Generic self-reported questionnaires measuring self-management: a scoping review

Clinical Nursing Research

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Abstract

This study aimed to 1) identify generic questionnaires that measure self-management in people with chronic conditions, 2) describe their characteristics, 3) describe their development and theoretical foundations, and 4) identify categories of self-management strategies they assessed. This scoping review was based on the methodological framework developed by Arksey and O'Malley and completed by Levac et al. A thematic analysis was used to examine self-management strategies assessed by the questionnaires published between 1976 and 2019. A total of 21 articles on 10 generic, self-reported questionnaires were identified. The questionnaires were developed using various theoretical foundations. The Patient Assessment of Self-Management Tasks and Partners in Health scale questionnaires possessed characteristics that made them suitable for use in clinical and research settings and for evaluating all categories of self-management strategies. This study provides clinicians and researchers with an overview of generic, self-reported questionnaires and highlights some of their practical characteristics.

Keywords: Chronic condition, questionnaire, scoping review, self-management, self-reported.
Introduction

Chronic conditions (CCs) are the leading causes of mortality worldwide (World Health Organization [WHO], 2017). One of the six objectives set out by the WHO (2013) for the prevention and control of CCs is to improve primary care services by supporting the self-management of people with CCs. Self-management “is the intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of his chronic condition(s) in partnership with his social network and the healthcare provider(s)” (Van de Velde et al., 2019). Based on the literature, this ability falls into one of the following four self-management strategy categories: behavioral/medical, emotional, cognitive and social (Grady & Gough, 2014; Miller, Lasiter, Bartlett Ellis, & Buelow, 2015; Schulman-Green et al., 2012; Unger & Buelow, 2009).

Up to the 2010s, the concept of self-management was often interchanged with related concepts, particularly the “self-care” concept described in the earlier literature (Grady & Gough, 2014). The distinction between self-management and self-care was only made in the last decade by Jones et al. (2011), who proposed that self-management is related to the management of CCs, while self-care is related to health and encompasses accident and disease prevention. Self-management was identified as a subset of self-care (Richard & Shea, 2011).

Problem

Self-management support for people affected by CCs can contribute to an improved quality of life and have a positive impact on the use of health services (Panagioti et al., 2014). In clinical settings, healthcare providers, including nurses, provide self-
management support for people with CCs. Particularly in primary care, nurses could benefit from the use of questionnaires designed to document self-management in people with CCs, identify people who need self-management support, justify interventions and evaluate self-management intervention outcomes (Loretz, 2005). In this setting, nearly a quarter of patients have comorbidities (at least two CCs) (Luijks, Lagro-Janssen, & van Weel, 2016) and suffer from a wide range of CCs (Dain, 2018). Regardless of the type of CCs affecting them, sufferers face similar issues such as pain, fatigue, physical and mental health, and the deterioration of social functioning (Working group on health outcomes for older persons with multiple chronic conditions, 2012). It may thus be relevant for healthcare providers and researchers to use a generic questionnaire (Bryan et al., 2013) to get an overview of the practical self-management strategies used by people with CCs following self-management support interventions (Dineen-Griffin, Garcia-Cardenas, Williams, & Benrimoj, 2019). Another advantage of using a generic questionnaire is its usefulness in measuring self-management in a person with more than one CC (Rutherford et al., 2019). Some studies demonstrated no significant differences between generic questionnaires and those focusing on specific conditions (Garster, Palta, Sweitzer, Kaplan, & Fryback, 2009; Seow, Tan, Abdin, Chong, & Subramaniam, 2019). Given the large number of available questionnaires on self-management, it can be difficult to select one for clinical or research purposes.

Three literature reviews have been published on self-management/self-care questionnaires. The first review concerning the concept of self-care, conducted by Sidani in 2003 and revised in 2011, aimed to identify self-care questionnaires without examining their theoretical foundations. The second is a scoping review by Matarese, Lommi, and De Marinis (2017) on self-reported questionnaires used to assess self-care
in healthy adults (i.e., not for people with CCs). The third, by Packer et al. (2017), is a scoping review on self-management questionnaires administered to adults with one or more CCs. The review covered the questionnaires, their definitions of self-management, their theoretical foundations, the reasons for their development, their target populations, the number of items they included and their dimensions. While the reviews identified 28 to 42 questionnaires on self-care and self-management developed between 1979 and 2015 (Matarese et al., 2017; Packer et al., 2017; Sidani, 2011), they did not focus on generic questionnaires.

To date, none of the literature provides any exhaustive list of generic self-management questionnaires for adults with CCs and the reviews fail to consider the theoretical foundations supporting these questionnaires. Practical characteristics (i.e., short and short item) (Tsang, Royse, & Terkawi, 2017), theoretical foundations (Prinsen et al., 2016) and psychometric properties (i.e., Cronbach’s alpha demonstrating an acceptable level of reliability) (Morgado, Meireles, Neves, Amaral, & Ferreira, 2017) can be relevant criteria in identifying the most suitable questionnaires. Therefore, for clinical and research purposes, it is advisable to obtain an overview of the generic questionnaires used to assess self-management in people with CCs.

**Purpose of the study**

The purpose of this study was to answer to following questions: 1) Do any generic, self-reported questionnaires that measure self-management among patients with CCs currently exist? 2) What are the questionnaires’ characteristics (i.e., length, item length, target population, target setting [research, clinical, or both] and psychometric qualities)? 3) What are the developmental and theoretical foundations of the questionnaires? 4)
Which self-management strategy categories (behavioral/medical, cognitive/decision-making, emotional and social) were measured by the instruments identified in this scoping review?

Methods

A scoping review was conducted, as this type of review is considered a “preliminary assessment of potential size and scope of available research literature” (Grant & Booth, 2009). This method allows for research questions to be answered by assessing the nature and extent of the literature without taking into account the quality criteria used to design the studies (Levac et al., 2010). It seems appropriate, given that our purpose was to identify a wide range of generic questionnaires.

We used the methodological framework developed by Arksey and O’Malley (2005) and completed by Levac, Colquhoun and O’Brien (2010) to conduct a scoping review in five steps, i.e., 1) identifying the research questions, 2) identifying relevant studies, 3) selecting studies, 4) charting the data and 5) collating, summarizing, and reporting the results.

Identifying the research questions

Stemming from the need to identify generic questionnaires that can be used in clinical and research settings, our team, which included three clinician researchers, used an iterative process and demonstrated theoretical foundations to develop questions covering a wide range of self-management strategies.

Identifying relevant studies
We worked with an information specialist to develop a strategy for conducting an electronic search of the CINAHL, Embase and Medline databases for articles published between 1976 and 2019 in English or French. The strategy was developed around the main theme, self-management, and measure and related keywords were included in the search strategy to avoid missing any relevant questionnaires. Among other related concepts, self-efficacy (Richard & Shea, 2011) and patient activation (Hibbard, Mahoney, Stock, & Tusler, 2007) were excluded because they are considered an antecedent of self-management.

The following keywords and Boolean operators were used to find studies of interest in the databases:

CINAHL: AB ([measur* or tool* or questionnaire* or scale* or psychometr*] N6 ["self management" or "self-management" or “self-care” or “self care”]).

Embase: ([measure* or tool* or questionnaire* or scale* or psychometr*] adj6 [“self management” or “self-management” or “self-care” or “self care”]).ab.

Medline: AB ([measur* or tool* or questionnaire* or scale* or psychometr*] N6 ["self management" or “self-management” or “self-care” or “self care”]).

“AB” means that the strategy was limited to the abstract. “N6” OR “adj6” means that the concepts of self-management and measure must be within six words of one another. After several attempts, this proximity operator allowed us to identify the most relevant articles containing the targeted keywords in the same sentence and avoid noisy data (Elsevier, 2020). The asterisk means that the search includes all alternate endings after it. As previously explained, the term self-care was included during the literature search because the distinction between the two concepts (self-management and self-care) was only made about ten years ago (Jones et al., 2011; Richard & Shea, 2011).
Selecting studies – Sample

Once the duplicates were eliminated (1,946 articles), 2,309 articles were screened by title and abstract, based on the inclusion and exclusion criteria, so that one of the research team members could exclude any clearly non-eligible articles. In case of uncertainty, the full articles were retrieved and read by a second team member. To be included, papers had to 1) be in French or English, 2) describe the development and/or validation of a self-reported questionnaire; 3) be designed to specifically measure the self-management or self-care of CCs, 4) be a generic questionnaire (i.e., not designed to measure self-management of a specific condition such as diabetes) as identified by the authors of the original questionnaires, and 5) focus on an adult population (18 or older). Papers concerning a questionnaire on a specific CC were excluded. Two hundred and ninety-six articles were retained for detailed evaluation by two of the research team members.

The reference list for each included article was used to search for other relevant articles (hand search). At this stage, the research team attempted to find the identified articles among available databases. The research team also contacted the primary authors to obtain more information on articles that were unavailable, or to obtain the questionnaires not included in the articles. This follow-up resulted in the identification of eight additional articles, all of which were examined by two team members and added to the list of selected articles. Thus, 21 articles describing ten different questionnaires were included in this scoping review, as shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram in Figure 1 (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).
Two questionnaires on self-care, i.e., the Appraisal of Self-Care Agency Scale (ASAS) (Evers, 1989) and the Appraisal of Self-Care Agency Scale – Revised (ASAS-R) (Sousa et al., 2009), were included in this study because they measure psychometric properties among patients with CCs. They also contain items that measured self-management strategies corresponding to other questionnaires included in this review.

**Charting the data – Data collection**

Using an extraction grid, two review team members independently extracted the following information from the 21 articles: the name of the questionnaire and its abbreviation; authors; year of publication; language of publication; country of development; number of items in the original and revised versions; format for response options; Cronbach’s alpha of the original and revised versions; length; item length; target population; setting (research, clinical or both); psychometric properties described; development stages; theoretical referents upon which the questionnaire was based; underlying constructs; definition of self-management; and dimensions/domains. Conflicts were resolved by consensus. For this article, we used the author names, year of publication and country of development for each questionnaire that appeared in the first publication pertaining to it.

**Collating, summarizing, and reporting the results – Data analysis**

The characteristics of the questionnaires are shown in Tables 1 to 3. The data was analyzed using the narrative analysis method (Lucas, Baird, Arai, Law, & Roberts, 2007), which allows for transparent heterogeneity between questionnaires, as identified by Barnett-Page and Thomas (2009). Related studies (one to three per questionnaire)
were grouped by questionnaire name. The definitions of self-management and/or other constructs on which the questionnaires were based were reviewed and summarized by two of the scoping review team members.

A thematic analysis (Vaismoradi, Turunen, & Bondas, 2013) of all the items in each questionnaire was used to establish categories for the self-management strategies covered. The items were independently classified by two team members into one of the four strategy categories established by the analysis, i.e., behavioral/medical, cognitive/decision-making, emotional and social. These categories were based on Schulman-Green et al. (2012), Miller et al. (2015) and Unger and Buelow (2009), since in investigating the self-management concept, they identified strategies that people develop to manage their CCs. The categories are summarized as follows:

1. Behavioral/medical strategies: actions taken to manage the medical aspects of CCs (e.g., treatment adherence, monitoring/managing signs and symptoms) (Battersby, Ask, Reece, Markwick, & Collins, 2003; Sidani & Diane, 2014; Van Houtum, Rijken, Heijmans, & Groenewegen, 2014) and to adopt/maintain healthy behaviors or new roles (Battersby et al., 2003; Eikelenboom, van Lieshout, Wensing, Smeele, & Jacobs, 2013; Sidani & Diane, 2014; Sousa et al., 2009; Van Houtum et al., 2014).

2. Cognitive/decision-making strategies: intellectual processes used for decision-making or to develop self-management skills (Evers, 1989; Jones et al., 2011; Osborne, Elsworth, & Whitfield, 2006) and knowledge about CCs, medication and treatment (Battersby et al., 2003).

3. Emotional strategies: processes used to adapt to or cope with the psychological consequences of CCs (Battersby et al., 2003; Eikelenboom et al., 2013; Van
Houtum et al., 2014) by adopting a positive attitude (Osborne et al., 2006; Van Houtum et al., 2014);

4. Social strategies: processes used to adapt to or cope with the social consequences of CCs (Battersby et al., 2003; Eikelenboom et al., 2013; Van Houtum et al., 2014).

Items not corresponding to a self-management strategy were classified in a new category named *Not self-management strategy*. The team researchers then compared the results of the classification and discussed any differences of opinion or questions. Finally, the results were compiled into a summary of the self-management strategy categories.

**Findings**

This scoping review identified 21 articles on ten self-reported questionnaires measuring the self-management of people with a CC. Table 1 lists them in alphabetical order.

**Characteristics of self-management questionnaires**

In order of frequency, the countries of development were the Netherlands, the United States, Australia and Canada. The oldest questionnaire was the Self-Care Agency Questionnaire, also called the Perception of Self-Care Agency Questionnaire (PS-CAQ) (Hanson, 1981) and the one most recently developed was Patient Assessment of Self-Management Tasks (PAST) (Van Houtum et al., 2014). The questionnaires encompassed three to ten dimensions and all used Likert scales with four to nine response options. Table 2 highlights the characteristics of all ten questionnaires, i.e.:
they were short (fewer than 25 items), they contained simple items (fewer than 20 words per item) (Burns et al., 2008; Passmore, Dobbie, Parchman, & Tysinger, 2002; Vaske, 2008) and the target population was made up exclusively of adults with CCs. According to the authors of the original articles, they were suitable for clinical (n = 8) or research (n = 4) use and their psychometric qualities were described. The Self-Management Ability Scale – 30 (SMAS-30) and Self-Management Ability Scale – Shorter (SMAS-S) questionnaires were developed for people with CCs, with particular focus on the senior population (≥65 years) (Cramm, Strating, de Vreede, Steverink, & Nieboer, 2012; Schuurmans et al., 2005). The Cronbach’s alpha coefficients of the questionnaires varied between 0.56 and 0.96. No coefficient was reported for two of the questionnaires (Cramm et al., 2012; Van Houtum et al., 2014).

Development and theoretical foundations

Questionnaire development

The authors of each questionnaire conducted a literature review on self-management, developed the questionnaire and the items in accordance with the dimensions of their theoretical foundation, and then validated it. The authors of the Health Education Impact Questionnaire (heiQ) (Osborne et al., 2006) and the one on Self-Management Screening (SeMaS) (Eikelenboom et al., 2013) developed their own conceptual framework by consulting various experts (patients, health professionals, managers and policymakers) and conducting focus groups and individual interviews to specify the final dimensions. Half the authors (Battersby et al., 2003; Eikelenboom et al., 2013; Osborne et al., 2006; Schuurmans et al., 2005; Van Houtum et al., 2014)
developed their questionnaires by consulting people with CCs in a clinical setting or within the population.

**Theoretical foundations and conceptualization of self-management**

Appendix 1 provides the questionnaires’ theoretical foundations, including theoretical referents and their main constructs and definitions, as well as their dimensions or domains. The following seven theoretical referents were identified: Orem’s Self-care Deficit Theory of Nursing (Evers, 1989; Hanson, 1981; Sidani & Diane, 2014; Sousa et al., 2009); the Program Logic Model for Patient Education (Osborne et al., 2006); the Theory of Stress and Coping (Van Houtum et al., 2014); self-management activities (Van Houtum et al., 2014); the Flinders Model (Battersby et al., 2003); the Theory of Successful Self-Management of Aging based on the Theory of Social Production Functions (Cramm et al., 2012; Schuurmans et al., 2005); and clarification of the difference between the concepts of self-care behavior and self-care ability (Sidani & Diane, 2014). The authors of the SeMaS did not refer to any theoretical referent (Eikelenboom et al., 2013). The definitions of self-management provided by the authors of the questionnaires varied and were most often guided by the theoretical model used.

The main constructs measured varied between questionnaires. They could be grouped into one of two main categories: self-care agency or self-management (tasks, abilities or strategies). All questionnaires measuring self-care agency were based on Orem’s Self-Care Deficit Theory of Nursing. Self-care agency corresponds to a person’s ability or capacity to meet his or her “continuing requirements for care that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well-being” or to perform self-care activities. Self-
care agency can be considered an antecedent of self-management behaviors (Van de Velde et al., 2019). The dimensions identified by the authors of the questionnaires also varied and the names of some of them did not clearly represent what they were intended to measure (e.g., investment behavior or time ordering) (Cramm et al., 2012; Hanson, 1981; Schuurmans et al., 2005).

**Evaluation of the self-management strategies of people with CCs**

Most items could be classified into one of the four categories of self-management strategies (Table 3). Some items evaluated more than one strategy, e.g., “To maintain my hygiene, I adjust the frequency of bathing and showering to the circumstances” (Evers, 1989), to reflect behavioral/medical strategies and cognitive/decision-making strategies. The ASAS, ASAS-R, PS-CAQ, SMAS-30, SMAS-S and TSC did not evaluate emotional strategies. The ASAS-R was the only questionnaire that did not evaluate social strategies. The other elements evaluated were functional capacity (flexibility) and recreation (hobbies, activities). The ASAS, ASAS-R, PS-CAQ, PIH, SeMaS and Therapeutic Self-Care (TSC) included items that specifically measured decision-making strategies. The PS-CAQ, SMAS-30 and SMAS-S included items categorized as not being part of a self-management strategy, as they were not related to self-management. It included activities, hobbies, work and volunteering, e.g., “My joints are flexible” (Hanson, 1981), or “Others benefit from the things I do for my pleasure” (Cramm et al., 2012; Schuurmans et al., 2005).

**Discussion**
This literature review aimed to identify generic questionnaires on self-management in people with CCs, describe the questionnaires’ characteristics, development and theoretical foundations, and identify questionnaires designed to assess the four main self-management strategy categories.

For the first purpose, the review identified ten questionnaires. Other reviews on self-management highlighted four to six generic questionnaires addressing self-management for adults in various settings but not specific to people with CCs (Matarese et al., 2017; Packer et al., 2017; Sidani, 2011).

For the second purpose, two of the questionnaires—the PAST and PIH—had all the desired characteristics (i.e., contained fewer than 25 items and fewer than 20 words per item, were intended for adults with CCs, were suitable for use by healthcare providers and described psychometrics properties). According its authors, the PIH could also be used for research purposes. These questionnaires were developed in collaboration with experts or population representatives. The PIH Cronbach’s alpha coefficient (0.86) was consistent with recommendations (Morgado et al., 2017). However, some PAST dimensions’ coefficients were under 0.70.

The questionnaires identified for the third purpose were based on seven theoretical foundations. Packer et al. (2017) identified theoretical foundations for five of the eight generic self-management questionnaires. Similarly, the theoretical foundations underpinning the generic questionnaires identified by Packer et al. (2017) were varied. Our review revealed that Orem’s Self-Care Deficit Nursing Theory was most widely used as a theoretical referent, as demonstrated in Matarese et al. (2017). Our scoping review highlights the lack of consensus regarding the theoretical foundations of self-management.
For the last purpose, more than half the questionnaires did not evaluate all self-management strategy categories. Rather, the items they encompassed essentially measured behavioral/medical and cognitive/decision-making strategies. The heiQ, PAST, PIH and SeMaS were the only questionnaires to address emotional aspects (anxiety, depression and emotional well-being) and included all measured self-management strategies. What these four questionnaires had in common was that the authors involved patients in their development. Other questionnaires mainly measured behavioral/medical strategies and provided little information on emotional strategies. Van de Velde et al. (2019) previously reported that the literature on self-management provides more evidence on medical management and less on emotional. Packer et al. (2017) examined the strategies measured by some of the questionnaires using their taxonomy, which includes seven domains, based on a close examination of the items they contained. In our review, we also grouped questionnaire items into four self-management strategy categories based on a concept analysis (Miller et al., 2015; Unger & Buelow, 2009) and qualitative metasynthesis (Schulman-Green et al., 2012) of self-management in CCs, which shed light on a more practical point of view.

Theoretical implications

Our review found that there is still no solid theoretical foundation for the generic measurement of self-management. This is due to the fact that there is no consensus on the definition of self-management, despite the fact that numerous studies of this concept have been conducted. For example, self-management attributes differed significantly between the concept analyses by Van de Velde et al. (2019), Udlis (2011) and Miller et al. (2015). The theoretical foundations used to develop the questionnaires appear to be
varied and the lack of understanding of the difference between self-management and self-care (Grady & Gough, 2014) suggests that the self-management concept lacks maturity as it is still only partially developed (Morse, Hupcey, Penrod, & Mitcham, 2002) and requires further theoretical exploration. There is still a need for consensus on the definition of self-management and its theoretical foundation to support healthcare providers’ interventions and ensure that patients’ needs are met (Budhwani, Wodchis, Zimmermann, Moineddin, & Howell, 2019).

**Strengths and limitations**

This study was conducted using the rigorous method developed by Arksey and O’Malley (2005) and completed by Levac et a. (2010). A more thorough search of the reference lists and communication with the authors allowed us to identify more questionnaires, even though they were not all selected for the study. The study involves a few limitations such as access to information. Some authors referred to unpublished works. The original articles on the development of three of the questionnaires (Evers, 1989; Hanson, 1981; Sidani, 2003) were over 20 years old, making it more difficult to contact the authors. Although this scoping review does not cover all the psychometric properties of each questionnaire, it is possible to compare the questionnaires based on the construct evaluated, dimensions included, number of items, number of studies validated the questionnaires, or Cronbach’s alpha for internal consistency (Prinsen et al., 2016). In addition, some of the characteristics (i.e., generic questionnaire, target setting [research, clinical, or both]) were based on information from the original authors, who may not have included it in the original articles. In developing future questionnaires, it would be relevant to review the aspects measured by each item related to a self-
management theoretical foundation to ensure an overall assessment of self-management.

**Application**

This scoping review constitutes a brief overview of generic self-management questionnaires having practical and theoretical characteristics that make them suitable for use by healthcare providers and researchers their clinical practice. Identifying the questionnaires that can be used by healthcare providers could guide them in their choice. Certain characteristics may further inform the selection of a specific questionnaire. For example, using a questionnaire containing as few statements as possible would reduce the time required to administer it in a clinical context and longer items may not be suitable for populations with a low degree of literacy. Lastly, though most questionnaires are unidimensional, healthcare providers could identify which dimensions they need to develop for self-management support interventions based upon the subdimensions in the questionnaire.

**Conclusions**

The scoping review identified 10 generic, self-reported questionnaires for people with CCs. Most of the questionnaires evaluated behavioral\medical strategies for the self-management of CCs. The PAST and PIH questionnaires were found to have certain clinically advantageous characteristics and evaluated all self-management strategy categories.

According to the original authors, most of the selected questionnaires can be used by healthcare providers to measure the patients’ initial level of self-management and
thus, determine whether their self-management support interventions have had a beneficial impact. By using these questionnaires, healthcare providers obtain an overview of patients’ self-management support needs.

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Declaration of conflicts of interest

The authors declare that there is no conflict of interest.

Research ethics and informed consent

This article was not produced using human or animal subjects.

Supplemental material

Appendix 1. Theoretical foundations of the questionnaires

Author biographies

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NOTES

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References


Figure 1

PRISMA flowchart of the literature review process

Legend Fig 1. Abbreviations CINAHL: Cumulative Index to Nursing and Allied Health Literature; CC: Chronic condition.
<table>
<thead>
<tr>
<th>Name</th>
<th>Authors and year</th>
<th>Language</th>
<th>Country</th>
<th>Number of items in initial version (final version*)</th>
<th>Likert scale levels in initial version (final version*)</th>
<th>Cronbach’s alpha for questionnaire and range for dimensions</th>
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<tr>
<td><strong>Appraisal of Self-Care Agency Scale – Revised (ASAS–R)</strong></td>
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<td>Australia</td>
<td>42 (40)</td>
<td>6 (4)</td>
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<td><strong>Patient Assessment of Self-Management Tasks (PAST) questionnaire</strong></td>
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<td>19 (15)</td>
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<td>Language</td>
<td>Country</td>
<td>Number of items in initial version (final version*)</td>
<td>Likert scale levels in initial version (final version*)</td>
<td>Cronbach’s alpha for questionnaire and range for dimensions</td>
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<tr>
<td><em>Partners in Health (PIH) scale</em></td>
<td>Battersby, Ask, Reece, Markwick &amp; Collins, 2003</td>
<td>English</td>
<td>Australia</td>
<td>11 (12)</td>
<td>9 (9)</td>
<td>0.86</td>
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<tr>
<td></td>
<td>Petkov, Harvey, &amp; Battersby, 2010</td>
<td>English</td>
<td></td>
<td></td>
<td></td>
<td>0.85</td>
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<tr>
<td></td>
<td>Battersby, Harris, Smith, Reed, &amp; Woodman, 2015</td>
<td>English</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Smith, Harvey, Lawn, Harris &amp; Battersby, 2016</td>
<td>English</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Kephart, Packer, Audulv &amp; Warner, 2019</td>
<td>English</td>
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<td></td>
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<tr>
<td><em>Perception of/ Perceived Self-Care Agency Questionnaire (PS-CAQ)</em></td>
<td>Hanson, 1981</td>
<td>English</td>
<td>United States</td>
<td>120 (53)</td>
<td>5 (5)</td>
<td>0.96</td>
</tr>
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<td></td>
<td>0.68-0.84</td>
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<tr>
<td><em>Self-Management Ability Scale – 30 (SMAS-30)</em></td>
<td>Schuurmans, Steverink, Frieswijk, Buunk, Slaets &amp; Lindenberg, 2005</td>
<td>English</td>
<td>Netherlands</td>
<td>30</td>
<td>6</td>
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<td>0.67-0.83</td>
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<tr>
<td>Name</td>
<td>Authors and year</td>
<td>Language</td>
<td>Country</td>
<td>Number of items in initial version (final version*)</td>
<td>Likert scale levels in initial version (final version*)</td>
<td>Cronbach’s alpha for questionnaire and range for dimensions</td>
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<tr>
<td>Self-Management Ability Shorter-Scale (SMAS-S)</td>
<td>Cramm, Strating, De Vreede, Steverink &amp; Nieboer, 2012</td>
<td>English</td>
<td>Netherlands</td>
<td>18</td>
<td>6</td>
<td>N/A 0.69-0.77</td>
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<tr>
<td>Self-Management Screening (SeMaS) questionnaire</td>
<td>Eikelenboom, Van Lieshout, Wensing, Smeele &amp; Jacobs, 2013</td>
<td>Dutch</td>
<td>Netherlands</td>
<td>27 (27)</td>
<td>7 (4-5)</td>
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<td>Eikelenboom, Smeele, Faber, Jacobs, Verhulst, Lacroix &amp; Van Lieshout, 2015</td>
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<td>Eikelenboom, Van Lieshout, Jacobs, Verhulst, Lacroix, Van Halteren &amp; Wensing, 2016</td>
<td>Dutch</td>
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<tr>
<td>Therapeutic Self-Care (TSC) scale</td>
<td>Sidani &amp; Doran, 1999</td>
<td>English</td>
<td>Canada</td>
<td>13 (12)</td>
<td>5 (7)</td>
<td>0.89 0.62-0.85</td>
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<tr>
<td></td>
<td>Richard, 2016</td>
<td>English</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Questionnaire</td>
<td>Characteristic</td>
<td>Length: short &lt;25 items</td>
<td>Item length: simple items &lt;20 words</td>
<td>Intended exclusively for adults with CCs</td>
<td>Usable in clinical settings according to authors</td>
<td>Usable in research settings according to authors</td>
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<tr>
<td>ASAS (Evers, 1989)</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>ASAS-R (Sousa et al., 2009)</td>
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<td>X</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>heiQ (Osborne et al., 2006)</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>PAST (Van Houtum et al., 2014)</td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
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<td>X</td>
</tr>
<tr>
<td>PIH (Battersby, et al., 2003)</td>
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<td>X</td>
<td></td>
<td>X</td>
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<td>X</td>
</tr>
<tr>
<td>PS-CAQ (Hanson, 1981)</td>
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<td></td>
<td></td>
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<td>X</td>
</tr>
<tr>
<td>SMAS-30 (Schuurmans et al., 2005)</td>
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<td>SMAS-S (Cramm et al., 2012)</td>
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<tr>
<td>SeMaS (Eikelenboom et al., 2013)</td>
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<td>X</td>
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<tr>
<td>TSC (Sidani, 1999)</td>
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<td></td>
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</table>

Table 3.  

*Categories of self-management strategies evaluated by the items in the 10 questionnaires*

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Behavioral/medical strategies</th>
<th>Cognitive/decision-making strategies</th>
<th>Emotional strategies</th>
<th>Social strategies</th>
<th>Not self-management strategies (functional capacity, hobbies and activities)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASAS (Evers, 1989)</td>
<td>X</td>
<td>X</td>
<td></td>
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<td>X</td>
</tr>
<tr>
<td>ASAS-R (Sousa et al., 2009)</td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>heiQ (Osborne et al., 2006)</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>PAST (Van Houtum et al., 2014)</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>PIH (Battersby, et al., 2003)</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>PS-CAQ (Hanson, 1981)</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>SMAS-30 (Schuurmans et al., 2005)</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>SMAS-S (Cramm et al., 2012)</td>
<td>X</td>
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<td>X</td>
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<tr>
<td>SeMaS (Eikelenboom et al., 2013)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>TSC (Sidani, 1999)</td>
<td>X</td>
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</table>

### Appendix 1. Theoretical foundations of the questionnaires

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Theoretical referents</th>
<th>Main construct measured</th>
<th>Definition of self-management and/or main construct measured</th>
<th>Dimensions/domains (sub-domains/domains)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASA (Evers, 1989)</td>
<td>Orem's Self-Care Deficit Theory of Nursing</td>
<td>Self-care agency</td>
<td>Self-care agency: the complex acquired ability to meet one’s continuing requirements for care that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well-being. Self-care: the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being [38].</td>
<td>Unidimensional</td>
</tr>
<tr>
<td>ASAS-R (Sousa et al., 2009)</td>
<td>Orem’s Self-Care Deficit Theory of Nursing</td>
<td>Self-care agency</td>
<td>Self-care agency: an individual’s capability to perform self-care activities or health-promoting behaviours on their own behalf to maintain life, health and well-being and is developed during an individual’s lifespan.</td>
<td>Multidimensional (3)</td>
</tr>
<tr>
<td>heiQ (Osborne et al., 2006)</td>
<td>Program Logic Model</td>
<td>Proximal outcomes of self-management programs</td>
<td>Outcomes of self-management include a positive and active engagement in life, health-directed behavior, skill and technique acquisition, constructive attitudes and approaches, self-monitoring and insight, health services navigation, social integration and support, and emotional wellbeing.</td>
<td>Multidimensional (8)</td>
</tr>
<tr>
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<tr>
<td>Questionnaire</td>
<td>Theoretical referents</td>
<td>Main construct measured</td>
<td>Definition of self-management and/or main construct measured</td>
<td>Dimensions/domains (sub-domains/domains)</td>
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</table>
| **PAST** (Van Houtum et al., 2014) | Theory of Stress and Coping | Self-management tasks | Self-management involves not only the medical management of a condition but also maintaining, changing and creating new meaningful behaviors or life roles, and coping with the psychosocial consequences of chronic illness. | **Multidimensional (4)**  
• Medical management  
• Communication with healthcare providers  
• Coping with the consequences of the illness  
• Making lifestyle changes |
| **PIH** (Battersby, et al., 2003) | Flinders model [39] | Self-management | Self-management: involves the individual working in partnership with their carer(s) and health professionals so that (s)he can: 1) Know their condition and various treatment options; 2) Negotiate a plan of care; (i.e., care plan); 3) Engage in activities that protect and promote health; 4) Monitor and manage the symptoms and signs of the condition(s); 5) Manage the impact of the condition on physical functioning, emotions and interpersonal relationships (Lorig, 1993) (Battersby et al., 2003). | **Unidimensional (4)**  
• Knowledge  
• Treatment adherence  
• Recognizing and managing symptoms  
• Dealing with / managing side effects |
<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Theoretical referents</th>
<th>Main construct measured</th>
<th>Definition of self-management and/or main construct measured</th>
<th>Dimensions/domains (sub-dimensions/domains)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PS-CAQ</strong>&lt;br&gt; (<em>Hanson, 1981</em>)</td>
<td>Orem’s Self-Care Deficit Theory of Nursing</td>
<td>Self-care agency</td>
<td>Self-care agency: the power or capacity to perform actions toward the goal of self-care. Two operations were identified to specify how the power of self-care agency is to be directed: the estimative operation (determining what needs to be done) and the productive operation (doing what needs to be done) [40].</td>
<td><strong>Multidimensional (10)</strong>&lt;br&gt;- Attention and vigilance&lt;br&gt;- Controlled use of energy&lt;br&gt;- Control of body position&lt;br&gt;- Reasoning&lt;br&gt;- Motivation&lt;br&gt;- Decision making&lt;br&gt;- Knowledge-acquisition&lt;br&gt;- Repertoire skills&lt;br&gt;- Time ordering&lt;br&gt;- Integration</td>
</tr>
<tr>
<td><strong>SMAS-30</strong>&lt;br&gt; (<em>Schuurmans et al., 2005</em>)</td>
<td>Theory of Successful Self-Management of Aging based on the Theory of Social Production Functions (SPF)</td>
<td>Self-management ability</td>
<td>Self-management ability: the core behavioral and cognitive abilities which contribute to sustainable well-being in later life [41].</td>
<td><strong>Unidimensional (6)</strong>&lt;br&gt;- Multifunctionality of resources&lt;br&gt;- Variety in resources&lt;br&gt;- Positive frame of mind&lt;br&gt;- Investment behavior&lt;br&gt;- Self-efficacious&lt;br&gt;- Taking initiative</td>
</tr>
<tr>
<td><strong>SMAS-S</strong>&lt;br&gt; (<em>Cramm et al., 2012</em>)</td>
<td>Theory of Successful Self-Management of Aging based on the Theory of Social Production Functions (SPF)</td>
<td>Self-management ability</td>
<td>Self-management ability: capacities to realize and sustain physical and social well-being using external and internal resources.</td>
<td><strong>Unidimensional (6)</strong>&lt;br&gt;- Multifunctionality of resources&lt;br&gt;- Variety in resources&lt;br&gt;- Positive frame of mind&lt;br&gt;- Investment behavior&lt;br&gt;- Self-efficacious&lt;br&gt;- Taking initiative</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Theoretical referents</td>
<td>Main construct measured</td>
<td>Definition of self-management and/or main construct measured</td>
<td>Dimensions/domains (sub-dimensions/domains)</td>
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<td>----------------------------------------------</td>
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<tr>
<td><strong>SeMaS (Eikelenboom et al., 2013)</strong></td>
<td>None stated</td>
<td>Self-management</td>
<td>Self-management: the care taken by individuals towards their own health and well-being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents. Following this definition, self-management also means that the patient takes more responsibility for his or her own health.</td>
<td><strong>Multidimensional (6)</strong></td>
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<tr>
<td></td>
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<td></td>
<td>Perceived burden of disease</td>
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<td>Locus of control</td>
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<td>Self-efficacy</td>
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<td>Social support</td>
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<td></td>
<td>Coping</td>
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<td></td>
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<td></td>
<td></td>
<td>Anxiety/depression</td>
</tr>
<tr>
<td><strong>TSC (Sidani, 1999)</strong></td>
<td>Concept clarification between self-care behavior and self-care ability</td>
<td>Self-care ability</td>
<td>Self-care behaviour refers to the actual performance of activities for the purpose of maintaining healthy functioning and treatment recommendations for managing an illness or disease. Self-care ability reflects the capacity to engage in self-care behaviour.</td>
<td><strong>Unidimensional (4)</strong></td>
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<tr>
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<td></td>
<td>Taking medication</td>
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<td>Recognizing and managing symptoms</td>
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<td></td>
<td></td>
<td>Carrying out activities of daily living</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Managing changes in condition</td>
</tr>
</tbody>
</table>