

# Decision-making and Related Outcomes of Patients with Complex Care Needs in Primary Care Settings : A Systematic Literature Review with A Case-based Qualitative Synthesis

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## Research Article

**Keywords:** patients with complex care needs, decisional needs, primary care, shared decision-making, patient-practitioner communication, interprofessional coordination, vulnerable population

**Posted Date:** February 11th, 2022

**DOI:** <https://doi.org/10.21203/rs.3.rs-1185708/v1>

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# Abstract

## Background

In primary care, patients increasingly face difficult decisions related to complex care needs (multimorbidity, polypharmacy, mental health issues, social vulnerability and structural barriers). There is a need for pragmatic conceptual model to understand decisional needs among patients with complex care needs and outcomes related to decision. We aimed to identify types of decisional needs among patients with complex care needs, and decision-making configurations of conditions associated with decision outcomes.

## Methods

We conducted a systematic mixed studies review. Two specialized librarians searched five bibliographic databases (Medline, Embase, PsycINFO, CINAHL and SSCI). A team of twenty crowd-reviewers selected empirical studies on: (1) patients with complex care needs; (2) decisional needs; (3) primary care. Two reviewers appraised the quality of included studies using the Mixed Methods Appraisal Tool. We conducted a 2-phase case-based qualitative synthesis framed by the Ottawa Decision Support Framework and Gregor's explicative-predictive theory type. A decisional need case involved: (a) a decision (what), (b) concerning a patient with complex care needs with bio-psycho-social characteristics (who), (c) made independently or in partnership (how), (d) in a specific place and time (where/when), (e) with communication and coordination barriers or facilitators (why), and that (f) influenced actions taken, health or well-being, or decision quality (outcomes).

## Results

We included 47 studies. Data sufficiency qualitative criterion was reach. We identified 69 cases (2997 participants across 13 countries) grouped into five types of decisional needs: "prioritization" (n=26), "use of services" (n=22), "prescription" (n=12), "behavior change" (n=4) and "institutionalization" (n=5). Many decisions were made between clinical encounters in situations of social vulnerability. Patterns of conditions associated with decision outcomes revealed four decision-making configurations: "well-managed" (n=13), "asymmetric encounters" (n=21), "self-management by default" (n=8), and "chaotic" (n=27). Shared decision-making was associated with positive outcomes. Negative outcomes were associated with independent decision-making.

## Conclusion

Our results could extend decision-making models in primary care settings and inform subsequent user-centered design of decision support tools for heterogenous patients with complex care needs populations.

## Background

Community-based primary health care (hereafter, primary care) plays a crucial role regarding patients with complex care needs (PCCNs) (1, 2). Typically, PCCNs combine multimorbidity, polypharmacy, mental health issues, and social vulnerability, and face structural barriers that hamper optimal use of health and social care services (3-5). PCCNs often face difficult decisions, yet they experience unmet care needs, fragmented care, inadequate quality of care, poor health outcomes, and services overuse or underuse (6, 7). However, the specific nature of PCCNs' decisional needs is unknown, and assessment of decision outcomes is lacking, which hinders the design of effective decision support strategies and implementation of shared decision-making (SDM).

### 1.1 Treatment decision-making models

In their seminal paper, first published in 1997 and then revisited in 1999, Charles, Gafni (8), Charles, Gafni (9) conceptualized SDM and described other treatment decision-making models. In the paternalistic model, the patient plays a passive role in the treatment decision-making process vis-a-vis the physician, who is seen as the expert and “guardian of the patient's best interest” (8: p.682-83). The role of the patient is limited to providing consent to the treatment (10). Three main models have since been proposed in reaction to the paternalistic model.

### **First - Professional-as-agent model**

In this model, deriving from the agency model in health economics, the physician directs health care as the patient's agent, making choices for them on the assumption that they understand what their patients want (11). One of the central critiques of this model is that physicians act on this assumption without first explicitly testing it (8: p.684). Medical anthropology studies also suggest that the PCCN's perception of his/her illness episode changes according to context, emotional state, cultural values and taboos, and intersubjectivity in clinical encounters (12, 13). During the clinical encounter, however, the practitioner only has access to one version of the patient's illness perception.

### **Second - Informed decision-making model**

This model puts the responsibility of the decision on the patient (11). The patient becomes autonomous once empowered by being informed of the possible risks of alternative therapeutic options and their clinical effectiveness, and can make decisions that reflect both their preferences and the best scientific knowledge available (Hurley et al., 1992 cited in 8: p.683). In this model, the physician's role is limited to giving information to the patient, who theoretically no longer needs to share the decision-making because the patient now possesses both components (information and preferences) viewed as essential to the task (Levine et al., 1992). In this case, “information transfer can be done without the presence of any health care worker, for example, by the patient viewing an interactive video” (8: p.683). In this model, decision aids are a form of educational intervention, presenting information to patients about treatment benefits and risks to “encourage evidence-based decision-making” (9: p.655). Gafni, Charles (11: p.352) argue “that the approach of transferring information to the patient is easier (but not easy) and, hence, more feasible than transferring each patient's preferences to the physician in each medical encounter.” These models both involve information sharing, but neither explicitly involves shared decision-making.

### **Third – Shared decision-making model**

SDM model advocates for a process where patient and practitioner work together to make an informed choice congruent with patient values (14, 15). This model “is seen as a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being” (8: p 682). Charles, Gafni (8) suggest that in SDM, (1) at least two participants, i.e., a clinician and a patient, are involved; (2) both parties share information; (3) both parties take steps to build a consensus about the preferred treatment; and (4) an agreement is reached on the treatment to implement. They subsequently revised this model to incorporate a more dynamic perspective on shared decision-making by recognizing the iterative nature of this process Charles, Gafni (9).

SDM has been associated with improving well-being and better experiences of the health and social care system. The SDM model has been revisited and adapted multiple times, e.g. to chronic disease (16) and primary care (17) . Nonetheless, PCCNs' decisional needs have not been considered in any of these adaptations. In this paper we revisit Charles et al.'s (1997) model and pay closer attention to what it implies for the specific needs of PCCNs.

SDM is not suitable for every patient, decision, and context. Some patients face uncertainty about their disease outcome and feel unwelcome time pressures to make a choice among competing alternatives. Extreme psychological and/or physiological vulnerability may make it difficult for patients to participate in decision-making, no matter how well informed

they feel (8: p. 684). Research indicates that SDM and thus effective support for decision-making is not experienced by the most vulnerable populations (18). However, practising SDM with vulnerable populations can reduce inequities in health (19). Although Charles et al. (1997) recognize that different models of decision-making are more or less appropriate depending on the context, they do not discuss this in depth. Faced with the enormous task of contextualizing decision-making, the authors focus instead on micro-level analysis, i.e. decision-making limited to that occurring during one-on-one clinical encounters, to the detriment of meso and macro levels (8: p. 682), such as decision making with interprofessional teams, which is more complex (20). While interprofessional SDM has been addressed since (21), the contextualization of this model with the PCCNs population has received little attention.

## **1.2 Theory of social systems**

We used Luhmann's theory of social systems (22) as a basis for exploring primary care, complexity and decisional needs. In line with this theory, we include primary care among communication-based social systems. Primary care systems' boundaries vary because they are structurally linked to other systems (interpenetration and mutual influence) such as the psychic systems of PCCN/caregivers and practitioners, and other social systems such as mental health services, social care services and hospital services. Researchers are beginning to apply Luhmann's work on communication-based, inter-related and multi-context social systems to health sciences, e.g., in studies on person-centered care and integrated care (23).

In Luhmann's theory, complexity refers to the impossibility of connecting every element with every other element of a system, including the relationships between people (psychic systems) and social systems (22, 24). Regarding decisional needs in primary care, complexity refers to the repeated pressure on PCCN/caregivers and practitioners to select one option among many, despite uncertainties and lack of consensus undermining the decision-making process. In social systems, complexity can be reduced by following a procedure that enables or facilitates the selection of options, such as decision support tool, an intervention, or a program. Such procedures can be complex in themselves, but often "only complexity can reduce complexity" (22: p.26). Information reduces complexity because it can suggest or exclude certain options, which helps reduce the options (22: p.68). Luhmann defines communication as the function of finding/receiving, sharing, and understanding information. According to the four main dimensions of the quality of care, satisfactory communication improves (a) equitable access to health and social care services, (b) continuity and coordination of care, (c) cost-effective care, (d) patient safety and maintenance of caregivers' health (25).

## **1.3 Decisional needs assessment**

Decisional needs assessments aim to describe the context of decision-making and the specific support required. Assessing the decisional needs of patients focuses on identifying specific decision points with multiple options that need considering (26, 27). Decision support interventions aim to address decisional needs by (a) resolving decisional conflict, (b) improving knowledge and information exchange, (c) clarifying patient values, preferences, and expectations, and (d) identifying the resources they need including social support. Unmet decisional needs affect the quality of decisions, e.g., leading to uninformed decisions that do not match what matters most to patients. This in turn may affect the uptake and maintenance of the chosen option, lead to negative emotions such as decision regret, and affect healthcare use (e.g., provoke overuse or underuse) as well as produce harmful health outcomes (e.g., harms of non-beneficial options). In the case of PCCNs, who face a cascade of difficult decisions which, in addition, often involve multiple stakeholders such as relatives, caregivers and health and social care practitioners, meeting decisional needs and reducing the harm caused by poor quality decisions is even more urgent. However, there are significant knowledge gaps regarding the decisional needs of PCCNs and their caregivers (28). In addition, no study presents testable propositions of outcomes associated with the decision-making conditions of PCCNs. Therefore, we aimed to identify types of decisional needs among PCCNs, and pattern of decision-making conditions associated with decision outcomes (hereafter, decision-making configurations).

# Methods

## 2.1 Study design

The protocol was previously published (29). We conducted a systematic mixed studies review (qualitative, quantitative, and mixed methods studies) with an international multidisciplinary team including primary care researchers and knowledge users (patient-partner, practitioners, service managers and policy makers) (30, 31). We systematically searched, identified, selected, appraised, and synthesized qualitative and quantitative evidence. This review combined the reporting recommendations from the PRISMA statement for systematic literature reviews (PRISMA checklist available in additional file 1) (32) and the ENTREQ statement for enhancing transparency in reporting a qualitative review (Tong et al., 2012).

## 2.2 Eligibility criteria

We based eligibility criteria on a pilot project, a case series (33) and a scoping review (34), that sought to identify characteristics of PCCNs and possible support interventions. We included empirical studies (using qualitative, quantitative or mixed methods) written in French, English or Spanish when they (1) dealt directly or indirectly with PCCNs, or a population with at least two of the following characteristics: multimorbidity; mental health issues; polypharmacy; social vulnerability (socio-economic deprivation, highly disabled people, marginalized population); or healthcare services overuse or underuse, (2) concerned a decision-making process and included a decision outcome description (quality of the decision, actions taken, health and well-being impacts); (3) were conducted in a primary care setting or dealt with primary care settings directly or indirectly, e.g., transition from hospital.

## 2.3 Search strategy

Two specialized librarians in systematic mixed studies reviews developed and tested the search strategy (available in additional file 2) to include the four main concepts: PCCNs, decisional needs, primary healthcare, and empirical research. They explored five bibliographic databases: Medline (Ovid), Embase (Ovid), PsycINFO (Ovid), CINAHL (EBSCOhost), and the Social Sciences Citation Index (Web of Science). In each data base, the search strategy was conducted from inception to December 2017. In addition, we asked the team members to point us to any other relevant studies.

## 2.4 Selection of eligible studies

We trained twenty crowd-reviewers to select relevant studies. This method of selection by crowdsourcing is detailed elsewhere (35). Crowdsourcing “draws on a large pool of people who individually make small contributions that add up to big efforts” (36).

We imported bibliographic records (including titles and abstracts) into EndNote and removed duplicates using Bramer’s method (37). Then, we imported all studies into specialized online software for selection (DistillerSR). Crowd-reviewers were researchers, graduate students, and practitioners from different disciplines (family medicine, nursing, occupational therapy, epidemiology, and social sciences). The lead author (A1) trained the crowd-reviewers. During the selection process, we randomly chose, for each crowd-reviewer, sets of excluded/included studies. The trainer met crowd-reviewers individually, and clarified the concept when they excluded relevant studies or included irrelevant ones. Based on this selection process, with continuous quality control, the interdisciplinary diversity of crowd-reviewers’ viewpoints helped us establish an initial raw classification of PCCNs- and decisional needs-related concepts. For each record, two independent reviewers performed the following two-step selection:

Step 1: For each title/abstract, two crowd-reviewers independently answered four questions: (a) Is this record about a study involving PCCNs?; (b) Is this record useful for decisional needs assessment?; (c) Does this record involve (deal with) a primary health care setting?; and (d) Is this an empirical study? The response options were: yes, no, cannot tell. A1 made the final decision concerning records with contradictory responses.

Step 2: For each full-text paper, two crowd-reviewers independently applied the same eligibility criteria and response options. A1 trained crowd-reviewers using a comprehensive codebook with definitions and illustrative examples. The codebook helped reviewers to quickly justify the inclusion of a study.

## 2.5 Critical appraisal of included studies

We used the Mixed Methods Appraisal Tool (MMAT) to appraise and describe the methodological quality of the included qualitative, quantitative and mixed methods studies (38). Two reviewers independently appraised all included studies and met to resolve disagreements (no third-party arbitration was needed).

## 2.6 Data extraction and qualitative synthesis

A1 extracted the characteristics of included studies (year, research design and number of PCCNs) and excerpts on decisional needs. The second author (A2) verified the extraction. With respect to the few studies that compared PCCNs with other patients, we retained only the PCCNs-related data. Then we performed a hybrid deductive/inductive thematic synthesis of the qualitative evidence (39) in two phases (31) to build a typology of decisional needs and decision-making configurations.

Qualitative methodologies is appropriate to get an in-depth and holistic understanding of complex phenomena (40), like PCCN decisional needs. Qualitative synthesis methodologies aim to explore people's perceptions of complex realities by synthesizing data from studies across a range of settings (41). Decision-making processes in complex care needs situations depend on several micro, meso and macro contexts and thus can be synthesized qualitatively. Given the importance of conducting an in-depth analysis, most qualitative syntheses are carried out on a small number of studies (41).

Data saturation is often used in qualitative research as a criterion to assess if the data collection and analysis cover the range of perspectives about the phenomenon of interest. It is an ideal to strive for, rather than a goal to achieve. This is particularly true when exploring heterogeneous populations and complex topics. As Suri states, "the stage of data saturation is not frequently reached in either primary research or research synthesis projects" (42: p. 73). Data sufficiency is the criterion used to appraise reviews with qualitative synthesis : "(1) data should be sufficient to permit comparisons among selected dimensions and constructs; (2) the reports should reflect the work of several distinct and independent investigators; and (3) the data should be sufficient to answer the research question" (42: p. 37 cited in (35)).

In addition, literature reviews with qualitative syntheses give an essential place to theories (43), and can combine qualitative and quantitative evidence (31). Our synthesis was cases-based which helps generate innovative, empirically validated, and testable conceptual frameworks (44, 45). While there is no ideal number of cases to build a theory, Eisenhardt, an expert in the field, suggested a minimum of four cases (46).

## Phase 1 – Typology of decisional needs

The deductive component of the synthesis was derived from the Ottawa Decision Support Framework (ODSF) (47). The ODSF workbook proposes a step-by-step guide for decisional needs assessment that can be performed using different data collection methods, including a review of the literature (27).

According to the ODSF workbook, our initial codebook included the following thematic categories: (a) type of decision; (b) PCCNs' bio-psycho-social characteristics; (c) stakeholders' roles in the decision-making; (d) decision-making context; (e) intrinsic or extrinsic conditions influencing decision-making; (f) decision outcomes (e.g., actions taken, health and well-being impacts, and decision quality, i.e., informed and/or value-based).

We conducted data extraction, interpretation, and coding iteratively, going back and forth from articles and data to themes. A1 coded articles using NVivo 11 (48), and made an inventory of decisional needs with written interpretations. A1 and A2 ensured consistency and rigor by holding weekly meetings and combining their interpretations of the decisional needs identified (49).

In the inductive component, A1 and A2 identified themes and subthemes suggested by the data. They performed the synthesis and produced an initial codebook including a structured list of these themes and subthemes with definitions and illustrative examples. In 2017, in the project design step, they had conducted four meetings with a core group of 12 co-researchers including a patient-partner and three members of the international advisory committee. This led them to revise the codebook (available on demand), clarifying the definitions and adding subthemes. In 2018, they conducted seven group meetings with the core group who discussed, approved, or improved Phase 1 results and Phase 2 methodological elements.

## **Phase 2 – Decision-making configurations**

A1 used NVivo's advanced queries functions (qualitative matrix) to cross-analyze the themes and establish relationships among them. Following Gregor's explicative-predictive theory type, we synthesized cases to explain decisional needs and predict testable propositions of pattern of decision-making conditions associated with decision outcomes (50). In line with Gregor (50), an explanation and prediction theory aims to answer the following question : what is, how, why, when, where, and what will be (e.g. outcome). We defined a case as a decisional need involving: (a) a decision, e.g. use of service (what), (b) concerning a PCCN with bio-psycho-social characteristics, e.g. social vulnerability (who), (c) made independently or in partnership, e.g. with the practitioner (how), (d) in a specific place and time, e.g. during a clinical encounter (where/when), (e) with communication and coordination barriers or facilitators , e.g. communication quality with practitioner or interprofessional team (why), (f) an influence on actions taken, health and well-being, decision quality (decision outcomes). For each case, A1 wrote a memo, i.e., a summary of the case-related data and themes, explaining decision-making configurations, i.e., the conditions (what, who, how, where, when, why) and related outcomes (6W-O). These memos were reviewed and discussed by A1 and A2 in weekly meetings and illustrated with a visual diagram in the form of a spider web representing the 6W-O relationships of each case (Fig. 1). Spider web diagrams are a visualization tool that helps compare different dimensions of a complex concept (51). To illustrate the types of decisional needs identified, we selected 31 typical memos (maximum 6W-O variation sampling) and discussed them with five knowledge users who validated the cases based on their expertise and practical experience. Second, we mapped each case on to our spider-web diagram, cross-associating similar outcomes, and conditions to create a series of different patterns. We then grouped these patterns into decision-making configurations, i.e., groups of patterns that could represent a higher or lower potential for SDM (Fig. 2).

# **Results**

## **3.1 Description of included studies**

As shown in Fig. 3, we screened 8616 records and 1293 full-text papers. Of those, 47 studies were included in the synthesis: 41 qualitative, two quantitative and four mixed-methods studies (Table 1). Together, these studies represent a large sample of 2997 participants (2107 patients, 698 practitioners and 192 caregivers) from 13 countries. Among the studies, we identified 69 decisional needs cases (see additional file 3 tables for more details about cases).

**Table 1. Table of characteristics of included studies (n=47)**

Sources	# of participants (total)	# of patients	# of caregivers	# of practitioners	Country
(52)	302	302	0	0	United States
(53)	57	40	0	17	United States
(54)	142	0	0	142	Norway
(55)	41	41	0	0	United Kingdom
(56)	32	19	0	13	United Kingdom
(57)	33	25	8	0	Canada
(58)	10	5	0	5	Switzerland
(59)	14	14	0	0	United Kingdom
(60)	180	0	0	180	Sweden
(61)	36	21	0	15	Germany
(62)	53	53	0	0	United States
(63)	40	20	0	20	United Kingdom
(64)	41	28	13	0	Lebanon
(65)	59	27	27	5	Canada
(66)	35	35	0	0	Canada
(67)	86	43	0	43	Germany
(68)	8	0	0	8	Australia
(69)	25	0	0	25	Netherlands
(70)	50	50	0	0	United States
(71)	30	30	0	0	United States
(72)	23	0	17	6	Canada
(73)	807	807	0	0	Belgium
(74)	65	16	37	12	Canada
(75)	18	18	0	0	United Kingdom
(76)	21	21	0	0	United States
(77)	7	0	7	0	United Kingdom
(78)	26	0	0	26	Australia
(79)	81	29	24	28	Canada
(80)	62	62	0	0	Canada
(81)	21	21	0	0	Ireland
(82)	20	20	0	0	United States
(83)	25	25	0	0	United States
(84)	40	20	0	20	United Kingdom

(85)	83	27	28	28	Canada
(86)	36	36	0	0	United States
(87)	55	35	0	20	United Kingdom
(88)	20	0	20	0	Australia
(89)	37	8	0	29	United Kingdom
(90)	50	50	0	0	United Kingdom
(91)	16	0	0	16	New Zealand
(92)	73	60	0	13	Netherlands
(93)	16	4	0	12	Sweden
(94)	26	26	0	0	Australia
(95)	28	28	0	0	United Kingdom
(96)	30	30	0	0	United Kingdom
(97)	15	0	0	15	United States
(98)	22	11	11	0	Netherlands

Overall, the quality of the 47 included studies was deemed good, according to the 2018 version of the MMAT (see additional file 4). Among the 41 qualitative studies, 14 addressed all five MMAT qualitative criteria, 23 did not specify the qualitative design (one criterion unmet), and four did not meet one or more criteria regarding data collection, analysis, interpretation, or coherence. One non-randomized study did not meet the measurement criterion and one descriptive quantitative study (descriptive statistics on baseline data of a trial) did not meet the criterion on sampling and sample representativeness. Of the four mixed methods studies, two met the five MMAT mixed-methods criteria, one presented an adequate rationale for using a mixed methods design to address the research question, and one did not adequately integrate the various components of the study to answer the research question or address divergences and inconsistencies.

### 3.2 Decisional needs typology

The decisional needs cases showed five types of decisional needs: “prioritization” (n=26 cases), “use of services” (n=22 cases), “prescription” (n=12 cases), “behaviour change” (n=4 cases), and “institutionalization” (n=5 cases). (Table 2)

**Table 2. Five types of decisional needs**

<b>DECISIONAL NEEDS TYPES / CONDITIONS AND OUTCOMES</b>	<b>PRIORITIZATION</b> (26 cases[i]; 1210 participants)	<b>USE OF SERVICES</b> (22 cases; 769 participants)	<b>PRESCRIPTION</b> (12 cases; 460 participants)	<b>BEHAVIOUR CHANGE</b> (4 cases; 267 participants)	<b>INSTITUTIONALIZATION</b> (5 cases; 982 participants)
<b>WHAT</b> Decision	Which health and psychosocial issues should I prioritise? (n=14)  Which health and psychosocial issues am I suffering from? (n= 5)  Which discussion topic should I present in clinical encounters? (n= 3)  Should I prioritize issues with daily living activities or with health? (n=3)  Which medication should I prioritise? (n=1)	Should I consult or not? (n=8)  Should I use home care / social care services or not? (n=5)  Should I engage or not in a program? (n=3)  Should I use an intervention or not? (n=3)  When to go to hospital or emergency? (n=3)	Should I prescribe or not ? (n=5)  How to deprescribe? (n=3)  Adhere or not? (n=4)	Stop or maintain unhealthy lifestyle behaviour (smoking, non-healthy eating & sedentariness)? (n=3)  Continue to drive a car? (n=1)	Stay home or institutionalization? (n=5)
<b>WHO</b> PCCN bio-psycho-social characteristics	Social vulnerability (n=11)  Mental health issues (n=12)  Multimorbidity (n=23)  Polypharmacy (n=9)  Frequent user (n=1)  Under user (n=2)	Social vulnerability (n=16)  Mental health issues (n=6)  Multimorbidity (n=17)  Polypharmacy (n=9)  Frequent user (n=7)  Under user (n=4)	Social vulnerability (n=9)  Mental health issues (n=8)  Multimorbidity (n=12)  Polypharmacy (n=11)  Frequent user (n=1)  Under user (n=1)	Social vulnerability (n=4)  Mental health issues (n=3)  Multimorbidity (n=1)  Polypharmacy (n=1)  Frequent users (n=1)  Under users (n=1)	Social vulnerability (n=5)  Mental health issues (n=5)  Multimorbidity (n=2)  Polypharmacy (n=1)
<b>HOW</b> Made in partnership or independently (decision driven by)	Partnership (n=9)  Independently (n=17)  (8 by practitioner; 9 by patient)	Partnership (n=4)  Independently (n=18)  (3 by practitioner; 13 by patient; 2 by caregiver)	All independently = (n=12)  (8 by practitioner; 4 by patient)	All independently = (n=4)  (3 by patient; 1 by caregiver)	All independently (n=5)  (4 by caregiver; 1 by patient)

<b>WHERE / WHEN</b> the decision is made	During (n=19)	During (n=7)	During (n=8)		
	Between (n=7)	Between (n=15)	Between (n=4)	All between (n=4)	All between (n=5)
<b>OUTCOMES</b> quality, actions, impacts <sup>i</sup>	Positive (n=8)	Positive (n=4)			
	Negative (n=16)	Negative (n=18)	Negative (n=11)	All Negative (n=4)	All Negative (n=5)
	Equivocal <sup>[ii]</sup> (n=2)		Equivocal (n=1)		

### 3.2.1 Prioritization

The most common decisional needs concerned the difficulty prioritizing mental, physical, social, or other issues (26 of 69 cases). We identified 26 “prioritization” cases derived from 20 studies, which represented 1210 participants (740 patients, 55 caregivers and 415 practitioners). Cases concerned patients with overlapping bio-psycho-social characteristics: multimorbidity (n=23/26), polypharmacy (n=9/26), mental health issues (n=12/26) and social vulnerability (n=11/26) (Table 2).

Prioritization occurred between or during clinical encounters and concerned three levels: the sharing of information; identifying care goals; and considering activities of daily living. In the context of multimorbidity, the patient often had a lot of information to share during clinical meetings. They had to decide which information to present, or sometimes intentionally omit, during a time-limited clinical encounter. Then, the practitioner would choose from among the patient’s multiple concerns which topics to focus on. After an information exchange, the patient, and the practitioner, independently or in partnership, determined the priorities and goals to address. PCCNs who were socially vulnerable might feel they needed to prioritize activities of daily living over health care issues.

In nine cases, practitioner and patient prioritized in partnership during the clinical encounter (see additional file 3.1). The prioritization was explicit, with discussion and decision-making on a few selected issues. Patients and caregivers tended to prioritize issues related to functional health, quality of life and autonomy, e.g., appropriate support for maintaining activities of daily living. In contrast, practitioners tended to prioritize issues related to the disease itself, e.g., the most severe health issues. In all nine cases the parties used a prioritization tool or strategy. First, some patients used tools (e.g., Collaborative goal-setting aid) to prepare for the clinical encounter or to use with the practitioner during the encounter. Second, they used another strategy if there was no tool available, e.g., choosing a few priorities beforehand to address in the clinical encounter, and scheduling several encounters to address all their priorities. Another strategy consisted of finding a balance between the practitioner’s disease-related priorities and the patient’s illness-related priorities during the clinical encounter. Eight of these nine cases reported positive outcomes and one presented an equivocal outcome (see section 3.3.1 Well-managed for more details).

In 10 cases, practitioners or patients prioritized independently during clinical encounters (see additional file 3.2). Of those, eight cases reported a lack of patient-practitioner communication. Typically, the practitioner led the discussion during the clinical encounter and selected the topics to be addressed (paternalistic prioritization). The patients realized that the practitioner was omitting certain issues but decided to remain silent. Some practitioners complained about the overloaded agenda of PCCNs. For their part, patients sometimes selected the topics they wanted to discuss and deliberately avoided others that were clinically important, e.g., masking depression symptoms to avoid being given antidepressants (prioritization by omission). Others patients thought their point of view was trivial and feared that the practitioners would laugh at them. One case reported an under-diagnosis resulting from lack of patient-practitioner communication. Three cases reported a lack of inter-professional coordination around prioritization decisions among numerous prescribers,

leading to polypharmacy. We detected dissonance between patients' and practitioners' perceptions of priorities. Patients and caregivers in these cases tended to prioritize information needs, self-care, loss of autonomy, and functional health, while the practitioners tended to prioritize the most severe health issues, problems with realistic solutions, specific disease issues, and a few essential tests and procedures. No case presented a patient-practitioner or interprofessional prioritization tool. One strategy used by a patient was reported. Some patients tended to prioritize conditions that could not be controlled through self-management. All cases reported negative outcomes for the three evaluated outcome dimensions: action taken, impacts on health and well-being, and decision quality (see section 3.3.2 Asymmetric encounters for more details).

In seven cases, patients prioritized independently between clinical encounters (see additional file 3.3). Six of these cases reported negative outcomes and one presented an equivocal outcome (see sections 3.3.3 Self-management by default and 3.3.4 Chaotic) and none presented a prioritization tool. One strategy used by the patient was reported. Some patients weighed the current and daily impact of some of their long-term conditions against those which they perceived could produce more serious and negative outcomes in the future.

### **3.2.2 Use of services**

Another common type of decisional needs concerned use of services (22 of 69 cases). The 22 cases, derived from 19 studies, represented 765 participants (463 patients, 52 caregivers and 250 practitioners). Patients with this type of decisional need were in situations of social vulnerability (n=16) and faced problems with patient-practitioner communication (n=15) and interprofessional coordination (n=8) (Table 2). In seven cases, practitioners perceived these patients as frequent users of services, although their patients did not share this perception. Patients reported that they used services when their self-management burden threatened to overwhelm them. Four cases concerned patients in situations of social vulnerability who underused health services due to limited access or being refused services, e.g., marginal people.

Four cases reported use of services decisions made in partnership with the practitioner during the clinical encounter (see additional file 3.4). None of these four cases reported patient-practitioner communication or inter-professional coordination issues, and all reported positive outcomes (see section 3.3.1 Well-managed). In all four cases, stakeholders used a tool, a strategy, or a program to facilitate decision-making. One case included a tool for helping caregivers to select appropriate home care services: patients and caregivers had to decide (accept/refuse) among multiple service options. Two cases presented patient-centred strategies. One case seems to have followed an informed decision-making model: this patient decided to refuse treatment that was legitimized by the care team. Due to the patient's nursing background, they had confidence in the patient's knowledge and ability to decide. Finally, one case presented a management program that established individualized care plans for patients identified by their physicians as frequent users.

Three "use of services" cases presented decisions made independently during clinical encounters (see additional file 3.5). Decisions were made independently by the physicians in two cases, and by patients or caregivers in one. All cases displayed a lack of patient/caregiver-practitioner communication, often associated with negative perceptions of the other stakeholders, perhaps due to an unpleasant previous interaction. Some patients and caregivers, for example, withheld health information, refused to comply with regulations, or declined assistance with activities of daily living for instance. Some practitioners felt dissatisfied about not being able to help. On the other hand, some practitioners felt uneasy with patients whom they saw as 'difficult' because they were non-compliant, frequent users of services, in situations of social vulnerability, time-consuming, or seriously ill and in need of high-intensity care. Some practitioners saw self-management as positive as it reduces use of services, while many patients considered seeing their doctor and nurse as a last resort, and their motivation to self-manage did not reflect a desire to reduce their use of healthcare services. Other difficult decisional needs concerned high-risk interventions, e.g., aneurysm surgery. Four of these resulted in negative outcomes and one in an

equivocal outcome (see section 3.3.2 Asymmetric encounters). None of these cases reported a decision-making tool or strategy.

In 15 other “use of services” cases, decisions were made independently, mostly by patients, between clinical encounters (see additional file 3.6). The patients decided independently in 14 cases and the practitioners in one case (exclusion of a patient from a program). Patients were mostly in situations of social vulnerability (10 of 14 cases). In six cases, the practitioners perceived patients as frequent users of services or under users of services (compared to their needs). Twelve cases explained the difficulty of the decision by lack of patient-practitioner communication (n=10) and/or a lack of inter-professional coordination (n=7). These 15 “use of services” cases concerned consultations with practitioners (n=6), social and home care services (n=4), emergency room or hospitalization (n=2), engagement in a program (n=2) and interventions (n=1). Regarding consultations, some patients preferred self-management and refused services, while others were lost in the complexity of services, felt abandoned. With respect to social and home care services, patients’ and caregivers’ decisional needs fluctuated over time depending on the evolution of patients’ multimorbidity and financial resources, or on their social support. Typically, elderly patients felt overwhelmed, overestimated their autonomy, and refused or delayed social and home care services. Regarding hospital services, patients reported the emergency room and hospitalization as last resort options when the burden of self-management exceeded their capacities. The 15 cases reported negative outcomes (see sections 3.3.3 Self-management by default and 3.3.4 Chaotic). None of these 15 cases reported use of a decision-making tool. Two cases reported strategies (see additional file 3.6) that could be developed further such as using online communication technologies (e.g., secure messaging and video-conferencing) to aid self-management and receiving specialized support (e.g., a social worker) to navigate the health and social services system.

### **3.2.3 Prescription**

Twelve cases out of 69 reported decisional needs related to medication prescription (hereafter, prescription), which represented 460 participants including 176 patients, 35 caregivers and 249 practitioners. Five cases concerned the practitioners’ decision-making about prescribing medication or not, three cases concerned de-prescribing (polypharmacy reduction), and four cases concerned the patients’ adherence to medication treatment. Patients faced multimorbidity, had polypharmacy and were in situations of social vulnerability (or all three) in 12, 11 and 10 cases, respectively (see Table 2). In all “prescription” cases, the patients or practitioners decided independently. Eight cases presented a lack of inter-professional coordination and six cases a lack of patient-practitioner communication.

In eight cases, “prescription” decisional needs concerned practitioners’ decisions made independently during clinical encounters (see additional file 3.7). The eight cases concerned prescribing vs no-prescription (n=5) or deprescribing (n=3). Seven cases reported negative outcomes, and one case an equivocal outcome (see section 3.3.2 Asymmetric encounters). None of these cases reported a decision-making tool, while two mentioned strategies to improve decision-making processes (see additional file 3.7). In one strategy, practitioners presented the positive and negative effects of the medication to the patient. In another strategy, patients enhanced the quality and amount of information provided by practitioners by bringing someone to the clinical encounter, preparing the encounter with a list of questions written in advance, reporting things mentioned previously by other practitioners, and searching information by themselves in diverse sources, e.g., the Internet.

In four cases, “prescription” decisional needs concerned patients’ decisions made independently, between clinical encounters (see additional file 3.8). Patients chose on their own not to adhere to prescriptions (medication not bought, or not taken). In all cases, patients were in situations of social vulnerability and faced mental health issues. None of these cases reported a decision-making tool or strategy and all of them resulted in negative outcomes (see section 3.3.4 Chaotic).

### **3.2.4 Behavior change**

Four cases reported decisional needs pertaining to behavior change (see additional file 3.9), and corresponded to 267 participants including 80 patients, 40 caregivers and 147 practitioners. Two cases reported alcohol use, sedentary lifestyles and smoking by patients with chronic obstructive pulmonary diseases. In a third case, patients with severe mental disorders did not alter their unhealthy lifestyles. In the fourth case, elderly patients with dementia continued to drive. All cases involved patients in situations of social vulnerability, combined with mental health issues in three cases. All cases reported a lack of patient-practitioner communication and two cases a lack of inter-professional coordination. Patients or caregivers decided independently between clinical encounters. Patients and caregivers did not adhere to prescribed behavioral strategies. All cases reported negative outcomes (see section 3.3.4 Chaotic) and none presented a decision support tool or strategy.

### **3.2.5 Institutionalization**

Five cases reported decisional needs concerning transfer to long term care (hereafter institutionalization), which represented 982 participants including 850 patients, 92 caregivers and 40 practitioners (see additional file 3.10). These cases showed that decisional needs about this issue are emotional and sometimes heart breaking. Typically, they involved caregivers making decisions for elderly patients in situations of social vulnerability with cognitive/mental disorders such as dementia who are unable to participate in decision-making. Also specific to this type of decisional need was that all cases presented family conflicts, aggravated in two cases by migration-related and generational cultural conflict (see Table 2). Decision-making confronted cultural clashes such as (a) communitarian values (favoring home care managed by the family) versus individualistic values (favoring transfer to long term care), and/or (b) traditional values regarding gender-based roles in decision-making roles versus feminist values. Multiple reasons triggered “institutionalization” decisional needs (unmanageable or unsafe patient behavior, uncontrolled chronic conditions, patients’ dependency on full-time care services, and caregiver burden). All cases reported negative outcomes (see section 3.3.4 Chaotic), e.g., caregiver burden, sometimes worsened by family conflict. No case reported using a decision support tool. Two cases presented decision-making strategies (see additional file 3.10). In the first case, relatives and practitioners were convinced that institutionalization was needed, waited for an incident to make it happen, or disguised the institutionalization as short-term hospitalization. In the second case, patients, caregivers, and practitioners had to negotiate between conflicting cultural values (North American versus Asian) and created alliances at turning points in the patients’ lives (alliances between a wide variety of family members and health care and social care practitioners).

## **3.3 Decision-making configurations: patterns of conditions in association with decision outcomes**

The visualization and interpretation of the 69 cases, documented by 6W-O memos using spider web diagrams (Fig. 1), revealed nine patterns of cases with similar outcomes and conditions (Fig. 2). As shown Fig. 2, we grouped patterns into four decision-making configurations: “well-managed” (n=13), “asymmetric encounters” (n = 21), “self-management by default” (n = 8), and “chaotic” (n = 27).

### **3.3.1 Well-managed**

The “well-managed” configuration represented the best-case scenario. In this decision-making configuration, 13 cases sharing conditions and outcomes (6W-O) grouped into three patterns (the green spider web diagrams in Fig. 2). Cases concerned decisional needs regarding “prioritization” (n=9) and “use of services” (n=4). Of the 13 cases, one had an equivocal outcome, and 12 reported positive outcomes. Positive outcomes were linked to actions taken (e.g., patient engagement in care plan; services use or access), to emotional impact (e.g., patient and caregiver experiencing positive emotion) and to the quality of the decision (informed and value-based). In this configuration, cases reported satisfactory patient-practitioner communication and interprofessional coordination between primary care services and other mental health and social care services, and decisions made in partnership by PCCN/caregivers and practitioners during clinical encounters. Fig. 2 shows, for this configuration, two patterns of conditions associated with positive outcomes. Of 12

cases, five corresponded to the “full circle” pattern and concerned patients with no major psychosocial issues; and seven cases corresponded to the “almost full circle” pattern concerning patients in situations of social vulnerability (e.g., socio-economic deprivation) or faced mental health issues (e.g., depression). Although some physicians reported that their patients’ psychosocial issues were challenging, their conditions were nevertheless well-managed. Decision outcomes were equivocal in one case because sharing a decision about health priorities seemed unusual for both the doctors and elderly patients. All cases reported a tool (n=5), a strategy (n=7) or a program (n=1).

### **3.3.2 Asymmetric encounters**

In the “asymmetric encounters” configuration, 21 cases sharing similar conditions grouped into three patterns (the three blue diagrams in Fig. 2). This decision-making configuration exposed informational and power asymmetries during clinical encounters. Practitioners decided independently in 17 cases (e.g., prescribed or deprescribed a drug), and patients made independent decisions in the four other cases (e.g., decisions about what information to prioritize for presenting to the practitioner during clinical encounters). In “asymmetric encounters”, decisional needs concerned “prioritization” (n=10), “use of services” (n = 3) and “prescription” (n = 8) decisions. Of 21 cases, 16 presented a lack of patient-practitioner communication and seven interprofessional coordination issues.

In this decision-making configuration, all 21 cases presented non-informed or non-value based decisions, 18 reported action-related issues (e.g., non-adherence, delaying the decision), and 18 reported negative well-being impacts (e.g., patients felt frustrated or pressured). Of 21 cases, 20 reported negative outcomes and one presented an equivocal outcome, which related to antibiotics and steroids prescriptions for patients with Chronic Obstructive Pulmonary Disease (COPD). In the “asymmetric encounters” configuration, no case reported using a tool. There is nevertheless hope for improving communication because the stakeholders made decisions during clinical encounters, i.e., patients and practitioners maintained contact for decision-making, and might consider an appropriate PCCN-oriented SDM tool.

### **3.3.3 Self-management by default**

In the “self-management by default” configuration, eight cases grouped into two patterns with similar conditions (orange diagrams in Fig. 2). In this decision-making configuration, decisions were made by PCCN/caregivers independently and decided between clinical encounters. “Self-management by default” cases concerned “prioritization” (n=3) and “use of services” (n=5) decisional needs. Of these eight cases, seven reported negative outcomes, and one an equivocal outcome. The negative outcomes corresponded to patients who felt overwhelmed and abandoned in the self-management of their multimorbidity and experienced polypharmacy. Some patients explained that their day-to-day routine required a great deal of energy and time due to their multiple health and social issues. The eight cases reported non-informed based decision related communicational issues. One case presented underuse of services and delay in a decision leading to hospitalization (action issues). Two cases reported caregivers’ cognitive burden when the patient decided to refuse services. Two other cases presented patients/caregivers in situations of social vulnerability that affected self-management. In the case with an equivocal outcome, the patients were guided by their values and actively engaged in their care but decided not to adhere to recommended prioritization or services and had not been adequately informed of the consequence of their action. No case reported a decision-making tool. In comparison to the next decision-making configuration (chaotic), an encouraging element of the “self-management by default” is that PCCNs remained reachable and had the cognitive capacities to participate in decision-making processes and might consider a PCCN-oriented decision-making tool.

### **3.3.4 Chaotic**

In the “chaotic” configuration, 27 cases with similar conditions grouped together into one pattern (the red square in Fig. 2). In this decision-making configuration, all cases had negative outcomes associated with mental health and social issues, unsatisfactory patient-practitioner communication and interprofessional coordination (e.g., between primary care services

and other services, specifically mental health, and social care services). All the decisions were made independently, between clinical encounters by PCCN/caregivers and practitioners. The “chaotic” decision-making configuration concerned all types of decisional needs: “use of services” (n= 10), “institutionalization” (n=5), “behavioural change” (n=4), “prescription” (n=4), and “prioritization” (n=4). Almost all cases concerned patients in situations of social vulnerability (n=26), often with high disability, e.g., frailty with dementia (n=18). Some patients were homeless, or experienced financial precariousness (n=8). In addition, many cases presented patients facing mental health issues (n=19). Twenty-five cases reported action-related issues (e.g., patient non-engagement, delay of decision, access to services, and non-adherence). Emotional impacts of decisions were negative in 21/27 cases: frustration, loneliness, regret, and uncertainty about the decision made, and feeling pressured. Fifteen cases reported disagreements among stakeholders (caregivers, patients, and practitioners). Some patients (e.g., marginalized people), expressed a loss of trust in the health system. In this configuration, those making decisions involving behavioural change or institutionalization reported major family or cultural conflicts (n=9). This configuration also concerned cases reporting a refusal of social services (n=4), consultation and navigation issues in a fragmented health system (n=3), non-adherence to prescriptions by patients in situations of social vulnerability (n=3), marginalized patients prioritizing urgent problems with their daily living activities over health care (n=3), and frequent hospitalization of socially isolated frail elders (n=2). No case reported a PCCN-oriented tool. In this configuration SDM was thus unlikely to occur.

[i] See additional file 3 tables for more details about cases.

[ii] Open to more than one interpretation. Could be positive or negative outcome.

## Discussion

This systematic review contributes to the ongoing reflections on decision-making by considering the challenging social contexts underlying the decisional needs among PCCNs. It includes 47 empirical studies, from 13 countries, about PCCNs in primary care, and representing a large sample of 2997 participants (2107 patients, 698 practitioners and 192 caregivers). The case-based qualitative synthesis allowed to identify 69 cases of decisional needs within the 47 studies. The five main types of decisional needs among PCCNs concerned “prioritization”, “use of services”, “prescription”, “behavior change” and “institutionalization”. For each case, we wrote a ‘6W-O’ memo and synthesized the data to create decision-making configurations in the form of spider web diagrams, illustrating patterns of conditions associated with decision outcomes. We entitled the four decision-making configurations “well-managed”, “asymmetric encounters”, “self-management by default”, and “chaotic”. These explanations and testable predictions could contribute to an adaptation of Charles et al.’s (1997) decision-making model to the needs of PCCNs, an endeavour of some urgency given the growing proportion of older adults and rising rates of chronic disease (2, 99). The nine main contributions of our results to a PCCNs-adapted decision-making model are as follows:

### 4.1 Five types of decisional needs

#### **Prioritization: Difficulty prioritizing which multiple mental, physical, and social issues to address is common among PCCNs**

The most common PCCN decisional need was a difficulty prioritizing which mental, physical, or social issue to address. The “prioritization” type of decisional need illustrates that PCNNs’ face many more decisions than simply choosing a treatment option, and that Charles et al.’s model must be expanded to accommodate this reality. According to Charles, Gafni (8), information sharing is a prerequisite to SDM. Some “prioritization” cases illustrate that before sharing information on care options, stakeholders need to decide which information is most relevant to address. Prioritization tools and strategies exist for PCCNs (53), and their use may lead to positive outcomes (i.e., the “well-managed” configuration). However, all independent prioritization cases, i.e., when practitioners or patients prioritize alone, lead to

negative outcomes (e.g., the “chaotic” configuration). Our results support the literature in finding that prioritization is a challenge for the PCCNs for four main reasons. Firstly, their experience of multimorbidity and polypharmacy increases tenfold the information to be communicated during consultations (66, 91). Second, these decisions are rarely shared between elderly PCCNs and their practitioners and sharing them is currently perceived as unusual by both parties Wrede, Voigt (67). Third, PCCNs are more likely to suddenly change their decision about what issue to prioritize because of a cascade of crises or sudden deterioration in their health (90). Fourth, PCCNs in situations of social vulnerability (socio-economically deprived, highly disabled and/or marginalized people) often have no choice but to prioritize daily living activities over health issues (59, 63, 81). This can lead to underuse of services needed, in turn leading to use of emergency services and hospitalization when a crisis point is reached, and even less likelihood they will share decisions with their healthcare provider.

### **Use of services: frequent users and under users of services are in situations of social vulnerability and feel unsupported**

Few PCCNs with decisional needs of the “use of services” type fit the informed decision-making model described by Charles, Gafni (8), and most lacked information. We found “use of services” type decisional needs across all four decision-making configurations, but it was particularly common in the “self-management by default” and “chaotic” configurations, in which all outcomes were negative. “Use of services” is a common type of decisional need among frequent users (28). In fact, this type of decisional needs included the highest proportion of frequent users of services, who are seen as difficult patients by some practitioners (54). These patients are often people with disabilities, e.g., frail and elderly (75). In addition, those with the “use of services” type of decisional need included the highest proportion of under users of service in relation to their needs. These are mostly marginalized people (81). These macro context, which are not presented in the Charles, Gafni (8) model but which have a large impact on the processes of SDM, must be considered in decision-making with PCCNs about use of services.

### **Prescription: lack of SDM and interprofessional coordination for patient with multimorbidity and polypharmacy**

Most cases of PCCNs “prescription” decisional needs followed the paternalist model as described by Charles et al. (1997). They mainly concerned patients with multimorbidity and polypharmacy. Some cases concerned non-adherence to prescription decision made by the patients independently between clinical encounters. Some patients in situations of polypharmacy stopped or reduced medication because they were afraid of iatrogenic drug-to-drug interaction (70). They criticized the lack of SDM and lack of interprofessional coordination between too many prescribers. Cases of non-adherence to medication could also result from a tacit prioritization process (58): most of these cases were in situations of socio-economic deprivation, so the decision to not adhere could be interpreted as a result of inability to pay, or a choice to prioritize daily living activities over medication. Financial contexts are also important to consider in sharing decisions about prescription with PCCNs.

### **Behavior change: changing lifestyle habits can be challenging in the context of social vulnerabilities**

Like “prioritization”, the “behavior change” type of decisional need showed once again that PCNNs’ decision-making is not limited to treatment options, the central focus of Charles, Gafni (8)’s model, but also concerns behavior change options chosen independently by the patient (e.g., to stop or continue an unhealthy habit). All cases in this decisional need type are mapped on to the “chaotic” configuration and reported a lack of communication between practitioners and highly disabled patients in socio-economic deprivation, as also found in studies on COPD (54). The adoption of new lifestyle habits and behaviors is a major challenge in case management programs (28). The “behavior change” type of decisional need also highlighted the importance of considering social vulnerabilities and macro contexts to extend the Charles et al. (1997)’s treatment decision-making model.

### **Institutionalization: caregivers experienced individual, interactional and organizational issues**

None of the “institutionalization” decisional need type cases presented the use of the professional-as-an-agent model, where the practitioner is an advocate of the patient’s perspective (8). Some of these cases suggested instead a new model of shared decision making that could be qualified as caregiver-as-an-agent by default. “Institutionalization” is the type of decisional needs with the highest level of complexity, following Luhmann’s definition, i.e., that it repeatedly puts pressure on stakeholders to select an option despite their uncertainties about the options in terms of health and social services. Typically, overwhelmed caregivers must decide for PCCNs, e.g., elderly patients with dementia, when the patients’ behavior becomes unmanageable. Advocating the patient’s perspective is however sometimes difficult for caregivers who are faced with having to institutionalize a loved one (due to unmanageable critical situations at home) even against his or her wishes (74). These cases are often experienced as heartbreaking by caregivers. They felt alone in making the decision. No case reported that caregivers were supported by a decision-making tool or program. The delay before institutionalization occurred also had negative impacts on caregivers, who had to investigate and approach several different institutions (88).

As Charles, Gafni (8: p.685) suggest, the complexity of interactional dynamics increases when agents with different perspectives interact in the decision-making processes. This complexity is exacerbated when interactions involve larger social, economic, and cultural forces such as in the process of institutionalization (77). Moreover, all “institutionalization” cases involved a family conflict that was sometimes aggravated by generational cultural conflicts and decision-makers taking positions as either allies or competitors (77). As Charles, Gafni (100) have pointed out, very few studies identified in their review were culturally sensitive. The development of a culturally sensitive caregiver-as-agent model and tools to support caregivers confronted with individual, interactional, and organizational issues are urgently needed (72).

## 4.2 Four decision-making configurations

### **Well-managed: PCCNs’ decisions made in partnership are associated with positive outcomes**

This decision-making configuration involved situations where it would be possible to apply SDM with PCCNs. By comparing the “well-managed” cases with those in the three other decision-making configurations, we observed that decisions made in partnership were always associated with positive outcomes. In this configuration, decision quality seemed informed and value-based and the decision process contained the key SDM characteristics suggested by Charles, Gafni (8). This configuration, containing 13 cases sharing similar outcomes and conditions, suggests a testable prediction for future research (table 3).

### **Table 3. Well-managed configuration testable prediction – high potential for SDM**

Regarding PCCNs’ decisional needs of the ‘prioritization’ and ‘use of services’ types, positive outcomes seem more likely when three conditions are met: (a) sufficient information is shared, understood and acted upon by PCCN/caregivers and all involved practitioners [satisfactory patient-practitioner communication and coordination between practitioners in primary care and other health and social care services], (b) all inter-related decision-making processes are based on PCCN/caregivers’ trust in their partnership with practitioners during every clinical encounter, and are centered on PCCN’s values and preferences, and (c) appropriate PCCN-oriented tools, strategies, or programs are used to reduce the complexity of the inter-related decision-making processes, and care needs.

### **Asymmetric encounters: informational and power asymmetries between PCCNs and practitioners**

This decision-making configuration exposed informational and power asymmetries between PCCNs and practitioners during clinical encounters, a barrier to overcome for the application of the SDM (8). All decisions in this configuration were made independently by practitioners or by patient during clinical encounters, resulting in non-informed or non-value based decisions about “prioritization”, “use of services” or “prescription”. Practitioners make independent decisions because they only consider medical explanations of disease, in isolation from the PCCNs’ own perceptions of their illness and their knowledge of its consequences on their lives (101, 102). In this configuration, some cases showed paternalistic

prioritization, i.e., the practitioner led the discussion and selected a few topics to prioritize. On the other hand, patients also intentionally omit certain information. This voluntary omission could be interpreted as an act of resistance to power asymmetry (103, 104). Some informational asymmetries can be explained by an unconscious “clinical habitus” (Bourdieu (105), socially embodied during patients’ experiences in other clinical settings, e.g., to adopt passive roles during clinical encounters and what information is pertinent to share with the practitioner (12, 13).

### **Self-management by default: PCCNs felt overwhelmed and abandoned**

The “self-management by default” decision-making configuration illustrate that many PCCN/caregivers’ decisions are made between clinical encounters. This configuration could contribute new dimensions to the Charles, Gafni (9) model, which fails, according to the authors, to conceptualize that many decisions take place outside the context of the medical encounter. The “self-management by default” decision-making configurations suggest that decisions made independently by PCCNs between clinical encounters lead to negative outcomes (e.g., patient or caregiver burden). They highlight the importance of better decision support for the self-management of PCCNs who feel overwhelmed by situations of multimorbidity and social vulnerability. The PCCNs self-managed their decisions by default because they did not have access to decisional support. Together, the “self-management by default” and the “asymmetric encounters” configurations, sharing similar outcomes and conditions (except for where the decision takes place, i.e., during or between), suggest the following testable predictions for future research (table 4).

### **Table 4. Self-management by default and “asymmetric encounters” configurations testable prediction - limited potential for SDM**

With respect to decisional needs relating to “prioritization”, “use of services” and “prescription”, negative outcomes (including poor health outcomes and caregiver burden) seem more likely when decisions are made independently by patients/caregivers or practitioners (between or during clinical encounters). The following conditions seem to contribute to negative outcomes: PCCNs’ mental health issues or social vulnerability, unsatisfactory patient-practitioner communication or interprofessional coordination, and non-use of appropriate PCCN-oriented tools, strategies, or programs (no practical attempt to decrease complexity).

### **Chaotic: SDM seems not to be applicable for PCCNs in times of crisis or if they mistrust services**

This decision-making configuration contributes Charles et al.’s (1997) model because it illustrates that there are decision situations that are mostly beyond the scope of any decision support tools. It seems that only high intensity health and social care programs, e.g., high quality integrated multidisciplinary care teams, can prevent the worsening of outcomes. This configuration included the largest number of cases and involved all types of decisional needs. Like the “self-management by default”, the “chaotic” decision-making configuration illustrates that many health-related decisions are made between clinical encounters by PCCNs and their caregivers. Almost all the PCCNs in this decision-making configuration were in situations of extreme social vulnerability (socio-economic deprivation, highly disabled and/or marginalized). According to our knowledge users with expertise in social work, the “chaotic” configuration reminds us that some marginalized people are not in a moment in time or in a state of mind to be able to accept services. It emphasizes the importance of the principle of Kairos, a dimension of time qualified as an opportune moment. For example, a social worker must intuitively sense when the time is right to reach people who mistrust services and see themselves excluded from the system. This configuration included 27 cases sharing similar outcomes and conditions, suggesting a testable prediction for future research (table 5).

### **Table 5. Chaotic configuration testable prediction – no current potential for SDM**

Across all types of PCCNs decisional needs, negative outcomes are more likely when four conditions are met: (a) patients face a crisis, are not reachable, fall through the cracks of the fragmented health and social care systems, and/or are

unable to navigate its complexities; (b) patient-practitioner communication and interprofessional coordination are unsatisfactory; (c) decisions are made independently by patients between clinical encounters because they mistrust services, i.e., patients perceive themselves as excluded from the health and social care systems (and other systems) and practitioners see these patients as an unwanted burden; and (d) no PCCN-oriented high intensity program is applied or applicable.

### 4.3 Practical implications

Findings from theory-generating qualitative synthesis can help guide policy and practice in many disciplines (45). Our results present PCCN-oriented tools, strategies and programs that are associated with the “well-managed” configuration. This suggests that while we must maintain the development and implementation of interventions that focus on decisional needs that are already relatively well-managed, we urgently need to address the three other decision-making configurations. In the literature, several services and tools for the diagnosis and management of complex care needs have been identified. For example, systematic reviews have shown that case management can improve PCCNs satisfaction, self-management, quality of care, services use/costs, and health outcomes (106-109). Decision aids have recently been proposed to improve patient engagement in case management programs (Poitras et al., 2020). Integrated care is a cost-effective intervention to improve the quality of care for PCCNs (110, 111). Also, tools exist that aim to detect, assess, prioritize, and follow up complex care needs, and ultimately to improve PCCN/caregiver-practitioner communication, and communication between practitioners. For example, the *Comprehensive Geriatric Assessment Toolkit+* ([cgakit.com](http://cgakit.com)) maps 80 validated tools for needs assessment and prioritization. Typically, tools can be completed during or between clinical encounters, usually by practitioners, rarely by PCCN/caregivers or both (practitioner and PCCN/caregivers). The main obstacle is lack of awareness of the tools (most are unknown to practitioners and PCCN/caregivers) and lack of integration of these tools into practitioners’ workflow and PCCN/caregivers’ routines.

Because complex care needs often involve multiple stakeholders, it is essential to broaden the conceptualization of SDM beyond the physician-patient dyad (112). The Inter-Professional Shared Decision-Making (IP-SDM) model extends SDM to include family members and other caregivers as well as a team of professionals in a patient-centered process (21). This model aims to stimulate deliberation and reaching a common understanding among all parties involved in the decision. PCCNs, whose decisional needs often involve a multitude of parties, may greatly benefit from IP-SDM programs. For example, the ID-SDM Dolce (Decision-making On Location of Care with the frail Elderly and their Caregivers) focused on the role of caregivers in the tough decisions about the institutionalization of their loved ones (113). If it is important to consider the decisional needs of PCCNs, we must consider the decision-making needs of caregivers who often feel overwhelmed by difficult decisions, especially when they are linked to family conflict. The Family Caregivers Support Agreement, a tool proposed in one of the studies identified in our review, offers a support to consider the needs of caregivers in decision-making (72).

### 4.3 Limitations and strengths

Our case-based qualitative synthesis has four main limitations. First, only detected PCCNs were involved in included studies, while PCCNs are usually under-detected (99, 114). The number of cases with negative outcomes was higher than those with positive outcomes, which may suggest that PCCNs facing severe issues were overrepresented in the included studies. Also, as with all systematic reviews, due to publication bias, this work may be biased by predetermined outcomes that were identified by authors of the included studies. However, this limitation was somewhat reduced by the knowledge users in our study (patient-partner, practitioners, service-managers, and policy-makers), who discussed and approved the case-based synthesis of the data extracted from included studies. Five of them who had relevant expertise validated the cases. Second, we defined complexity of care needs in accordance with the Luhmann’s theory, which assumes that PCCNs and caregivers are integrated into social systems (22), while competing social theories suggest otherwise. For instance, a critical theory would suggest the PCCNs’ lifeworld tends to resist the colonization of the practitioners’ organizational world,

and an actor-network theory would mix PCCN human and non-human actors in socio-technical networks (23, 115). Third, because of the specificity of their decisional needs, we excluded two PCCN populations: children with complex care needs and people at the end of life (palliative care). Fourth, we classified cases by types of decisional needs, but patient's decisional needs may evolve and change over time for a variety of reasons (a cascade of crises, self-perceptions of control, clinician interactions).

Notwithstanding the above-mentioned limitations, several strengths of our review should be underscored. First, this systematic mixed studies review proposes an innovative, empirically validated, and testable conceptual framework of decisional needs among PCCNs, and outcomes related to decision. This conceptual framework is original. We reviewed the literature published since completing our search strategy (Scopus data base search up to October 2021) and found no framework or theory decisional needs among PCCNs and outcomes related to decision. Second, following data sufficiency criterion (42, 116) our sample provided ample qualitative and quantitative data to compare constructs and dimensions, reflect the work of several independent researchers, and reach our objectives. Compared to usual qualitative syntheses, we included a large number of studies (47 empirical studies) and we identified 69 decisional needs cases representing 2997 participants from 13 countries.

Knowledge user involvement in this review helped to understand decision-making processes in complex care needs situations and help to build a conceptual framework based on many cases (45). Third, this review offer rich theoretical, methodological, and practical contributions. Luhmann's conception of complexity is broader and more comprehensive than is included in usual definitions of complex care needs. Combining this with the Charles et al. treatment decision-making model (8, 9, 11, 100, 117) and the Ottawa Decision Support Framework (27) led to a comprehensive description of PCCNs' decisional needs. There was large sample of participants enrolled in the included studies, which allowed us to cover a diversity of PCCN contexts. This diversity enabled us to extend the Charles et al.'s model with five types of decisional needs prevalent among PCCNs and four decision-making configurations. Three testable predictions are proposed for future research (see Tables 3, 4 and 5). This case-based qualitative synthesis helped bridge two knowledge gaps: (a) the majority of intervention studies address simple care needs rather than complex ones; and (b) current systematic reviews typically focus on one health condition and one homogeneous population (110, 118).

## Conclusion

The ultimate contribution of this review is a typology of PCCNs' decisional needs and testable predictive decision-making configurations. The decisional needs typology shows that in contexts of social vulnerability many health decisions are made outside clinical encounters and concern issues other than treatment options. The decision-making configurations shows that shared decision-making is associated with positive outcomes, and that negative outcomes are associated with practitioners, patients or caregivers making health decisions independently. This can contribute to informing the subsequent user-centered design of decision support tools. Further research is needed to identify the necessary and sufficient conditions associated with positive or negative decision outcomes. To do so, a configurational comparative analysis could be conducted using QCA (Qualitative Comparative Analysis) (119). It would also be relevant to study the management of decision-making needs of patients with complex care needs during a pandemic (120). Finally, further research could study Luhmann's notion of after-decisional thoughts, e.g., risks of post-decisional regrets, and explore combinations and cascades of interrelated decisional needs in a longitudinal manner.

## Abbreviations

**6W-O** : What, Who, How, Where, When, Why and related Outcomes

**MMAT** : Mixed Methods Appraisal Tool

**ODSF** : Ottawa Decision Support Framework

**PCCN** : Patients with Complex Care Needs

**SDM** : Shared Decision-Making

## Declarations

### Ethics approval and consent to participate

Not applicable

### Consent for publication

Not applicable

### Competing interests

The authors declare that they have no competing interests.

### Availability of data and materials

The dataset supporting the conclusions of this article is included within the article and its additional files

### Funding

PP (principal investigator) & FL (co- principal investigator). This work is funded by the Canadian Institutes for Health Research grant number 201630KRS-367087. This review was sponsored by the Quebec-SPOR SUPPORT Unit. The funders had no role in study design, data set collection and analysis, decision to publish, or preparation of the manuscript.

### Authors' contributions

MB, PP and FL conceived and designed the review with input from all team members. MB and PP drafted the manuscript. All authors, including Participatory Review Team members, read, critically revised, and approved the final manuscript.

### Acknowledgements

We warmly thank all the members of the participatory review team, named here in alphabetical order: Marie-Claude Beaulieu, Paula L. Bush, Yves Couturier, Reem El Sherif, Justin Gagnon, Anik Giguère, Genevieve Gore, Serge Goulet, Roland Grad, Vera Granikov, Quan Nha Hong, Catherine Hudon, Edeltraut Kröger, Irina Kudrina, Christine Loignon, Marie-Eve Poitras, Rebekah Pratt, Marie-Therese Lussier, Benoit Rihoux, Nicolas Seen, Isabelle Vedel, and Michel Wensing.

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## Figures

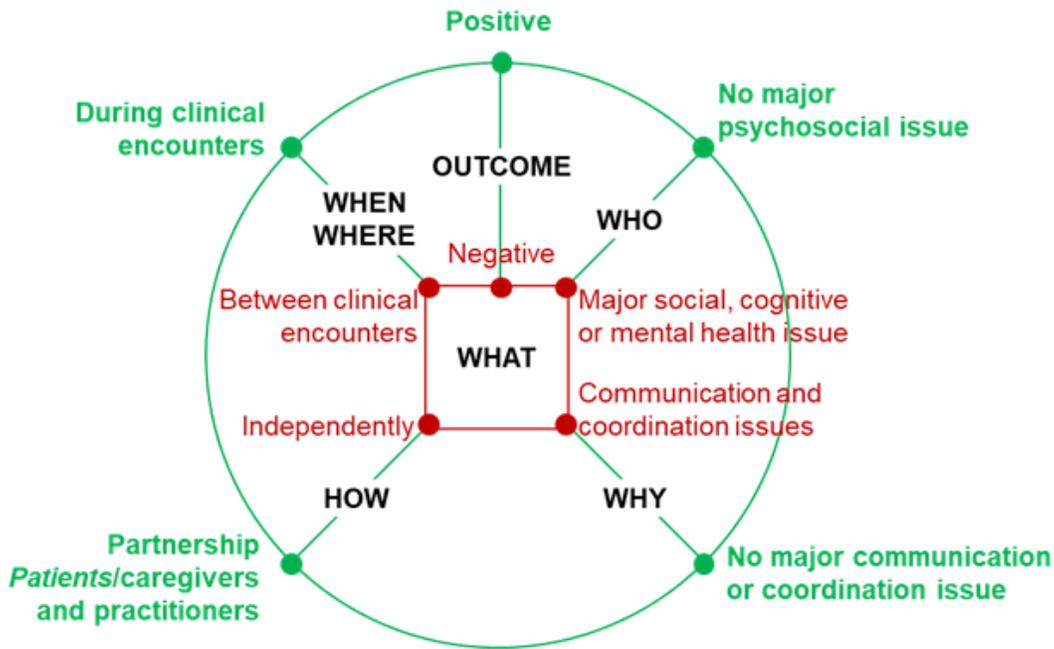


Figure 1

**Decisional needs of patients with complex care needs: Template diagram for data visualization**

Legend: The PCCN’s decision type (what) is at the center of each circle. The lines reaching out to the periphery represent the various decision-making conditions such as partnership, and decision outcomes. Points closer to the circle’s periphery represent best-case scenarios in terms of conditions and outcomes (e.g., decisions made together, and outcome of increased wellbeing), while points closer to the centre approach worst-case scenarios (e.g., decisions made alone, outcome of high patient burden). Each case was illustrated on this spider web diagram by locating specific conditions on these lines, allowing to reveal nine patterns of conditions associated with decision outcomes which were then grouped into four decision-making configurations (Fig. 2).

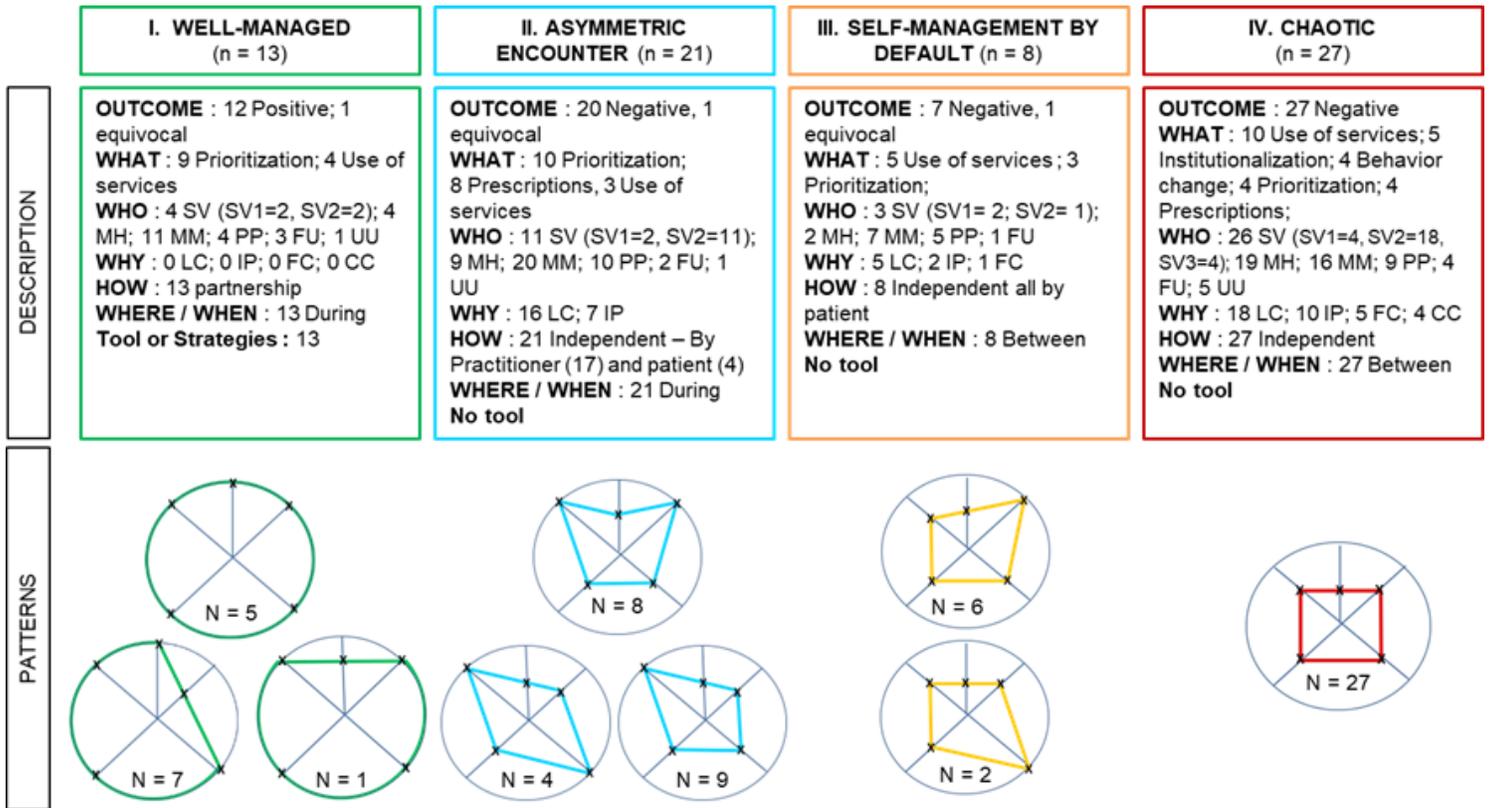


Figure 2

#### Four decision-making configurations in primary care

Legend: CC (Cultural conflict); FC (family conflict); FU (Frequent Users); IP (InterProfessional coordination issues); LC (Lack of patient-practitioner Communication); MH (Mental Health issues); MM (Multimorbidity); PP (Polypharmacy); SV (Social Vulnerability); SV1 (socio-economic deprivation); SV2 (highly disabled people, e.g., frail elderly); SV3 (marginal, e.g., homeless); UU (Under Users).

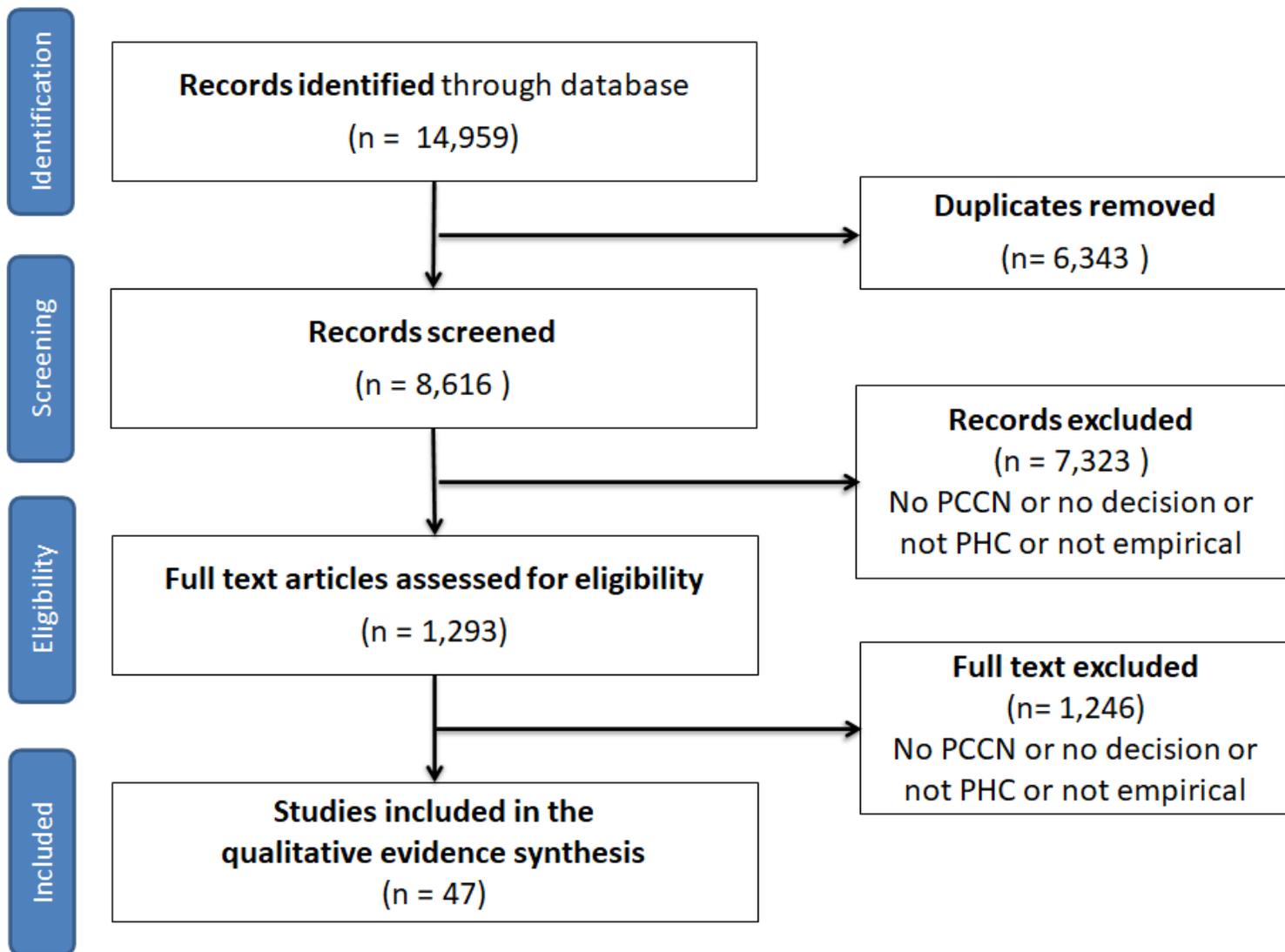


Figure 3

Flow Chart

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