

Self-care research: How to grow the evidence base?

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ABSTRACT

Background and objective: The number of studies in the area of self-care is growing and international researchers are increasingly developing self-care interventions to improve outcomes of individual patients and communities. However, growth of the evidence is still slow due to challenges with designing and testing self-care interventions. In this article we address major methodological challenges with regard to the definition of self-care, use of theory, and research design, intended to provide guidance to researchers in this field.

Method: During the inaugural conference of the International Center for Self-Care Research held in Rome, Italy in June 2019 we identified important issues in existing self-care research. Discussion and literature review lead to eight recommendation for future self-care research.

Results: In preparation, begin with a theoretically sound definition of self-care. In planning the intervention, build on and extend previous studies. Use theory to develop self-care interventions and consider translational models to guide development, evaluation and implementation of complex self-care interventions. Employ a study design that fits the current phase and objectives of the research and measure self-care and related factors carefully. In reporting, describe the sample and setting sufficiently so that others can draw conclusions about generalizability and applicability to their practice and patient population. In interpretation, describe how the intervention is assumed to work (causal assumptions) and its key components.

Conclusion: Our review of existing self-care research clearly illustrates that the recommendations we provide are needed if we are to substantially grow the evidence base supporting self-care. Embracing a core set of principles will allow us to build on each other's work.

Tweetable abstract: A core set of methodological principles is needed to substantially grow the evidence base supporting self-care.

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What is already known about the topic?

- The body of evidence for self-care interventions is growing, but slowly.
- To advance the science, it is important to build on previous work and improve the quality of research in the area of self-care.

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What this paper adds

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- Eight recommendations can help researchers who study self-care to improve their definition of self-care, use of theory, the development, evaluation and implementation of a self-care intervention and their reporting and interpretation of their research.
- Self-care interventions are complex interventions. A study design that fits the current phase and objectives of the research should be chosen with care.

1. Introduction

There is increasing interest in self-care research and in improving knowledge about the different aspects of self-care (Riegel et al., 2019; Riegel and Jaarsma, 2019). The scope of self-care includes health promotion, disease prevention, treatment, rehabilitation and palliative care.² Several theories, models and frameworks address self-care with the goal of describing the process and improving patient outcomes.

While the number of self-care research studies is increasing worldwide, there seems to be slow progress in building a strong evidence base for self-care interventions. We recently (Riegel et al., 2019) proposed a research agenda to deepen our theoretical understanding of self-care, identify mechanisms underlying self-care behaviors, and develop efficacious and effective self-care interventions that improve patient outcomes. We identified six specific knowledge gaps to address in future self-care research: the influence of habit formation on behavior change, resilience in the face of stressful life events that interfere with self-care, the effect of culture on self-care decision-making, the difficulty performing self-care for individuals with multiple chronic conditions or severe mental illness, and the influence of others (care partners, family, peer supporters, healthcare professionals) on self-care.

To adequately address these knowledge gaps, researchers are challenged to improve the quality of research addressing self-care and to build on previous work. In this paper we discuss eight methodological recommendations for advancing self-care research. These recommendations were formulated during the inaugural conference of the International Center for Self-Care Research held in Rome, Italy in June 2019. They give due consideration to the roles of theories and concepts, contexts and samples, interventions, research designs, and measurements of self-care and related factors.

2. Theory and concepts

2.1. Recommendation #1: define self-care carefully

Self-care of chronic illness involves complex behaviors, some of which are common across conditions and others that are situation specific. Self-care can be defined broadly as a process of maintaining health through treatment adherence and health-promoting practices (self-care maintenance), behavior and condition monitoring (self-care monitoring), and managing signs and symptoms when they occur (self-care management). When self-care involves all three aspects of the process and complex regimens, simplification in operationalization (e.g. only focusing on medication or dietary adherence, blood glucose monitoring, or symptom management) misses the opportunity to examine the full scope of self-care.

A common root cause of poor operationalization of self-care in research is the lack of a clear and empirically/theoretically based definition. Further, as cross-condition research gains more popularity, harmonization of self-care definitions across many chronic

illnesses is required to move large and previously siloed research agendas forward in a common and symbiotic fashion. Hence, we recommend using the common definitions of self-care maintenance, self-care monitoring and self-care management as explicated in the middle range Theory of Self-Care of Chronic Illness (Riegel et al., 2012). When necessary, situation- or disease-specific insights can be used to further refine definitions within specific illness contexts.

2.2. Recommendation #2: build self-care research studies on previous work

Development of complex self-care interventions often requires multiple studies. Unfortunately, when multiple studies are necessary, they may or may not be conducted in a well-organized or systematic manner. One of the best ways to accelerate progress in behavioral intervention research is to embrace a systematic approach. Relatively little of the self-care research conducted to date has used a systematic process. It is not uncommon, for example, for a novel self-care intervention to emerge from a broad theory or from clinical experience, to be tested in a small, underpowered, “preliminary” trial, but to never be tested again in a larger and more rigorous trial. This haphazard approach has been an impediment to the development of robust, evidence-based self-care interventions that could change clinical practice.

Isolated or one-off studies almost never produce fully fledged, practice-ready, evidence-based behavioral interventions. Usable interventions typically emerge from multiple studies. Research in self-care has grown exponentially in the last two decades, so there is an impressive body of work upon which to build. Replication of prior research is important; however, investigators are encouraged to consider the goal of replication and explore the possibility to have a broader and more creative view of their efforts. We recommend building upon prior research rather than simply replicating a study in a new environment.

2.3. Recommendation #3: use theory to develop self-care interventions

We encourage investigators to consider the use of theory in research and specifically in the development of self-care interventions. A theory can be defined as an interrelated system of ideas or as a systematic approach to understanding complex phenomena that is communicated as a meaningful whole. Theories present an interrelated system of ideas based on concepts and propositions that explain or predict observed phenomena. As such, theory can be useful in research, when used wisely. Investigators often struggle with identifying why they should use theory, which theory to use, and how to use the theory. These issues are addressed here.

In deciding which theories are the best guides for self-care research, a wide variety of options exist. The middle range Theory of Self-Care of Chronic Illness could be used alone or in combination with other theories (Riegel et al., 2012, 2019). Self-care is a behavior that often is targeted for improvement, so any of the many theories of behavior change (e.g. the Theory of Reasoned Action (Fishbein, 1980; Hennessy et al., 2012)) can guide research hypotheses or intervention design. Self-Determination Theory (Ryan and Deci, 2000), which addresses motivation to change, is another option. Numerous other self-care, behavior change, and motivation theories exist.

In deciding how to use a theory in research, (Glanz et al., 2008) distinguishes between *applying* theory and *testing* theory. Research that applies theory involves mentioning a theory, with allusion to the theory having framed the way the issue was addressed. Using theory in this way facilitates the accumulation of evidence across

¹ <https://www.who.int/reproductivehealth/self-care-interventions/definitions/en/>.

different contexts, populations, and behaviors (Michie and Prestwich, 2010). There is some evidence of this in self-care research, with numerous investigators identifying self-care confidence or self-efficacy as a key contributor to success in self-care behavior change (Cene et al., 2013; Chang et al., 2017; Hammash et al., 2017; Pancani et al., 2018; Vellone et al., 2015; Vellone et al., 2016). Experience with application of a theory can also contribute to its refinement. This occurred when the concept of self-care monitoring was examined in greater detail and symptom detection, interpretation, and response were developed in a recent modification of the middle range Theory of Self-Care of Chronic Illness (Riegel et al., 2019).

Theoretical concepts that are hypothesized to be causally related to a change-worthy behavior such as self-care may be identified as appropriate targets for intervention. In the original middle range Theory of Self-Care of Chronic Illness, factors proposed as influencing self-care included experience, skill, motivation, confidence, cultural beliefs and values, habits, functional and cognitive abilities, support from others, reflection, and access to care (Riegel et al., 2012). Any of these factors could be targeted for intervention, and many investigators have done so (Chen et al., 2017; Chew et al., 2019; Freedland et al., 2015; Macedo et al., 2017).

Theory testing through intervention research involves identifying the modifying factors, explaining how these factors bring about change, using methods designed to demonstrate that the changes took place, and demonstrating how those changes contribute to behavioral change. Michie and Prestwich (2010) operationalize these processes in three categories: (1) whether the relevant theoretical constructs or modifying factors were targeted by intervention techniques, (2) whether these constructs were measured, and (3) whether mediation effects were tested. Unfortunately, rigorous tests of theories are relatively uncommon. However, efforts are underway to link various theories of behavior change to various behavior change techniques, and to provide a web-based tool for researchers to make use of these connections (the Theory & Techniques Tool, accessible here <https://theoryandtechniquetool.humanbehaviourchange.org/>). This approach may facilitate the appropriate use of theory in future self-care research.

The benefits of drawing upon theories in health behavior research are said to include potentially stronger effects, but a recent systematic review of systematic reviews of randomized controlled trials of health behavior change interventions questioned that proposition (Dalgetty et al., 2019). Theory use was reported by less than half (47%) of the studies included in the nine systematic reviews. Seven of the reviews failed to distinguish between applying a theory versus true testing of a theory. Based on these results, the investigators advocated that we focus on the benefits of theory as providing a framework for the design, evaluation, and optimization of interventions, providing a common language for communication, allowing for accumulation of evidence over time, and facilitating predictions in uncertain or new contexts (Michie and Prestwich, 2010; Dalgetty et al., 2019; Prestwich et al., 2014).

2.4. Recommendation #4: development, evaluation and implementation of complex self-care interventions should be guided by a translational model

Several new translational research models and optimization frameworks have emerged over the past decade to guide the systematic development and testing of health-related behavioral interventions. These frameworks differ in various ways but all of them encourage researchers to (1) work towards long-term goals that entail improving clinically important outcomes, (2) draw upon relevant basic and applied research findings when looking for new ways to improve interventions, (3) proceed systematically – and iteratively when necessary – from the early phases of interven-

tion development, refinement, and testing to definitive efficacy and effectiveness trials and implementation research, and 4) employ study designs that fit the current phase and objectives of the research.

Some of the models that are having the greatest impact on health-related behavioral intervention research include the NIH Obesity-Related Behavioral Intervention Trials (ORBIT) model (Czajkowski et al., 2015), the NIH Science of Behavior Change (SOBC) model, the NIH Stage Model (Nielsen et al., 2018), the Medical Research Council Framework for Developing and Evaluating Complex Interventions (Craig et al., 2008), the Multiphase Optimization Strategy (MOST) (Collins et al., 2013), and the Behaviour Change Wheel that was developed from 19 behaviour change frameworks and that is based on the COM-B (Capability, Opportunity, Motivation and Behaviour) model (Fishbein, 1980). Investigators do not necessarily have to choose one of these models and stick with it to the exclusion of all others; in some cases, it may be advantageous to draw upon two or more models for different reasons. For example, MOST provides tools for simplifying complex interventions that may include ineffective components, the SOBC framework provides tools for identifying key mechanisms underlying health behavior change, and the NIH Stage Model provides ways to examine the mechanisms of action of interventions. These tools, as well as other features of translational and optimization frameworks, can be very useful at various points in a systematic program of research testing a chronic disease self-care intervention.

3. Context and sample

3.1. Recommendation #5: describe the sample and setting sufficiently so others can draw conclusions about generalizability and applicability to their practice and patient population

The rigor and reproducibility of self care intervention studies can be improved by paying more attention to the characteristics of the sample and setting. Doing so may make it possible to achieve better self-care outcomes and may also increase the usefulness of empirically-supported interventions for clinical practice.

A behavioral intervention trial is unlikely to yield favorable findings if the sample includes numerous participants who do not have the problem or deficit that the intervention is designed to improve. Thus, we strongly recommend pre-assessment of self-care during participant screening and clearly defined inclusion criteria to select participants with suboptimal self-care of the behavior(s) being targeted. Likewise, when there are ceiling effects of desired outcomes, such as quality of life, or floor effects of low symptom severity, intervention studies will likely not demonstrate significant changes. Enrolling a sample with highly selected inclusion and exclusion criteria is important in early trials where efficacy is being determined. However, as the self-care intervention moves to effectiveness trials, the intervention may require modification for a more typical population encountered in clinical practice (Bauer et al., 2015).

Many studies of self care focus on a specific population. Some self-care interventions are specific for certain diseases, for example if they are related to the medical treatment or to lifestyle problems or symptoms that are specific to the condition (Jaarsma et al., 2017). The recipient of the intervention is the person and/or caregiver who needs to improve self-care, or the provider or system that provides care or services for people who need to engage in self-care. Multilevel interventions may be warranted, and while complex, may yield better results in some situations than would single-level interventions. Our primary recommendation for improving the description of interventions in publications is to be

explicit about the recipient(s) of the intervention (Jaarsma et al., 2017).

Currently, studies of disease-specific self-care dominate the literature, and persons with multimorbidity are often excluded or poorly analyzed and reported. This practice limits the external validity of the results for clinical populations (Kenning et al., 2014). However, as the prevalence of multimorbidity increases due to the aging of the population worldwide, addressing the relationship between multimorbidity and self-care behaviors becomes more essential. Additionally, it is becoming increasingly necessary to incorporate multimorbidity into self-care interventions. Approaches may include describing and addressing the congruence and discordance (competing and conflicting) (Aga et al., 2019; Piette and Kerr, 2006) or malignant versus benign phenotypes (Chen et al., 2019) of self-care. Multimorbidity is also relevant to the reporting of the study sample to enhance applicability, generalizability and replicability efforts. Regarding study design, researchers need to make explicit who the self-care intervention is for and be clear about whether multimorbidity was included or excluded in the intervention development process.

Some self-care interventions work in certain settings while others do not. That is, a self-care intervention might not be effective in a setting where usual care to support self-care is already strong. For example, planning a self-care intervention to decrease hospitalization rates in a setting that already has a low rate of patients returning to the hospital will reduce the effect of the intervention. Cultural differences, health beliefs and local customs may also influence the effect of a self-care intervention. Researchers should therefore carefully describe the usual care provided related to self-care including the content and approach so that the intervention can be viewed as either an augmentation of usual care or a novel intervention. Additionally, a clear description of the health care setting(s) where the research was performed is warranted. These two details can provide an informative context for explaining what the intervention is designed to accomplish.

4. Intervention

4.1. Recommendation #6 describe how the intervention is assumed to work (causal assumptions) and its key components

When designing and testing a self-care intervention, the first step is to evaluate the existing research to identify existing interventions of proven efficacy as well as lessons learned from trials of ineffective interventions. Important steps in developing the intervention include developing a conceptual model of how the intervention is expected to affect its target; describing the population(s) for which the intervention is being designed and context(s) in which it will be used; identifying the components of the intervention or its active ingredients; and developing the mechanisms of intervention implementation such as the processes of understanding, engagement, and adherence (Mills et al., 2014).

Because self-care itself is complex, interventions tend to be complex and incorporate feedback loops. Interventions often involve multiple components that interact over time as patients move back and forth between intervention processes and day-to-day life (Mills et al., 2014). Hence, the causal pathways are not linear and can be complicated and interwoven (Wight et al., 2016). This inherent complexity makes it all the more important to identify the nodes along the causal chain that are likely to be the most modifiable and beneficial to patients, including ones that the patients can manage themselves.

The description of how a self-care intervention is thought to work should take patient preferences and intervention acceptability into consideration. Patients may choose or reject self-care interventions for various reasons, including convenience, cost, empow-

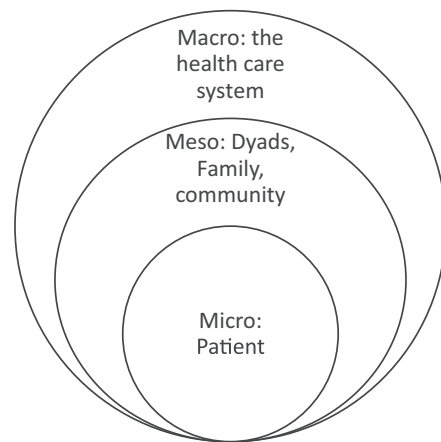


Fig. 1. Levels of self-care interventions.

erment, proven effectiveness, approval by the health system, and fit with values or lifestyle (Narasimhan et al., 2019).

Interventions are most likely to be effective if they target causal determinants of behaviour and behaviour change (Lennon et al., 2018). A four-step systematic theory-informed approach to guide the choice of intervention components includes (i) an examination of what behaviour change is required by patients and healthcare professionals to effectively promote self-care; (ii) identification of the barriers and enablers to behaviour change; (iii) identification of behaviour change techniques and mode(s) of delivery to overcome the modifiable barriers and enhance the enablers; and (iv) determination of the outcome measures of behaviour change (French et al., 2012).

The efficacy of a behavioral intervention depends in part on whether the optimal dosage has been determined and whether the intervention is aimed at the right level(s). Duration, frequency, and amount are dose parameters that can vary within and between many different types of interventions. Duration refers to the period over which the intervention is intended to be administered; frequency refers to how often contact is made with participants; and the amount is the length of each contact (Voils et al., 2012).

Levels of intervention can range from micro (e.g., patient-level) to meso (e.g., the families to which the patients belong) to macro (e.g., the health care systems at which the patients and families are treated) (Fig. 1). Some self-care behaviors are affected not only by patient-level factors but also by variables that operate at other levels. Multilevel interventions are designed to produce changes in two or more levels in ways that have mutually reinforcing or synergistic effects. Various strategies have been proposed for combining interventions at different levels (Weiner et al., 2012; Lewis et al., 2017) and may be considered to guide the design of multi-level self-care interventions.

Implementation strategies constitute the 'how to' component of changing behaviour and subsequent healthcare practice (Proctor et al., 2013). Implementation strategies refer to the methods or techniques used to enhance the uptake, implementation, and sustainability of an evidence-based intervention. It is desirable to think ahead to implementation strategies during the design and testing phases of novel self-care interventions. A single-component strategy may suffice in some situations, such as educational instruction to encourage uptake of an exercise rehabilitation intervention (Dobkin, 2016). A multifaceted strategy might be needed in other situations. For example, a combination of practice, coaching, feedback and role modeling may be needed to increase uptake of a self-care management COPD intervention (Bourbeau et al., 2004). A number of lists and taxonomies reflecting the range of imple-

| | | | |
|--------------------------|--------|--------------------------|-----------------|
| | | Intervention component A | |
| | | Both A + B | Only B |
| Intervention component B | Only A | | Neither A nor B |

Fig. 2. Factorial design.

mentation strategies have been published (Michie et al., 2013; Powell et al., 2012) and may be used as a guide for selection of the most appropriate strategy for the intervention under study.

Finally, it is essential to follow reporting guidelines and to describe interventions in sufficient detail to allow replication. The Template for Intervention Description and Replication (TIDieR) checklist was developed to improve completeness in reporting of interventions (Hoffmann et al., 2014). In addition, clear articulation within self-care research papers of intervention fidelity, the degree to which an intervention maintained its original form or is delivered as designed, is also crucial as loss of fidelity may alter the positive outcomes previously associated with an intervention (Carroll et al., 2007).

5. Research designs

5.1. Recommendation #7: employ a study design that fits the current phase and objectives of the research

Self-care research follows a flexible and nonlinear trajectory with studies addressing development, evaluation and implementation using a range of methods from case studies to clinical trials. Self-care interventions are often defined as complex interventions and can benefit from a mixed methods approach with the collection, analysis and integration of quantitative and qualitative data.

While many researchers might have been trained to assume that a randomized controlled trial (RCT) is the optimal (or even the only) approach to evaluate the effectiveness of an intervention, it is increasingly recognized that the conventional individually-randomised parallel group design may not be the best design to evaluate a complex intervention. There are many other study designs that might be more suitable for different questions and circumstances (Craig et al., 2008).

Limitations of the parallel group RCT in self-care research include the inability to handle interventions that manipulate more than one factor, which is often needed in complex self-care research. An alternative design in self-care research is the factorial design, which allows different components to be tested at the same time (Fig. 2). For example, with a factorial design one could test components of an intervention anticipated to support weight loss, using four groups where group education is tested alone or in combination with reinforcing text messages or text messages alone or no intervention.

The Sequential Multiple Assignment Randomized Trial (SMART) is a special type of factorial study design (also known as an Adaptive Design Clinical Trial). Such designs add a so called 'review-adapt loop' to the linear design-conduct-analysis sequence of a classical trial (Pallmann et al., 2018). Scheduled interim looks at the data are allowed while the trial is ongoing, and pre-specified changes to the trial's course can be made based on analyses of accumulating data, while maintaining the validity and integrity of the trial (Pallmann et al., 2018).

There are additional challenges in self-care research that might make a conventional individually-randomised parallel group design impossible or inappropriate. For example, if a self-care intervention is population-based or implies a change in health care services, it

is hard to avoid contamination of the control group. A cluster randomized trial design might be preferred under such circumstances. It might also be difficult to evaluate a self-care intervention when there is already some evidence of effectiveness and a very limited risk of the intervention being harmful. In such a case it might be practically and ethically difficult to do an experimental study. In such a case, the stepped wedge design can be used with the additional advantage that the first group randomized can serve as the pilot group (Fig. 3). This design is also useful in implementation studies (e.g. a self-care intervention has been found to be effective but there are challenges getting it implemented in a particular health care setting).

Patients might have strong preferences for or against certain self-care interventions. In these situations, using a traditional design where patients are randomized to control or intervention without considering preferences might cause severe attrition. One solution is to use a waitlist control group, giving the participants randomized to the control group the opportunity to receive the intervention after the study ends. Basing treatment allocation on patients' preferences might also be appropriate. For example, a design targeting a more person-centered approach is the preference-based design. In a preference clinical trial (PCT), two or more self-care interventions are compared and all or some proportion of the study participant have purposefully chosen which intervention they prefer to receive. A stronger preference-based design involves determining preferences prior to randomization and only stratifying randomization by preference.

The ultimate design for individualizing the self-care intervention may be an n-of-1 design. This design focuses solely on empirically determining an optimal intervention to improve self-care for the individual patient. An example of this type of design was an intervention where study patients and their physicians used a mobile device to select from eight options for pain treatment including combinations of treatment type and treatment durations. The mHealth app gave reminders to take designated treatments on assigned days and to upload responses to daily questions on pain and treatment-associated adverse effects (Kravitz et al., 2018). The distinction that defined this as research instead of clinical practice is the planned method of treatment administration and the intensity of data collection.

Finally, not to be forgotten is the rich source of information that can be derived from secondary analyses of existing data sources. The power of this approach highlights the importance of including valid measures of self-care in all studies that target areas within this scope of clinical science.

6. Measurement of self-care and related factors

6.1. Recommendation #8: measure self-care and related factors well

In most instances, investigators will need to measure self-care using multiple methods including self-report and objective measurement. Examples of purely objectively measured self-care reflect a small subset of behaviors such as medication adherence (Tan et al., 2019). Conversely, purely subjectively reported self-care behaviors may reflect an optimistic view of one's own behavior

| Site or team | Baseline | Period 1 | Period 2 | Period 3 | Period 4 | Period 5 | Period 6 | Period n |
|--------------|----------|----------|----------|----------|----------|----------|----------|----------|
| 1 | | | | | | | | |
| 2 | | | | | | | | |
| 3 | | | | | | | | |
| 4 | | | | | | | | |
| 5 | | | | | | | | |
| 6 | | | | | | | | |
| n | | | | | | | | |

Legend

| | |
|--|--------------------------|
| | Control /no intervention |
| | Intervention |

Fig. 3. Stepped wedge design.

Illustration of a stepped wedge randomized trial design: This design involves sequential roll-out of an intervention to participants (individuals or clusters) over a number of time periods. By the end of the study, all participants will have received the intervention, although the order in which participants receive the intervention is determined at random (Brown and Lilford, 2006).

and may be the joint product of both actual behaviors and social desirability (Colin-Ramirez et al., 2015; Cook et al., 2018). Valid and reliable measures must be used in both the objective and subjective measurement of self-care. Caution should be exercised when comparing objective and subjective measures of self-care across sub-populations including studies performed in different gender and cultural groups as well as different countries and across languages. Regarding objective measures of self-care behaviors, laboratory standards, units of measure and procedures for sample processing vary considerably across countries (Bonar and Favalaro, 2017; Ezzelle et al., 2008). Hence, it is important to consider both within and across study differences when comparing objective measures of self-care across studies.

In a related fashion, subjective reporting of self-care behaviors, even when collected using the same measure may not always reflect the same constructs across sub-populations. Systematic measurement error (differential item functioning) (Teresi, 2006) may lead investigators to conclude no difference when indeed there are significant differences in the construct; similarly, systematic measurement error may lead investigators to conclude there are differences when indeed there are no differences in the underlying construct (Carle, 2010; Teresi et al., 2016). Testing for measurement bias/measurement inequivalence using item response theory methods, multiple indicator multiple cause models (Teresi and Jones, 2016), or established measurement equivalence methods is essential before comparisons can be made across subpopulations (De

Maria et al., 2019). Accordingly, establishing measurement equivalence of self-report measures is a critical recommendation of this paper.

Finally, there are many methods of computer adaptive testing (Smith et al., 2019) and other item response theory-driven approaches (Nguyen et al., 2014; Petrillo et al., 2015) aimed at reducing the items necessary to capture effectively a construct of interest. As the science of self-care moves forward, these methods should be employed to minimize participant burden and finally do away with unnecessarily lengthy questionnaires. Although this section is focused on self-care itself, the sample principles of optimizing construct validity apply equally to both factors influencing self-care and outcomes of self-care.

Self-care is influenced by a variety of individual- and societal-level factors (Table 1) that are important to measure in self-care studies. We recommend using psychometrically sound instruments to measure these variables and consulting other studies to identify how others working in the same area are measuring these factors. This approach will facilitate comparison of your results with those of others. Individual factors include both demographical factors (e.g., age, gender), socio-economic factors (e.g., social support, income adequacy), disease related factors (e.g., disease severity, stage of the disease) and multimorbidity (e.g. cognition, other long-term conditions). Societal factors influencing self-care include the built environment and access to care. The manner in which houses, buildings, open spaces, streets and sidewalks are built in-

Table 1

Suggestion for variables to collect in self-care research with references to papers that described relationship with self-care.

| | References |
|---|--|
| Individual factors | |
| Age | (Zhang et al., 2020; Khezerloo et al., 2019; Sedlar et al., 2017) |
| Gender | (Zhang et al., 2020; Khezerloo et al., 2019; Sedlar et al., 2017; Association, 2020) |
| Cultural background/race/religion | (Association, 2020; Osokpo and Riegel, 2019) |
| Social support | (Kamp et al., 2019; Fivecoat et al., 2018) |
| Cognition | (Seong et al., 2019) |
| Disease severity /stage of disease | (Dong et al., 2018) |
| Signs and symptoms | (Riegel et al., 2019) |
| Knowledge, skill, motivation, experience | (Latter et al., 2016; Essery et al., 2017; Cocchieri et al., 2015) |
| Self-efficacy | (Dineen-Griffin et al., 2019) |
| Stressors | (Dineen-Griffin et al., 2019; Muller-Tasch et al., 2018) |
| Multimorbidity | (Mills et al., 2014) |
| Frailty | (Ferguson et al., 2017) |
| Societal factors | |
| Quality of the healthcare system, providers | (Meranius and Hammar, 2016; Huntink et al., 2015) |
| Built environment (neighborhood assessment) | (Botticello et al., 2019; Lee et al., 2018) |
| Access to resources and basic needs | (Botticello et al., 2019; Lee et al., 2018) |

fluences the ability of people to perform certain self-care activities, especially those who have compromised mobility (e.g., stroke survivors) (Hendriks et al., 2020). A study conducted on people with spinal cord injuries showed that individuals who live close to a park or in a neighborhood with more accessible destinations have better self-care (Botticello et al., 2019). Similar results were seen in people affected by other physical disabilities (Lee et al., 2018). Access to available resources is another factor that can work as a facilitator or a barrier to self-care (Franklin et al., 2019). In a recent concept analysis (Van de Velde et al., 2019), “using resources” was identified as an attribute of self-care. Resources may include libraries, consultations with providers, websites, community agencies etc.

Depending on the theoretical orientation used to guide the self-care study and the statistical procedures, all of the above factors related to self-care can be considered as simple determinants (or predictors) or as mediators or moderators of the self-care processes.

7. Concluding remarks

Self-care is inherently complex, requiring a comparable level of complexity in research design and implementation. Although most of the recommendations outlined above apply to any variety of research topics, we have tried to address some of the issues that we see in existing self-care research. If investigators worldwide attend to these eight core recommendations, we can make great strides in improving the self-care of individuals.

BOX 1. Eight methodological recommendations for advancing self-care research.

1. Define self-care carefully
2. Build self-care research studies on previous work
3. Use theory to develop self-care interventions
4. Development, evaluation and implementation of complex self-care interventions should be guided by a translational model
5. Describe the sample and setting sufficiently so others can draw conclusions about generalizability and applicability to their practice and patient population
6. Describe how the intervention is assumed to work (causal assumptions) and its key components
7. Employ a study design that fits the current phase and objectives of the research.
8. Measure self-care and related factors well

Conflicts of interest

None.

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