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Shared decision-making with patients with complex care needs: a scoping review

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Abstract

Background A number of patients have complex care needs that arise from interactions among multiple factors, such as multimorbidity, mental health issues, and social vulnerability. These factors influence decisions about health-care and health services. Shared decision-making (SDM), a collaborative process between patients and professionals, is known to improve the quality of the decision-making process. However, follow-up challenges of patients with complex care needs (PCCNs) can lead to SDM specificities.

Objective To identify specificities of SDM with PCCNs.

Methods We conducted a scoping review using the Joanna Briggs Institute (JBI) methodology. We conducted a systematic search across MEDLINE, CINAHL, PsycINFO, and Academic Search Complete databases. Empirical studies about SDM with PCCNs published between 1997 and 2023 were eligible for inclusion. We conducted a mixed thematic analysis using deductive (Ottawa Decision Support Framework and Interprofessional Shared Decision-Making Model) and inductive approaches. Following Arksey & O'Malley's and Levac et al.'s methodological recommendations, we consulted experts (researchers, healthcare professionals, and patient partners) to enhance the findings.

Results Twelve studies were included in the review. Overall, our results demonstrated the importance of recognizing some specificities of SDM with PCCNs, such as the simultaneous presence of multiple decisions and the multidisciplinary and intersectoral nature of the healthcare and health services they receive.

Conclusion This scoping review highlights some specificities that must be considered in SDM with PCCNs to maintain its already-known benefits and ensure positive health and decision-making outcomes.

Keywords Shared decision-making, Complex care needs, Primary care, Patient-centered care, Scoping review, Interdisciplinary

Background

Complex care needs are increasingly seen in practice and literature as the rate of chronic diseases in an ageing population constantly grow [1–4]. In literature, complex care needs have been defined in different ways. The definitions frequently focus on multimorbidity as a strong vector of healthcare complexity [5–7]. However, some authors complete the definition of complex care needs by shedding light on relationships between multiple factors going beyond multimorbidity. They discussed the relationship between multimorbidity, and psychosocial vulnerability [8] or focused on mental health issues as a

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relevant factor of complex care needs and high level of health resources utilization [9]. Some others take the definition further by stating that complex care needs are defined by the interaction between an individual's biological, socioeconomic, cultural, environmental and behavioural determinants [10].

A recent scoping review on nursing care coordination for patients with complex care needs (PCCNs) suggests a definition of complex and social needs integrating multiple key points of these conceptions [11]. Developed from relevant sources in the field of healthcare complexity [12–14], this representation of complex care needs includes biological, socioeconomic, cultural, environmental, and behavioural determinants as areas of vulnerability. Moreover, it describes the specific elements composing these areas. According to this definition: “*complex health and social needs result from [either a combination of two or more elements, or a major vulnerability related to] multiple concurrent chronic conditions, functional and cognitive impairments, mental health challenges and social vulnerability, the individual's characteristics, or a major change in his life or care trajectory*” [11].

As PCCNs are frequently living with multiple elements of vulnerability (e.g. polypharmacy, chronic conditions, neurological or mental health issues, older age, etc.), they may also face several physical, cognitive, social and economic difficulties [15]. These difficulties influence their healthcare utilization, as PCCNs may also frequently use healthcare services, resulting in higher costs to the individual and healthcare system [11, 13]. Complex needs and frequent use of healthcare services may influence decisional needs by inducing several decision-making processes about patients' health [16, 17].

Decisional needs refer to the gap between information and resources owned by patients and those they would benefit from to ensure an informed and value-based decision [18]. Several factors influence decisional needs. Decisional conflict, peer pressure, motivation, support, age, and education are a few examples [17]. It is essential to consider decisional needs within a decision-making process, even more so with PCCNs, as uncertainty may interfere with the decision process and results [19]. Evaluating the decisional needs of patients enhances the understanding of what they need to achieve the best decision and determines what the professional needs to provide the support requested [20].

PCCNs face multiple and frequent decisions of all kinds. According to the literature, management and acceptance of the health condition (e.g. prescriptions, level of care, etc.), use of services, choice of care providers, and management of the physical and social environment are the decision-making situations that cause the most important decision needs for them [21, 22].

Responding to these needs and ensuring the quality of these decisions involves an efficient decision-making process. As PCCNs usually face follow-up and engagement challenges [23], the decision-making process between them and professionals may be suboptimal and fail to produce the desired outcomes [22]. Unmet expectations, decisional conflict, decisional regret and dissatisfaction may arise [22, 24].

Shared decision-making (SDM), a collaborative process between patients and professionals, is known to improve the quality of the decision-making process [25]. It may enhance the engagement and participation of PCCNs and minimize the challenges encountered. However, the complexity of PCCNs' needs could have an important influence on the principles of SDM, as demonstrated by a recent systematic review conducted by Pel-Little et al. (2021). This review aimed to identify barriers and facilitators for SDM as experienced by older patients with multiple chronic conditions. Overall, they found that being in poor health and dealing with cognitive or physical impairments were the most frequent barriers to SDM (58). However, the influence of these barriers needs to be further described to ensure a better understanding of their impact, which was not covered by the review. Thus, our scoping review aimed to identify literature about the specificities of SDM with PCCNs to provide a better understanding of the influence of these patients' characteristics (as hinders) on the process of SDM.

Methods and design

Study design

We conducted a scoping review of SDM with PCCNs to clarify the key characteristics of this concept and guide the conduct of future research on this topic [26–28]. We followed the methodology proposed by the Joanna Briggs Institute (JBI): 1) develop a search strategy; 2) screen and select sources of evidence; 3) extract the data; 4) analyze and present the results [29]. We also added an experts' consultation as proposed in the methodology of Arksey & O'Malley [28] and further enhanced by Levac et al. [26]. This consultation improves the scoping review methodological quality and provides more valuable results at multiple levels (clinical, organizational, research) [26, 28]. We reported data using the Preferred Reporting Items Systematic reviews and Meta-Analyses extension for Scoping Review (PRISMA-ScR) [30].

Research question and Population, Concept, Context (PCC)

How does the shared decision-making process work with patients with complexcare needs?

Population: PCCNs as defined by Karam et al. [11].

Concept: SDM as defined by the authors of the studies minimally including a shared decision process between a PCCN and a healthcare professional.

Context: Decision(s) about healthcare or health services utilization of the patient involved in the SDM process.

Search strategy

We identified relevant studies by performing a literature search using “shared decision-making; patient values; patient preferences; patient priorities; complex problems; complex issues; complex patients; complex needs; complex care; complex existence; complex experience; complex live; complex reality; complex journey and complex situation” as key terms related to the research question mentioned above. The search strategy was developed in collaboration with a librarian (Appendix 1). We conducted our search across four different databases: MEDLINE, CINAHL, PsycINFO and Academic Search Complete. The search strategy was adapted for the EBSCOHost platform, as a simultaneous search in all our selected databases was possible within this platform which is particularly useful for identifying journal articles and other publications on a particular topic within the subject areas covered by each database. We limited this literature search between 1997 and 2023, as the concept of SDM appeared in the literature around 1997 [31].

Eligibility criteria

To be included, studies had to meet three eligibility criteria concerning research design: (i) Primary study, (ii) Full-text available, and (iii) Published in English or French. Furthermore, studies had to meet eligibility criteria concerning research focus, based on the definition of our population, our concept and our context already described in the research question section of this paper regardless of the country and the healthcare settings. Studies describing a decision-making process considering only the patients, only the professional (e.g. clinical decision-making) or only a third party (e.g. legal representative, family member, etc.) were excluded as SDM must at least involve two participants [31]. Studies concerning populations other than PCCNs or decisions other than on healthcare or health services were also excluded.

Screening and selection of sources of evidence

Two independent reviewers (MEPe and PHRL) participated in the screening process. These two reviewers have expertise in the field of healthcare, as MPEP is an RN, BSc, and PHRL is an MD PhD. Using the Covidence (www.covidence.org) web-based collaborative software platform for literature reviews, they assessed the titles and abstracts of 10 studies for standardization, then

evaluated the titles and abstracts of all relevant studies identified by the search strategy using the eligibility criteria described above in increments of 40. As the second part of this process, MPEP and PHRL screened the full text of selected studies. Any disagreements were resolved by discussion between the two investigators until consensus was reached or with a third reviewer (MEPo or CH) if necessary.

Data charting process

Two reviewers (MEPe and PHRL) developed an Excel data-charting form based on relevant variables selected within the decisional needs, decision support and decisional outcomes dimensions of the Ottawa Decision Support Framework (ODSF) and the environment, actors and SDM process dimensions of the Interprofessional Shared Decision-Making Model (IP-SDM) [17, 55]. The form was tested independently for one study and adapted following discussions. The two reviewers performed the extraction of all full text included in the form.

Data items

The final chart allowed for the extraction of study characteristics (authors, year of publication, country, language, study design, objectives, type and number of participants if applicable); population characteristics for patients (age, sex, family settings, education, occupation, culture, home setting, diagnosis/prognosis, complex care needs disposition, others if applicable) and professional characteristics (age, sex, education, specialization, culture, practice setting, experience, counselling style, others if applicable); concept of SDM (definition, key decision factors, decision support, evaluation, decision to be made, first choice, choice selected, feasibility, time); and context of decision(s) (actors, environment, healthcare settings). The extraction grid can be found in Appendix 2.

Data analysis and presentation

We performed a thematic analysis using deductive and inductive methods following Miles, Huberman & Saldana's approach: 1) Data condensation 2) Data display and 3) Drawing and verifying conclusions [32]. The deductive analysis was completed using the ODSF framework and the IP-SDM model. The rationale of this decision relies on our interest in capturing the SDM phenomenon in integrality as the ODSF covers the SDM process, and the IP-SDM covers external factors influencing SDM as well.

1) MPEP extracted all the information from the two reviewers' extraction grid (MEPe and PHRL) and merged it together.

2) As the data was merged, MPEP organized the information regarding the ODSF and IP-SDM domains.

Inductive codes that appeared during this data organization process were also integrated at this step. We performed a second cycle of condensation to ensure a coherent display of the data and confirm the relevance of the inductive codes that appeared during the process. We then compared the data from our codes with the information available within ODSF and IP-SDM and adapted, if applicable, their components to a complex care needs context. The relevance of these adaptations was also triangulated with the experts' perspectives during the consultation.

3) The data display created was presented and discussed with the other research team members (PHRL, MEPO and CH). We identified the relationships between the inductive and deductive codes to organize them in a final data display. Authors discussed codes and themes to reach consensus throughout the analysis process.

Consultation

We conducted a consultation with experts by interviewing, through a deliberative process, one researcher, two case managers, and one patient partner to present the preliminary findings of our scoping review and determine what findings are the most important in SDM with PCCNs. These experts were identified throughout the networks of the research team for their expertise, either with SDM or PCCNs. We consulted researchers because their input may enhance our adaptation of the ODSF and IP-SDM models and contribute to translating these results into clinical practice. We consulted two case managers as representatives of healthcare professionals because they frequently collaborate with PCCNs and are the reference for these patients on an ongoing basis when healthcare decisions must be made. We also consulted patient partners because their perspectives are the central point of the SDM process, and the relevance of the results to them is mandatory for feasibility. The principal investigator (MEPE) conducted two consultations (one with the two case managers and the patient partner and another with the researcher) by videoconference on Teams in March 2024. The meetings were recorded for fidelity but not transcribed.

Ethical approval and consent to participate

This project was approved by the ethics committee of the Centre Intégré Universitaire de Santé et de Services sociaux du Saguenay – Lac-Saint-Jean through an ethics amendment for the consultation requested on December 18th, 2023, and approved on January 08th, 2024. All participants of the consultation phase signed an informed consent form before enrolling in the study.

Results

Selection of sources of evidence

We screened 135 full-text articles. Twelve studies met the inclusion criteria and were included in this review. Our search results and the selection of studies are presented in a flow diagram (Fig. 1), as recommended by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). The studies included in our review shed light on how components of two conceptual frameworks about decision-making (ODSF and IP-SDM) may be adapted to ensure an efficient operationalization of SDM with PCCNs. All included papers, their main features, and their results are presented in Table 1.

Characteristics of sources of evidence

All the included studies were published between 2006 and 2022, with a higher proportion of studies published between 2018 and 2022 (83%). Of these studies, six (50%) used a qualitative design, two (16%) used framework development, two (16%) used case studies, and two (16%) used mixed methods. Most studies (73%) were conducted in a European or North American context. Almost all studies (83%) were conducted in chronic disease healthcare settings, and chronic conditions and older age were the two main elements that justify a population with complex care needs. Options (50%), preferences (50%), and values (33%) were the primary components used to define the SDM process. Characteristics of included studies, such as study design, objectives, and population, are presented in Table 1.

Results of individual sources of evidence

The studies reported SDM particularities with PCCNs in the form of key decision factors ($n=11$), actors ($n=8$), decision support ($n=7$), decision to be made ($n=5$), environment/time ($n=9$), and evaluation feasibility ($n=5$). The SDM process with PCCNs was mainly reported as a collaborative process between at least a patient and a healthcare professional ($n=9$). Still, some studies reported other actors, such as family members ($n=1$), caregivers ($n=2$), or a legal third party ($n=2$). The SDM particularities are presented in Table 1.

Synthesis of results

Several existing components of the ODSF and the IP-SDM can be adapted to operationalize SDM within a complex care needs population. This adaptation results from the data analysis process [32] and the experts' consultation step in this scoping review process. The components of ODSF and IP-SDM for which the mixed thematic analysis produces no data were not included in the synthesis of results.

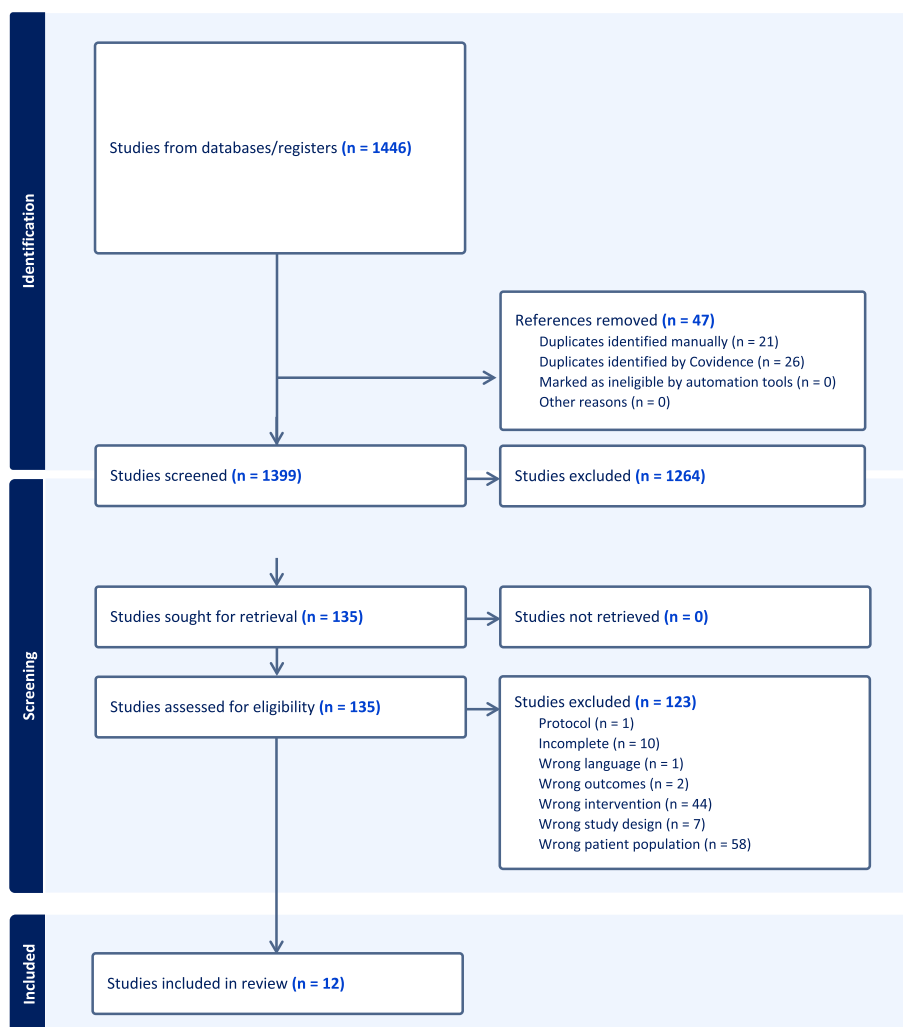


Fig. 1 Flow diagram

Ottawa Decision Support Framework (ODSF – Appendix 3)

ODSF – decisional needs

With PCCNs, goal setting, as the establishment of desired care results based on personal values, is an important component of decisional needs [33–37]. Goals, such as reduced loneliness, improved house-keeping or better sleep, and the resulting options must be prioritized as PCCNs face several healthcare decisions [34, 36, 38, 39]. Also, the patient’s engagement must be considered, as PCCNs face many challenges regarding engagement in healthcare, as well as professional(s) engagement, which can influence their participation [33, 35, 36, 40]. PCCNs frequently request a higher implication of professional(s) in the SDM process [35, 36]. They often fall between the “shared” or “passive” category of roles in decision-making because they rely on providers’ expertise and knowledge [33, 40].

ODSF – decision support

PCCNs frequently collaborate with interdisciplinary and intersectional teams composed of several healthcare and social services professionals who also collaborate with each other. For example, Belcher et al. [33] reported a 1 to 6 range of physicians by patient with a mean of 2.8. Doekhie et al. [42] evaluated the number of primary care professionals (PCPs) most involved for every patient where only 3 patients out of 19 had two or less PCPs involved. This situation results in communication, information sharing and confidentiality challenges [33–36, 40, 41], which should be considered in the establishment of rapport and facilitation of interactive communication.

ODSF – decisional outcomes

First, the ‘quality of the decision-making process’ component should recognize that PCCNs often face multiple health decisions related to disease(s), symptom(s),

Table 1 Included studies

Authors, Publication year, Country	Study design/ Objectives	Healthcare/ Complex care needs settings	SDM definition
Belcher & al; (2006) United States	Qualitative study/ Explore the perceptions of older adults regarding patient involvement in medication decision-making	Chronic diseases/ Physical vulnerability (chronic conditions) Individuals characteristics (polypharmacy, older age)	Physician and patient share information with each other. The physician provides information, or acknowledges uncertainty regarding the harms and benefits of available and benefits of available treatment options and the patient provides information regarding beliefs and preferences; both participate in the decision-making process, although in different aspects
Doekhie & al;(2018) Netherlands	Phenomenological/ Explore the perspectives of patients, informal caregivers, and primary care professionals on patient involvement in the decision-making process in primary care team interactions	Chronic diseases and Primary care/ Physical vulnerability Physical vulnerability Individuals characteristics (older age)	Patient involvement is not a clear-cut concept, rather, it is coproduced through dialogue and interaction by patients, informal caregivers, and professionals in their reciprocal relationships in the primary care team
Elwyn & al;(2020) United States	Framework development/ Develop and integrate goal-based model for SDM to provide both patients and clinicians with an SDM approach suitable for complex healthcare problems	Chronic diseases/ Physical vulnerability (chronic conditions) Psychiatric vulnerability (substance abuse) Individuals characteristics (older age, challenges to self-manage care needs, negative health behaviours)	Goal-based SDM represents a shift in perspective: previous models of SDM assume a model of SDM assume a model of SDM assume a model of SDM assume a relevant options to be considered relevant options to be considered relevant options to be considered
Ng & al; (2019) Malaysia	Case study/ A dual-layer approach is proposed whereby PCPs and patients make decisions on which disease(s) (layer 1) and treatments (layer 2) to prioritize	Chronic diseases and Primary care/ Physical vulnerability (chronic conditions, polypharmacy, functional impairment), Individuals characteristics (older age, challenges to self-manage care needs, low literacy, negative health behaviours)	SDM is a consultation model for preference-sensitive decisions for preference-sensitive decisions for preference-sensitive decisions for preference-sensitive decisions pros and cons of options are discussed, and a consensus on which option is best is agreed between patient and doctor
Ozavci & al;(2022) Australia	Focused ethnographic/ Explore through a discursive lens, strategies that enable patient-centered medication communication at transitions of care	Chronic diseases and Palliative care/ Physical vulnerability (chronic conditions), Individuals characteristics (older age), Care trajectory change (transition to palliative stage)	[Patient-centered communication] comprises health professionals responding to patients' informal needs, preferences, and concerns, being sensitive to patients' emotions and beliefs, providing empathy and support, and enabling patients' self management and involvement in decision-making
Parimbelli & al;(2018) Canada	Framework development/ Address the challenges of providing decision support to SDM by 1) formalizing the process, situating it as part of team-based care delivery, and 2) incorporating workflow concepts allowing workflow concepts allowing tasks	Chronic diseases and Palliative care/ Physical vulnerability (chronic conditions) Individuals characteristics (older age), Care trajectory change (transition to palliative stage)	SDM fosters active involvement of a patient in a process where physician presents evidence-based treatment information and options while openly eliciting and incorporating patient values and preferences
Roodbeen & al;(2021)	Explanatory sequential mixed methods study Examine SDM in palliative care for low health literacy patients conducted by specialized palliative care clinicians and professionals integrating a palliative approach and assess these professionals' perspectives on their own SDM	Oncology and Palliative care/ Physical vulnerability Physical vulnerability Individuals characteristics (low health literacy)	In SDM, health care professionals and patients decide the best treatment and care option together treatment and care option together their pros and cons and personal preferences, and the circumstances of the patient

Table 1 (continued)

Authors, Publication year, Country	Study design/ Objectives	Healthcare/ Complex care needs settings	SDM definition
Sbai & al; United Kingdom	Case study/ Contextualizes the application of SDM through Physical Assessment (CGA) in Older patients with Gynecological malignancy	Chronic diseases and Oncology/ vulnerability (chronic conditions, polypharmacy, physical impairment), Cognitive impairment (dementia, Neurological disorders), Individuals characteristics (older age)	SDM is a collaborative process in SDM is a collaborative process in patients (or their appointed/nominated deputies) work in partnership to reach a deputies) work in partnership to reach a deputies) work in partnership to reach a values
Schoot & al;(2022) Netherlands	Netherlands Provide greater insight into the current decision making process by exploring the expectations, experiences, and health outcome priorities of all stakeholders	Chronic diseases/ Physical vulnerability (chronic conditions) Individuals characteristics (older age)	[SDM] is an approach where clinicians and patients make clinicians and patients make best available evidence
Treichler & al;(2021) United States	Framework development/ Propose a novel paradigm, Collaborative decision making (CDM), which has the promise to advance SDM and to increase patient- SDM and to increase patient- mental health settings	Mental health care/ Physical vulnerability (chronic conditions) Psychiatric vulnerability (common and severe mental illnesses)	SDM typically includes three steps:1) the patient describes the problem2) the clinician assesses the patient, describes the treatment options and provides clinical expertise and3) the two (or more, if family or others are involved) discussed and come to a consensus about the treatment decision
Van de Pol & al; (2016) Netherlands	Delphi study/ Develop and gain consensus for a model of SDM in frail older patients with multimorbidity	Chronic diseases/ Physical vulnerability (chronic conditions), Individuals characteristics (older age)	In SDM, professionals and patients share their knowledge, values, and preferences about healthcare choices and, together, they explore beneficial solutions
Vermunt & al;(2019) Netherlands	Qualitative study/ Analyze clinician perceptions of the concept of goal setting within the context of SDM with older patients with multimorbidity	Chronic diseases/ Physical vulnerability (chronic conditions) Individuals characteristics (older age)	Define/explain the issue, present the options, discuss pros/cons, preference/values of the user, discuss auto-efficacy and capacities of the user, recommendations and knowledge of the professional, clarify understanding, the professional, clarify understanding.

functionality or about fundamental aspects of life such as independence. The evaluative elements of the quality of the decision-making process must then consider this situation to ensure the feasibility of the evaluation. It should also consider patient engagement and professionals' engagement as new elements of evaluation coming from decisional needs are assessed upstream [33, 35, 36, 40].

Second, the 'quality of the decision' component should also recognize that PCCNs face multiple health decisions to ensure the utilization of coherent evaluative elements in evaluating the quality of the decision (e.g., evaluating decisional outcomes vs. prioritization). Goal attainment should also be considered as a new element of evaluation based on decisional needs assessed upstream [34].

Interprofessional Shared Decision-Making Model (IP-SDM – Appendix 4)

IP-SDM – environment

First, 'social norms' within the environment concept should consider already existing relationships between professionals from the interdisciplinary/intersectional team and the patient [33, 41–43] to maximize the creation and maintenance of trust.

Second, 'organizational routines' (e.g. procedures) within the environment concept should be adapted to ensure patient participation [36, 38–40, 43], knowing that PCCNs may face challenges related to engagement in their care.

IP-SDM – actors

First, 'family/surrogate/significant others' within the actors' concept should, with appropriate consent, support PCCNs as they face multiple difficulties daily. They should also support the engagement and empowerment of the patient [36, 41, 42].

Second, 'patient' within the actors' concept may present with more than one health decision to make. Sometimes, professionals may be the ones who must initiate the SDM process by informing the patient that there are issues that deserve decision-making [33, 34, 36, 39].

Third, 'healthcare and social services professionals' within the actors' concept should see themselves as an interdisciplinary/intersectional team and adopt a shared vision to deliver a coherent message to the patient and avoid the development of decisional conflict [33, 34, 39–41, 43].

IP-SDM – SDM process

First, the 'decision to be made' within the SDM process concept should also consider the fact that PCCNs face multiple difficulties daily, leading to several health decisions. However, discussing more than one issue during a consultation may lead to a greater use of SDM.

Second, 'information exchange' within the SDM process concept would benefit from integrated goal setting, as it facilitates discussion about options. PCCNs may observe multiple goals as they face several health conditions and issues. This situation may influence the type, number, nature and extent of available options. For example, a patient experiencing hip pain and dizziness may want to continue to live at home independently, meet a wider circle of friends, and reduce their risk of falls and pain [34].

Third, 'feasibility' within the SDM process concept should, as it considers the feasibility of options, also consider the feasibility of goals as this component ensures the quality of the decision.

Finally, 'time' within the SDM process concept should specify the time associated with the evolution of the patient's health condition, as PCCNs may have conditions evolving differently than single disease conditions. This temporality should fit within the time associated with the SDM process.

Discussion

Summary of evidence

The aim of this scoping review was to understand how the SDM process works with PCCNs. Our synthesis allowed us to identify 12 studies published between 2006 and 2022 identifying specificities of SDM with PCCNs. Overall, we found that when PCCNs must face healthcare decisions, specific components of the SDM process must be considered. The emergence of a new decision-making role between passive and shared participation for PCCNs led us to the following observations: 1) they face multiple healthcare decisions and options simultaneously and on a daily basis; 2) they constantly collaborate with interdisciplinary and intersectoral teams to manage the health care and services they receive; 3) organizational adaptations of procedures and policies regarding decision-making are mandatory; and 4) actual models must be adapted to maintain the benefits of SDM in a complex care needs context.

One of the findings of this scoping review is that the SDM process with PCCNs must consider the multiple healthcare decisions and options their condition generates and that they must deal with. As demonstrated by our results, PCCNs are frequently elders living with multimorbidity [33–38, 41–44]. This situation may induce multiple physical, psychological, socioeconomic, and cultural difficulties that can lead to several healthcare decisions [22]. Integrating care is recognized as the best approach to delivering care to patients living with several chronic conditions [45]. However, the literature shows that PCCNs frequently face fragmented, incomplete, and

ineffective care, even in the decision-making field [46, 47].

In this scoping review, interdisciplinary and intersectionality were identified as contextual factors to consider when an SDM process occurs with PCCNs. Many studies we included in our scoping review demonstrated the influence of multiple healthcare and social services professionals on patient collaboration in terms of SDM [33, 39–41]. This is in line with the literature. As the effectiveness of this teamwork organization is recognized, it also comes with its own set of challenges [48, 49]. PCCNs may trust health information sources differently [21, 50]. Moreover, their mistrust of healthcare, frequently associated with their experiences, could negatively impact their healthcare and service utilization and the management of their health conditions [51, 52]. SDM with PCCNs should take account of this specificity by identifying the most significant and trustworthy relationships for the patient to ensure his or her full engagement in SDM and better decision-making outcomes. Communication is also a key challenge in this context. Our results show that multidisciplinary and intersectionality raises communication issues related to information sharing and confidentiality [33, 35, 41–43]. This is consistent with the literature that mentions that fragmented communication among multidisciplinary care teams leads to adverse health outcomes [53, 54]. Fragmented communication within an SDM process with PCCNs may lead to higher decisional conflicts for patients.

This scoping review also reinforced the importance of adapting the actual organizational procedures for decision-making to adequately address the issues of PCCNs and maintain a positive evaluation of the decision-making process and the outcomes of the decisions taken. Our results demonstrated that the structure and the vision of health and social services institutions may limit the benefits for PCCNs that don't necessarily fit into the usual trajectories implemented for a single decision [33, 36, 38–40, 43]. PCCNs have different decisional needs than the usual patients. They require a different level of support and must make multiple decisions about different health and social care topics. This is coherent with the literature, which identified several decisional needs for this population related to use of services and choice of providers, management of the physical and social environment, level of care and end-of-life, management of their health condition, and acceptance of their health condition [21, 22]. As PCCN populations are growing, there is a need to think about innovative ways to ensure adequate responses to their specific needs and issues.

Finally, although the Ottawa Decision Support Framework and the Interprofessional Shared Decision-Making Model are widely recognized models for SDM, they

must be adapted for contexts where multiple decisions may arise, such as with PCCNs. Indeed, although the IP-SDM has been previously validated in primary care, the over-representation of healthcare professionals ($n=76$) compared to patients ($n=3$) coupled with the lack of description of the patients who took part in this validation undermines the transferability of results from the use of this model with a population with complex healthcare needs [55]. Furthermore, although ODSF supports healthcare decisions under uncertainty, it has never been formally validated in the context of complex care needs following its development. It has, however, been widely used in many contexts and for many different indications [56]. Their utilization is limited in a context where patients face multiple healthcare and social services decisions for which there is more than one possible and valid option.

More specifically, we suggest three adaptations to current models so that they can better respond to the specific reality of SDM with PCCNs: 1) modulate components of needs and decision outcomes assessment so that they recognize the influence of multiple decisions and options that PCCNs often face by adding, among others, a prioritization exercise of decisions and options; 2) modulate components used to evaluate the decision-making support required and those used to recognize key actors in the process as an indicator of challenges related to interprofessionality and intersectorality by integrating the notion of communication, information sharing, and confidentiality to models and 3) modulate components used to assess organizational procedures and policies to recognize whether they meet the specificities of SDM with PCCNs. This can be done by adding indicators to assess the concordance between the process and the participation and commitment desired by PCCNs as assessed in the decision-making needs upstream.

Strengths and limitations

Our study has some limitations. We did not carry out a study on quality assessment. Such assessments should be carried out in the context of systematic review-type knowledge synthesis [57]. This enhances the methodological rigor of a review study by enabling it to recognize the overall quality of the studies, particularly in terms of the risks of bias they contain. This evaluation, therefore, guides the choice of studies to be included in the synthesis. A study of inferior quality may be excluded if the risk of bias is too high. The fact that we did not carry out this assessment is in line with the recommendations but is nevertheless a limitation of our study. A second limitation is our decision to restrict ourselves to literature published only in English or French, as well as literature published in

databases, and not to examine grey literature. Moreover, although we followed the methodology proposed by the Joanna Briggs Institute, we did not establish inter-rater reliability within the study selection process as recommended [29]. However, discussions between the reviewers allowed to achieve consensus. Another limitation directly concerns the studies included in the synthesis. Our results are based on studies from West European and North American contexts, which limits their contextual implication for other countries as health systems contexts may be different. The fact that no protocol was done before the conduct of this scoping review constitutes a fourth limitation of our study. Finally, we decided to consider articles for inclusion only when authors explicitly referred to complexity. This is the reason why our search strategy yielded only 1,446 references.

Conclusion

This scoping review highlights multiple specificities that must be considered to maintain already known benefits of SDM for a population with complex care needs and ensure positive health and decision-making outcomes. Future research will be necessary to examine the recommended adaptations of the ODSF and the IP-SDM. It could evaluate the operationalization of the components of SDM with PCCNs by testing its feasibility of use in clinical practice with different types of professionals. It would allow us to evaluate the real influence of these specificities on outcome measures.

Abbreviations

SDM	Shared decision-making
PCCNs	Patients with complex care needs
ODSF	Ottawa Decision Support Framework
IP-SDM	Interprofessional Shared Decision-Making Model
JBI	Joanna Briggs Institute

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12875-024-02633-9>.

Supplementary Material 1.
Supplementary Material 2.
Supplementary Material 3.
Supplementary Material 4.

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Authors' contributions

MEPe, MEPo, CH, and PHRL are the principal contributors to this study. MEPe drafted the paper, and MEPo, CH, and PHRL improved and approved the manuscript.

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Data availability

The datasets used and analyzed in this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This scoping review is part of a larger project that has received ethics approval from the Centre Intégré Universitaire de Santé et de Services sociaux du Saguenay – Lac-Saint-Jean ethics committee on November 22nd, 2021, under reference 2022–289. An ethical amendment was submitted on December 18th, 2023 for the data collection within the experts' consultation with researchers, healthcare professionals, and patient partners of this scoping review. This ethical amendment was approved on January 8th, 2024. All methods followed the relevant guidelines and regulations (Declaration of Helsinki).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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