-management interventions.

Chronic conditions on the rise

Over the last century, life expectancy has almost doubled worldwide (Kinsella & Velkoff, 2002). The reasons for this are diverse but mainly can be traced back to advances in medical technology. Several diseases have been completely eradicated (e.g., polio, thanks to vaccination), and several others have transformed from deadly to chronic. This phenomenon is known as the "epidemiological transition" of the 20th century (Omram, 2001). Longer life expectancy, however, is not the only distinctive phenomenon of the current healthcare landscape: the decrease in mortality, combined with other demographic changes, such as a decrease in natality rates, has created an aging population. In 2011, the worldwide population over the age of 60 was around 800 million (11%), and it is estimated that the number will increase to more than two billion in 2050 (22%) (Bloom, Boersch-Supan, McGee, & Seike, 2011). Longer life expectancy and an aging population mean, in turn, a higher prevalence of chronic conditions (Divo, Martinez, & Mannino, 2014).

A chronic condition is broadly defined as a condition or a disease "that lasts one year or more and requires ongoing medical attention or limits activities of daily living or both" (National Center for Chronic Disease Prevention and Health Promotion [CDC], 2020a). Recent estimates suggest that up to 60% of people live with one or more chronic conditions and that up to three-quarters of older adults live with multiple chronic conditions in developed countries (CDC, 2020a). Chronic diseases are currently the leading cause of death worldwide, with around 38 million deaths a year attributable to non-communicable diseases (Divo et al., 2014; Hajat & Stein, 2018; World Health Organization [WHO], 2020a).

Addressing (complex) chronic conditions: the central role of self-management

The high prevalence of chronic conditions has important implications for both individuals and society as a whole. At the individual level, people living with chronic conditions, especially if poorly managed, often have difficulties performing many activities of daily living and participating actively in society. This has been shown to negatively impact the well-being, mental health, and overall quality of life of the affected individuals and their families (Baanders & Heijmans, 2007). The increasing prevalence of chronic conditions has important repercussions for healthcare costs as well as for communities and society. Recent figures suggest that chronic conditions are major drivers of countries' healthcare expenditures, with up to 90% estimates in the US (CDC, 2020b).

Several policy actions are currently being implemented to reduce the health and economic burden of chronic disease, such as epidemiology and surveillance (e.g., collecting data to understand who is most at risk), environmental approaches (e.g., introducing regulations and bans), and system-level interventions (e.g., improving access to health care for disadvantaged populations). Two main strategies can be implemented at the individual level: prevention and management (CDC, 2020b). While prevention programs hold great potential for limiting the number of new chronic conditions, especially those related to lifestyle factors, prevention is not possible in many cases. Additionally, prevention does not in any way address those already living with one or more chronic conditions. This is where the importance of management comes into play.

For healthcare systems, the management of chronic conditions entails a multifaceted response over an extended time, coordinating the impacts of various health professionals, medicines, and monitoring equipment (Nolte, Knai, & McKee, 2008). Over the last several decades, we witnessed a shift from an approach to healthcare centered on the disease to one that emphasizes the patient's needs, preferences, and autonomy (Sacristán, 2013). An increasingly central role in managing chronic diseases has subsequently been assigned to individuals, who are now required to act as "partners" and take on an active role in the self-management of their conditions (Holman & Lorig, 2000; Meyer et al., 2020).

Self-management has been defined as "learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" (Lorig, 1993). It entails three types of skills: those needed to care for the disease, such as taking medications, visiting physicians, exercising, or maintaining a special diet; those required to keep one's normal life, including doing chores and maintaining social contacts and hobbies; and the emotional skills necessary to deal with feelings like frustration, anger, and depression, as well as to adjust to a future altered by the disease (Corbin & Strauss, 1988; Velde et al., 2019). Good self-management is widely recognized as an invaluable asset for people living with a chronic condition and is associated with a broad range of positive outcomes, including improved clinical (e.g., reduced pain) and psychological outcomes (e.g., sense of control and empowerment), as well as reduced healthcare expenditures (e.g., decrease in hospital stays and visits to physicians) (Boger et al., 2015; Du & Yuan, 2010; Fries & McShane, 1998; Lorig, 1993; Lorig et al., 1999; Ory et al., 2013). According to Whittemore and Dixon (2008), a chronic condition is well managed when it is integrated into a person's life. Such integration largely depends on one's resources, including one’s ability to learn about the health condition and try out solutions to emerging problems. The self-management of a health condition includes a long list of tasks and requires excellent knowledge and skills from the patient (Clark, Gong, & Kaciroti, 2001; Velde et al., 2019).

All this is particularly true in the case of complex chronic conditions or conditions involving multiple morbidities (Weiss, 2007) and numerous self-management requirements (Sevick et al., 2007). The precise options of, for example, diabetes management (a relatively normal life achieved by following straightforward regimens of medication and diet, or significant health consequences including amputation and death) are present in complex chronic conditions as well. However, complex chronic conditions are noted for the fact that integrating self-management in everyday life efficiently and sustainably often requires complex trade-offs in life plans and projects. Usually, all the available options come with substantial costs in terms of quality of life (Sevick et al., 2007; Van Leeuwen, Kraaijeveld, Lindeman, & Post, 2012; van Leeuwen et al., 2012). Current estimates show that an increasing number of individuals live with multiple chronic conditions (or complex chronic conditions), and the numbers are predicted to rise further in the coming decades (Hajat & Stein, 2018).

Research on self-management behavior in complex chronic conditions

Given the important implications of living with a chronic condition, healthcare systems are urged to find viable ways to support individuals in their self-management activities. In this context, the potential of self-management behavior has inspired a whole stream of research investigating its relation to health outcomes. As a result, there is now a large body of evidence showing that together or as an alternative to surgical and pharmaceutical interventions, self-management behavior can indeed play a central role in health outcomes for people living with a chronic condition (Du & Yuan, 2010). Among other things, engaging in self-management behaviors is associated with fewer hospitalizations, less pain, less disability, and higher participation in activities of daily living. A second significant stream of research in the context of self-management behavior of chronic conditions has been devoted to understanding the factors that play a role in the acquisition and implementation of self-management health behaviors. This stream of research has produced a large body of evidence showing that different self-management behaviors are determined by personal, interpersonal, and environmental factors (see, e.g., Hirsche, Williams, Jones, & Manns, 2011; Munce et al., 2014). Finally, the evidence on the vital role of potentially modifiable factors in self-management behavior has stimulated research to assess the effectiveness of interventions targeting these factors. Over the years, numerous interventions have been developed addressing one or the other aspect to foster different self-management behaviors (Nolte & Osborne, 2013; Richardson et al., 2014).

As shown in this brief overview, research into self-management behaviors in the context of complex chronic conditions has taken many necessary steps forward in understanding the phenomenon. On the other hand, current research in the field is very fragmented. It usually focuses on one specific health condition or self-management behavior and addresses a few determinants while neglecting the existential perspective of self-management. In particular, it does not fully take into account that patients nowadays have at their disposal a large amount of information (and mis/disinformation) which can have a significant impact in shaping the decision regarding their health. We will address these aspects in detail in the next section.

The missing existential perspective and the lack of integration of insights from health communication

As outlined in the previous section, there is now agreement on the importance of self-management behaviors in relation to outcomes; there is a comprehensive understanding of its determinants at the personal, interpersonal, and environmental levels; and there is a significant body of evidence from the field of health communication on what are effective interventions addressing these determinants to support specific self-management requirements. What is largely missing from current research in the area is a systematic focus on the existential dimension of self-management; in other words, the fact that people newly diagnosed with a chronic condition—and especially with a complex one—have to learn and apply multiple self-management requirements at the same time and find ways to integrate them into their lives. The centrality of this aspect and its possible implications are clearly shown, for instance, in a recent qualitative study on pressure ulcers among individuals living with spinal cord injury by Zanini and colleagues (2018). The study confirmed the findings from previous studies suggesting that self-efficacy plays a central role in the self-management of pressure injuries. At the same time, however, it also highlighted how its translation in the actual self-management behavior is not as linear as it seems but is dependent on many different factors, including conflicting priorities. So, people with high levels of self-efficacy would sometimes report not performing some of the required behaviors for various reasons, for instance because they would conflict with leisure and social activities. For example, it can be challenging to change position regularly to release pressure when traveling by flight or attending a concert.

Furthermore, this is not only an issue in the case of complex chronic conditions such as spinal cord injury, but it can also be relevant for chronic conditions with relatively more straightforward self-management requirements, such as diabetes. For instance, in their study about a diabetes self-management app for adolescents, Ledderer, Møller and Fage-Butler (2019) showed how sometimes barriers to its use were due to there being an incompatibility between the app and how the adolescents wanted to live their lives. For example, some adolescents in the study reported preferring to spend time outside with friends or interacting on social media rather than typing in blood glucose measurements in the app. The fragmentation of current research and the focus on single determinants or specific self-management behaviors while neglecting the existential perspective might therefore hinder the effectiveness of interventions to support self-management of (complex) chronic conditions (Bratzke et al., 2015; Ko, Bratzke, & Roberts, 2018; Koch, Wakefield, & Wakefield, 2015; Schmidt-Busby, Wiles, Exeter, & Kenealy, 2018).

Concerning this existential aspect, one further important point that cannot be overlooked in the context of research aimed at understanding and addressing health behavior and behavior change is the role played by information provided at all levels of society, which more and more often informs and shapes individuals' health-related decision-making. As clearly highlighted during the recent COVID-19 pandemic, this information is increasingly taking the form of an "infodemic" (WHO, 2020b.). People now have easy access to an unprecedented amount of health-related information. Owing to its uncontrolled nature, some of this information is unsubstantiated and, in many cases, even contradicts the main messages of planned interventions (Kitchens, Harle, & Li, 2014). It contains significant levels of disinformation (i.e., wrong information spread with the deliberate intent to mislead) or misinformation (i.e., inaccurate information spread unknowingly). For many, especially those with limited education or health literacy, mis/disinformation can translate into a reason not to engage in a specific behavior or to develop a negative attitude toward the behavior itself. The Internet has also contributed to a shift in what information sources are trusted by the public. Whereas healthcare professionals were an undisputed source of advice in the past, people now trust more the personal experiences of others, whom they consider more likely to share their perspectives (Smith, 2011). When developing a behavior change intervention, it is crucial to review publicly available information on the topic and, if necessary, to find ways to address or refute it. Similarly, efforts should be devoted to identifying the most trusted sources within the target group and using them to convey necessary messages (Rubinelli, Myers, Rosenbaum, & Davis, 2020). All these aspects can have harmful consequences in the context of the self-management of a chronic condition. Some, for instance, could underestimate the importance of performing regularly a particular self-management behavior because of information they read on a blog or social media. Alternatively, they could perform a specific self-management behavior incorrectly following advice from a friend based on personal experience and not on solid scientific evidence. Nevertheless, all these aspects have barely been researched in the context of the self-management of complex chronic conditions, with possible important repercussions for the effectiveness of interventions.

Lesson learned for health communication research

To respond to the urge for increased scientific efforts to establish tailored self-management in individuals living with complex chronic conditions (Trappenburg et al., 2013), there is a need for research aimed at delivering tools to support healthcare professionals, health educators, and policymakers in the design of tailored communication interventions to support people living with complex chronic conditions in the integration of effective and sustainable health-related self-management behaviors in their lives. Based on the limitations of current research outlined above, we suggest three critical implications for health communication research in the field of self-management of (complex) chronic conditions:

Key implication 1 – Systematically consider the existential dimension of self-management

Health behaviors do not happen in the void but are largely determined by an individual's circumstances (Rubinelli & Diviani, 2020). This is very well recognized in psychology and the behavioral sciences (Michie, van Stralen, & West, 2011). The shift towards a more person-centered approach to healthcare and the whole body of research around person-centeredness has contributed significantly to our understanding of the factors that might play a role in this context and to help ensure that the individuals' preferences and expectations are considered and that decisions are shared among patients and healthcare professionals (Håkansson Eklund et al., 2019; Zoffmann, Harder, & Kirkevold, 2008). However, we argue that integrating self-management behaviors in one's life is not only about preferences and desires at an abstract level, but it requires a concrete and continuous negotiation of priorities and goals, which might result in limited adherence and, in turn, in suboptimal outcomes. This aspect, which we define as the existential dimension of self-management, has not been studied in detail so far. Studying individual behaviors in relation to individual determinants and neglecting the existential perspective might result in a limited understanding of the real-life barriers and facilitators to sustainable behavior change. In turn, this might hinder the effectiveness of communication interventions. A concrete example in this context is the plethora of apps that have been designed to support people in a variety of behaviors, ranging from physical activity (Mateo, Granado-Font, Ferré-Grau, & Montaña-Carreras, 2015) to more complex health behaviors such as those related to diabetes management (Brzan, Rotman, Pajnkihar, & Klanjsek, 2016). Although, in many cases, these apps have shown positive effects in trials, rarely are these effects sustained in the long run, likely because their use conflicts with other priorities. Therefore, health communication research must start to systematically take the existential dimension of self-management into account when studying it and designing dedicated tailored communication interventions.

Key implication 2 – Recognize and address the impact on behaviors of the current information landscape

Most research on the role of information and communication in the self-management of chronic conditions has focused on the interaction between patients and healthcare providers (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Liddy, Blazkho, & Mill, 2014). Various tools have been developed to facilitate the communicative exchange and ensure shared decision-making and patient-centeredness (see, e.g., Austin, Mohottige, Sudore, Smith, & Hanson, 2015). All this work is undoubtedly fundamental and has contributed enormously to an overall improvement of the medical encounters. However, the number of alternative sources of information that are available to patients is now greater than ever (Smith, 2011). Furthermore, most importantly, information coming from these alternative sources might be false, partial, and even completely contradict medical advice. All this has the potential to exacerbate health disparities and inequality (Viswanath & Kreuter, 2007). Especially for people with limited health literacy skills, it becomes challenging to make sense of the conflicting information and use it to make informed self-management decisions (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). Therefore, health communication research must consider this complexity when studying self-management behaviors and devote particular attention to the individuals' health literacy skills. Here, it is vital to recognize the central role of critical health literacy (Chinn, 2011; Diviani, Obrenovic, Montoya, & Karcz, 2020), or one's ability to critically evaluate the vast amount of information and misinformation surrounding health issues.

Key implication 3 – Put more emphasis on qualitative insights

Cobley, Fisher, Chouliara, Kerr, & Walker (2013) stated that qualitative methods are "more appropriate if patient and carer experiences are to be more fully understood and are of value in informing future service delivery and development." Despite its potential, research in this field predominantly investigates the patients' perspective using quantitative methods. The focus has been on collecting epidemiological data on the prevalence of chronic conditions and their impact on healthcare services utilization, costs, and quality of life (see, e.g., Golics, Basra, Salek, & Finlay, 2013; Hussey et al., 2014). Similarly, a great deal of attention has been devoted to investigating the role of specific self-management behaviors in this context, their determinants, and possible ways to address them in targeted interventions (see, e.g., Ahn et al., 2013). While this has provided us with a good picture of the importance of self-management in chronic conditions, evidence on its determinants and on ways to address them, as well as solid reasons to investigate them further, the predominantly quantitative focus and its emphasis on the standardized assessment of predictors, behaviors, and outcomes do not allow researchers to take into account fully the individuals' lived experiences of self-management of a complex chronic condition and, consequently, to reach a comprehensive understanding of the phenomenon. Future research endeavors in this context should therefore make sure to collect qualitative insights systematically.

Conclusions

To ensure the patients' perspective is taken into account, health communication research needs to qualitatively explore the process of integration of self-management behaviors among persons living with a complex chronic condition with a focus on barriers and facilitators at the level of opportunities, capabilities, and motivation. Here a particular emphasis should be devoted to the exploration of the role played by communication and information. Examples of research questions in this context are, for instance, "How do people newly diagnosed with a chronic condition integrate self-management requirements in their lives?" or "How do chronic patients make sense of conflicting information from their healthcare professionals and other sources when making self-management decisions?". Doing so will enrich the body of evidence around self-management of complex chronic conditions by complementing existing quantitative data on prevalence and outcomes with in-depth qualitative insights on their self-management and its determinants. Most importantly, it will bring the existential perspective to the table, an aspect that has only marginally been investigated. From a clinical perspective, gaining in-depth insights into the adjustment process for complex chronic health conditions is of central importance for developing tailored interventions that can assist newly diagnosed individuals in integrating multiple self-management behaviors in their lives. This has the potential to result in improved health outcomes for the individuals and reduced costs for society.

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