BMJ Open

Characteristics of self-management among patients with complex health needs: a thematic analysis review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-028344
Article Type:	Research
Date Submitted by the Author:	03-Dec-2018
Complete List of Authors:	Gobeil-Lavoie, Annie-Pier; Universite du Quebec a Chicoutimi, Chouinard, Maud-Christine; Universite du Quebec a Chicoutimi departement des science de la sante Danish, Alya; Université de sherbrooke, Département of family medecine and emergency medicine Hudon, Catherine; Université de Sherbrooke, Department of family medicine and emergency medicine
Keywords:	self-management, chronic diseases, complexity, multimorbidity, thematic analysis, vulnerability

Characteristics of self-management among patients with complex health needs: a thematic analysis review

Annie-Pier Gobeil-Lavoie*, RN, MSc(c)[1]

Maud-Christine Chouinard, RN, PhD[1]

Alya Danish, PhD[2]

Catherine Hudon MD, PhD[23]

[1]Département des sciences de la santé, Université du Québec à Chicoutimi, 555 Boulevard de l'Université, Chicoutimi, Québec, Canada, G7H 2B1

[2]Faculté de médecine et des sciences de la santé, Université de Sherbrooke, 3001 12e Avenue Nord, Sherbrooke, Québec, Canada, J1K 3C6

[3]Département de médecine de famille et de médecine d'urgence, Université de Sherbrooke, 3001 12e Avenue Nord, Sherbrooke, Québec, Canada, J1K 3C6

E-mail addresses:

Annie-Pier Gobeil-Lavoie - annie-pier.gobeil-lavoie@usherbrooke.ca

Maud-Christine Chouinard - maud-christine_chouinard@uqac.ca

Alya Danish - alya.danish@usherbrooke.ca

Catherine Hudon* - catherine.hudon@usherbrooke.ca

*** Corresponding author:**

Annie-Pier Gobeil-Lavoie

Département des sciences de la santé, Université du Québec à Chicoutimi,

555 Boulevard de l'Université, Chicoutimi, Québec, Canada, G7H 2B1

Telephone: 418-541-1234 poste: 3233

Fax: 819-564-5386

Email: - annie-pier.gobeil-lavoie@usherbrooke.ca

ABSTRACT

Objective The management of a complex health issue may lead to important self-management challenges. There is a gap of knowledge among healthcare providers on the ways to offer self-management support to patients with complex needs. Consequently, the objective of this paper was to identify characteristics of self-management among patients with chronic diseases and complex healthcare needs.

Design Thematic analysis review of the literature

Methods We developed search strategies for the Medline and CINAHL databases, covering the January 2000-October 2018 period. All articles in English or French addressing self-management among an adult clientele (18 years and older) with complex healthcare needs (multimorbidity, vulnerability, complexity, frequent use of health services), were included. Studies that addressed self-management of a single disease, or that did not have any notion of complexity or vulnerability were excluded. A thematic analysis was performed on the results of all articles by three evaluators as described by Miles, Huberman & Saldana.

Results Twenty-one articles were included. Patients with complex healthcare needs present specific features related to self-management that can be exacerbated by deprived socioeconomic conditions. These patients must often prioritize care based on one dominant condition. They are more at risk for depression, psychological distress and

low self-efficacy, as well as for receiving contradictory information from healthcare providers. On the other hand, the knowledge and experiences acquired in the past in relation to their condition may help them improve their self-management skills.

Conclusions This review identifies challenges to self-management for patients with complex healthcare needs, which are exacerbated in contexts of socio-economic insecurity, and proposes strategies to help healthcare providers better adapt their self-management support interventions to meet the specific needs of this vulnerable clientele.

Strengths and limitations of this study

- This review sheds light on the challenges of self-management faced by a great majority of patients.
- A limitation of any review is the potential omission of relevant articles as well as any unpublished material.
- The emergent themes were represented across the included studies, supporting the validity of the findings

INTRODUCTION

A great majority of patients who consult the healthcare system worldwide present one or more chronic diseases [1]. Responsible for 63% of deaths, chronic diseases represent the first cause of mortality in the world [2]. Characterized by periods of stability and deteriorations, the health condition of people with chronic diseases requires constant attention by the persons who are affected, as well as by those who surround them, in order to manage symptoms and consequences. Persons living with chronic diseases must develop self-management skills.

Self-management has been defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" and "developing the skills needed to devise, implement, evaluate, and revise an individualized plan for lifestyle change" [3]. Self-management incorporates an array of skills that a person must possess in order to take charge of his or her health. Lorig and Holman [4] developed a theoretical model for self-management involving three self-management tasks: medical management, emotional management and role management. According to this model, self-management requires six self-management skills in the patient: decision-making, action-planning, development of a patient–provider partnership, self-tailoring, resource utilization, and problem solving.

To date, self-management has mainly been studied in the context of a specific chronic disease, even though the management of a more complex health issue may lead to important self-management challenges [5 6]. Therefore, there is a gap in knowledge on the

ways to offer self-management support to patients with complex needs [7]. Providers constantly work with this clientele whether it be in hospitals, emergency services, medical clinics, in homecare, etc. Thus, they play an important role in self-management support [8]. However, the scarcity of knowledge on the specifics of self-management among these complex patients can be detrimental to healthcare providers' capacity to adequately support and accompany such patients in the self-management of their chronic conditions. Consequently, it is important to increase our understanding of the characteristics of self-management for this clientele, for whom the current norm for care in regards to the management of a single disease may not be appropriate[1].

The aim of this paper was to review the literature to identify the characteristics of self-management among patients with chronic diseases and complex healthcare needs.

METHODS

Design

A review of the literature including quantitative, qualitative and mixed studies was conducted on papers addressing the self-management of persons with complex healthcare needs. We were inspired by the thematic analysis published in 2012 by Hudon et al. [9].

Search methods

We conducted an electronic literature search in the Medline and CINAHL databases, for articles in English and in French published between January 2000 and October 2018.

An information specialist developed and ran the specific search strategies for each database. The following MeSH terms and keywords were used: self-care OR self-management OR self-monitoring AND multimorbidity OR comorbidity OR vulnerability OR complex* OR multiple chronic diseases OR multiple chronic conditions OR frequent users OR high users. We also examined articles found in the reference lists of collected articles (hand search).

Data collection

All search results were transferred to the Endnote X7 reference software and duplicates were eliminated. Articles retained had to respect the following criteria: (1) refer to self-management, (2) among a clientele with complex healthcare needs (multimorbidity, vulnerability, complexity, frequent use of health services), and (3) in a population of patients eighteen years and older. One team member (APGL) read all titles and abstracts to exclude articles that were clearly not eligible. We excluded references that did not meet our inclusion criteria and retained all other references for complete evaluation. Two reviewers (APGL and CH or APGL and MCC) independently appraised the full text of the retained papers to identify potentially eligible articles. Discrepancies between the two reviewers regarding the inclusion or exclusion of papers were resolved by the third evaluator.

Analysis and synthesis

A three-stage review and thematic analysis of qualitative, quantitative and mixed-methods similar to Hudon et al. 2012 was undertaken. First, the literature was reviewed and all selected articles were imported into the NVivo 11 qualitative analysis software.

Second, analysis was performed on the results of the articles by three evaluators as described by Miles, Huberman & Saldana [10] with the Lorig and Holman model (six self-management skills and three self-management tasks) as a guide [4]. Excerpts were extracted from each of the reviewed articles and classified according to the self-management skills and tasks particular to patients with complex care needs. Third, a second reading of the collected excerpts and familiarization with the data allowed for the identification of emergent themes. Pair debriefing, and team validation minimized the influence of researcher subjectivity and preconceptions [11]. This was an iterative process where interpretations of the data extracted from the articles were validated, and where disagreements or questions were discussed and resolved by consensus among the three evaluators.

RESULTS

Included studies

Figure 1 shows the number of references found at each stage of the selection process. The search strategies identified 1192 references, of which 980 were kept after removing duplicates. The majority of these references were rejected because they addressed the self-management of a single disease and did not contain any notion of complexity. References found through hand searching (n = 3) were also included, for a total of 60 potentially eligible references. Sixty papers were read completely. Of these, 38 articles were excluded after the full reading step: 15 did not contain any notion of complexity in the studied population; 11 did not address self-management; 9 did not address the challenges of self-management; 1 was an editorial and 2 articles were on the validation of a measuring tool. A final sample of 22 articles was retained. Table 1 presents the characteristics of the included articles.

Characteristics of self-management by patients with complex health needs

Five main themes emerged that describe the distinctive features of self-management in these patients.

Need for prioritization of self-care

Prioritization of self-care is an important self-management challenge for patients with multiple chronic diseases. When the number of self-care activities or tasks to accomplish surpasses the amount of time available, patients will establish a daily plan around the management of their chronic conditions[12], and must inevitably determine which self-care activities to prioritize. Patients with multimorbidity prioritize self-care activities based on the identification of one dominant condition [13].

Three types of conditions are more frequently identified as a dominant condition: a poorly controlled condition that tends to cause important exacerbations or negatively affect the control of other conditions, a condition that cannot be controlled solely by medication, or an unstable condition for which it is impossible to anticipate daily self-management needs. The patient is more likely to adopt a self-management strategy if he or she thinks that it will benefit more than one condition [6 14 15].

Lack of motivation and greater risk for depression

Patients with complex needs may experience less energy, and lack time and motivation to take part in self-management activities [16 17]. They report feelings of sadness, anger and anxiety related to their illness[12]. They are more at risk for depression [17]. The

emotional impact of disease can play an important role in decision-making. A depressive state may give patients the impression that they will never be capable of participating in self-management activities [13 18]. Even when patients are committed to adopting healthier lifestyle habits, they admit that depression could delay them from taking action [16 17 19]. If they focus on their inability to control a situation, patients tend to ruminate on the negative aspects of their health status and sink into emotional distress which prevents them from taking appropriate action when faced with a problem [15].

Increased risk of presenting poor self-efficacy

Self-efficacy is an important mediator of taking action. People's beliefs about their own self-efficacy reflect "their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" and determine how they "feel, think and motivate themselves and behave" [20]. Patients presenting numerous comorbidities are more at risk of presenting poor self-efficacy [19]. A person with low self-efficacy may experience difficulty in taking action to change lifestyle habits or in preventing the exacerbation of symptoms, leading to frequent hospital visits [21].

Patients living in situations of poverty often perceive that their poor health status is the norm, which greatly limits their motivation to improve their health [16]. Patients with multimorbidity living in underprivileged neighborhoods have lower expectations in regard to health and aging than patients from privileged neighborhoods [16].

Increased risk of receiving conflicting information

Patients with complex care needs are more at risk of receiving conflicting information on the management of their diseases by the numerous health professionals that they meet [6 18 22]. This can lead to increased anxiety and decreased self-management capacity [14].

A personalized evaluation of learning capacity, behavior change and the desire to commit to self-management, as well as regular monitoring, facilitates patient self-management. Initiating too many changes at one time may overload the patient and his or her self-management capacity [1 22]. Treatment goals should be selected based on patient motivation and willingness to change [23].

Opportunity to use personal experience

Complex healthcare needs do not necessarily require a new set of practices for each new diagnosis. Patients with complex care needs can use the knowledge and personal experience acquired in the past and apply them in various situations to better manage their health [18 22]. However, economic hardship reduces structural and emotional capacity, which may often prevent people living in economically precarious areas from adopting self-management behaviors that have synergistic effects on many of their health issues [16].

DISCUSSION

This thematic analysis synthetized the theoretical and empirical literature on the characteristics of self-management of patients with complex healthcare needs. This clientele presents additional self-management challenges in regard to: the prioritization

of self-care, a greater risk for depression or psychological distress, a greater risk of poor self-efficacy and the risk of receiving conflicting information from healthcare professionals. However, they can rely on their knowledge and previous experience gained in other situations.

Liddy et al. (2014) conducted a literature review aiming to explore barriers to self-management through the perspective of patients living with multiple chronic conditions. Of the 21 articles used in our thematic analysis, seven of them were also included in their review. Common themes emerged from both studies, such as contradictory information and high risk for depression. Our analysis also highlights other particularities such as poor self-efficacy, often observed in this clientele, and the fact that patients frequently rely on past experience to adequately take charge of their health.

One of the main challenges of self-management is the prioritization of self-care. Patients with numerous chronic diseases are constantly confronted with having to make choices amongst the care activities to prioritize. Most will identify a dominant disorder on which to focus their efforts [13]. In certain situations, the characteristics of a condition are in conflict with the management of others and the successful management of a condition can hinder the taking in hand of another [24]. Patients will more easily accept to engage in self-care activities that they consider beneficial to more than one of their conditions [6 14 15]. Social issues and economic situations will influence how patients prioritize self-care [25]. The healthcare provider can explore the reasons that guide this prioritization for a given patient. Interventions may have a greater impact if the healthcare provider takes

time to explain the benefits of self-management behaviours for the different conditions facing the patient.

Depression and emotional distress may impair self-management by decreasing motivation, prioritization skills and problem-solving. Negative emotions may also decrease self-confidence and self-efficacy [26] and distress is often present in this vulnerable clientele [27 28]. Healthcare providers must remain vigilant during their self-management support activities with this clientele, for the quick detection of psychological distress and the treatment of mental health issues.

Patients with complex care needs reported receiving conflicting information from the health professionals they consulted. Between 25% and 80% of patients received contradictory information on their diseases and their management [29]. Receiving conflicting information from two sources that the person trusts can complicate self-management [29]. In order to help these patients as much as possible, it is important that healthcare providers offer a personalized evaluation of their needs, as well as proper follow-up, and ensure good coordination between their various health professionals [23]. Healthcare providers can ensure coordination of the information provided by various health professionals involved in the patient's follow-up.

Although the majority of studies report that complexity is an additional challenge to self-management, the coexistence of many chronic conditions can also become an opportunity to call on past learning experiences [30]. The healthcare provider can help the

patient become aware of the knowledge and skills gained in the past as well as positive experiences.

Limitations

Our study presents some limitations. There is a lack of consensus in the literature regarding the definition of patients with complex needs. We ensured that the selection criteria developed for this study were broad enough to include a range of definitions for complexity. A limitation of any review is the potential omission of relevant articles as well as any unpublished material. However, all necessary measures were taken to ensure an exhaustive document review: our search strategy was adapted to various databases and was developed in collaboration with an information specialist. Furthermore, we identified additional papers by hand search.

CONCLUSIONS

Patients with complex healthcare needs are confronted with extra challenges with self-management, these being exacerbated in the presence of socioeconomic insecurity. These patients must often prioritize self-care according to one dominant condition. They are more at risk for depression, psychological distress and low self-efficacy, as well as for receiving contradictory information from healthcare providers. On the other hand, their previous experiences may help them improve their self-management skills. Future studies could empirically validate the results of this research and contribute to the understanding of the experience of these patients. Healthcare providers can learn from these results to better adapt their self-management support interventions to meet the specific needs of this vulnerable clientele.

DECLARATIONS

Acknowledgements

The authors would like to thank Ms. Janie Boudreault an information specialist at Université du Québec à Chicoutimi for her help in the development and running of specific search strategies for each database and Ms. Susie Bernier for her contribution to the translation of the article to English.

Authors' contributions

APGL found the articles, analyzed, interpreted the data and drafted the manuscript under the supervision of MCC and CH. MCC and CH co-analyzed and interpreted the data. All authors approved and read the manuscript.

Competing interests

The authors declare that they have no competing interests.

Patient consent

None.

Provenance and peer-review

Not commissioned; externally peer review

Funding

This research did not receive any specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

REFERENCES

1. Bayliss EA, Bosworth HB, Noel PH, et al. Supporting self-management for patients with complex medical needs: recommendations of a working group. *Chronic Illness* 2007;3(2):167-75. doi: 10.1177/1742395307081501 [published Online First: 2007/12/18]
2. World Health Organization. Maladies Chroniques 2017 [Available from: http://www.who.int/topics/chronic_diseases/fr/.
3. Orem DE. Nursing: Concepts of practice. St. Louis, MO: Mosby-Year Book Inc. 1991.
4. Lorig KR, Holman HR. Self-Management Education: History, Definition, Outcomes, and Mechanisms. . *Annals of Behavioral Medecine* 2003;26(1):1-7.
5. Bardach SH, Tarasenko YN, Schoenberg NE. The role of social support in multiple morbidity: self-management among rural residents. *Journal of Health Care for the Poor and Underserved* 2011;22(3):756-71. doi: 10.1353/hpu.2011.0083 [published Online First: 2011/08/16]
6. Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. *Annals of Family Medecin* 2007;5(5):395-402. doi: 10.1370/afm.722 [published Online First: 2007/09/26]
7. Sevick MA, Trauth JM, Ling BS, et al. Patients with Complex Chronic Diseases: perspectives on supporting self-management. *Journal Of General Internal Medicine* 2007;22 Suppl 3:438-44.
8. Registered Nurses' Association of Ontario. Stratégies permettant de soutenir l'autogestion des états chroniques : la collaboration avec les clients Toronto, Canada2010.
9. Hudon C FM, Haggerty JL, Loignon C, Lambert M, Poitras ME. Patient-centered care in chronic disease management: a thematic analysis of the literature in family medicine. *Patient education and counseling* 2012;88(2):170-76.
10. Miles MB, Huberman MA, Santana J. Qualitative data analysis : A Method Sourcebook. . London: Sage 2014.
11. Creswell JW. Quantitative inquiry & research design: choosing among five approaches. Thousand Oaks: Sage 2006.
12. Restorick RA, Betts AK, Beckette WC. Effects of chronic illness on daily life and barriers to self-care for older women: A mixed-methods exploration. *Journal of Women & Aging* 2017;29(2):126-36. doi: 10.1080/08952841.2015.1080539
13. Bratzke LC, Muehrer RJ, Kehl KA, et al. Self-management priority setting and decision-making in adults with multimorbidity: a narrative review of literature. *International Journa of Nursing Study* 2015;52(3):744-55. doi: 10.1016/j.ijnurstu.2014.10.010 [published Online First: 2014/12/04]
14. Bower P, Hann M, Rick J, et al. Multimorbidity and delivery of care for long-term conditions in the English National Health Service: baseline data from a cohort study. *Journal of Health Services Research and Policy* 2013;18(2 Suppl):29-37. doi: 10.1177/1355819613492148 [published Online First: 2013/10/23]
15. Leach CR, Schoenberg NE. Striving for control: cognitive, self-care, and faith strategies employed by vulnerable black and white older adults with multiple chronic conditions. *Journal Cross- Cultural Gerontology* 2008;23(4):377-99. doi: 10.1007/s10823-008-9086-2 [published Online First: 2008/11/07]

16. Coventry PA, Fisher L, Kenning C, et al. Capacity, responsibility, and motivation: a critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity. *BMC Health Services Research* 2014;14:536. doi: 10.1186/s12913-014-0536-y [published Online First: 2014/11/05]
17. Hill N, Joubert L, Epstein I. Encouraging self-management in chronically ill patients with co-morbid symptoms of depression and anxiety: an emergency department study and response. *Social work in health care* 2013;52(2-3):207-21. doi: 10.1080/00981389.2012.737900 [published Online First: 2013/03/26]
18. Morris RL, Sanders C, Kennedy AP, et al. Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. *Chronic Illness* 2011;7(2):147-61. doi: 10.1177/1742395310393365 [published Online First: 2011/02/24]
19. Harrison M, Reeves D, Harkness E, et al. A secondary analysis of the moderating effects of depression and multimorbidity on the effectiveness of a chronic disease self-management programme. *Patient education and counseling* 2012;87(1):67-73. doi: 10.1016/j.pec.2011.06.007 [published Online First: 2011/07/20]
20. Bandura A. Self-efficacy. In V. S. Ramachaudran : Encyclopedia of human behavior. New York: Academic Press 1994.
21. Gallagher R, Donoghue J, Chenoweth L, et al. Self-management in older patients with chronic illness. *International Journal of Nursing Practice* 2008;14(5):373-82.
22. Liddy C, Blazkho V, Mill K. Challenges of self-management when living with multiple chronic conditions: systematic review of the qualitative literature. *Canadian Family Physician* 2014;60(12):1123-33.
23. Noel PH, Parchman ML, Williams JW, Jr., et al. The challenges of multimorbidity from the patient perspective. *Journal of general internal medicine* 2007;22 Suppl 3:419-24. doi: 10.1007/s11606-007-0308-z [published Online First: 2007/12/06]
24. Sharry JM, Bishop FL, Moss-Morris R, et al. The chicken and egg thing': Cognitive representations and self-management of multimorbidity in people with diabetes and depression. *Psychology & Health* 2013;28(1):103-19. doi: http://dx.doi.org/10.1080/08870446.2012.716438
25. Bosworth HB, Powers BJ, Oddone EZ. Patient Self-Management Support: Novel Strategies in Hypertension and Heart Disease. *Clinical Cardiology* 2010;28(4):655-63.
26. Lin MT, Burgess Jr JF, Carey K. The association between serious psychological distress and emergency department utilization among young adults in the USA. *Social Psychiatry and Psychiatric Epidemiology* 2012;47:939-47. doi: 10.1007/s00127-011-0401-9
27. Dinkel A, Schneider A, Schmutzer G, et al. Family physician–patient relationship and frequent attendance of primary and specialist health care: Results from a German population-based cohort study. *Patient education and counseling* 2016;99(7):1213-19.
28. Fortin M, Bravo G, Hudon C, et al. Psychological distress and multimorbidity in primary care. *Annals of Family Medecine* 2006;4(5):417-22.

29. Elstad E, Carpenter DM, Devellis RF, et al. Patient decision making in the face of conflicting medication information. *International Journal of Qualitative Studies on Health and Well-being* 2012;7(1):1-12.

30. Vellone E, Riegel B, D'Agostino F, et al. Structural equation model testing the situation - specific theory of heart failure self - care. *Journal of Advanced Nursing* 2013;69(11):30-34.

Table 1. Characteristics of the articles included (n = 22)

	Number of articles
Type of publication/study design	
Qualitative studies (Bayliss, Ellis, & Steiner, 2007; Clarke & Bennett, 2013; Coventry, Fisher, Kenning, Bee, & Bower, 2014; Eton et al., 2015; Morris, Sanders, Kennedy, & Rogers, 2011; Restorick, Betts, & Beckette, 2017; Roberto, Gigliotti, & Husser, 2005; Sevick et al., 2007)	8
Quantitative studies (Bower et al., 2013; Gallagher, Donoghue, Chenoweth, & Stein-Parbury, 2008; Harrison et al., 2012; Hill, Joubert, & Epstein, 2013; Islam, McRae, Yen, Jowsey, & Valderas, 2015; Noel et al., 2007)	6
Mixed methods (Bardach, Tarasenko, & Schoenberg, 2011; Leach & Schoenberg, 2008)	2
Recommendations of a working group (Bayliss, Bosworth, et al., 2007)	1
Reviews (Bratzke et al., 2015; Dorsey & Murdaugh, 2003; Hujala, Rijken, Laulainen, Taskinen, & Rissanen, 2014; Liddy, Blazkho, & Mill, 2014; Novak, Costantini, Schneider, & Beanlands, 2013)	5
Principal authors location	
United States (Bardach et al., 2011; Bayliss, Bosworth, et al., 2007; Bayliss, Ellis, et al., 2007; Bratzke et al., 2015; Dorsey & Murdaugh, 2003; Eton et al., 2015; Hill et al., 2013; Leach & Schoenberg, 2008; Noel et al., 2007; Restorick et al., 2017; Roberto et al., 2005; Sevick et al., 2007)	12
United Kingdom (Bower et al., 2013; Coventry et al., 2014; Harrison et al., 2012; Morris et al., 2011)	4
Canada (Clarke & Bennett, 2013; Liddy et al., 2014; Novak et al., 2013)	3
Australia (Gallagher et al., 2008; Islam et al., 2015)	2
Finland (Hujala et al., 2014)	1
Complexity referred to in the article	
Multimorbidity (Bower et al., 2013; Bratzke et al., 2015; Coventry et al., 2014; Harrison et al., 2012; Hujala et al., 2014; Islam et al., 2015; Liddy et al., 2014; Morris et al., 2011; Noel et al., 2007; Restorick et al., 2017)	10
Vulnerability (Bardach et al., 2011; Clarke & Bennett, 2013; Dorsey & Murdaugh, 2003; Gallagher et al., 2008; Leach & Schoenberg, 2008; Roberto et al., 2005)	6
Complexity (Bayliss, Bosworth, et al., 2007; Bayliss, Ellis, et al., 2007; Eton et al., 2015; Hill et al., 2013; Novak et al., 2013; Restorick et al., 2017; Sevick et al., 2007)	7
Frequent users (Bower et al., 2013; Gallagher et al., 2008; Hill et al., 2013; Noel et al., 2007)	4

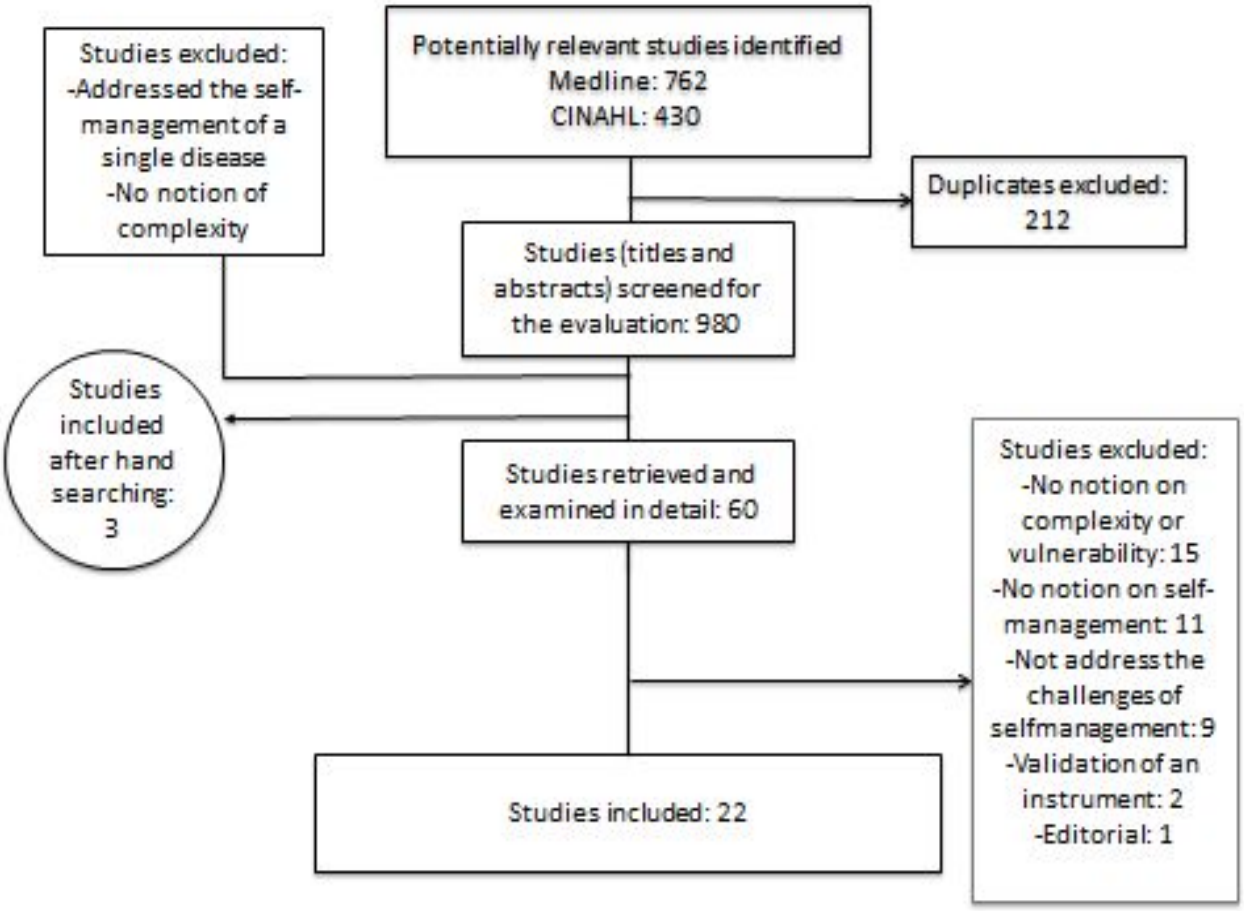


Figure 1. Number of references identified throughout the stages of the thematic analysis

BMJ Open

Characteristics of self-management among patients with complex health needs: a thematic analysis review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2018-028344.R1
Article Type:	Research
Date Submitted by the Author:	23-Apr-2019
Complete List of Authors:	Gobeil-Lavoie, Annie-Pier; Universite du Quebec a Chicoutimi, Chouinard, Maud-Christine; Universite du Quebec a Chicoutimi departement des science de la sante Danish, Alya; Université de sherbrooke, Département of family medecine and emergency medicine Hudon, Catherine; Université de Sherbrooke, Department of family medicine and emergency medicine
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	General practice / Family practice, Nursing
Keywords:	self-management, chronic diseases, complexity, multimorbidity, thematic analysis, vulnerability

Characteristics of self-management among patients with complex health needs: a thematic analysis review

Annie-Pier Gobeil-Lavoie, RN, MSc(c)[1]

Maud-Christine Chouinard, RN, PhD[1]

Alya Danish, PhD[2]

Catherine Hudon* MD, PhD[23]

[1]Département des sciences de la santé, Université du Québec à Chicoutimi, 555 Boulevard de l'Université, Chicoutimi, Québec, Canada, G7H 2B1

[2] Département de médecine de famille et de médecine d'urgence, Université de Sherbrooke, 3001 12e Avenue Nord, Sherbrooke, Québec, Canada, J1H 5N4

[3]Centre de recherche du CHUS, 3001 12e Avenue Nord, porte 6, Sherbrooke, Québec, Canada, J1H 5N4

E-mail addresses:

Annie-Pier Gobeil-Lavoie - annie-pier.gobeil-lavoie@usherbrooke.ca

Maud-Christine Chouinard - maud-christine_chouinard@uqac.ca

Alya Danish - alya.danish@usherbrooke.ca

Catherine Hudon* - catherine.hudon@usherbrooke.ca

*** Corresponding author:**

Catherine Hudon

Département de médecine de famille et de médecine d'urgence, Université de Sherbrooke, 3001 12e Avenue Nord, Sherbrooke, Québec, Canada, J1H 5N4

Telephone: 819-346-1110 ext. 70540

Email: - catherine.hudon@usherbrooke.ca

ABSTRACT

Objective There is a gap of knowledge among healthcare providers on characteristics of self-management among patients with chronic diseases and complex healthcare needs. Consequently, the objective of this paper was to identify characteristics of self-management among patients with chronic diseases and complex healthcare needs.

Design Thematic analysis review of the literature

Methods We developed search strategies for the Medline and CINAHL databases, covering the January 2000-October 2018 period. All articles in English or French addressing self-management among an adult clientele (18 years and older) with complex healthcare needs (multimorbidity, vulnerability, complexity, frequent use of health services), were included. Studies that addressed self-management of a single disease, or that did not have any notion of complexity or vulnerability were excluded. A mixed thematic analysis, deductive and inductive, was performed by three evaluators as described by Miles, Huberman & Saldana.

Results Twenty-one articles were included. Patients with complex healthcare needs present specific features related to self-management that can be exacerbated by deprived socioeconomic conditions. These patients must often prioritize care based on one dominant condition. They are at risk for depression, psychological distress and low self-efficacy, as well as for receiving contradictory information from healthcare providers. On the other hand, the knowledge and experiences acquired in the past in relation to their condition may help them improve their self-management skills.

Conclusions This review identifies challenges to self-management for patients with complex healthcare needs, which are exacerbated in contexts of socio-economic insecurity, and proposes strategies to help healthcare providers better adapt their self-

management support interventions to meet the specific needs of this vulnerable clientele.

Strengths and limitations of this study

- The analysis was conducted using a recognized conceptual model of self-management.
- There is a lack of consensus in the literature regarding the definition of patients with complex needs, so we ensured that the selection criteria developed for this study were broad enough to include a range of definitions for complexity.
- A limitation of any review is the potential omission of relevant articles as well as any unpublished material.

INTRODUCTION

A great majority of patients who consult the healthcare system worldwide present with one or more chronic diseases [1]. Responsible for 63% of deaths, chronic diseases represent the first cause of mortality in the world [2]. Characterized by periods of stability and deteriorations, the health condition of people with chronic diseases requires constant attention by the persons who are affected, as well as by those who surround them, in order to manage symptoms and consequences. People with chronic diseases often have to develop self-management skills.

Self-management has been defined as "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" and "developing the skills needed to devise, implement, evaluate, and revise an individualized plan for lifestyle change" [3]. Self-management incorporates an array of skills that a person must possess in order to take charge of his or her health. Lorig and Holman[4] developed a theoretical model for self-management involving three self-management tasks: medical management, emotional management and role management. According to this model, self-management requires six self-management skills in the patient: decision-making, action-planning, development of a patient–provider partnership, self-tailoring, resource utilization, and problem solving.

To date, self-management has mainly been studied in the context of a specific chronic disease, even though the management of a more complex health issue may lead to important self-management challenges [5 6]. Therefore, there is a gap in knowledge on the ways to offer self-management support to patients with complex needs [7]. Providers

constantly work with this clientele whether it be in hospitals, emergency services, medical clinics, in homecare, etc. Thus, they play an important role in self-management support [8]. However, the scarcity of knowledge on the specifics of self-management among complex patients can be detrimental to healthcare providers' capacity to adequately support and accompany such patients in the self-management of their chronic conditions. Consequently, it is important to increase our understanding of the characteristics of self-management for this clientele, for whom the current norm for care in regards to the management of a single disease may not be appropriate[1].

The aim of this paper is to review the literature to identify the characteristics of self-management among patients with chronic diseases and complex healthcare needs.

METHODS

Patient or public participation

Patients and/or the public were not involved in this study.

Design

A review of the literature including quantitative, qualitative and mixed studies was conducted on papers addressing the self-management of persons with complex healthcare needs. We followed the same synthesis process of the thematic analysis published in 2012 by Hudon et al. [9].

Search methods

We conducted an electronic literature search in the Medline and CINAHL databases, for articles in English and in French published between January 2000 and October 2018. An information specialist developed and ran the specific search strategies for each database. The following MeSH terms and keywords were used: self-care OR self-management OR self-monitoring AND multimorbidity OR comorbidity OR vulnerability OR complex* OR multiple chronic diseases OR multiple chronic conditions OR frequent users OR high users. We also examined articles found in the reference lists of collected articles (hand search).

Data collection

All search results were transferred to the Endnote X7 reference software and duplicates were eliminated. Articles retained had to respect the following criteria: (1) refer to self-management, (2) among a clientele with complex healthcare needs (multimorbidity, vulnerability, complexity, frequent use of health services), and (3) in a population of patients eighteen years and older. One team member (APGL) read all titles and abstracts to exclude articles that were clearly not eligible. We excluded references that did not meet our inclusion criteria and retained all other references for complete evaluation. Two reviewers (APGL and CH or APGL and MCC) independently appraised the full text of the retained papers to identify potentially eligible articles. Discrepancies between the two reviewers regarding the inclusion or exclusion of papers were resolved by the third evaluator.

Analysis and synthesis

All selected articles were imported into the NVivo 11 qualitative analysis software. A mixed thematic analysis, deductive and inductive, was then performed on the results of the articles by three evaluators as described by Miles, Huberman & Saldana,[10] using the Lorig and Holman model (six self-management skills and three self-management tasks) [4]. Excerpts were extracted from each of the reviewed articles and classified according to the self-management skills and tasks particular to patients with complex care needs. A second reading of the collected excerpts and familiarization with the data allowed for the identification of emergent themes. Pair debriefing, and team validation minimized the influence of researcher subjectivity and preconceptions [11]. This was an iterative process where interpretations of the data extracted from the articles were validated, and where disagreements or questions were discussed and resolved by consensus among the three evaluators.

RESULTS

Included studies

Figure 1 shows the number of references found at each stage of the selection process. The search strategies identified 1192 references, of which 980 were kept after removing duplicates. The majority of these references were rejected because they addressed the self-management of a single disease and did not contain any notion of complexity. References found through hand searching (n = 3) were also included, for a total of 60 potentially eligible references. Sixty papers were read completely. Of these, 38 articles were excluded after the full reading step: 15 did not contain any notion of complexity in the studied population; 11 did not address self-management; 9 did not address the

challenges of self-management; 1 was an editorial and 2 articles were on the validation of a measuring tool. A final sample of 22 articles was retained. Table 1 presents the characteristics of the included studies.

Table 1. Characteristics of the articles included (n = 22)

	Number of articles
Type of publication/study design	
Qualitative studies [6 7 12-17]	8
Quantitative studies [18-23]	6
Mixed methods [5 24]	2
Recommendations of a working group [1]	1
Reviews [25-29]	5
Principal authors location	
United States [1 5-7 14 16 17 21 23-25 29]	12
United Kingdom [13 15 18 20]	4
Canada [12 27 28]	3
Australia [19 22]	2
Finland [26]	1
Complexity referred to in the article	
Multimorbidity [13 15 17 18 20 22 23 26 27 29]	10
Vulnerability [5 12 16 19 24 25]	6
Complexity [1 6 7 14 17 21 28]	7
Frequent users [18 19 21 23]	4

Characteristics of self-management by patients with complex health needs

Five main themes emerged that describe the distinctive features of self-management in these patients.

Need for prioritization of self-care

Prioritization of self-care is an important self-management challenge for patients with multiple chronic diseases. When the number of self-care activities or tasks to accomplish surpasses the amount of time available, patients will establish a daily plan around the management of their chronic conditions [17], and must inevitably determine which self-care activities to prioritize. Patients with multimorbidity prioritize self-care activities based on the identification of one dominant condition [29].

Three types of conditions are more frequently identified as dominant: a poorly controlled condition that tends to cause important exacerbations or negatively affect the control of other conditions, a condition that cannot be controlled solely by medication, or an unstable condition for which it is impossible to anticipate daily self-management needs. The patient is more likely to adopt a self-management strategy if he or she thinks that it will benefit more than one condition [6 18 24].

Lack of motivation and greater risk for depression

Patients with complex needs may experience less energy, and lack time and motivation to take part in self-management activities [13 21]. They report feelings of sadness, anger and anxiety related to their illness [17]. They are at an increased risk for depression [21]. The emotional impact of disease can play an important role in decision-making. A

depressive state may give patients the impression that they are not capable of participating in self-management activities [15 29]. Even when patients are committed to adopting healthier lifestyle habits, they admit that depression could delay them from taking action [13 20 21]. If they focus on their inability to control a situation, patients tend to ruminate on the negative aspects of their health status and sink into emotional distress which prevents them from taking appropriate action when faced with a problem [24].

Increased risk of presenting poor self-efficacy

Self-efficacy is an important mediator of taking action. People's beliefs about their own self-efficacy reflect "their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" and determine how they "feel, think and motivate themselves and behave" (p.72) [30]. Patients with numerous comorbidities are more at risk of poor self-efficacy [20]. A person with low self-efficacy may experience difficulty in taking action to change lifestyle habits or in preventing the exacerbation of symptoms, leading to frequent hospital visits [19].

Patients with multimorbidity living in underprivileged neighborhoods have lower expectations in regard to health and aging than patients from privileged neighborhoods[13]. Patients living in situations of poverty often perceive that their poor health status is the norm, which greatly limits their motivation to improve their health [13]. They may believe that if others are not able to improve their health status, neither will they. Social isolation can also affect the self-efficacy of these patients who think they do not have the capacity to engage in self-management activities[13]. Support of family, friends and health providers can play an important role to improve self-efficacy[19].

Increased risk of receiving conflicting information

Patients with complex care needs are at risk of receiving conflicting information on the management of their diseases by the numerous health professionals that they meet [6 15 27]. This can lead to increased anxiety and decreased self-management capacity [18].

A personalized evaluation of learning capacity, behavior change and the desire to commit to self-management, as well as regular monitoring, facilitates patient self-management. Initiating too many changes at one time may overload the patient and his or her self-management capacity [1 27]. Treatment goals should be selected based on patient motivation and willingness to change [23].

Opportunity to use personal experience

Complex healthcare needs do not necessarily require a new set of practices for each new diagnosis. Patients with complex care needs can use the knowledge and personal experience acquired in the past and apply them in various situations to better manage their health [15 27]. However, economic hardship reduces structural and emotional capacity, which may often prevent people living in economically precarious areas from adopting self-management behaviors that have synergistic effects on many of their health issues [13].

DISCUSSION

Patients with complex healthcare needs are confronted with self-management challenges, these being exacerbated in the presence of socioeconomic insecurity. These patients must often prioritize self-care according to one dominant condition. They

are at risk for depression, psychological distress and low self-efficacy, as well as for receiving contradictory information from healthcare providers. On the other hand, their previous experiences may help them improve their self-management skills.

Liddy et al. (2014) conducted a literature review aiming to explore barriers to self-management through the perspective of patients living with multiple chronic conditions. Of the 21 articles used in our thematic analysis, seven of them were also included in their review. Common themes emerged from both studies, such as contradictory information and high risk for depression. Our analysis also highlights other particularities such as poor self-efficacy, often observed in this clientele, and the fact that patients frequently rely on past experience to adequately take charge of their health.

One of the main challenges of self-management is the prioritization of self-care. Patients with numerous chronic diseases are constantly confronted with having to make choices amongst the care activities to prioritize. Most will identify a dominant disorder on which to focus their efforts [29]. In certain situations, the characteristics of a condition are in conflict with the management of others and the successful management of a condition can hinder the taking in hand of another [31]. Patients will more easily accept to engage in self-care activities that they consider beneficial to more than one of their conditions [6 18 24]. Social and economic conditions will influence how patients prioritize self-care [32]. The healthcare provider can explore the reasons that guide this prioritization for a given patient. Interventions may have a greater impact if the healthcare provider takes time to explain the benefits of self-management behaviours for the different conditions facing the patient.

Depression and emotional distress may impair self-management by decreasing motivation, prioritization skills and problem-solving. Negative emotions may also decrease self-confidence and self-efficacy [33] and distress is often present in this vulnerable clientele [34 35]. Healthcare providers must remain vigilant during their self-management support activities with this clientele, for the quick detection of psychological distress and the treatment of mental health issues.

Patients with complex care needs reported receiving conflicting information from the health professionals they consulted. Between 25% and 80% of patients received contradictory information on their diseases and their management [36]. Receiving conflicting information from two sources that the person trusts can complicate self-management [36]. In order to help these patients as much as possible, it is important that healthcare providers offer a personalized evaluation of their needs, as well as proper follow-up, and ensure good coordination between various health professionals [23].

Although the majority of studies report that complexity is an additional challenge to self-management, the coexistence of many chronic conditions can also become an opportunity to call on past learning experiences [37]. The healthcare provider can help the patient become aware of the knowledge and skills gained in the past as well as positive experiences.

Limitations

Our study presents some limitations. There is a lack of consensus in the literature regarding the definition of patients with complex needs. We ensured that the selection

criteria developed for this study were broad enough to include a range of definitions for complexity. A limitation of any review is the potential omission of relevant articles as well as any unpublished material. However, all necessary measures were taken to ensure an exhaustive document review: our search strategy was adapted to various databases and was developed in collaboration with an information specialist. Furthermore, we identified additional papers by hand search.

CONCLUSIONS

Patients with complex health needs present challenges to self-management related to the prioritization of self-care, a greater risk for depression or psychological distress, a greater risk of poor self-efficacy, and the risk of receiving conflicting information from healthcare professionals. However, they can rely on their knowledge and previous experience gained in other situations to improve their self-management skills. Future studies could empirically validate the results of this research and contribute to the understanding of the experience of these patients. Healthcare providers can learn from these results to better adapt their self-management support interventions to meet the specific needs of this vulnerable clientele.

DECLARATIONS

Acknowledgements

The authors would like to thank Ms. Janie Boudreault an information specialist at Université du Québec à Chicoutimi for her help in the development and running of

specific search strategies for each database and Ms. Susie Bernier for her contribution to the translation of the article to English.

Authors' contributions

APGL found the articles, analyzed, interpreted the data and drafted the manuscript with the participation of AD, under the supervision of MCC and CH. MCC and CH co-analyzed and interpreted the data. All authors approved and read the manuscript.

Competing interests

The authors declare that they have no competing interests.

Patient consent

None.

Provenance and peer-review

Not commissioned; externally peer review

Funding

This research did not receive any specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Data sharing

No additional data are available.

REFERENCES

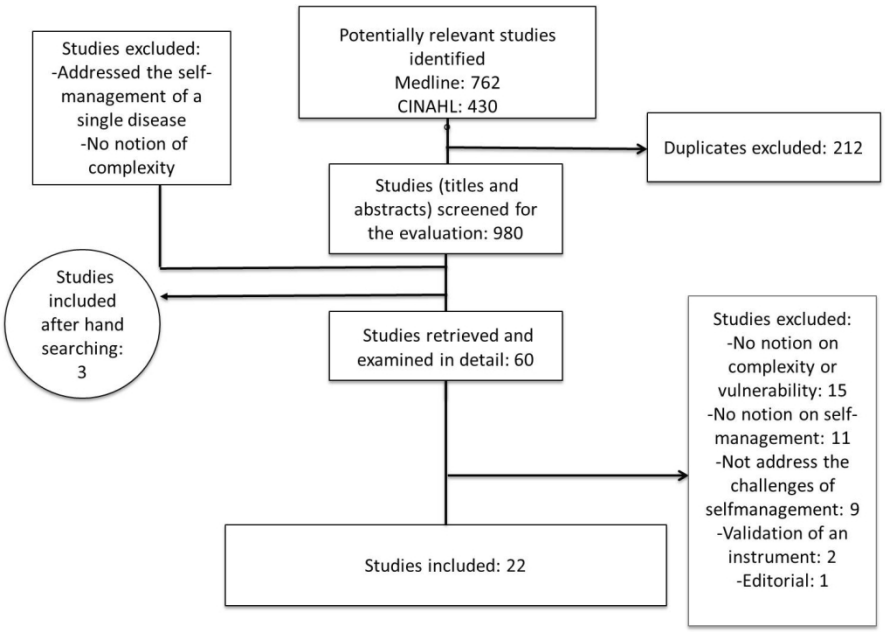
1. Bayliss EA, Bosworth HB, Noel PH, et al. Supporting self-management for patients with complex medical needs: Recommendations of a working group. *Chronic illness* 2007;3(2):167-75. doi: 10.1177/1742395307081501 [published Online First: 2007/12/18]
2. World Health Organization. Maladies Chroniques 2017 [Available from: http://www.who.int/topics/chronic_diseases/fr/ accessed 03-05 2015.
3. Orem DE. Nursing: Concepts of practice. St. Louis, MO: Mosby-Year Book Inc. 1991.
4. Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine* 2003;26(1):1-7.
5. Bardach SH, Tarasenko YN, Schoenberg NE. The role of social support in multiple morbidity: Self-management among rural residents. *Journal of health care for the poor and underserved* 2011;22(3):756-71. doi: 10.1353/hpu.2011.0083 [published Online First: 2011/08/16]
6. Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. *Annals of family medicine* 2007;5(5):395-402. doi: 10.1370/afm.722 [published Online First: 2007/09/26]
7. Sevick MA, Trauth JM, Ling BS, et al. Patients with complex chronic diseases: Perspectives on supporting self-management. *Journal of General Internal Medicine* 2007;22 Suppl 3:438-44.
8. Registered Nurses' Association of Ontario. Stratégies permettant de soutenir l'autogestion des états chroniques : la collaboration avec les clients Toronto, ON2010.
9. Hudon C FM, Haggerty JL, Loignon C, Lambert M, Poitras ME. Patient-centered care in chronic disease management: A thematic analysis of the literature in family medicine. *Patient Education and Counseling* 2012;88(2):170-76.
10. Miles MB, Huberman MA, Santana J. Qualitative data analysis : A method sourcebook. London: Sage 2014.
11. Creswell JW. Quantitative inquiry & research design: Choosing among five approaches. Thousand Oaks, CA: Sage 2006.
12. Clarke LH, Bennett EV. Constructing the moral body: Self-care among older adults with multiple chronic conditions. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness & Medicine* 2013;17(3):211-28 18p. doi: 10.1177/1363459312451181
13. Coventry PA, Fisher L, Kenning C, et al. Capacity, responsibility, and motivation: A critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity. *BMC health services research* 2014;14:536. doi: 10.1186/s12913-014-0536-y [published Online First: 2014/11/05]
14. Eton DT, Ridgeway JL, Egginton JS, et al. Finalizing a measurement framework for the burden of treatment in complex patients with chronic conditions. *Patient related outcome measures* 2015;6:117-26. doi: 10.2147/PROM.S78955 [published Online First: 2015/04/08]
15. Morris RL, Sanders C, Kennedy AP, et al. Shifting priorities in multimorbidity: A longitudinal qualitative study of patient's prioritization of multiple conditions.

Chronic illness 2011;7(2):147-61. doi: 10.1177/1742395310393365 [published Online First: 2011/02/24]

16. Roberto KA, Gigliotti CM, Husser EK. Older women's experiences with multiple health conditions: Daily challenges and care practices. *Health care for women international* 2005;26(8):672-92. doi: 10.1080/07399330500177147 [published Online First: 2005/10/20]
17. Restorick RA, Betts AK, Beckette WC. Effects of chronic illness on daily life and barriers to self-care for older women: A mixed-methods exploration. *Journal of Women and Aging* 2017;29(2):126-36. doi: 10.1080/08952841.2015.1080539
18. Bower P, Hann M, Rick J, et al. Multimorbidity and delivery of care for long-term conditions in the English National Health Service: Baseline data from a cohort study. *Journal of health services research & policy* 2013;18(2 Suppl):29-37. doi: 10.1177/1355819613492148 [published Online First: 2013/10/23]
19. Gallagher R, Donoghue J, Chenoweth L, et al. Self-management in older patients with chronic illness. *International Journal of Nursing Practice* 2008;14(5):373-82. doi: 10.1111/j.1440-172X.2008.00709.x [published Online First: 2008/09/24]
20. Harrison M, Reeves D, Harkness E, et al. A secondary analysis of the moderating effects of depression and multimorbidity on the effectiveness of a chronic disease self-management programme. *Patient Education and Counseling* 2012;87(1):67-73. doi: 10.1016/j.pec.2011.06.007 [published Online First: 2011/07/20]
21. Hill N, Joubert L, Epstein I. Encouraging self-management in chronically ill patients with co-morbid symptoms of depression and anxiety: An emergency department study and response. *Social Work in Health Care* 2013;52(2-3):207-21. doi: 10.1080/00981389.2012.737900 [published Online First: 2013/03/26]
22. Islam MM, McRae IS, Yen L, et al. Time spent on health-related activities by senior Australians with chronic diseases: What is the role of multimorbidity and comorbidity? *Australian and New Zealand journal of public health* 2015;39(3):277-83. doi: 10.1111/1753-6405.12355 [published Online First: 2015/04/24]
23. Noel PH, Parchman ML, Williams JW, Jr., et al. The challenges of multimorbidity from the patient perspective. *Journal of General Internal Medicine* 2007;22 Suppl 3:419-24. doi: 10.1007/s11606-007-0308-z [published Online First: 2007/12/06]
24. Leach CR, Schoenberg NE. Striving for control: cognitive, self-care, and faith strategies employed by vulnerable black and white older adults with multiple chronic conditions. *Journal of cross-cultural gerontology* 2008;23(4):377-99. doi: 10.1007/s10823-008-9086-2 [published Online First: 2008/11/07]
25. Dorsey CJ, Murdaugh CL. The theory of self-care management for vulnerable populations. *Journal of Theory Construction & Testing* 2003;7(2):43-49 7p.
26. Hujala A, Rijken M, Laulainen S, et al. People with multimorbidity: Forgotten outsiders or dynamic self-managers? *Journal of health organization and management* 2014;28(5):696-712. doi: 10.1108/JHOM-10-2013-0221 [published Online First: 2014/01/01]
27. Liddy C, Blazkho V, Mill K. Challenges of self-management when living with multiple chronic conditions: Systematic review of the qualitative literature. *Canadian Family Physician* 2014;60(12):1123-33.

28. Novak M, Costantini L, Schneider S, et al. Approaches to self-management in chronic illness. *Seminars in dialysis* 2013;26(2):188-94. doi: 10.1111/sdi.12080 [published Online First: 2013/03/26]
29. Bratzke LC, Muehrer RJ, Kehl KA, et al. Self-management priority setting and decision-making in adults with multimorbidity: A narrative review of literature. *International journal of nursing studies* 2015;52(3):744-55. doi: 10.1016/j.ijnurstu.2014.10.010 [published Online First: 2014/12/04]
30. Bandura A. Self-efficacy. In V. S. Ramachaudran : *Encyclopedia of human behavior*. New York: Academic Press 1994.
31. Sharry JM, Bishop FL, Moss-Morris R, et al. The chicken and egg thing': Cognitive representations and self-management of multimorbidity in people with diabetes and depression. *Psychology & Health* 2013;28(1):103-19. doi: http://dx.doi.org/10.1080/08870446.2012.716438
32. Bosworth HB, Powers BJ, Oddone EZ. Patient self-management support: Novel strategies in hypertension and heart disease. *Clinical Cardiology* 2010;28(4):655-63.
33. Lin MT, Burgess Jr JF, Carey K. The association between serious psychological distress and emergency department utilization among young adults in the USA. *Social Psychiatry and Psychiatric Epidemiology* 2012;47:939-47. doi: 10.1007/s00127-011-0401-9
34. Dinkel A, Schneider A, Schmutzer G, et al. Family physician–patient relationship and frequent attendance of primary and specialist health care: Results from a German population-based cohort study. *Patient Education and Counseling* 2016;99(7):1213-19.
35. Fortin M, Bravo G, Hudon C, et al. Psychological distress and multimorbidity in primary care. *Annals of family medicine* 2006;4(5):417-22.
36. Elstad E, Carpenter DM, Devellis RF, et al. Patient decision making in the face of conflicting medication information. *International Journal of Qualitative Studies on Health and Well-being* 2012;7(1):1-12. doi: http://dx.doi.org/10.3402/qhw.v7i0.18523
37. Vellone E, Riegel B, D'Agostino F, et al. Structural equation model testing the situation‐specific theory of heart failure self‐care. *Journal of Advanced Nursing* 2013;69(11):30-34.

Figure 1: Number of references found



284x179mm (150 x 150 DPI)

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	p.1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	P.2-3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	P.5
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	P.6
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	NA
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	P.7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	P.7
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	P.7
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	P.7
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	P.8
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	P.7
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	P.8

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	P.11-12-13
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	P.11-12-13
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	P.11-12-13
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	P.14-15
Limitations	20	Discuss the limitations of the scoping review process.	P.16
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	P.16
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	P.18

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. ;169:467–473. doi: 10.7326/M18-0850