Engaging Older Adults in Health Care Decision-Making: A Realist Synthesis

Jacobi Elliott¹ · Heather McNeil¹ · Jessica Ashbourne¹ · Kelsey Huson² · Veronique Boscart¹,²,³ · Paul Stolee¹,³

Abstract

Background Engagement in healthcare decision making has been recognized as an important, and often lacking, aspect of care, especially in the care of older adults who are major users of the healthcare system.

Objective We aimed to conduct a review of available knowledge on engagement in healthcare decision making with a focus on older patients and their caregivers.

Methods We conducted a realist synthesis focusing on strategies for engagement of older patients and their caregivers in healthcare decision making. The synthesis encompassed theoretical frameworks and both peer-reviewed and grey literature. Expert consultations included interviews (n = 2) with academics and group consultations (n = 3) with older adults and their caregivers. Abstracts that reported description, assessment, or evaluation of strategies for engagement of adult patients, families, or caregivers (i.e., that report on actual experiences of engagement) were included.

Results The search generated 15,683 articles, 663 of which were pertinent to healthcare decision making. Theoretical and empirical work identified a range of strategies and levels of engagement of older patients and their families in healthcare decision making. The importance of communication emerged as a key recommendation for meaningful engagement among providers and patients and their caregivers. The principles developed in this study should be implemented with consideration of the context in which care is being provided.

Conclusions We have developed a framework that promotes the engagement of patients and their caregivers as equal partners in healthcare decision making. Future research should implement and test the framework in various clinical settings.

Key Points for Decision Makers

- Engagement is complex and should be viewed as an evolving relationship.
- Communication is key to developing an open, honest, and trusting relationship.
- Patients/caregivers need to know they have a right to be engaged in decision making and—together with providers—should decide which level of engagement is appropriate for the specific situation.

1 Background

Patient and citizen engagement has been recognized as a crucial element in healthcare reform; however, limited attention has been paid to how best to engage older adults,
the largest growing segment of the population and heavy users of healthcare systems. Engagement of these individuals and their caregivers is essential to disease prevention and self-management, as older adults with multiple chronic diseases are major users of the system [1]. Playing a more active role in healthcare can improve patients’ quality of care, efficiency, and health outcomes [2, 3]. To improve care and outcomes for this population, older adults and their caregivers need to be engaged as active partners in their healthcare decision making.

Patient involvement, client engagement, public involvement, patient-centered care, and other terms have all been used to describe patient engagement. For the purposes of this paper, the term “patient engagement” is used and defined as “a relative term subjectively defined by individuals or groups/organizations that are planning to actively involve patients and their families in various health care advisory committees or care decision making” [4]. This specific definition recognizes the importance of engaging families (caregivers) who play a significant role as care partners for older adults.

Preliminary searches by the authors indicated published literature focused on the engagement of older adults in healthcare decision making is limited. The preliminary search identified the importance of patient engagement, patient-centered care, and patient experience; however, information on strategies for how best to engage older adults was limited. This synthesis answered the following research question: What are the contexts and underlying mechanisms needed to achieve the outcome of meaningful engagement of older adults in healthcare decision making? Specifically, we wanted to understand: (1) the contextual factors that influence meaningful engagement; (2) the outcomes (levels of engagement) achieved through various engagement encounters; and (3) the mechanisms necessary to achieve meaningful engagement in healthcare decision making. The review yields principles for engagement to promote more productive partnerships and collaborations among healthcare providers and patients and their caregivers during healthcare decision making.

2 Methods

2.1 Study Design: The Realist Review Method

We synthesized knowledge on patient, family, and caregiver engagement in healthcare decision making using a realist synthesis approach. As there is currently no consensus on the best approach to conduct a knowledge synthesis, Kastner et al. [5] proposed a scoping review to identify the most appropriate knowledge synthesis method. Of the 25 approaches listed, the realist synthesis approach developed by Pawson et al. [6] and Greenhalgh et al. [7] is most appropriate for this study. Realist syntheses address limitations of more traditional approaches to systematic reviews and meta-analyses. Such traditional approaches address effectiveness, often narrowly defined, but do not consider why, for whom, and in what circumstances an intervention or policy works [8]. This method provided rich information and explanation that can guide real-world decision making.

The basic phases of a realist review are similar to those followed in a conventional Cochrane review but involve more sub-steps and may be overlapping and iterative rather than sequential [6]. Realist synthesis involves identifying a theoretically based framework (“initial rough theories” [9]), which is then populated with evidence that is used to enrich and refine the theory. The refined theory then becomes the basis for practice and policy recommendations. The search methodology was informed by the framework for realist synthesizes put forward by Wong et al. [10].

The processes of scope clarification, stakeholder involvement, systematic search and review, and development/dissemination of recommendations are consistent with accepted practice for creation of best practice guidelines [11]. The synthesis encompassed peer-reviewed and grey literature; conceptual/theoretical as well as empirical work; research conducted using qualitative, quantitative, and mixed methods; and expert opinion, including the opinions of seniors, older patients, and their social support networks. The realist synthesis comprised the five phases described below and illustrated in Table 1. A more detailed description of the methods can be found in the protocol paper by Stolee et al. [12].

2.1.1 Phase One: Clarifying Scope

We first conducted in-depth discussions with stakeholders to refine the review question and purpose, and to find and articulate relevant theories. We initially focused on Canadian information at provincial and national levels, but identified frameworks used internationally through hand searching papers from countries with similar healthcare systems.

We conducted two key informant interviews with research leaders recognized as experts in patient, family, and community engagement in Canada. The 30-min interviews were audio-recorded and later transcribed. The interviews helped to identify frameworks commonly used in research and practice. Data were coded using the line-by-line coding technique by Lofland et al. [13]. A group discussion was held with older adults, patients, and their caregivers (n = 8) from the Seniors Helping as Research Partners (SHARP) network: a network created by the
Geriatric Health Systems (GHS) research group (University of Waterloo) [14] that engages older adults and caregivers in meaningful partnerships through discussions about healthcare issues and research. We also conducted a full-day workshop with participants \((n = 17)\) from Patients Canada who discussed the meaning of patient engagement and reviewed the frameworks we had identified.

The consultation components of this review involving patients and caregivers received ethics clearance from the University of Waterloo Office of Research Ethics (ORE# 19094).

2.1.2 Phase Two: Search for Evidence

We conducted an extensive purposive search of peer-reviewed literature.

**Inclusion and Exclusion Criteria** Papers were included if they reported description, assessment, or evaluation of strategies for engagement of adults (patients or citizens aged \(\geq 18\) years), families, or caregivers. All papers that discussed outcomes that could distinguish an actual experience or process of engagement were included. Papers containing strategies relevant to older adults (aged \(\geq 65\) years) were highlighted in the abstraction. Papers focused strictly on engagement of children (aged \(< 18\) years) were excluded.

**Search Methodology** A systematic search of the following licensed databases was conducted: MEDLINE, Embase, CINAHL, Sociological Abstracts, Scopus, and the Cochrane Database of Systematic Reviews. The search included the following key concepts: healthcare; decision making; healthcare decision making; patient-centered care; public; engagement; public engagement. The date limits of the literature search ranged from the earliest coverage of individual databases to the date of the final search, January 2014. The review included both English and French language content. The search results were exported to RefWorks, a reference management system, and duplicate results were deleted. The search strategy was modified to conduct a grey literature search using Google. Following advice from the librarian, the reviewers went through the Google results and retrieved any relevant documents. The grey literature search also included searching relevant government and organizational websites (e.g., Patient Voice Network, UK Department of Health).

The reviewers applied the inclusion and exclusion criteria. To assess inter-reviewer agreement on peer-reviewed article retention, two reviewers independently reviewed a sample of articles, and results were compared using a kappa statistic until a score of “good” was achieved using Altman’s [15] criteria (>0.60).

2.1.3 Phase Three: Appraise Primary Studies and Extract Data

In realist syntheses, data abstraction is an ongoing, iterative process that is dependent on information gathered. Data abstraction, including an assessment of relevance and rigour was conducted following guidelines outlined by Pawson et al. [6] and by Wong and colleagues [9, 10]. The data abstraction table was developed through consultation with stakeholders and frequent research team meetings. Relevance was assessed by asking questions similar to those suggested by Kastner et al. [16], such as, “does the research address the theory under investigation? In what context does the engagement occur? Does the engagement involve older patients, family, or caregivers?”. Rigour is used in a realist synthesis to apply judgement to the articles being reviewed to assess their quality—does the research support the conclusions drawn from it? [6].

2.1.4 Phase Four: Synthesize Evidence and Draw Conclusion

As each article was reviewed and re-read, the reviewer created and iteratively revised codes to capture themes or concepts related to both the initial rough theories and the engagement experiences and processes that emerged from

| Table 1 Phases of the realist review |
|-------------------------------------|
| **1. Clarify scope**                |
| Refine question and purpose; search for major theories and frameworks |
| Interview key informants to help identify theories and frameworks |
| Consult with patients to discuss project and review theories and frameworks |
| **2. Search for evidence**           |
| Develop search strategy with library scientist |
| **3. Appraise primary studies and extract data** |
| Develop data abstraction table |
| **4. Synthesize evidence and draw conclusions** |
| Review articles, searching for context, mechanisms, outcomes, and patterns related to meaningful engagement |
| Compare information against “initial rough theory” (candidate framework) |
| **5. Disseminate, implement, evaluate** |
| Develop program theory; workshop participants review |
the data. The investigators (JE, HM, JA, KH) independently conducted article abstraction and line-by-line coding using an approach that allowed for themes and patterns to emerge from the data [13]. Data were coded until saturation was reached. The analysis process was guided by a process similar to that used by Wong et al. [17]. Nvivo 10 was used to code themes that emerged through the reading of the data. We then examined these themes for information related to the context, potential mechanisms, and outcomes (CMO). The CMO structure aims to explain, within a particular context, what underlying process ( mechanism) occurs to achieve a specific outcome. The researchers also looked for patterns that aim to explain how to achieve meaningful engagement. The research team met frequently to discuss the emerging CMO patterns by applying realist logic to the analysis. For a realist review, Pawson et al. [18] suggest that “the reviewer should aim not for encyclopaedic coverage of all possibly relevant literature but for a concept borrowed from qualitative research, that of theoretical saturation … stop searching at the point when no new information is added”. The emerging CMO structures were compared against the candidate framework, which confirmed and refined components of the framework in an effort to explain how meaningful engagement can be achieved. The findings either supported or refined the original theories/framework. In line with a realist review, this was an ongoing and iterative process, using information from all phases of the process.

2.1.5 Phase Five: Disseminate, Implement, and Evaluate

During the final phase of the study, we conducted a half-day workshop with participants (n = 11) from Patients Canada to discuss the findings from the realist review. Notes from the discussions were recorded by three researchers. Information was amalgamated to finalize the principles for engagement of older adults and their caregivers in healthcare decision making.

3 Results

3.1 Key Informant and Focus Group Interviews and Grey Literature Search

Information gathered through key informant and focus group interviews helped to narrow the grey literature search, key concepts, and words, and assisted in the identification of key engagement frameworks.

The informants suggested one commonly used framework in the area of patient and citizen engagement, the Spectrum of Engagement [19]. They also emphasized the importance of the context, “it’s not that you can take the framework and apply it across the whole spectrum of care for that particular group, it’s based on that particular situation that is impacting them for the moment, and it might be a very specific kind of approach or strategy, very specific …” (key informant).

As strategies emerge through the literature search, the specific situation for which that strategy can be applied must be considered.

3.2 Selecting Candidate Frameworks Through Group Consultations

Using data from the grey literature and key informant and focus group interviews, eight frameworks were selected for further review: Person-Centered Practice Conceptual Framework [20]; Shared Decision Making [20]; Ladder of Engagement [21]; Spectrum of Participation [19, 22]; Community Engagement Model [23]; and the Eight Dimensions of Patient-Centered Care [24]. After each framework was reviewed in detail with members of Patients Canada, the participants suggested that the Spectrum of Participation [22] and Picker’s Eight Dimensions of Patient-Centered Care [24] would be the most appropriate “initial rough theory” frameworks. The Spectrum of Participation provides a framework of different levels of engagement; inform, consult, involve, collaborate, and empower. The Eight Dimensions of Patient-Centered Care provide a list of elements that should be considered when treating a patient, including patient preferences, emotional support, physical comfort, information and education, continuity and transition, coordination of care, access to care and family and friends. One participant said, I can understand this model [Spectrum of Participation], which is important. For a diagram to work, it should be intuitively comprehensible. Participants preferred the spectrum illustrated as a circle rather than as a linear model, as it most depicts reality; patients and families should be able to move between any levels of engagement at any time. The ‘Preferences’, ‘Emotional Support’, and ‘Access to Care’ components of the Eight Dimensions of Patient-Centered Care were very important to participants. However, there was concern that this particular model did not reference the importance of partnerships or collaborations and did not consider the skills and knowledge of the patient or the provider to engage in meaningful discussions.

3.3 Search Results

Figure 1 shows the number of studies included at each stage of the review. The search yielded a total of 15,683 articles once duplicates were removed. The articles first
underwent a title and abstract review in which 10,467 articles were excluded; 562 articles focused on engagement in research and healthcare planning, and these were set aside for another realist review conducted by a member of the team. Articles focusing on cognitive impairment were also set aside because it was hypothesized that engagement techniques for this population would be unique. The remaining 663 (652 English and 11 French) articles underwent a full-text review. Reviewers (independently reviewed the remaining articles, sorting them into three categories: “Exclude,” “Theory,” or “Evidence/Intervention”. One reviewer was responsible for the French language articles. The reviewers met numerous times to discuss the process and ensure it remained consistent.

Of the 652 English language articles, 281 articles focused on theory and were set aside. The remaining 371, considered to have sufficient evidence, were included for data abstraction. Of the 11 French articles, two focused on theory and nine were included in the final sample to be abstracted. In total, 213 articles (208 English, 5 French) were abstracted and coded before saturation was reached. In total, 36 % (77/213) of the studies were conducted in the USA, 19 % (41/213) were conducted in the UK, and 10 % (22/213) were conducted in Canada. The articles identified research conducted across different settings, including community care (32 %, 68/213), primary care (17 %, 37/213), and hospital (20 %, 42/213). Methods used in each study varied. Of the articles analyzed, 15 % (33/213) focused on older adults.

Components of both the Spectrum of Participation [22], and the Eight Dimensions of Patient-Centered Care framework [24] were included on the data abstraction form (see the Electronic Supplementary Material for an example of the data abstraction form). Of the 213 articles abstracted,
the majority of the studies discussed aspects related to patient preferences (80%, 170/213) or information and education (67%, 143/213). Only 15% (32/213) discussed friends and family. In terms of level of engagement, 62% (133/213) discussed engagement at the level of involving patients, but only 11% (23/213) discussed empowering patients in healthcare decision making.

3.4 Program Theory Development and Context, Potential Mechanisms, and Outcomes (CMO)

Structures

A number of “codes” emerged from a thorough line-by-line analysis [13] of the data abstraction table. Example codes include trust, respect, shared decision making, power dynamics, communication breakdown, expectations, involving family, wait time, and system complexities. The research team met frequently to discuss the codes and subsequent emerging themes. Through the analysis process, in collaborations with stakeholders, the results of this project indicated that, regardless of the level of engagement (as indicated by the Spectrum of Participation [22]), two levels need to be considered when engaging older adults in healthcare decision making. These levels include the individual actors (patients, providers, social support systems) and the broader health system (health sectors, environment, time, complexity). Following the emergent analysis technique, a more deductive coding approach using The Eight Dimensions of Patient-Centered Care [24] guided further analysis. This analysis both supported and countered elements of the candidate frameworks. We engaged stakeholders to review the resulting program theory and gain further insight from older adults into how to understand the context and mechanisms necessary to achieve outcomes of meaningful engagement. Figure 2a–c illustrate the theoretical relationship and underpinning of

![Diagram](image-url)

Fig. 2 CMO: a developing meaningful relationships; b developing trust between patient and providers; c improving communication between patients and providers

△ Adis
CMO examples that emerged from the literature review to engage older adults in healthcare decision making. The CMO examples a specific context (C), the underlying mechanism (M), and the subsequent outcome (O).

In the context of a doctor’s appointment, the patients’ past experience (positive or negative) (C) can affect the interaction they have with the healthcare provider. The mechanism of building trust (M) between the patient and provider is needed to develop a meaningful relationship (O) where the patient feels engaged in the decision making. This example is illustrated in Fig. 2a.

3.4.1 Patient, Social Support, and Provider

The CMO pattern in Fig. 2a considers the patient at the individual level and their interactions with the healthcare provider. Characteristics of the patient, provider, and social support networks (caregiver) (depicted in the center of this framework) must be considered for any engagement interaction that occurs. Considerations of the patient are central to developing an environment where meaningful partnerships and engagement of patients and their social support networks can take place. Many articles discussed the importance of understanding the patient in terms of their characteristics (e.g., disease status, ability to engage in conversations and make decisions, perceived quality of life; ability to perform activities of daily living) [25–29] and their demographics (e.g., age, culture, ethnicity, sex, language, education, social economic status, marital status) [27, 30, 31]. The preferences, goals, needs, and expectations of the patients (and social support network) need to be discussed [32–36]. Skills and knowledge play an important role in the level of engagement, as patients with more knowledge and education will be empowered and more likely to engage in decision making [37–39].

In some contexts, the social support network (family, friend, neighbor) must also be acknowledged [37, 40–43]. The term “social support networks” better describes the informal support that we previously termed “family caregiver.” Social support networks could include family, friends, neighbors, or peers, as identified through our literature review.

Attitudes and characteristics of healthcare providers were reported as playing a role in how and the extent to which patients and their social support networks are engaged in healthcare decision making [3, 37]. As with patients, the skills and knowledge of healthcare providers are important, and the provision of education and resources can help healthcare providers engage patients and their families in meaningful partnerships [3, 44].

3.4.2 Interaction: Relationship Building

Positive interactions between a supportive environment (i.e., context, broader health system), healthcare providers, patients, and social support networks create relationships necessary for meaningful partnerships and engagement in decision making. A strong relationship between providers and patients is built on trust and respect [45–47]. The power dynamic typically displayed in patient-provider relationships must be minimized so that patients (and their social support networks) can become active partners in their care [45, 48].

Communication is a key element of successful patient engagement. Healthcare providers, patients, and their social support networks need to engage in open and honest conversation for the purposes of sharing information, educating each other, making decisions, and planning care [3, 49, 50]. Educational materials could assist with the appropriate and effective facilitation of this communication and support engagement among providers, patients, and social support networks [29, 43].

Another CMO example (Fig. 2b) involves the providers’ characteristics (knowledge) (C). If the provider has knowledge on appropriate engagement techniques, this will contribute to respectful communication (M) between the patient and provider and thus lead to a relationship of trust (O) between the patient and provider. These two examples illustrate a pattern of the importance of communication and trust in building a relationship, influenced by provider and patient characteristics, as described above.

The third example (Fig. 2c) represents the broader complex health system (C) and the need for reducing patient confusion (M), which ultimately allows for better communication across the system (O). Reducing confusion for the patient could occur in many ways, such as providers clarifying roles when working with patients or patients receiving appropriate information. This CMO represents the need for the system to support continuity of care among providers and patients across the broader health system.

3.4.3 Broader Health System

The literature suggests that coordination and continuity of care is important for successful engagement of patients, providers, and the social support network [25, 43, 51, 52] across the broader health system. Engagement needs to be supported within and across care settings through communication among providers, patients, and social support networks to provide continuity of care. Healthcare providers need to collaborate within and across settings to provide efficient and effective care [53]. The use of documentation (multiple methods) eases the information sharing that is necessary for seamless care coordination [25, 34, 46].

It is difficult to discuss principles for engagement without considering the context in which these principles would be implemented and the barriers and facilitators that
impact patient engagement at the system(s) level. Resources (e.g., time and money) are necessary for a system to support patient engagement [3, 36, 51, 54, 55]. A shift in organizational structure is essential to allow patients and their social support network to be engaged in meaningful partnerships. At the clinical level, literature suggests that a healthcare environment that provides comfortable space with a warm and welcoming atmosphere better supports patient engagement [41, 56, 57].

4 Discussion

4.1 Summary of Findings

The realist synthesis of 213 abstracted and coded articles, and consultations with older adults and experts, produced a number of key findings. First, engagement in healthcare decision making is complex, and the specific strategies used will vary depending on the patient, setting, and situation; however, the key principles discussed in the framework above remain consistent. The skills and knowledge of the patient, their social support network, and the healthcare provider will influence the patients’ desired level of engagement. Some patients have limited or no understanding that they can participate in decision making with care providers. Patients and their social support networks should be educated on what engagement is and what the different levels of engagement are [44, 48, 58]. It is up to the patient to decide how much they want to participate in healthcare decision making; they should be encouraged by healthcare providers and supported by the system to do so [34, 37, 45]. Second, communication between providers, patients, and the social support network is key to the development of an open, honest, and trusting relationship, which in turn impacts the coordination of care [47]. Third, within a meaningful relationship, patients and their social support network will need to continuously evaluate their level of engagement and recognize that this level is fluid and evolving [51]. Providers, patients, and social support networks will gain knowledge, skills, and experiences as time passes, which may influence their desired engagement level. Therefore, in collaboration with healthcare providers, levels of engagement should be discussed and partnerships adjusted periodically. The idea of recognizing different levels of engagement has been supported by others, such as Facey et al. [59].

The focus of the realist review aimed to understand the engagement of older adults in decision making. Only a small number of articles focused specifically on this population. We found no significant difference in the literature that would lend itself to different engagement strategies. Our expectation is that our mechanisms for engagement would be the same for older adults and adults. The consultations with older adults were helpful to verify the findings from the literature and ensure that the engagement strategies were appropriate. However, our discussions with older adults did identify that consideration of family and friends is important. Only a small number of the abstracted articles discussed the aspect of family and friends [37, 40–43]. However, the consultations conducted for this realist review, and other research our group has conducted [60, 61], indicated support for the inclusion of caregivers as important members of the circle of care. Thus, the inclusion of caregivers became a central component of the program theory.

4.2 Comparison with Existing Literature

As illustrated in Fig. 2a–c, the components of the framework used to understand engagement have evolved as a result of the literature search and consultation with stakeholders. Many of the dimensions in the Eight Dimensions of Patient-Centered Care [24] are elements within the components of the program theory. Information about the patient, social support network, and the provider is imperative to the building of a positive interaction that supports meaningful engagement. A strong relationship (interaction between patients, social support networks, and providers), supports the occurrence of more seamless coordination of care, access to services, and continuity of care across the complex system. When the frameworks were chosen in phase 1 of the study, participants commented on the absence of partnership or collaboration in the Eight Dimensions of Patient-Centered Care [24]. The importance of the relationship between patients, providers, social support network, and the context emerged through the review and consultation process, and it is the central element of the newly developed engagement framework. However, the elements of the candidate theory are evident in each level of the program theory. For instance, understanding patient preferences becomes an important consideration when looking at the patient at the individual level. Patient preferences will influence how the patient–provider–social support interaction occurs, thus resulting in different outcomes. Family and friends is one of the eight elements in the patient-centered care model and is also important in the new program theory. Social support networks play a large role in the care of patients, especially older adults.

The Spectrum of Participation [22], was found to be no longer important as its own framework, but rather to inform the idea of levels of participation/engagement, which need to be an ongoing consideration during the care process. The desired level of engagement should be considered at the
patient level and will affect the mechanism and subsequent outcome.

4.3 Strengths and Limitations of the Review

By using a realist synthesis method, the review has begun to explain, how, why, and the context in which patient engagement occurs. A realist review is subjective and interpretive in nature, and although our methods and steps have been documented, other researchers reviewing the same literature may arrive at different conclusions depending on the theory used and how the data are interpreted [17].

At first, we perceived the number of articles generated through our search to be unmanageable; however, this provided a range of studies (methods, context, and populations) through which to understand the process of engagement. The amount of literature focused on engaging older adults was also limited, but the workshops held with Patients Canada, as well as the focus group with SHARP members, contributed to, and verified, the knowledge learned through the literature review.

We also recognize that a large number of theories and frameworks exist; however, information from our key informants and the focus of our search directed us to the candidate theories chosen for this review. Participants in our consultations provided feedback on the theories, a process unique to a realist synthesis.

We have reported on all of the items in the RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) publication standards [10], except for iterative searching. This review obtained a large sample of literature for which we felt we had sufficient data.

4.4 Contribution to the Literature

This review provides a better understanding of how meaningful engagement can be achieved and is grounded in literature searches (peer-reviewed and grey literature) and consultations with older adults, patients, and caregivers. The examples outlined throughout the result sections are meant as a guide. Given the specific situation, a number of processes can occur that influence meaningful engagement. The purpose of this paper is not to be prescriptive, but rather to give examples of different processes that can occur in different situations that may lead to meaningful engagement. The process will depend on the extent to which the patient (and social support network) wishes to be involved in decision making (Spectrum of Engagement) and their knowledge and skills (Individual Level). An interaction will then occur at the individual level or broader system level in hopes of achieving meaningful engagement.

5 Conclusions

Based on the findings of this review, we present a set of suggested principles that address the key components related to successful patient engagement that could be implemented in healthcare decision-making settings to engage older adults and their social support networks as partners in care. We have also developed a number of engagement strategies that can assist healthcare providers, patients, and social support networks throughout the engagement process. Further consultation with the SHARP network and Patients Canada representatives have been ongoing to finalize the strategies. These strategies will then be tested in a clinical setting. Overall, engagement is dependent on relationship building established through honest and open communication. If nothing else, healthcare providers, patients, and their social support network must communicate and share information with one another to develop and sustain successful partnerships necessary for meaningful engagement.

Acknowledgments Jacobi Elliott was involved in all phases; she was responsible for writing this manuscript. Heather McNeil was also involved in all of the project phases. Kelsey Huson and Jessica Ashbourne participated in the sorting, abstracting, and analyzing of the articles. Veronique Boscart was involved in the creation of the project and provided valuable insight into the results of this study. Paul Stolee conceived of the study, participated in its design and coordination, and helped draft the manuscript. All authors read and approved the final manuscript. We are grateful to Rebecca Hutchinson, Health Sciences Librarian at the University of Waterloo, for her assistance with the search strategy. We would also like to acknowledge members of the Seniors Helping as Research Partners Network and of Patients Canada who participated in our workshops and provided feedback on the work. Thank you to Dr. Sholom Glouberman (Patients Canada), Maria Judd (Canadian Foundation for Healthcare Improvement), Dr. George Heckman, Dr. Kerry Byrne, Margaret Hedley, and Samantha Black, who provided support and feedback throughout this project.

Compliance with Ethical Standards

Funding This work was supported by a Knowledge Synthesis Grant from the Technology Evaluation in the Elderly Network (TVN), Grant # KS2013-08, which is funded by the Government of Canada’s Networks of Centres of Excellence (NCE) Program.

Conflicts of interest JE, HM, JA, KH, VB, and PS declare they have no conflicts of interest.

Open Access This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (http://creativecommons.org/licenses/by-nc/4.0/), which permits any noncommercial use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.
References

1. Brand C, Scott I, Greenberg P, Sargious P. Chronic disease management: time for consultant physicians to take more leadership in system redesign. Intern Med. 2007;37:653–9.

2. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? BMJ. 1999;318(7179):318–22.

3. Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. BMJ. 2007;335:24–7.

4. Gallivan J, Kovacs Burns K, Bellows M, Elgenseher C. The many faces of patient engagement. J Participat Med. 2012;4:32.

5. Kastner M, Tricco A, Soobiah C, Lillie E, Perrier L, Horsley T, Welch V, Cogo E, Antoni J, Straus S. What is the most appropriate knowledge synthesis method to conduct a review? Protocol for a scoping review. BMC Med Res Methodol. 2012;12:114. doi:10.1186/1471-2288-12-114.

6. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review: a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy. 2005;10(Suppl 1):21–34. doi:10.1258/1355819054308530.

7. Greenhalgh T, Wong G, Westhorp G, Pawson R. Protocol: realist and meta-narrative evidence synthesis: evolving standards (RAMESES). BMC Med Res Methodol. 2011;11:115.

8. Grimshaw J. A guide to knowledge synthesis. 2010. Canadian Institutes of Health Research. http://www.cihr-irc.gc.ca/e/41382.html. Accessed 25 Oct 2014.

9. Wong G, Westhorp G, Pawson R, Greenhalgh T. Realist synthesis: RAMESES training materials. http://www.ramesesproject.org/media/Realist_reviews_training_materials.pdf. Accessed 10 Mar 2016.

10. Wong G, Greenhalgh T, Westhorp G, Buckingham J, Pawson R. RAMESES publication standards: realist syntheses. BMC Med. 2013;11:21.

11. Brouwers M, Kho ME, Browman GP, Burgers JS, Cluzeau F, Gallivan J, Kovacs Burns K, Bellows M, Elgenseher C. The many faces of patient engagement. J Participat Med. 2012;4:32.

12. Stolee P, Elliott J, McNeil H, Boscart V, Heckman G, Hutchinson R, Hedley M, Gloubemer S, Judd M. Choosing healthcare options by involving Canada’s elderly: a protocol for the CHOICE realist synthesis project on engaging older persons in healthcare decision-making. BMJ Open. 2015;5(11):e008190.

13. Loffland J, Snow DA, Anderson L, Loffland LH. Analyzing social settings: a guide to qualitative observation and analysis. 4th ed. Belmont: Wadsworth Publishing; 2006.

14. University of Waterloo, Geriatric Health Systems Research Group. Seniors Helping as Research Partners (SHARP). 2013. https://uwaterloo.ca/geriatric-health-systems-research-group/sharp. Accessed 1 Jun 2015.

15. Altman DG. Practical statistics for medical research. London: Chapman and Hall; 1991.

16. Kastner M, Estey E, Parrier L, Graham I, Grimshaw J, Straus S, Zwarenstein M, Bhattacharyya O. Understanding the relationship between the perceived characteristics of clinical practice guidelines and their uptake: protocol for a realist review. Implement Sci. 2011;6:69. doi:10.1186/1748-5908-6-69.

17. Wong G, Greenhalgh T, Pawson R. Internet-based medical education: a realist review of what works, for whom and in what circumstances. BMC Med Educ. 2010;10:1–10.

18. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist synthesis: an introduction. ESRC research methods programme. Manchester: University of Manchester; 2004.

19. International Association for Public Participation (IAP2). Spectrum of participation. 2007. http://www.iap2.org/resource/resmgr/imported/IAP2%20Spectrum_vertical.pdf. Accessed 20 Sept 2013.

20. New Brunswick. A Primary Care Framework for New Brunswick. 2013. http://www.gnb.ca/en/policy/pdf/2012/8752_EN%20Web.pdf. Accessed 20 Sept 2013.

21. Arnstein S. A ladder of citizen engagement. J Am Plann Assoc. 1969;35:216–24.

22. Vancouver Coastal Health. Community Engagement Framework: Spectrum of Participation. 2009. http://www.vch.ca/media/CE%20Booklet%202009.pdf. Accessed 20 Sept 2013.

23. Manitoba Family Services and Housing. Community Engagement Framework. 2008. http://www.gov.mb.ca/fs/ccpubs/community_engagement_framework_May08.pdf. Accessed 20 Feb 2014.

24. National Research Corporation. Picker Institute. Eight Dimensions of Patient-Centered Care. 1987. http://www.nationalresearch.com/products-and-solutions/patient-and-family-experience/eight-dimensions-of-patient-centered-care/. Accessed 20 Sept 2013.

25. Berry LL, Seiders K, Wilder SS. Innovations in access to care: a patient-centered approach. Ann Intern Med. 2003;139:568–74.

26. Mirzaei M, Aspin C, Essue B, et al. A patient-centred approach to health service delivery: improving health outcomes for people with chronic illness. BMC Health Serv Res. 2013;13:251.

27. Mead N, Bower P, Hann M. The impact of general practitioners’ patient-centredness on patients’ post-consultation satisfaction and enablement. Soc Sci Med. 2002;55:283–99.

28. Hogland AT, Winblad U, Arnetz B, Arnetz JE. Patient participation during hospitalization for myocardial infarction: perceptions among patients and personnel. Scand J Caring Sci. 2010;24:482–9.

29. Caress AL, Beaver K, Luker K, Campbell M, Woodcock A. Involvement in treatment decisions: what do adults with asthma want and what do they get? Results of a cross sectional survey. Thorax. 2005;60:199–205.

30. Kahana E, Kahana B, Lovegreen L, Kahana J, Brown J, Kulle D. Health-care consumerism and access to health care: educating elders to improve both preventive and end-of-life care. Res Soc Health Care. 2011;29:173–93.

31. Korner M, Ehthardt H, Steger A. Designing an interprofessional training program for shared decision making. J Interprof Care. 2013;27:146–54.

32. Coulter A. Patient-centered decision making: empowering women to make informed choices. Women Health Iss. 2001;11:325–30.

33. Rotar-Pavlic D, Svab I, Wetzels R. How do older patients and their families evaluate shared decision-making in healthcare? BMC Geriatr. 2008;8:9.

34. Elwyn G, Edwards A, Hood K, et al. Achieving involvement: process outcomes from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. Fam Pract. 2004;21:337–46.

35. Jorm CM, Dunbar N, Sudano L, Travaglia JF. Should patient safety be more patient centred? Aust Health Rev. 2009;33(3):390–9.

36. Philibert I, Patow C, Cichon J. Incorporating patient- and family-centered care into resident education: approaches, benefits, and challenges. J Grad Med Educ. 2011;3:272–8.

37. Lavoie-Tremblay M, Bonin J, Bonneville-Roussy A, et al. Families’ and decision makers’ experiences with mental health care reform: the challenge of collaboration. Arch Psych Nurs. 2012;26:e41–50.

38. Fraenkel L, McGraw S. What are the essential elements to enable patient participation in medical decision making? J Gen Int Med. 2007;22:614–9.
39. Powers TL, Bendall D. Improving health outcomes through patient empowerment. J Hosp Mark Public Relat. 2003;15:45–59.
40. Neeman N, Isaac T, Leveille S, Dimonda C, Shin JY, Aronson MD, et al. Improving doctor-patient communication in the outpatient setting using a facilitation tool: a preliminary study. Int J Qual Health Care. 2012;24:357–64.
41. Vosbergen S, Janzen J, Stappers PJ, van Zwieten MCB, Lacroix J, Idema K, et al. A qualitative participatory study to identify experiences of coronary heart disease patients to support the development of online self-management services. Int J Med Inform. 2013;82:1183–94.
42. Auerbach SM. The impact on patient health outcomes of interventions targeting the patient-physician relationship. Patient. 2009;2:77–84.
43. MacDonald RC, Weeks LE, McInnis-Perry G. End-of-life healthcare decision-making: the intermediary role of the ethicist in supporting family caregivers and health professionals. Work. 2011;40:63–73.
44. Porter Z, Simpson B. Preparing to introduce personal health budgets: Zoe porter and Bernadette Simpson discuss the benefits of a new scheme that enables patients to take charge of their healthcare resources and plan individualised care in collaboration with the professionals caring for them. Nurs Manag. 2013;20:18–23.
45. Muthalagappan S, Johansson L, Kong WM, Brown EA. Dialysis or conservative care for frail older patients: ethics of shared decision-making. Neph Dial Transpl. 2013;28:2717–22.
46. Small DC, Small RM. Patients first! Engaging the hearts and minds of nurses with a patient-centered practice model. Online J Issues Nurs. 2011;16(2):2.
47. Bernabeo E, Holmboe ES. Analysis and commentary: patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. Health Aff. 2013;32:250–8.
48. Toofany S. Empowering older people. Nurs Older People. 2007;19:12–4.
49. Harrington SE, Smith TJ. The role of chemotherapy at the end of life: ‘when is enough, enough?’”. JAMA. 2008;199:2667–78.
50. Solbjør M, Steinsbekk A. User involvement in hospital wards: professionals negotiating user knowledge. A qualitative study. Patient Educ Couns. 2011;85(2):e144–9.