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Stakeholder involvement in care transition planning and the factors guiding their decision-making: a scoping review

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TITLE: Stakeholder involvement in care transition planning and the factors guiding their decision-making: a scoping review

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ABSTRACT

Objective: To synthesize the existing literature on care transition planning from the perspectives of older adults, caregivers, and health professionals and to identify the factors that may influence these stakeholders' transition decision-making processes.

Design: A scoping review guided by Arksey & O'Malley's six step framework. A comprehensive search strategy was used to identify articles in five databases. Records were included when they described care transition planning in an institutional setting from the perspectives of the care triad (older adults, caregivers, and health professionals). No date or study design restrictions were imposed.

Setting: This review explored care transitions involving older adults from an institutional care setting to any other institutional or non-institutional care setting. Institutional care settings include communal facilities where individuals dwell for short or extended periods of time and have access to health care services.

Participants: Older adults (aged 65 or older), caregivers, and health professionals.

Results: 39 records were included. Stakeholder involvement in transition planning varied across the studies. Transition decisions were largely made by health professionals, with limited or unclear involvement from older adults and caregivers. Seven factors appeared to guide transition planning across the stakeholder groups: (a) institutional priorities and requirements; (b) resources; (c) knowledge; (d) risk; (e) group structure and dynamic; (f) health and support needs; and (g) personality preferences and beliefs. Factors were described at micro-, meso- and macro-levels.

Conclusions: This review explored stakeholder involvement in transition planning and identified seven factors that appear to influence transition decision-making. These factors may be useful in advancing the delivery of person- and family-centered care by determining how individual-, group- and system-level values guide decision-making. Further research is needed to understand how various stakeholder groups balance these factors during transition planning in different health contexts.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This review considered transition planning among the care triad (defined as older adults, caregivers, and healthcare professionals).
- A wide range of transition experiences were described across the records, involving various care settings and patient conditions.
- The identification of factors required subjective interpretation, as few records specifically focused on identifying the factors that guided participants' decision-making.
- Participant characteristics were lacking in several records, making it difficult to assess participant diversity.
- Some relevant information may have been missed, as inclusion criteria was focused on describing transitions from institutional care settings.

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INTRODUCTION

Increased interest in person- and family-centered care (PFCC) has emerged over the past several decades (1). PFCC is an approach to healthcare, whereby care decisions are driven by the individual's needs, preferences, and desired outcomes (2). In this values-based approach, patients and families are considered partners in their care and contribute important knowledge and experience to care and treatment decisions. The growing popularity of this approach represents an ideological shift from the biomedical model to one that emphasizes a holistic view of the individual with specific medical, social, mental, emotional and spiritual needs (3). PFCC policies and practices are now widely recognized as an important indicator of healthcare quality, and many healthcare systems globally are making progress towards achieving a higher standard of PFCC (4).

While many believe that a PFCC approach is justified on moral grounds (5), the benefits of adoption include improved individual- and system-level outcomes as demonstrated by studies showing greater self-efficacy, levels of satisfaction and individual wellbeing (6–8) amongst patients and families. Additionally, PFCC interventions have been associated with a better use of resources and decreased health system costs in certain therapeutic areas (6,9,10).

The successful delivery of PFCC may be a particularly important contributor to enhanced management of complex health processes like care transitions. Care transitions are broadly defined as the transfer of patients between different settings, services or care providers (11,12). They represent periods of high vulnerability and risk, due to the potential for adverse events and breakdowns in communication (13). Despite the promise of PFCC, a recent review on care transitions reported a mixed effect of the impact of PFCC on patient-oriented outcomes leading the authors to reflect on the core components of the approach, and conclude that PFCC interventions must incorporate several core components to successfully improve transition outcomes (14).

Shared decision-making (SDM) is often viewed as one of the core components of PFCC (15). SDM is a collaborative approach to decision-making, whereby health professionals and patients consider options and evidence together before making joint decisions (16). This approach may be particularly useful in the context of care transitions, since the decisions will likely impact

caregivers and health professionals in addition to the patient. Specifically, the outcomes of transition decision-making can influence health professionals' planning and resource allocation, as well as caregivers' responsibilities for care coordination and delivery.

Despite the significant impact that care transition decisions can have on the lives of these stakeholders, there is considerable evidence that patients and families are not included in, and have limited influence over, transition planning and decision-making (17–25). This may be particularly true for older patient populations, as SDM becomes more complex due to their higher health needs and reduced ability to self-manage (26). This lack of involvement is further problematized by the reality that different stakeholders may have conflicting goals during the transition (13,27). The absence of patient and family voice during care transitions may therefore result in system goals being prioritized over the goals of the individual patients and their families (13).

A lack of patient and family involvement in care transition planning and decision-making raises important questions about the quality of care during transitions and the extent to which they are person-centered. Therefore, the aim of this review is to synthesize the available literature on care transition planning from the perspectives of older adults, caregivers and health professionals, and identify the core factors that appear to influence transition decision-making. By identifying these factors, we may better determine the extent to which care transitions are person-centered, and how they may be strengthened in the future.

METHODS

This scoping review examined care transition planning and decision-making from the perspectives of older adults, caregivers, and health professionals. We followed the methods outlined by Arksey & O'Malley (2005) and adhered to Tricco et al's (2018) PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist to report our findings (28,29). Arksey and O'Malley (2005) advanced a six-step framework for conducting scoping reviews: [1] identifying the research question; [2] identifying relevant studies; [3] study selection; [4] charting the data; [5] collating, summarising and reporting; and optionally [6] consulting and translating knowledge. A copy of the review protocol can be accessed by contacting the authors. Ethical approval was granted by the University of Toronto's Research Ethics Board (Protocol 41349).

Inclusion criteria

We included all published literature where the record: [1] reported empirical peer-reviewed research; [2] described a care transition from an institutional care setting (e.g., hospital, rehabilitation facility, nursing home) to any other care setting; [3] described decision-making and/or planning related to the transition; and [4] included data collected from the multiple perspectives of older adults, caregivers, and health professionals. Data from these multiple perspectives was necessary in order to better understand the extent to which the stakeholder groups were involved in decision-making and the different factors that they considered during their transition experiences. Only records published in English were included. Records were excluded when their methodology was unclear and when the perspectives of older adults could not be clearly identified or differentiated from younger participants. A small selection of records describing hypothetical transitions were excluded due to potential differences in predicted and

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3 actual transition decisions. Records focused on transitions at the end-of-life were excluded due to
4 the unique nature of this type of transition and the factors that may be considered by
5 stakeholders. Consistent with scoping review methodology, a critical appraisal to assess the
6 quality of the included records was not undertaken (30).
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9 **Search strategy**

10 A comprehensive search strategy was developed in consultation with a health sciences librarian
11 at the University of Toronto (Supplementary File 1). The search was designed to retrieve records
12 that described all of the following concepts: [1] a care transition; [2] decision-making or care
13 planning; [3] the triad perspectives of older adults, caregivers and health professionals (see Table
14 1). Relevant search terms relating to these concepts were drawn from published reviews and
15 expanded upon through a preliminary literature search and using the research teams' existing
16 knowledge. The search strategy was executed in the following databases due to their focus on
17 health research: MEDLINE, AgeLine, EMBASE, PsycINFO, and CINAHL Plus. No date or
18 study design restrictions were imposed. The search strategy was validated by ensuring the
19 retrieval of a selection of key publications identified through a preliminary literature search.
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23 **Selection of sources of evidence**

24 The search was executed in January 2021 and all records retrieved were imported into
25 Covidence, a web-based software platform designed to facilitate screening. Duplicates were
26 removed and records were screened in two stages. First, 90% of titles and abstracts were
27 independently reviewed by two authors (SC, KMK) based on pre-identified selection criteria.
28 Discrepancies were resolved between the authors through periodic discussions. The remaining
29 10% of records were screened by one author (SC) as a high degree of screening consistency was
30 observed. In the second stage of screening, two authors (SC, KMK) independently screened and
31 discussed the full text of all remaining records.
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34 **Data extraction and synthesis**

35 Two authors (SC, KMK) independently reviewed and charted the data from included records into
36 a detailed data abstraction form. Data charting was used to summarize, organize and interpret the
37 data from the records according to key themes. For each record, the following types of data were
38 extracted: general record information (i.e., journal, author, publication date, country of
39 publication, title); and research methods and design (i.e., study objective, settings, participant
40 characteristics, methods of data collection and analysis). Information on the factors that
41 influenced transition planning and decision-making were also extracted. Factors were defined as
42 any ideas or circumstances that appeared to have an influence on the transition decisions and
43 care arrangements made. Although the authors of some records had explicitly identified these
44 factors (e.g., perceived costs of care deterring participants from certain options), in most cases
45 they were identified iteratively using the central themes reported in the research. To present an
46 overview of all information retrieved, and to establish the breadth and scope of the literature, the
47 results of the review are reported in two formats: [1] a simple numerical description of the
48 distribution of the records coupled with data visualizations; and [2] a narrative synthesis and
49 content mapping of core topics of interest. Data synthesis and mapping was an iterative process
50 facilitated through multiple team meetings. Due to limited time and resources, the optional sixth
51 step of Arksey and O'Malley's scoping review framework, 'consulting and translation
52 knowledge', was not completed.
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Patient and public involvement

No patient involved.

RESULTS

The initial search resulted in 10,356 records. After deduplication, 7198 records remained for title and abstract screening. A total of 266 full text records were reviewed, and 39 were included in this review (Figure 1). A summary of the characteristics of the included records is presented in Table 2. Records were published between 1981 and 2019, with the majority published in the last 11 years (n=20; 51.3%). Included records described studies conducted in North America (n=28; 71.8%), Europe (n=10; 25.6%) and Australia (n=1; 2.6%).

Nearly all of the included records described qualitative studies (n=37; 94.9%). The remaining two records used mixed methods (5.1%). Common study designs included: ethnography (n=14; 35.9%); case study (n=6; 15.4%); exploratory qualitative (n=6; 15.4%); interpretive research (n=4; 10.3%); and grounded theory (n=3; 7.7%). Interviews were the predominant method for collecting data across the studies (n=37; 94.9%). Records also described observational data collection (n=22; 56.4%), document review (n=13; 33.3%) and focus groups or group workshops (n=4; 10.3%). The majority of included records described studies with more than one method of data collection (n=24; 61.5%).

All studies collected data from the perspectives of older adults, caregivers and health professionals. Many studies included health professionals from the initial transition setting as well as the final transition destination (n=16; 41.0%). Three records describing two studies included data from key informants throughout the health system (7.7%). In general, the study populations included more women than men. Only 7 studies reported the participants' ethnicities (17.9%), the majority of whom were white.

A variety of patient populations and transition types were described. Nearly all records described transition experiences from a hospital setting (n=34; 87.1%). Transition destinations varied across the studies; however, in most cases at least a portion of the older adults transitioned home (n=30; 76.9%). Other transition destinations included: nursing homes; retirement homes; skilled nursing facilities; rehabilitation facilities; rest homes; long-term care; and convalescent care homes. In many cases, the older adult participants transitioned between more than two locations.

Degree of stakeholder involvement

The degree of stakeholder involvement in transition planning and decision-making varied across the records. In many cases, there was evidence that health professionals made transition decisions with limited communication with the patients and families (18,23,31–50). At times, patients and families appeared comfortable with this arrangement, deferring decision-making to the health professionals (33,34,38,42,45,51–53). However, a few records alluded to complex power struggles between patients, families and health professionals over decision-making authority (23,54). In these cases, patients and families had limited control over the transitions, and were at times even purposefully excluded from transition planning (23,54).

Decisions were generally made by health professionals in team meetings or through exchange of informal communications. A few records mentioned cases where family conferences were held to include the patient or family in planning (34,40,44,49,51,54–59). Although it was not clearly stated in the records, authors implied that many decisions were made through informal conversations between health professionals, patients and families. Jewell (1993) noted that although this style of communication was often preferred by health professionals, “patients and/or carers felt poorly served by such an approach” (35; p. 1293).

Records reported conflicting views on transition planning between stakeholders (18,35,36,40,43,60). When patients and families disagreed with health professionals’ recommendations, their capacity to make decisions was questioned (23,35,58,61). In one study, Durocher et al (2017b) noted that all participants associated ageing with a gradual loss of agency and decline in capacity (34). This led to the expectation among participants that older adults’ engagement in decision-making would decline over time. Similarly, other records suggested that some health professionals held paternalistic or ageist attitudes (23,32–34,49,52,54), which compromised patients’ and families’ capacity to influence transition planning.

Factors influencing transition planning and decision-making

A variety of factors influencing transition planning and decision-making processes across stakeholder groups were described and are summarized in Table 3. These factors included: (a) institutional priorities and requirements; (b) resources; (c) knowledge; (d) risk; (e) group structure and dynamic; (f) health status and support needs; and (g) personality, preferences and beliefs. Typically, the factors were described at the level of the individual (micro-level); however, in some cases the factors were described at the group- or system-levels (meso- and macro- levels).

Institutional priorities and requirements

Several records described how institutional- and system-level priorities and requirements influenced transition options and decision-making. These institutional priorities were sometimes privileged over the priorities of the patients and families (36,49,56). Challenges emerged in transition planning due to requirements of the initial transition settings and the transition destinations. Records noted that institutions were under pressure to discharge patients as quickly as possible in order to comply with insurance requirements and free up beds (32,44,46,49,61–63). As a result, discharge planning often began upon admission; however, this early focus hindered the process of preparing patients for discharge (42,46,47,49,55). In one record, health professionals reported trying to conserve resources by discharging patients on certain days to maximize insurance usage (64). Transition options were further constrained by the admission criteria set by the discharge destinations (37,47,64). Lack of space and availability of services in the community exacerbated challenges by limiting transition options (41,48). Finally, privacy and confidentiality concerns restricted communication between different stakeholders both within and between settings, complicating transition planning (43,47,63).

Resources

Transition decisions were influenced by the decision-support resources available to the patient and family, as well as in the community. Social, psychological, financial and familial resources were identified (40,49,61). The most critical resource influencing transition decisions was the

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3 availability and support of a caregiver. Caregivers acted as an advocate for the patients during
4 transition planning, ensuring that their interests were upheld (18,31,37,46,51,53,60). Lack of
5 caregiver involvement sometimes resulted in care arrangements that the patients did not prefer
6 (18,33,65). Caregivers also helped to share information and knowledge with the patient, ensuring
7 that they understood what was happening (39). Despite this, it was important not to over-rely on
8 caregivers, as there were limits to the support that they could provide (46,60). Several records
9 also described how financial resources influenced transition decisions. In particular, perceived
10 costs of care might shift the older adults' and families' decisions (60,64), while availability of
11 health insurance might alter health professionals' recommendations (64). Ultimately, without
12 sufficient social and financial supports, certain transition 'options' were not executable (23).
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16 Time also influenced transition planning, both in terms of its availability as a resource, and
17 identifying the most appropriate timing for decisions. In a few records, health professionals
18 described insufficient time to prepare and plan for the transition (33,61,63). Depending on the
19 type of service, different amounts of time were required to prepare (54). Similarly, patients and
20 families found that decisions needed to be made rapidly, creating a challenge for transition
21 planning (41,46,48). However, limited time was not universal, as Rhynas et al (2018) found that
22 time pressure had no influence on transition decisions (18). The success of the care transitions
23 was sometimes dependent on the timing of the decisions being made. Robinson et al (2012)
24 described how discharge dates may be manipulated by health professionals in order to ensure
25 that relevant staff and services were available (62). Additionally, since many patients' care needs
26 and capacity fluctuated over time, it was important to make decisions when the patients'
27 condition had stabilized and they could participate effectively (40,49,51,58–60,65).
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31 **Knowledge**

32 Knowledge of the patient and the various options for transition settings influenced planning.
33 Several records described how patients and families were insufficiently informed and prepared to
34 make or follow a transition plan (18,37,38,40,44,46,47,49,56,59). Further, authors noted that
35 patients and families at times lacked the knowledge to prepare themselves to participate in
36 decisions, or felt ambivalent or reluctant to seek information (37,42). This reality constrained
37 decision-making, by limiting the patients' and families' capacity to participate. Conversely,
38 health professionals' medical expertise garnered them power and authority when making
39 decisions on behalf of patients and families (23). Health professionals' confidence in their
40 decisions was strengthened with knowledge of the patient themselves (62) and a clear
41 understanding of their role in transition planning, as well as the roles of others (42,46,47,51,63).
42 One record described how health professionals privileged their own knowledge above the
43 knowledge of the patients and families when making decisions (55). Similarly, two records
44 described how health professionals utilized the knowledge imbalance between themselves and
45 the patients by withholding information about different options (37,38). Finally, in some
46 instances patients, families, and health professionals each lacked knowledge and awareness of
47 the benefits and resources available in the community (41,51). This impeded transition planning,
48 by restricting the number of options under consideration.
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52 **Risk**

53 Perceptions of risk and safety had an important influence on how different stakeholders viewed
54 the transitions and justified their decisions. In some cases, health professionals and caregivers
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3 delayed or interrupted transitions due to concerns that the older adult was not ready (33,50,54).
4 As a result, they sometimes prioritized patient's safety over their preferences (18,23,34,55,58). A
5 language of risk was used to justify the transition decisions being made or recommended (18). In
6 one record, a caregiver "defined capacity as being capable of making a decision that was safe"
7 (53; p. 8). However, stakeholders appeared to weigh the risks associated with each transition
8 option differently. In particular, while older adults were often comfortable transitioning home,
9 health professionals and caregivers sometimes expressed concern with this option. These
10 conflicting views meant that certain transition options could not be executed by the older adults,
11 due to the perceived risks involved (23).
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14 ***Group structure and dynamic***

15 The quality of the relationships and communication between different stakeholders had an
16 important influence on transition planning. Several records suggested that poor communication
17 and coordination between health professionals challenged transition planning
18 (31,40,42,46,51,54,59,62). In particular, limited communication between institutional providers
19 and community providers resulted in poor continuity in care. Unclear responsibilities and roles
20 within teams was also a challenge, therefore some participants suggested having one health
21 professional in charge of coordinating transition efforts (33,51,54). It was often unclear whether
22 patients and families were recognized as equally valuable team members during transition
23 planning. Further, several records described how caregivers were often responsible for
24 navigating the health system and arranging services (39,41,65,66). Thus, their inclusion in the
25 team was important to ensure successful planning. In fact, Robinson et al (2012) noted that
26 strong relationships between family and health professionals led to greater likelihood that all
27 stakeholders would agree on decisions (62). Ultimately, trust was a recurring theme across the
28 records, as it helped to strengthen all stakeholders' comfort and confidence with the decisions
29 (37,44,53,54,62,63).
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34 ***Health status and support needs***

35 Although a patients' health status and support needs should logically influence their involvement
36 in transition decisions, many records did not describe consideration of this factor. Two records
37 described how the patients' current health statuses impeded their capacity to participate in
38 decision-making (37,38). Specifically, patients with sensory loss, language barriers, or high
39 medication use had limited opportunities to share their perspectives during planning. Records
40 also referenced discordance between the individuals' preferences for care, and their medical and
41 social needs (18,23). In these cases, the patients' health needs were typically prioritized over
42 their preferred choice of care arrangement. Finally, higher health needs influenced transition
43 planning by reducing the number of executable options (18,23,48,53). Patients who required
44 complex care needed more health professionals and services to be involved (63). For example,
45 Mead et al (2005) described how patients were transferred between assisted living facilities as a
46 result of their shifting care needs (53).
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50 ***Personality, preferences and beliefs***

51 Many records emphasized the importance of recognizing the older adults' and families'
52 personalities and incorporating their preferences into transition planning; however, it was unclear
53 whether this occurred in practice. Several records described conflicting stakeholders' views
54 towards transitions, which challenged planning processes (35,36,43,60,62). Health professionals
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3 in two studies specifically noted difficulty incorporating family preferences into transition
4 decisions (43,61). Finally, two records described how older adults' mindsets and attitudes
5 influenced transition planning, suggesting that more positive mindsets led to greater autonomy in
6 decision-making and subsequent care (51,52).
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8 9 **DISCUSSION**

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11 This review explored stakeholder involvement in transition planning and identified seven key
12 factors that appeared to influence stakeholders' decision-making. Findings were analyzed with a
13 specific focus on PFCC to determine the extent to which SDM occurs during care transition
14 planning. SDM is an approach to care planning that is expected to strengthen healthcare
15 experiences and outcomes by better aligning care with the preferences and needs of patients and
16 families; however, it can be challenging to implement in practice due to conflicting stakeholder
17 expectations.
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20 Across the included records, transition decisions were largely made by health professionals.
21 While there was evidence that some patients and families were involved in the transition
22 planning, their involvement varied on a case-by-case basis. This finding is consistent with
23 existing literature on transition planning (17), which shows that "although the majority of older
24 people would wish to be involved in decision-making in practice they are often not encouraged,
25 or enabled, to participate in SDM" (23; p. 10). Transition decisions were influenced by a variety
26 of micro-, meso- and macro-level factors. These factors included: (a) institutional priorities and
27 requirements; (b) resources; (c) knowledge; (d) risk; (e) group structure and dynamic; (f) health
28 status and support needs; and (g) personality, preferences and beliefs. The factors both
29 influenced, and were influenced by, the broader context in which decision-making occurred,
30 including who was involved, to what extent, and what options were considered.
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34 Power impacted the extent to which each factor influenced the transition decisions. Power has
35 been previously defined as "the degree of control over material, human intellectual and financial
36 resources by different sections of society" (62; p. 41). In this review, power permeated factors
37 like resources, time, knowledge, and group structure to impact the transition options under
38 consideration. As Joseph-Williams et al (2014) points out, if patients do not know or understand
39 the options available, then they are unable to participate in SDM (68). To date, many scholars
40 have written about the deep-rooted power imbalances between patients, families and health
41 professionals during clinical encounters. This review affirmed the existence of a power
42 imbalance during transition planning, as health professionals' knowledge and training was often
43 privileged over the patients' and families' perspectives. As Kaminskiy (2015) notes, power in
44 SDM can be so pervasive that "certain groups do not question, but instead accept certain
45 situations without conflict" (64; p. 24). This reality was reinforced in this review, as in many
46 cases patients and families willingly deferred decision-making authority to the health
47 professionals.
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51 Factors were weighed differently depending on the broader context of the transitions. In several
52 records, the older adults' available resources and anticipated health needs took precedence over
53 theirs and their families' preferences for the transition. These factors also influenced health
54 professionals' recommendations for transitional care. This reality illustrates the lasting influence
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of the biomedical model, where medical outcomes are valued more highly than other outcomes that might be more meaningful to the individual (e.g., quality of life). Similarly, although health professionals appeared to lead decision-making in many cases, their decisions were often impacted by structural factors beyond their control. These included, for example, institutional goals to discharge patients as quickly as possible, and a lack of available bed spaces in the community. According to Thomas et al (2020), these structural factors can have a profound impact on SDM by constraining the control health professionals have over their decisions, and prioritizing health system efficiencies over PFCC (70).

Future research might explore the relative weighing of these different factors during transition planning from the perspectives of patients, families and health professionals. As Kaminskiy (2015) comments, SDM is a complex process and power imbalances, conflict between stakeholders, and resource constraints have served to limit its uptake in practice (69). Therefore, greater understanding of how each stakeholder weighs these factors when making transition decisions may offer an opportunity to address these tensions and move towards more person- and family-centered transition planning. Stakeholders' specific social contexts should also be explored as prior research has shown that patient characteristics (e.g., ethnicity, gender) can influence healthcare experiences (71).

Further research on how the broader context shapes transition planning is also needed. During the COVID-19 pandemic there has been evidence that the factors influencing transition decisions may have been altered or re-weighted. For example, in April 2021 the Government of Ontario, Canada issued emergency orders to allow hospitals to transfer patients without consent in an effort to alleviate pressure on the healthcare system (72). Additionally, there is evidence that some older adults and families left care institutions like long-term care, a decision that was rarely executed pre-pandemic (73–76). These examples show the significant impact that the broader social and political context can have on transition decision-making. Research in this area may help to emphasize the complexity of transition planning, and which factors are most critical for guiding decision-making in different contexts.

Limitations

This review has several limitations. First, some relevant articles may have been missed, due to the complexity of care transitions, the breadth of literature on the topic, and limiting records to the English language. Second, while the included records all described transition planning and decision-making, they did not focus specifically on the factors influencing this process. Therefore, the identification of factors required the subjective interpretation of the authors. Despite this, common factors persisted across the records, all of which had been previously described in the literature on care transitions. Finally, the included records often lacked demographic information on the sex and ethnicity of participants making it impossible to assess participant diversity across the records.

CONCLUSION

This review described stakeholder involvement in transition planning and identified key factors influencing transition decisions. Findings may be useful for developing a framework on transition planning, guiding future research, raising awareness of the variation in stakeholder involvement during care transitions, and supporting the successful implementation of PFCC.

CONTRIBUTORS

All authors contributed to conceptualizing the study. SC and KK developed the initial literature search. SC and KMK independently performed screening and data extraction. SC performed initial data synthesis and KMK, KK, WB and SL refined it. SC drafted the manuscript and KMK, KK, WB and SL made revisions. All authors approved the final manuscript.

COMPETING INTERESTS

The authors have no competing interests to declare.

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DATA SHARING STATEMENT

No additional data are available.

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Table 1. Operational definitions of core concepts

Concept	Definition
Institutional care setting	Communal facilities where individuals may dwell for short or extended periods of time and have access to health care services. Examples may include: hospitals, rehabilitative centres, nursing homes, long-term care facilities, assisted living facilities, aged care homes, personal care homes, residential facilities, etc.
Care transition	The transfer of patients between different services, providers and/or settings.
Transition planning and decision-making	The process of preparing for a care transition and choosing between multiple options.
Older adult	Person aged 65 years or older.
Caregiver	A family member or friend who provides unpaid care to another person, either at home or in a care institution.
Health professional	A licensed or unlicensed care provider who offers paid medical, treatment or support services to a patient.

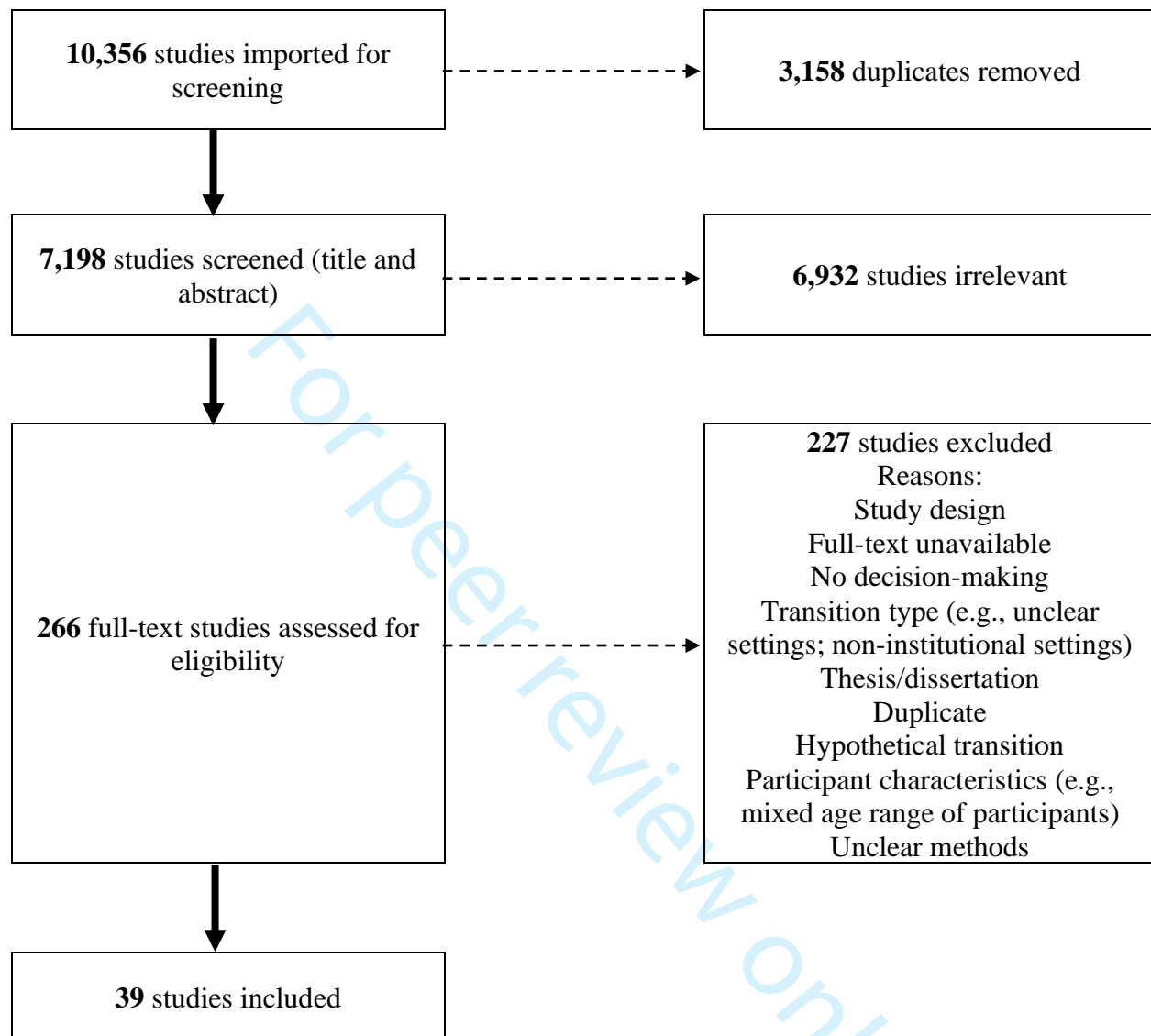
Table 2. Overview of included record characteristics (N=39)

Characteristic	n(%)
Year	
1980-1989	1 (2.5)
1990-1999	9 (23)
2000-2009	9 (23)
2010-2015	8 (20.5)
2016-2021	12 (31)
Country	
Australia	1 (2.5)
Canada	15 (38)
Finland	1 (2.5)
Multiple (European)	1 (2.5)
Sweden	3 (8)
USA	13 (33)
United Kingdom	5 (13)
Average number of participants	
Older adults	16
Caregivers	19
Health professionals	37
Other	20*

*Only 3 records included participants categorized as “Other”. In all three cases, these participants were described as key informants.

Table 3. Factors that influence transition planning and decision-making.

Factor	Description
Institutional priorities and requirements	Policies and objectives of the organization or care institution.
Resources	Individual, group or organizational-level supports or assets. These may be tangible (e.g., financial) or intangible (e.g., time) in nature.
Knowledge	Information and awareness of the patient, the healthcare system, and the variety of options available for transition.
Risk	Perceptions of risk and safety associated with a decision.
Group structure and dynamic	The extent to which stakeholders are involved (or not involved) in planning, their agreed-upon roles and responsibilities, and the quality of their interpersonal relationships and communication.
Health and support needs	Perceived current and future physical and mental capacity of the patient and their anticipated support needs.
Personality, preferences and beliefs	The individual's unique pattern of thinking, feeling or behaving, and what they want and hope to achieve.

Figure 1. PRISMA flow diagram depicting record identification and selection

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Supplementary File 1. Sample search strategy executed in MEDLINE.

- 1 Continuity of Patient Care/
- 2 Patient Transfer/
- 3 Patient Handoff/
- 4 Patient Navigation/
- 5 Aftercare/
- 6 Transitional Care/
- 7 Patient Discharge/
- 8 Retention in Care/
- 9 (care adj3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or path* or coordinat*)).tw,kf.
- 10 ((patient* or client*) adj3 (transiti* or transport* or transfer* or handoff* or hand off* or discharge*)).tw,kf.
- 11 ((optimal or ideal or plan or plans or plann*) adj2 (transiti* or transfer* or handoff* or hand off* or discharge*)).tw,kf.
- 12 (aftercare or after care).tw,kf.
- 13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
- 14 Decision Making/
- 15 Clinical Decision-Making/
- 16 Patient Participation/
- 17 Patient-Centered Care/
- 18 Patient Preference/
- 19 Decision Support Systems, Clinical/
- 20 Decision Support Techniques/
- 21 Goals/
- 22 ((make or making) adj3 decision*).tw,kf.
- 23 ((share* or joint* or collaborat* or mutual* or transition* or discharg*) adj2 (decision* or negotiat* or plan*)).tw,kf.

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- 24 ((patient* or client* or carer* or care giv* or caregiv* or family or families or provider* or clinician* or health professional* or medical professional* or clinician*) adj3 (decide or deciding or decision* or participat* or preferenc* or choice* or choos* or autonom* or engage* or involv* or agency or value* or expect* or desire* or attitud*)).tw,kf.
- 25 (patient centered or patient centred or client centered or client centred).tw,kf.
- 26 (individuali#ed adj2 care).tw,kf.
- 27 (decision* adj2 support*).tw,kf.
- 28 ((goal* or priorit*) adj3 (care* or set or sett*)).tw,kf.
- 29 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
- 30 exp Aged/
- 31 Geriatrics/
- 32 (aged or senior* or elder* or geriatric* or gerontolog*).tw,kf.
- 33 (old* adj3 (age* or people or peoples or person or persons or men or women or man or woman or adult* or patient* or client*)).tw,kf.
- 34 30 or 31 or 32 or 33
- 35 Caregivers/
- 36 Family/
- 37 Adult Children/
- 38 Spouses/
- 39 Parents/
- 40 Friends/
- 41 ((nonprofessional* or non professional* or informal or unpaid or volunteer* or relative or relatives or peer or peers or spous* or parent or parents or father or fathers or mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or brother* or sibling* or offspring or son or sons or daughter* or adult child*) adj3 (help* or care or caring or support* or aid or aids or aided or aiding or assist* or succor*)).tw,kf.
- 42 (care giv* or caregiv* or carer* or family or families).tw,kf.
- 43 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42

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44 exp Health Personnel/

45 exp Health Occupations/

46 (provider or providers or professional or professionals or practitioner or practitioners or clinician or clinicians or specialist or specialists or doctor or doctors or physician or physicians or nurse or nurses or social worker or social workers or physiotherapist or physiotherapists or therapist or therapists or case worker or case workers or manager or managers or pharmacist or pharmacists or dietician or dieticians or nutritionist or nutritionists or coordinator or coordinators or discharge planner or discharge planners or transition planner or transition planners).tw,kf.

47 44 or 45 or 46

48 13 and 29 and 34 and 43 and 47

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Supplementary File 2. Breakdown of factors influencing transition planning and decisions by record.

	Institutional Priorities and Requirements	Resources	Knowledge	Risk	Group Structure and dynamic	Health and support needs	Personality, preferences and beliefs
Ayele (2019)	X	X	X				
Bailey (2016)		X			X		
Bull (1996)	X	X	X		X		
Bull (2001)	X	X	X		X	X	X
Congdon (1994)		X			X		
Dill (1995)	X	X		X	X	X	X
Durocher (2017a)	X	X	X	X		X	
Durocher (2017b)			X	X	X		X
Durocher (2018)		X		X		X	X
Efraimsson (2003)	X		X		X		X
Efraimsson (2006)						X	X
Gladden (2000)	X	X	X			X	
Hedberg (2008)	X	X				X	X
Hicks (2012)	X	X	X	X	X	X	X
Jeffs (2017a)			X			X	
Jeffs (2017b)		X	X		X	X	
Jewell (1993)		X	X		X	X	
Magilvy (1991)		X				X	
Magilvy (2000)	X	X	X				X
McWilliam (1992)		X			X		X
McWilliam (1994a)	X	X	X		X		
McWilliam (1994b)					X		X
Palonen (2016)	X	X	X		X		
Poole (2014)		X	X	X	X	X	X
Popejoy (2011)		X			X	X	X
Rhynas (2018)		X		X		X	X
Robinson (2012)	X	X	X		X	X	X
Slatyer (2013)	X		X		X		
Toscan (2012)	X	X	X		X		
Toscan (2013)	X		X		X		
Trigg (2018)		X	X			X	X
Wells (1997)	X	X	X			X	
Wells (2002)			X		X		
Jenkins (2000)		X		X		X	X

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Mead (2005)	X	X			X	X	X
Smallegan (1981)		X				X	X
Stolee (2019)	X	X	X		X		
Toles (2012)			X			X	X
Toles (2016)			X		X	X	

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Supplementary File 3. Main findings related to transition planning and decision-making.

Author (Year)	Aim	Participants	Main settings	Major findings related to transition planning and decision-making
Ayele (2019)	To understand the role of perceived costs in decision making about post-acute care around the time of hospital discharge.	S (n=34) C (n=23) P (n=45)	Hospital >> SNF	<ul style="list-style-type: none"> Perceived costs of post-acute care had an important impact on transition decision-making. Insurance coverage and perceived costs of care constrained transition options and decisions. Some hospital professionals changed their treatment recommendations based on the patients' insurance coverage.
Bailey (2016)	To explore the experiences of patients with advanced COPD and lung cancer, their carers and their health professionals following emergency admission to the hospital.	S (n=39) C (n=20) P (n=50)	Hospital >> Home	<ul style="list-style-type: none"> During recovery, decisions were made by hospital staff and not communicated with patients or family. Caregivers were often excluded from planning, and information about care was often conveyed inaccurately, or was vague and confusing. There was a lack of continuity in care where information was not transferred successfully between the hospital and community, and patients often reported waiting for updates on their care plans.
Bull (1996)	To describe the nature of the difficulties encountered by elders and family caregivers following hospitalization, and identify the system constraints encountered in	S (n=25) C (n=253) P (n=38)	Hospital >> Home (or other community setting)	<ul style="list-style-type: none"> Communication gaps existed between health professionals, older adults and families. This resulted in problems with care and conflicting information being presented to the older adult and their caregiver. Health professionals reported having inadequate time for discharge planning and felt pressure from insurance companies to discharge quickly. Older adults and families were typically not involved in discharge planning and as a result often left the hospital with inadequate information.

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	planning for discharge.			<ul style="list-style-type: none"> Rural areas had less resources available for the transition, so professionals needed to expend extra effort to arrange care.
Bull (2001)	The purpose of this study was to identify the components of effective discharge planning for elders and factors that impede planning.	S (n=2) C (n=1) P (n=21)	Hospital >> Home; Nursing home	<ul style="list-style-type: none"> A ‘proper’ discharge relies on strong communication and trust between members of the multidisciplinary team, the patient, their family and the community professionals. Discharge planning involves four key stages: (a) getting to know the patient; (b) setting a discharge date; (c) getting ready to go home; and (d) making the transition. Older adults and families were not always included in discharge planning and were purposefully excluded when the professionals thought the decision would upset them. In these cases, plans often had to be revised.
Congdon (1994)	To gather information about the hospital discharge experience from elderly patients, their family members and nurses.	S (n=8) C (n=8) P (n=8)	Hospital >> Home or nursing home	<ul style="list-style-type: none"> Perceived readiness for discharge varied between participants, with patients believing they were ready, family members believing the patient was not ready, and nurses feeling uncertain. Family support was a key determinant in the discharge destination of the patient. The availability of family support resulted in patients’ transfer to homes in the community, rather than nursing homes. Decisions were made by the health professionals without the participation of patients and families. Some patients and families found ways to normalize their lack of involvement.
Dill (1995)	To augment current critical examinations of the principle of autonomy in medical decision making.	S (n=3+) C (n=3+) P (n=NA)	Hospital >> Home or Nursing home	<ul style="list-style-type: none"> Those who can authorize decisions are not always those involved in the planning. Health professionals planned multiple discharge options, regardless of patient and family preferences, so that once a decision was made they could act quickly. Patients’ decisional capacity was questioned when their views conflicted with the views of health professionals.

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Durocher (2017a)	To examine how the intersection of various influences on the process of discharge planning and how these may lead to unintended outcomes.	S (n=5) C (n=7) P (n=8)	Hospital >> Home	<ul style="list-style-type: none"> Health professionals established recommendations for discharge prior to family conferences. There was pressure on patients and families to meet these timelines. Discharge planning began on admission: some older adults and family members felt rushed and pressured to make decisions without sufficient information. Health professionals often prioritized safety over peoples' preferences and values; however, older adults expressed little concern over their safety.
Durocher (2017b)	To examine social and political influences affecting perspectives and practices associated with discharge planning with older adults.	S (n=5) C (n=7) P (n=8)	Hospital >> Home or unspecified	<ul style="list-style-type: none"> All participants expected that as older people aged they would experience a loss of agency and reduced participation in decision-making. This lack of autonomy over decision-making was sometimes not a choice. Health professional participants privileged their own knowledge and expertise when determining the best course of action and privileged safety over all other factors influencing the decision. Family conferences did not encourage older adults' contributions. Plans reflected the health professionals' beliefs rather than the patients' goals.
Durocher (2018)	To discern relational approaches adopted by families in planning for the discharge of older adults from inpatient settings and to explore how such approaches may inform practice in	S (n=3) C (n=5) P (n=NA)	Hospital >> Rehabilitation >> Retirement Home or Home	<ul style="list-style-type: none"> In this study, older adults either shared decision-making authority with their caregivers, or deferred it. In some cases, caregivers questioned the older adults' decisional capacity. Transition decisions required compromise from the older adults and caregivers who may have different preferences and beliefs.

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	discharge planning with older adults.			
Efrainsson (2003)	To illuminate and describe the phenomenon of power as it appeared in a discharge planning conference.	S (n=1) C (n=3) P (n=3)	Hospital >> Nursing home	<ul style="list-style-type: none"> This case study showed that in the discharge planning conference, the institutional frame was privileged over the client frame. At the conference, the hospital staff occupied most of the speaking time, often talking about the patient in the third person. The patient found the conference to be valuable; however, often lacked information on the transition options available and were unsure of how to obtain this information.
Efrainsson (2006)	To describe how patients, relatives, and healthcare professionals deal with the variety of problems and responsibilities that occur in discharge planning conferences and especially how they managed to do this given the institutional frame that surrounds the meeting.	S (n=8) C (n=8) P (n=23)	Hospital >> Home; nursing home	<ul style="list-style-type: none"> There was a clear discrepancy between the ideological intent of the discharge planning conference and its actual realization. Multiple challenges emerged during discharge planning, particularly when patient and family preferences did not align with institutional routines and professional judgements. Patients and families needed fight to achieve their transition goals; however, if their transgressions were too obvious they were at risk of not being taken seriously.
Gladden (2000)	To describe the process of decision-making used by older adults, their	S (n=13) C (n=8) P (n=11)	Hospital >> Home; nursing home or basic care facility	<ul style="list-style-type: none"> Patients and families perceived that they had little control over information exchange and transition decision-making. Patients and families were sometimes reluctant to seek information, and health professionals admitted to

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	families and care providers during admission into a discharge from subacute care settings.			<p>withholding information to reduce stress and anxiety for the patient.</p> <ul style="list-style-type: none"> Patients, family members and health professionals felt mistrust towards one another, questioning the information provided and subsequent decisions.
Hedberg (2008)	To illustrate how stroke survivors, their relatives, and different professionals participated and interacted in care-planning meetings when negotiating the stroke survivors' health and further needs of support from the health and social system	S (n=14) C (n=26) P (n=41)	Hospital or Rehabilitation Centre >> Not reported	<ul style="list-style-type: none"> Health professionals took up more of the discourse time in care planning meetings than patients and family members. Communication during the care planning meetings could be broken down into two main activities: the 'assessment process' and the 'decision-making process'. Communicative alliances between different stakeholder groups in the care planning meetings were important in advancing with a decision. Alliances between patients and caregivers were particularly important for increasing patients' opportunities to influence decisions. When relatives were absent, there was an increased risk that the patients' perspective would not be taken into account.
Hicks (2012)	This paper examines the autonomy, choice, options and power in healthcare decision making for older people.	S (n=6) C (n=5) P (n=49)	Hospital >> Rehabilitation hospital >> Home	<ul style="list-style-type: none"> Health professionals may question clients' choices when they do not align with their own. This can result in the choice being perceived as 'risky'. The older adult in this study learned over time that she did not have the freedom to choose among the different options, as she had limited resources and many 'options' were determined to be unrealistic or risky. The client felt limited control over the decision, rather it was borne by the health professionals and the institution.
Jefferies (2017a)	To explore the perceptions of patients, their	S (n=13) C (n=9) P (n=50)	Hospital	<ul style="list-style-type: none"> Patients and caregivers described being unaware of their transition plan. Professionals were often uncertain

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	caregivers and healthcare professionals associated with the exchange of information during transition from hospital to rehab.		>> Rehabilitation Hospital	<p>whether the transition plan had been communicated to patients.</p> <ul style="list-style-type: none"> • Professionals withheld details of the plan from patients and caregivers until they knew what would be happening. • Overall, professionals led decision-making about transitions and patients and caregivers had limited involvement and knowledge of the plans.
Jeffs (2017b)	This study was undertaken with the aim of gaining insight into the nature of caregiver involvement in care transitions of patients being transferred from two acute care hospitals to a rehab hospital.	S (n=13) C (n=9) P (n=50)	Hospital >> Rehabilitation Hospital	<ul style="list-style-type: none"> • Caregivers in this study were actively involved in the patient's transitional care, but were not actively engaged by health professionals. • Caregivers advocated on behalf of the patient, provided care, and helped to organize the transitions. • Patients and caregivers expressed concern that had the caregivers not been included in transition planning, the patient would not have understood the plan and their needs may not have been met.
Jenkins (2000)	To investigate how a range of care arrangement decisions for frail older unmarried women are made.	S (n=11) C (n=9) P (n=6)	Hospital >> Home; nursing home	<ul style="list-style-type: none"> • Family members played a central role in decision-making for care arrangements. • In some cases, the unavailability of family members resulted in the older women preferences for care arrangements not being followed. • Care arrangement decisions changed, often repeatedly, as their needs fluctuated.
Jewell (1993)	To establish areas of concern and importance to all those involved in, and affecting the	S (n=4) C (n=2) P (n=26)	Hospital >> Home, rest home, or nursing home	<ul style="list-style-type: none"> • Discharge in this study was viewed as an ongoing process that began upon admission. • It was unclear if the patient and family were identified as team members during discharge planning and decision-making. Although staff implied this was the case, patients and families demonstrated non-involvement.

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	discharge of patients.			<ul style="list-style-type: none"> Community personnel were also not involved in the planning, which created challenges and discontinuity in care.
Magilvy (1991)	To discover the process of admission and transition of older adults to home care following hospital discharge, or during periods of illness.	S (n=13) C (n=~13) P (n=47+)	Hospital >> Home	<ul style="list-style-type: none"> Patients transitions sometimes did not account for all of their care needs, or their living situation. Family members played a crucial role in facilitating the transition, by gathering information on available services. Community planners indicated that sometimes transition planning had not occurred, and they received patient referrals with little or no plan.
Magilvy (2000)	To examine the health care transition experiences of older adults, families and health care providers in a longitudinal rural ethnography.	S & C (n=49) P (n=113) O (n=13)	Various institutional and community transitions	<ul style="list-style-type: none"> In many cases, family members were left alone to discover appropriate resources. Staff sometimes lacked knowledge of community services, making transition decisions more challenging. Patients and family members often not included in decision-making and didn't understand what was happening to them. Families experienced uncertainty over the best living arrangement for their loved one.
McWilliam (1992)	To describe hospital discharge as experienced by a group of elderly patients.	S (n=12) C (n=12) P (n=62)	Hospital >> Home	<ul style="list-style-type: none"> Patients' mindset and attitudes towards ageing impacted the transition planning. All patients deferred decision-making to health professionals. Role confusion among health professionals led to social problems during discharge. Confusion existed between hospital staff and community staff. Physicians often did not attend family conferences where decisions were made. Communication challenges created problems for discharge, resulting in delay and confusion.
McWilliam (1994a)	To explore and describe factors	S (n=21) C (n=22)	Hospital >> Home	<ul style="list-style-type: none"> Professionals in the rural and urban settings made decisions with limited involvement from patients and

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	other than medical condition and treatment which shaped the quality of discharge experiences of older patients.	P (n=127) O (n=23)		<p>families. This led to learned helplessness from the patients.</p> <ul style="list-style-type: none"> • Patients, families and professionals often lacked an understanding of the roles of others (e.g., the social worker, community care staff), which complicated decisions. • Patients, families and professionals complained about inadequate discharge teaching.
McWilliam (1994b)	To explore factors other than medical condition and treatment which contributed to discharge experiences of rural and urban patients.	S (n=21) C (n=22) P (n=127) O (n=23)	Hospital >> Home	<ul style="list-style-type: none"> • Patients with a positive mindset achieved control over their own care after discharge and remained successfully autonomous. • In many cases, patients were comfortable deferring to professional authority. Professionals often adopted a paternalistic approach to treatment and decisions. • The more negative a patient's mindset was, the more compromised their autonomy.
Mead (2005)	To explore the decision-making process regarding retention or transfer of persons with dementia.	S (n=23) C (n=20) P (n=19)	Assisted living facility >> Multiple	<ul style="list-style-type: none"> • Facility managers made relocation decisions, often based on perceptions of the facility's culture, the specific care requirements related to dementia and the role of the family. • Problematic behaviours (e.g., wandering) from patients influenced their admission and possible relocation from the facilities. • Family members and residents had varied involvement in decision-making, including the process and timing and ultimate placement decision.
Palonen (2016)	To describe the experiences of emergency department service users and nurses regarding older	S (n=7) C (n=5) P (n=15)	Hospital >> Home	<ul style="list-style-type: none"> • Family members were sometimes expected to support decision-making when the patients and staff views were different. • Nurses in the study sometimes saw family involvement as a nuisance and challenge.

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	peoples' discharge education.			<ul style="list-style-type: none"> The nurses encouraged family involvement in decision-making and viewed them as a resource in certain situations. Patients did not feel the family members should be left responsible to make decisions about discharge.
Poole (2014)	To understand how, on medical wards, judgements about capacity and best interests with respect to going home are made for people with dementia and how decision-making around hospital discharge for people with dementia and their families might be improved.	S (n=29) C (n=34) IP (n=35)	Hospital >> Home or care home	<ul style="list-style-type: none"> Patients who were judged to have capacity were discharged home, and all those without capacity went to care homes. Patients' capacity fluctuated over time, and so decisions needed to be made at the right time. Perceptions of risk had a clear influence on assessments of capacity. If a person disagreed with the care team or wanted to make a decision that was viewed as "unsafe", they were likely to be determined to lack capacity. One narrative frequently dominated the decisions, and so any doubts about the patient capacity meant they might be disbelieved.
Popejoy (2011)	To examine decisions made by hospitalized older adults, families and care providers about hospital discharge.	S (n=13) C (n=12) P (n=7)	Hospital >> Home, nursing home	<ul style="list-style-type: none"> Many older adults in this study didn't even consider a destination other than home. This option was more feasible when older adults were cared for by a spouse, rather than adult children. Some older adults made discharge plans alone and did not disclose their care needs to their children so they did not burden their family. Professionals had the task of reconciling differing opinions within families. Sometimes they were unable to change the minds of older adults and families who were resolute in their plans.

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Rhynas (2018)	To gain understanding of the decision-making processes involved in the discharge of people admitted to hospital from home and discharged to a care home.	S (n=10) C (n=NA) P (n=NA)	Hospital >> Care home	<ul style="list-style-type: none"> • Absence of a family member in discharge planning resulted in limited consideration for patient preferences. In some cases, patients felt powerless to make decisions. • Admission was often seen as the last straw for family members, who tried to rationalize their care home placement decisions. Often, families had difficulty reconciling the patients' current care needs with their expressed preferences. • Professionals often used the language of risk to justify a care home discharge. This language objectified the individual's circumstances and excluded the individual from decision-making
Robinson (2012)	To identify key elements, from multiple perspectives, that influence the success of transition experienced by nursing home residents when they required transfer to a hospital emergency department.	S (n=7) C (n=20) P (n=44)	Nursing home >> Hospital >> Nursing home	<ul style="list-style-type: none"> • Having knowledge of the patient increased professionals' confidence in the transfer decision. When personal knowledge of the patient was not available, the transition was negatively affected (e.g., family absent). • All stakeholder groups viewed family involvement as an important element for transitions. Families often filled the gaps, and were essential for successful transitions. However, health professionals and families sometimes clashed in what they believed were the best interests for the patient. • Emergency departments were under pressure to discharge patients as soon as possible.
Slatyer (2013)	To explore the perceptions of older patients who re-presented to hospital within 28 days of discharge,	S (n=12) C (n=15) P (n=35)	Home or residential care >> Hospital >> Home or residential care	<ul style="list-style-type: none"> • Patients and families had difficulty recalling their communication with health professionals during admission. This resulted in them being discharged without awareness of their care and treatment needs. • Most patients and families trusted the professionals to make decisions.

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	their family caregivers, and care providers.			<ul style="list-style-type: none"> Families often involved in the decision to return to the hospital or to go see a general practitioner.
Smallegan (1981)	To gather information on the factors affecting decisions to admit a patient to a nursing home.	S (n=9) C (n=14) P (n=11)	Hospital; Home >> Nursing home	<ul style="list-style-type: none"> Roughly half of the people admitted to the nursing home agreed they had a role in decision-making. However, in most cases, transition to the nursing home occurred when there were no other options available. In most cases, participants had no satisfactory options other than admission. Patients and their adult children were the most prominent decision-makers, and others were mostly consulted about the decision.
Stolee (2019)	To identify and conceptually organize the domains relevant to improving care transitions of older patients with hip fracture, so as to inform future ToC interventions.	S (n=23) C (n=19) P (n=92)	Multiple >> Multiple	<ul style="list-style-type: none"> System constraints (e.g., rushed discharges) impeded transitions. Family members were interested in being involved in the care, but were not always included due to conflicting responsibilities and other contextual factors. Strong working relationships between professionals from the sites (as well as professionals, patients and families) helped to foster trust and ease transition.
Toles (2012)	To describe transitional care provided by existing staff in an skilled nursing facility and to explore the influence of staff interaction strategies on the	S (n=3) C (n=2) P (n=20)	Skilled nursing facility >> Home	<ul style="list-style-type: none"> Family members were not consistently involved in care. In some cases, the staff were responsible for preparing the patient and family to go home both in terms of ensuring necessary skills and also building confidence. Staff used three main interaction strategies to support transitional care: 1) creating connections with patients and families to integrate their preferences into the plan; 2) uncovering and relaying new information needed; and 3) engaging patients and families in problem solving conversations.

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	delivery of transitional care.			
Toles (2016)	To describe how organizational structures and staff interactions are used by existing skilled nursing facility staff to deliver transitional care services.	S (n=3) C (n=2) P (n=49)	Skilled nursing facility >> Home	<ul style="list-style-type: none"> • Staff often did not engage family caregivers and sufficiently prepare them for the transition. • In one facility, various meetings were held with staff, the patients and/or family to decide the patients care needs. Not all facilities had a care planning meeting with the patient/family, and in one facility, the meeting was 2 days before the patient returned home. • Communication challenges emerged in some facilities, for e.g. in one case the care coordinator planned the discharge date but the occupational therapist and physician were not aware that it was pending.
Toscan (2012)	To investigate care coordination for older hip fracture patients from multiple perspectives to determine the core factors related to poorly integrated care when patients transition from one care setting to another.	S (n=6) C (n=6) P (n=18)	Hospital >> Multiple (Home; Inpatient rehabilitation; Long-term care)	<ul style="list-style-type: none"> • Breakdowns in communication occurred between health professionals, making it difficult to make transition plans. Caregivers were even further removed from the flow of information. • Patients did not feel central to their own care and expressed lack of involvement in decision-making. • Professionals felt pressured to prioritize system needs (e.g. early discharge) over the needs of their patients. Patients felt rushed to recover and make decisions, and sometimes learned of decisions without remembering conversations about them.
Toscan (2013)	To explore the experience of transitional care over the complete care trajectory for a single hip fracture patient,	S (n=1) C (n=2) P (n=10)	Hospital >> Rehabilitation hospital >> Assisted living facility >> Home	<ul style="list-style-type: none"> • The patient and family felt left out of the decision-making processes around the transition. They also did not always know who to direct questions to. • Professionals felt that the health care system's focus on discharge-centred care planning added pressure to initiate transitions early. Their discharge options were also restricted by the facilities' admission criteria.

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	from multiple perspectives.			<ul style="list-style-type: none"> • Privacy barriers made communication between the facilities and family difficult.
Trigg (2018)	To compare how people use quality information to choose residential care providers in England, the Netherlands, and Spain.	S (n=83) C (n=49) P (n=38)	Multiple (hospital, home) >> Care home	<ul style="list-style-type: none"> • The most important information influencing decisions was that gathered during visits. • Many of the decisions about transition were made with or on behalf of the older adult. Few residents were involved in both the decisions to move into residential care, and the selection of provider. Families and professionals felt that decisions needed to be taken away from the senior as they were not aware of their reduced ability to live independently. • In some cases, choices were restricted and so the quality information (e.g. care home indicators) provided was redundant.
Wells (1997)	To study the process of decision making for elderly patients over the total course of their hospital stay and the consequences of that process.	S (n=31) C (n=22) P (n=23)	Hospital >> Multiple (Home; residential care; chronic care; convalescence)	<ul style="list-style-type: none"> • Discharge decision making often took place early in the patients' hospital stays, when the patient's condition was still fluctuating. Patients and families were only included sporadically. Decisions often had to be revised as the patient's condition progressed. • Decisions were not tied to the patient's condition, but rather to their social situation (e.g., living arrangements, age of caregiver, etc.) • Institutional priorities (e.g. get the patients out) were often emphasized over the patients' interests, and families were pressured to accept the first place that became available.
Wells (2002)	To evaluate the process and impact of the Integrated Model of Discharge Planning.	S (n=48) C (n=~8) P (n=NA)	Hospital >> Home	<ul style="list-style-type: none"> • At both hospital sites, patients were involved in most of time discharge planning, and families were involved around 40% of the time. • Community professionals were not always involved in discharge planning.

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				<ul style="list-style-type: none"> Most patients and families were satisfied with the discharge process, and a few felt they were told to go before they were ready.
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S= Senior or Older Adult; C = Caregiver; P = Provider or Health Professional

For peer review only

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

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2-3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	3
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	4
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	4-5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	16
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	4-5
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	5; Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	5
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Suppl Files 2-3
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	5-9
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	5-9
Limitations	20	Discuss the limitations of the scoping review process.	10-11
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	11
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	2

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

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

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

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

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

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).



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TITLE: Stakeholder involvement in care transition planning for older adults and the factors guiding their decision-making: a scoping review

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ABSTRACT

Objective: To synthesize the existing literature on care transition planning from the perspectives of older adults, caregivers, and health professionals and to identify the factors that may influence these stakeholders' transition decision-making processes.

Design: A scoping review guided by Arksey & O'Malley's six step framework. A comprehensive search strategy was conducted on January 7, 2021 to identify articles in five databases (Medline, Embase, Cinahl Plus, PsycINFO, and AgeLine). Records were included when they described care transition planning in an institutional setting from the perspectives of the care triad (older adults, caregivers, and health professionals). No date or study design restrictions were imposed.

Setting: This review explored care transitions involving older adults from an institutional care setting to any other institutional or non-institutional care setting. Institutional care settings include communal facilities where individuals dwell for short or extended periods of time and have access to health care services.

Participants: Older adults (aged 65 or older), caregivers, and health professionals.

Results: 39 records were included. Stakeholder involvement in transition planning varied across the studies. Transition decisions were largely made by health professionals, with limited or unclear involvement from older adults and caregivers. Seven factors appeared to guide transition planning across the stakeholder groups: (a) institutional priorities and requirements; (b) resources; (c) knowledge; (d) risk; (e) group structure and dynamic; (f) health and support needs; and (g) personality preferences and beliefs. Factors were described at micro-, meso- and macro-levels.

Conclusions: This review explored stakeholder involvement in transition planning and identified seven factors that appear to influence transition decision-making. These factors may be useful in advancing the delivery of person- and family-centered care by determining how individual-, group- and system-level values guide decision-making. Further research is needed to understand how various stakeholder groups balance these factors during transition planning in different health contexts.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This review considered transition planning among the care triad (defined as older adults, caregivers, and healthcare professionals).
- A wide range of transition experiences were described across the records, involving various care settings and patient conditions.
- The identification of factors required subjective interpretation, as few records specifically focused on identifying the factors that guided participants' decision-making.
- Participant characteristics were lacking in several records, making it difficult to assess participant diversity.
- Some relevant information may have been missed, as inclusion criteria was focused on describing transitions from institutional care settings.

INTRODUCTION

Increased interest in person- and family-centered care (PFCC) has emerged over the past several decades (1). PFCC is an approach to healthcare, whereby care decisions are driven by the individual's needs, preferences, and desired outcomes (2). In this values-based approach, patients and families are considered partners in their care and contribute important knowledge and experience to care and treatment decisions. The growing popularity of this approach represents an ideological shift from the biomedical model to one that emphasizes a holistic view of the individual with specific medical, social, mental, emotional and spiritual needs (3). PFCC policies and practices are now widely recognized as an important indicator of healthcare quality, and many healthcare systems globally are making progress towards achieving a higher standard of PFCC (4).

While many believe that a PFCC approach is justified on moral grounds (5), the benefits of adoption include improved individual- and system-level outcomes as demonstrated by studies showing greater self-efficacy, levels of satisfaction and individual wellbeing (6–8) amongst patients and families. Additionally, PFCC interventions have been associated with a better use of resources and decreased health system costs in certain therapeutic areas (6,9,10).

The successful delivery of PFCC may be a particularly important contributor to enhanced management of complex health processes like care transitions. Care transitions are broadly defined as the transfer of patients between different settings, services or care providers (11,12). They represent periods of high vulnerability and risk, due to the potential for adverse events and breakdowns in communication (13). Despite the promise of PFCC, a recent review on care transitions reported a mixed effect of the impact of PFCC on patient-oriented outcomes leading the authors to reflect on the core components of the approach, and conclude that PFCC interventions must incorporate several core components to successfully improve transition outcomes (14).

Shared decision-making (SDM) is often viewed as one of the core components of PFCC (15). SDM is a collaborative approach to decision-making, whereby health professionals and patients consider options and evidence together before making joint decisions (16). This approach may be particularly useful in the context of care transitions, since the decisions will likely impact caregivers and health professionals in addition to the patient. Specifically, the outcomes of transition decision-making can influence health professionals' planning and resource allocation, as well as caregivers' responsibilities for care coordination and delivery.

Despite the significant impact that care transition decisions can have on the lives of these stakeholders, there is considerable evidence that patients and families are not included in, and have limited influence over, transition planning and decision-making (17–25). This may be particularly true for older patient populations, as SDM becomes more complex due to their higher health needs and reduced ability to self-manage (26). This lack of involvement is further problematized by the reality that different stakeholders may have conflicting goals during the transition (13,27). The absence of patient and family voice during care transitions may therefore result in system goals being prioritized over the goals of the individual patients and their families (13).

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4 A lack of patient and family involvement in care transition planning and decision-making raises
5 important questions about the quality of care during transitions and the extent to which they are
6 person-centered. Therefore, the aim of this review is to synthesize the available literature on care
7 transition planning from the perspectives of older adults, caregivers and health professionals, and
8 identify the core factors that appear to influence transition decision-making. By identifying these
9 factors, we may better determine the extent to which care transitions are person-centered, and
10 how they may be strengthened in the future.
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13 **METHODS**

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16 This scoping review examined care transition planning and decision-making from the
17 perspectives of older adults, caregivers, and health professionals. We followed the methods
18 outlined by Arksey & O'Malley (2005) and adhered to Tricco et al's (2018) PRISMA Extension
19 for Scoping Reviews (PRISMA-ScR) checklist to report our findings (28,29). Arksey and
20 O'Malley (2005) advanced a six-step framework for conducting scoping reviews: [1] identifying
21 the research question; [2] identifying relevant studies; [3] study selection; [4] charting the data;
22 [5] collating, summarising and reporting; and optionally [6] consulting and translating
23 knowledge. A copy of the review protocol can be accessed by contacting the authors. Ethical
24 approval was granted by the University of Toronto Research Ethics Board's Human Research
25 Ethics Unit (Protocol 41349). This scoping review did not involve any direct collection of data
26 from participants therefore informed consent was not required.
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29 **Inclusion criteria**

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31 We included all published literature where the record: [1] reported empirical peer-reviewed
32 research; [2] described a care transition from an institutional care setting (e.g., hospital,
33 rehabilitation facility, nursing home) to any other care setting; [3] described decision-making
34 and/or planning related to the transition; and [4] included data collected from the multiple
35 perspectives of older adults, caregivers, and health professionals. Data from these multiple
36 perspectives was necessary in order to better understand the extent to which the stakeholder
37 groups were involved in decision-making and the different factors that they considered during
38 their transition experiences. No study type or design restrictions were implemented, however due
39 to the focus on reporting of stakeholder experiences, included records often adopted qualitative
40 methodologies. Differences in qualitative methodologies and approaches were not accounted for
41 during analysis. Only records published in English were included. Records were excluded when
42 their methodology was unclear and when the perspectives of older adults could not be clearly
43 identified or differentiated from younger participants. A small selection of records describing
44 hypothetical transitions were excluded due to potential differences in predicted and actual
45 transition decisions. Records focused on transitions at the end-of-life were excluded due to the
46 unique nature of this type of transition and the factors that may be considered by stakeholders.
47 Consistent with scoping review methodology, a critical appraisal to assess the quality of the
48 included records was not undertaken (30).
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52 **Search strategy**

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54 A comprehensive search strategy was developed in consultation with a health sciences librarian
55 at the University of Toronto (Supplementary File 1). The search was designed to retrieve records
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3 that described all of the following concepts: [1] a care transition; [2] decision-making or care
4 planning; [3] the triad perspectives of older adults, caregivers and health professionals (see Table
5 1). Relevant search terms relating to these concepts were drawn from published reviews and
6 expanded upon through a preliminary literature search and using the research teams' existing
7 knowledge. The search strategy was executed in the following databases due to their focus on
8 health research: MEDLINE, AgeLine, EMBASE, PsycINFO, and CINAHL Plus. No date or
9 study design restrictions were imposed. The search strategy was validated by ensuring the
10 retrieval of a selection of key publications identified through a preliminary literature search.
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13 **Selection of sources of evidence**

14 The search was executed in January 2021 and all records retrieved were imported into
15 Covidence, a web-based software platform designed to facilitate screening. Duplicates were
16 removed and records were screened in two stages. First, 90% of titles and abstracts were
17 independently reviewed by two authors (SC, KMK) based on pre-identified selection criteria.
18 Discrepancies were resolved between the authors through periodic discussions. The remaining
19 10% of records were screened by one author (SC) as a high degree of screening consistency was
20 observed. In the second stage of screening, two authors (SC, KMK) independently screened and
21 discussed the full text of all remaining records.
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25 **Data extraction and synthesis**

26 Two authors (SC, KMK) independently reviewed and charted the data from included records into
27 a detailed data abstraction form. Data charting was used to summarize, organize and interpret the
28 data from the records according to key themes. For each record, the following types of data were
29 extracted: general record information (i.e., journal, author, publication date, country of
30 publication, title); and research methods and design (i.e., study objective, settings, participant
31 characteristics, methods of data collection and analysis). Information on the factors that
32 influenced transition planning and decision-making were also extracted. Factors were defined as
33 any ideas or circumstances that stakeholders considered when making transition decisions and
34 selecting subsequent care arrangements. Although the authors of some records had explicitly
35 identified these factors (e.g., perceived costs of care deterring participants from certain options),
36 in many cases they were identified iteratively using the central themes reported in the research.
37 To determine the themes, two authors (SC, KMK) identified an initial list of factors that were
38 clearly expressed in the records. Each extracted factor represented a theme, as it was a recurring
39 idea presented across multiple records (Supplementary File 2). The factors were then reviewed
40 by all members of the research team who then refined the list of factors by making suggestions
41 for further grouping or un-grouping. Once the parameters of each factor were defined, one author
42 (SC) reviewed all included records again to ensure that the factors were extracted consistently.
43 One author (SC) then explored and compared these factors by participant type and demographics
44 (e.g., sex and ethnicity, when available) and discussed these findings with the research team.
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49 To present an overview of all information retrieved, and to establish the breadth and scope of the
50 literature, the results of the review are reported in two formats: [1] a simple numerical
51 description of the distribution of the records coupled with data visualizations; and [2] a narrative
52 synthesis and content mapping of core topics of interest (Supplementary File 3). Data synthesis
53 and mapping was an iterative process facilitated through multiple team meetings. In these
54 meetings, team members discussed, refined and defined the final list of factors. Due to limited
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time and resources, the optional sixth step of Arksey and O'Malley's scoping review framework, 'consulting and translation knowledge', was not completed.

Patient and public involvement

No patient involved.

RESULTS

The initial search resulted in 10,356 records. After deduplication, 7198 records remained for title and abstract screening. A total of 266 full text records were reviewed, and 39 were included in this review (Figure 1). A summary of the characteristics of the included records is presented in Table 2. Records were published between 1981 and 2019, with the majority published in the last 11 years (n=20; 51.3%). Included records described studies conducted in North America (n=28; 71.8%), Europe (n=10; 25.6%) and Australia (n=1; 2.6%).

Nearly all of the included records described qualitative studies (n=37; 94.9%). The remaining two records used mixed methods (5.1%). Common study designs included: ethnography (n=14; 35.9%); case study (n=6; 15.4%); exploratory qualitative (n=6; 15.4%); interpretive research (n=4; 10.3%); and grounded theory (n=3; 7.7%). Interviews were the predominant method for collecting data across the studies (n=37; 94.9%). Records also described observational data collection (n=22; 56.4%), document review (n=13; 33.3%) and focus groups or group workshops (n=4; 10.3%). The majority of included records described studies with more than one method of data collection (n=24; 61.5%).

All studies collected data from the perspectives of older adults, caregivers and health professionals. Many studies included health professionals from the initial transition setting as well as the final transition destination or community (n=16; 41.0%). Three records describing two studies included data from key informants throughout the health system (7.7%). In general, the study populations included more women than men. Only 7 studies reported the participants' ethnicities (17.9%), the majority of whom were white.

A variety of patient populations and transition types were described. Nearly all records described transition experiences from a hospital setting (n=34; 87.1%). Transition destinations varied across the studies; however, in most cases at least a portion of the older adults transitioned home (n=30; 76.9%). Other transition destinations included: nursing homes; retirement homes; skilled nursing facilities; rehabilitation facilities; rest homes; long-term care; and convalescent care homes. In many cases, the older adult participants transitioned between more than two locations.

Degree of stakeholder involvement

The degree of stakeholder involvement in transition planning and decision-making varied across the records. In many cases, there was evidence that health professionals made transition decisions with limited communication with the patients and families (18,23,31–50). Decisions were generally made by health professionals in team meetings or through exchange of informal communications. A few records mentioned cases where family conferences were held to include the patient or family in planning (34,40,44,49,51–57). Although it was not clearly stated in the records, authors implied that many decisions were made through informal conversations between health professionals, patients and families. Jewell (1993) noted that although this style of

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3 communication was often preferred by health professionals, “patients and/or carers felt poorly
4 served by such an approach” (40, p.1293). Several records also described limited involvement
5 and knowledge of, communication with, and recognition of the role of community health
6 professionals during transitions, creating challenges during and after transitions (31,40–42,52).
7 Despite this, there was recognition that involvement of community health professionals could
8 strengthen transition planning and decision-making (18).
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11 Records reported conflicting views on transition planning between stakeholders
12 (18,35,36,40,43,58). When patients and families disagreed with health professionals’
13 recommendations, their capacity to make decisions was questioned (23,35,56,59). In one study,
14 Durocher et al (2017b) noted that all participants associated ageing with a gradual loss of agency
15 and decline in capacity (34). This led to the expectation among participants that older adults’
16 engagement in decision-making would decline over time. Similarly, other records suggested that
17 some health professionals held paternalistic or ageist attitudes (23,32–34,49,52,60), which
18 compromised patients’ and families’ capacity to influence transition planning.
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21 **Factors influencing transition planning and decision-making**

22 A variety of factors influencing transition planning and decision-making processes across
23 stakeholder groups were described and are summarized in Table 3. These factors included: (a)
24 institutional priorities and requirements; (b) resources; (c) knowledge; (d) risk; (e) group
25 structure and dynamic; (f) health status and support needs; and (g) personality, preferences and
26 beliefs (Figure 2). Typically, the factors were described at the level of the individual (micro-
27 level); however, in some cases the factors were described at the group- or system-levels (meso-
28 and macro- levels).
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31 *Institutional priorities and requirements*

32 Several records described how institutional- and system-level priorities and requirements
33 influenced transition options and decision-making. These institutional priorities were sometimes
34 privileged over the priorities of the patients and families (36,49,54). Challenges emerged in
35 transition planning due to requirements of the initial transition settings and the transition
36 destinations. Records noted that institutions were under pressure to discharge patients as quickly
37 as possible in order to comply with insurance requirements and free up beds
38 (32,44,46,49,59,61,62). As a result, discharge planning often began upon admission; however,
39 this early focus hindered the process of preparing patients for discharge (42,46,47,49,53). In one
40 record, health professionals reported trying to conserve resources by discharging patients on
41 certain days to maximize insurance usage (63). Transition options were further constrained by
42 the admission criteria set by the discharge destinations (37,47,63). Lack of space and availability
43 of services in the community exacerbated challenges by limiting transition options (41,48).
44 Finally, privacy and confidentiality concerns restricted communication between different
45 stakeholders both within and between settings, complicating transition planning (43,47,62).
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50 *Resources*

51 Transition decisions were influenced by the decision-support resources available to the patient
52 and family, as well as in the community. Social, psychological, financial and familial resources
53 were identified (40,49,59). The most critical resource influencing transition decisions was the
54 availability and support of a caregiver. Caregivers acted as an advocate for the patients during
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3 transition planning, ensuring that their interests were upheld (18,31,37,46,51,58,64). Lack of
4 caregiver involvement sometimes resulted in care arrangements that the patients did not prefer
5 (18,33,65). Caregivers also helped to share information and knowledge with the patient, ensuring
6 that they understood what was happening (39). Despite this, it was important not to over-rely on
7 caregivers, as there were limits to the support that they could provide (46,58). Several records
8 also described how financial resources influenced transition decisions. In particular, perceived
9 costs of care might shift the older adults' and families' decisions (58,63), while availability of
10 health insurance might alter health professionals' recommendations (63). Ultimately, without
11 sufficient social and financial supports, certain transition 'options' were not executable (23).
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15 Time also influenced transition planning, both in terms of its availability as a resource, and
16 identifying the most appropriate timing for decisions. In a few records, health professionals
17 described insufficient time to prepare and plan for the transition (33,59,62). Depending on the
18 type of service, different amounts of time were required to prepare (52). Similarly, patients and
19 families found that decisions needed to be made rapidly, creating a challenge for transition
20 planning (41,46,48). However, limited time was not universal, as Rhynas et al (2018) found that
21 time pressure had no influence on transition decisions (18). The success of the care transitions
22 was sometimes dependent on the timing of the decisions being made. Robinson et al (2012)
23 described how discharge dates may be manipulated by health professionals in order to ensure
24 that relevant staff and services were available (61). Additionally, since many patients' care needs
25 and capacity fluctuated over time, it was important to make decisions when the patients'
26 condition had stabilized and they could participate effectively (40,49,51,56–58,65).
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29 **Knowledge**

30 Knowledge of the patient and the various options for transition settings influenced planning.
31 Several records described how patients and families were insufficiently informed and prepared to
32 make or follow a transition plan (18,37,38,40,44,46,47,49,54,57). Further, authors noted that
33 patients and families at times lacked the knowledge to prepare themselves to participate in
34 decisions, or felt ambivalent or reluctant to seek information (37,42). This reality constrained
35 decision-making, by limiting the patients' and families' capacity to participate. Conversely,
36 health professionals' medical expertise garnered them power and authority when making
37 decisions on behalf of patients and families (23). Health professionals' confidence in their
38 decisions was strengthened with knowledge of the patient themselves (61) and a clear
39 understanding of their role in transition planning, as well as the roles of others (42,46,47,51,62).
40 One record described how health professionals privileged their own knowledge above the
41 knowledge of the patients and families when making decisions (53). Similarly, two records
42 described how health professionals utilized the knowledge imbalance between themselves and
43 the patients by withholding information about different options (37,38). Finally, in some
44 instances patients, families, and health professionals each lacked knowledge and awareness of
45 the benefits and resources available in the community (41,51). This impeded transition planning,
46 by restricting the number of options under consideration.
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51 **Risk**

52 Perceptions of risk and safety had an important influence on how different stakeholders viewed
53 the transitions and justified their decisions. In some cases, health professionals and caregivers
54 delayed or interrupted transitions due to concerns that the older adult was not ready (33,50,52).
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As a result, they sometimes prioritized the older adults' safety over the older adults' preferences (18,23,34,53,56). A language of risk was used to justify the transition decisions being made or recommended (18). In one record, a caregiver "defined capacity as being capable of making a decision that was safe" (56, p.8). However, stakeholders appeared to weigh the risks associated with each transition option differently. In particular, while older adults were often comfortable transitioning home, health professionals and caregivers sometimes expressed concern with this option. These conflicting views meant that certain transition options could not be executed by the older adults, due to the perceived risks that others held (23).

Group structure and dynamic

The quality of the relationships and communication between different stakeholders had an important influence on transition planning. Several records suggested that poor communication and coordination between health professionals challenged transition planning (31,40,42,46,51,52,57,61). In particular, limited communication between institutional providers and community providers resulted in poor continuity in care. Unclear responsibilities and roles within teams was also a challenge, therefore some participants suggested having one health professional in charge of coordinating transition efforts (33,51,52). It was often unclear whether patients and families were recognized as equally valuable team members during transition planning. Further, several records described how caregivers were often responsible for navigating the health system and arranging services (39,41,65,66). Thus, their inclusion in the team was important to ensure successful planning. In fact, Robinson et al (2012) noted that strong relationships between family and health professionals led to greater likelihood that all stakeholders would agree on decisions (61). Ultimately, trust was a recurring theme across the records, as it helped to strengthen all stakeholders' comfort and confidence with the decisions (37,44,52,61,62,64).

Health status and support needs

Although a patients' health status and support needs should logically influence their involvement in transition decisions, few records described consideration of this factor. Two records described how the patients' current health statuses impeded their capacity to participate in decision-making (37,38). Specifically, patients with sensory loss, language barriers, or high medication use had limited opportunities to share their perspectives during planning. Records also referenced discordance between the individuals' preferences for care, and their medical and social needs (18,23). In these cases, the patients' health needs were typically prioritized over their preferred choice of care arrangement. Finally, higher health needs influenced transition planning by reducing the number of executable options (18,23,48,64). Patients who required complex care needed more health professionals and services to be involved (62). For example, Mead et al (2005) described how patients were transferred between assisted living facilities as a result of their shifting care needs (64).

Personality, preferences and beliefs

Many records emphasized the importance of recognizing the older adults' and families' personalities and incorporating their preferences into transition planning; however, it was unclear whether this occurred in practice. Several records described conflicting stakeholders' views towards transitions, which challenged planning processes (35,36,43,58,61). Health professionals in two studies specifically noted difficulty incorporating family preferences into transition

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3 decisions (43,59). Finally, two records described how older adults' mindsets and attitudes
4 influenced transition planning, suggesting that more positive mindsets led to greater autonomy in
5 decision-making and subsequent care (51,60).
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8 **DISCUSSION**

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10 This review explored stakeholder involvement in transition planning and identified seven key
11 factors that appeared to influence stakeholders' decision-making. Findings were analyzed with a
12 specific focus on PFCC to determine the extent to which SDM occurs during care transition
13 planning. SDM is an approach to care planning that is expected to strengthen healthcare
14 experiences and outcomes by better aligning care with the preferences and needs of patients and
15 families; however, it can be challenging to implement in practice due to conflicting stakeholder
16 expectations.
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19 Across the included records, transition decisions were largely made by health professionals.
20 While there was evidence that some patients and families were involved in the transition
21 planning, their involvement varied on a case-by-case basis. This finding is consistent with
22 existing literature on transition planning (17), which shows that "although the majority of older
23 people would wish to be involved in decision-making in practice they are often not encouraged,
24 or enabled, to participate in SDM" (26, p.10). Transition decisions were influenced by a variety
25 of micro-, meso- and macro-level factors. These factors included: (a) institutional priorities and
26 requirements; (b) resources; (c) knowledge; (d) risk; (e) group structure and dynamic; (f) health
27 status and support needs; and (g) personality, preferences and beliefs. The factors both
28 influenced, and were influenced by, the broader context in which decision-making occurred,
29 including who was involved, to what extent, and what options were considered.
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33 In reflecting on the range of factors that influenced transition decisions, it appears that power
34 may also play a role. Power impacted the extent to which each factor influenced the transition
35 decisions. Power has been previously defined as "the degree of control over material, human
36 intellectual and financial resources by different sections of society" (67, p.41). In this review, it
37 appeared that power permeated factors like resources, time, knowledge, and group structure to
38 impact the transition options under consideration. As Joseph-Williams et al (2014) points out, if
39 patients do not know or understand the options available, then they are unable to participate in
40 SDM (68). To date, many scholars have written about the deep-rooted power imbalances
41 between patients, families and health professionals during clinical encounters. This review
42 affirmed the existence of a power imbalance during transition planning, as health professionals'
43 knowledge and training was often privileged over the patients' and families' perspectives. As
44 Kaminskiy (2015) notes, power in SDM can be so pervasive that "certain groups do not question,
45 but instead accept certain situations without conflict" (69, p.24). This reality was reinforced in
46 this review, as in many cases patients and families willingly deferred decision-making authority
47 to the health professionals. Similarly, although health professionals appeared to lead decision-
48 making in many cases, their decisions were often impacted by structural factors beyond their
49 control. These included, for example, institutional goals to discharge patients as quickly as
50 possible, and a lack of available bed spaces in the community. According to Thomas et al (2020),
51 these structural factors can have a profound impact on SDM by constraining the control health
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professionals have over their decisions, and prioritizing health system efficiencies over PFCC (70).

It also appeared that factors were weighed differently depending on the broader context of the transitions. In several records, the older adults' available resources and anticipated health needs took precedence over their preferences for the transition. This was most apparent in records where the older adults expressed a clear preference to return home, and their caregivers or health professionals resisted this transition due to lack of available supports and perceived risks involved. In several records, factors like health and support needs, risk and resources also influenced health professionals' recommendations for transitional care. The subjective weighting of these factors sometimes led to disagreements between stakeholders. This reality illustrates the lasting influence of the biomedical model, where medical outcomes are valued more highly than other outcomes that might be more meaningful to the individual (e.g., quality of life).

Future research might explore the relative weighing of these different factors during transition planning from the perspectives of patients, families and health professionals. As Kaminskiy (2015) comments, SDM is a complex process and power imbalances, conflict between stakeholders, and resource constraints have served to limit its uptake in practice (69). Therefore, greater understanding of how each stakeholder weighs these factors when making transition decisions may offer an opportunity to address these tensions prioritize them and move towards more person- and family-centered transition planning.

Although SDM has emerged as a high priority in many health settings, concerns have been raised over the value of the approach and its implementation. For example, some scholars have questioned the assumption that all patients wish to, and are capable of, participating in SDM (71). This finding was also observed in this scoping review as some health professionals and caregivers questioned the capacity of the older adults to safely participate in decision-making. A recent systematic review by Waddell et al (2021) observed similar attitudes among health professionals and suggested that these perspectives can act as a barrier to successful SDM implementation (72). Other clinician-related, patient-related, organizational-level and system-level characteristics can also negatively influence the implementation of SDM, and Elwyn et al (2016) have argued that recognition of SDM as the 'right thing to do' may not be sufficient to support its implementation in practice (73). Rather, specific strategies from the field of implementation science and evaluation of the broader, long-term outcomes associated with SDM may be required. Some strategies to support the implementation and maintenance of SDM include: training stakeholders in the use of decision support tools, engaging champions to raise awareness and support for SDM, embedding SDM in policies and clinical practice guidelines, offering incentives to participate in SDM, and monitoring performance related to SDM (74,75). Future research may focus on evaluating the effectiveness of each of these strategies and the short- and long-term consequences of implementing SDM overall.

Stakeholders' specific social and cultural contexts should also be explored as prior research has shown that patient characteristics (e.g., ethnicity, gender) can influence healthcare experiences (76). Records included in this review had inconsistent reporting of participant demographics, and often did not offer an in-depth analysis of experiential differences based on participants' age, sex, gender or ethnicity. However, existing literature suggests that there may be gendered

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3 differences in care transition pathways (77), and that minority groups may experience enhanced
4 difficulties during care transitions (76). This review did find some potential differences in
5 transition planning and decision-making between urban and rural geographies. Specifically,
6 some records reported that rural institutions faced challenges related to access to community care
7 and nuanced differences between rural and urban transition practices and cultures. Yet, while
8 health care inequities facing rural populations are often described in health research, further
9 exploration of the multidimensional and heterogenous health care experiences of older adults in
10 rural settings is warranted (78).
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14 Further research on how the broader context shapes transition planning is also needed. During
15 the COVID-19 pandemic there has been evidence that the factors influencing transition decisions
16 may have been altered or re-weighted. For example, in April 2021 the Government of Ontario,
17 Canada issued emergency orders to allow hospitals to transfer patients without consent in an
18 effort to alleviate pressure on the healthcare system (79). Additionally, there is evidence that
19 some older adults and families left care institutions like long-term care, a decision that was rarely
20 executed pre-pandemic (80–83). These examples show the significant impact that the broader
21 social and political context can have on transition decision-making. Research in this area may
22 help to emphasize the complexity of transition planning, and which factors are most critical for
23 guiding decision-making in different contexts. Research may also focus on examining the unique
24 roles of older adults, caregivers, and institutional and community health professionals in these
25 new care contexts.
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28 **Limitations**

29 This review has some limitations. First, some relevant articles may have been missed, due to the
30 complexity of care transitions, the breadth of literature on the topic, and limiting records to the
31 English language. Second, while the included records all described transition planning and
32 decision-making, they did not focus specifically on the factors influencing this process.
33 Therefore, the identification of factors required the subjective interpretation of the authors.
34 Despite this, common factors persisted across the records, all of which had been previously
35 described in the literature on care transitions. Third, records included in this review adopted a
36 myriad of designs, approaches and methodologies which result in subtle differences in data and
37 reporting. Although we did not account for these differences when synthesizing findings across
38 the records, we focused on consistently defining and extracting our findings across all records.
39 Fourth, there was no patient or family involvement in the identification of factors for this review.
40 Including patient and family representation on the authorship team may have added further
41 nuance to the interpretation of factors and served to validate our findings. Finally, the included
42 records often lacked demographic information on the sex and ethnicity of participants making it
43 impossible to assess participant diversity across the records.
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48 **CONCLUSION**

49 This review described stakeholder involvement in transition planning and identified key factors
50 influencing transition decisions. Findings may be useful for developing a framework on
51 transition planning, guiding future research, raising awareness of the variation in stakeholder
52 involvement during care transitions, and supporting the successful implementation of PFCC.
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55 **CONTRIBUTORS**

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All authors contributed to conceptualizing the study. SC and KK developed the initial literature search. SC and KMK independently performed screening and data extraction. SC performed initial data synthesis and KMK, KK, WB and SL refined it. SC drafted the manuscript and KMK, KK, WB and SL made revisions. All authors approved the final manuscript.

COMPETING INTERESTS

The authors have no competing interests to declare.

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DATA SHARING STATEMENT

No additional data are available.

FIGURES

Figure 1. PRISMA flow diagram depicting record identification and selection

Figure 2. Visual display of the factors influencing stakeholders' transition decisions

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Table 1. Operational definitions of core concepts

Concept	Definition
Institutional care setting	Communal facilities where individuals may dwell for short or extended periods of time and have access to health care services. Examples may include: hospitals, rehabilitative centres, nursing homes, long-term care facilities, assisted living facilities, aged care homes, personal care homes, residential facilities, etc.
Care transition	The transfer of patients between different services, providers and/or settings.
Transition planning and decision-making	The process of preparing for a care transition and choosing between multiple options.
Older adult	Person aged 65 years or older.
Caregiver	A family member or friend who provides unpaid care to another person, either at home or in a care institution.
Health professional	A licensed or unlicensed care provider who offers paid medical, treatment or support services to a patient.

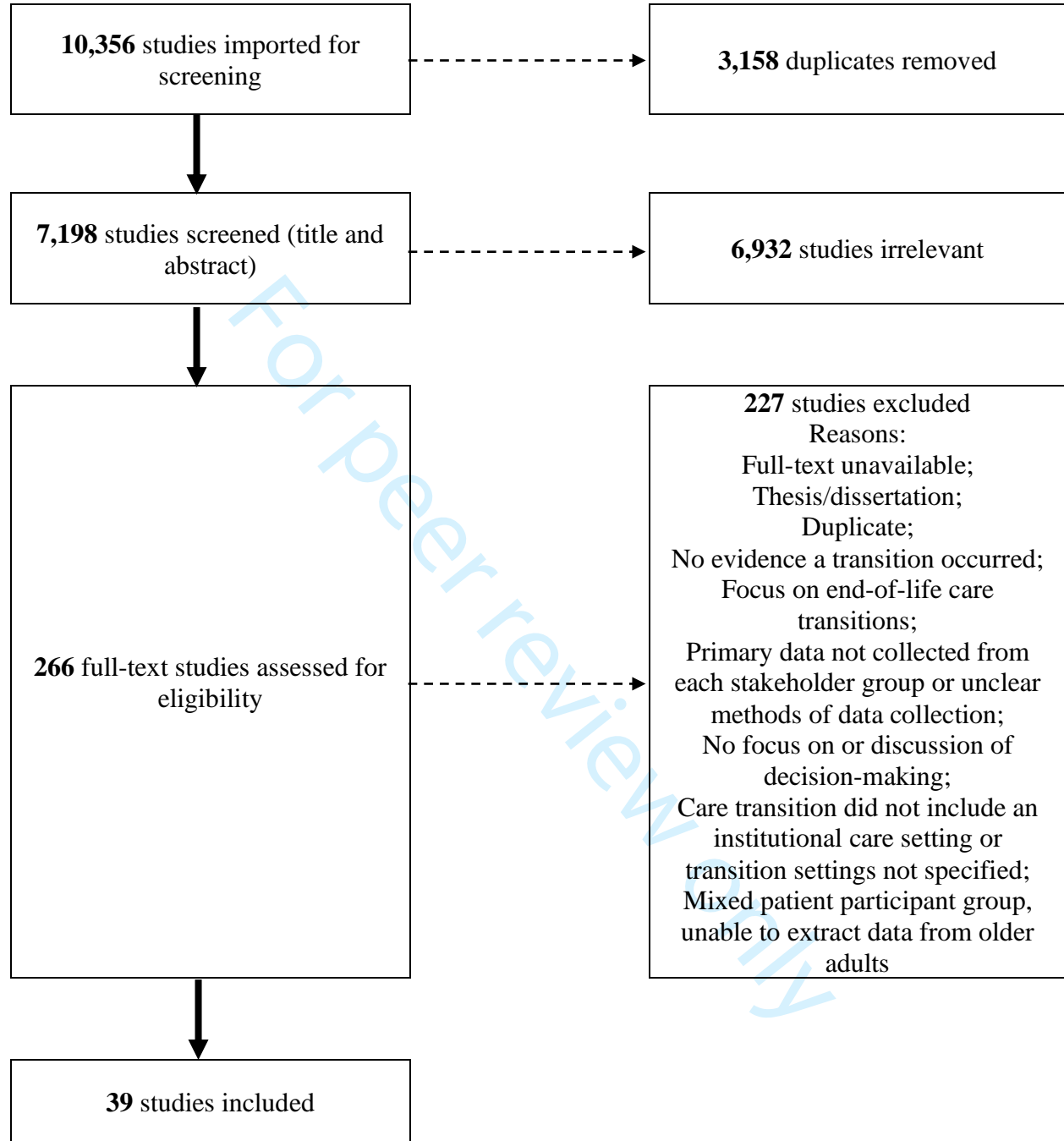
Table 2. Overview of included record characteristics (N=39)

Characteristic	n(%)
Year	
1980-1989	1 (2.5)
1990-1999	9 (23)
2000-2009	9 (23)
2010-2015	8 (20.5)
2016-2021	12 (31)
Country	
Australia	1 (2.5)
Canada	15 (38)
Finland	1 (2.5)
Multiple (European)	1 (2.5)
Sweden	3 (8)
USA	13 (33)
United Kingdom	5 (13)
Average number of participants	
Older adults	16
Caregivers	19
Health professionals	37
Other	20*

*Only 3 records included participants categorized as “Other”. In all three cases, these participants were described as key informants.

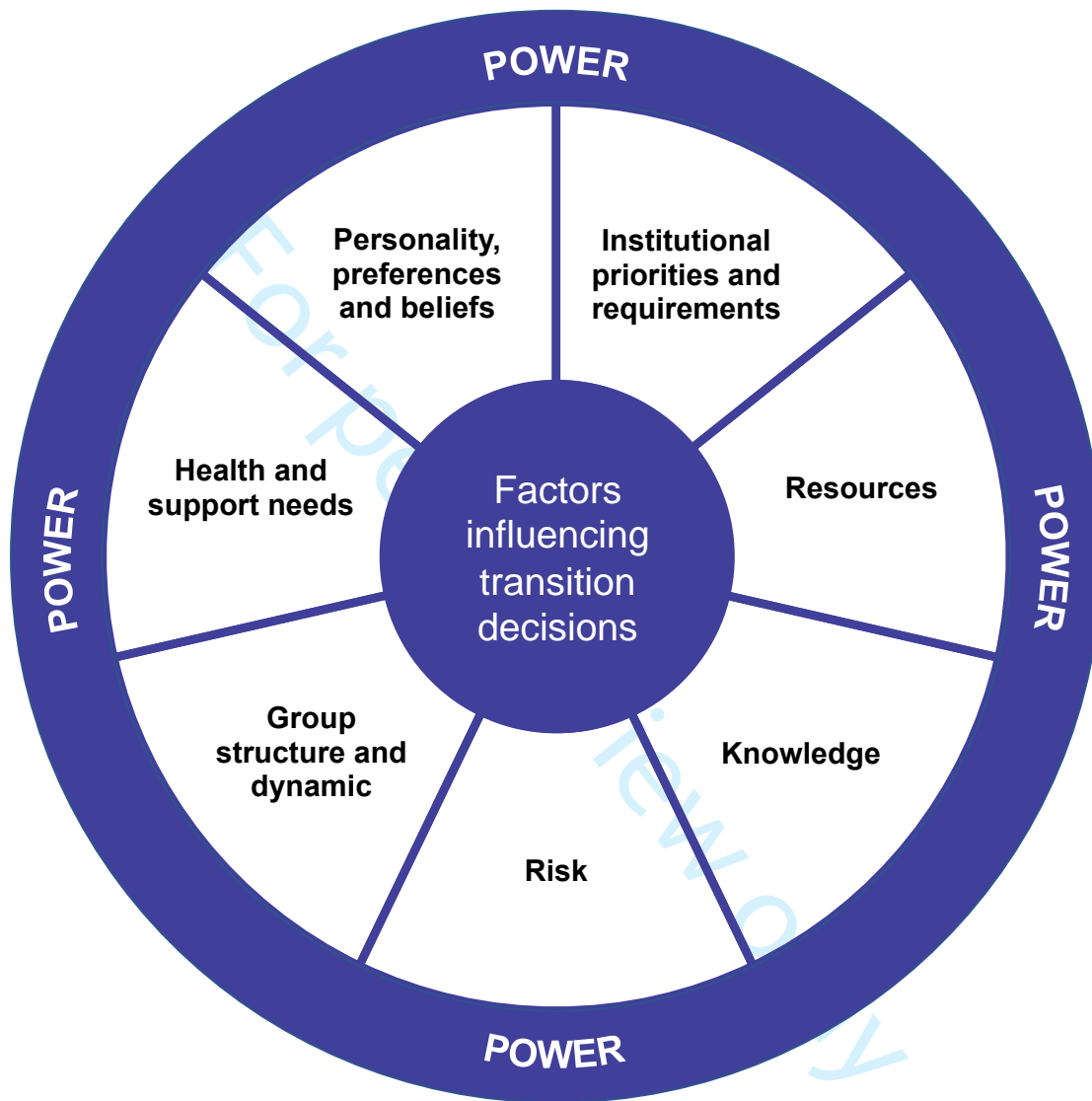
Table 3. Factors that influence transition planning and decision-making.

Factor	Description
Institutional priorities and requirements	Policies and objectives of the organization or care institution.
Resources	Individual, group or organizational-level supports or assets. These may be tangible (e.g., financial) or intangible (e.g., time) in nature.
Knowledge	Information and awareness of the patient, the healthcare system, and the variety of options available for transition.
Risk	Perceptions of risk and safety associated with a decision.
Group structure and dynamic	The extent to which stakeholders are involved (or not involved) in planning, their agreed-upon roles and responsibilities, and the quality of their interpersonal relationships and communication.
Health and support needs	Perceived current and future physical and mental capacity of the patient and their anticipated support needs.
Personality, preferences and beliefs	The individual's unique pattern of thinking, feeling or behaving, and what they want and hope to achieve.

Figure 1. PRISMA flow diagram depicting record identification and selection

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Figure 2. Visual display of the factors influencing stakeholders' transition decisions



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Supplementary File 1.

MEDLINE search strategy

- 1 Continuity of Patient Care/
- 2 Patient Transfer/
- 3 Patient Handoff/
- 4 Patient Navigation/
- 5 Aftercare/
- 6 Transitional Care/
- 7 Patient Discharge/
- 8 Retention in Care/
- 9 (care adj3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or path* or coordinat*)).tw,kf.
- 10 ((patient* or client*) adj3 (transiti* or transport* or transfer* or handoff* or hand off* or discharge*)).tw,kf.
- 11 ((optimal or ideal or plan or plans or plann*) adj2 (transiti* or transfer* or handoff* or hand off* or discharge*)).tw,kf.
- 12 (aftercare or after care).tw,kf.
- 13 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
- 14 Decision Making/
- 15 Clinical Decision-Making/
- 16 Patient Participation/
- 17 Patient-Centered Care/
- 18 Patient Preference/
- 19 Decision Support Systems, Clinical/
- 20 Decision Support Techniques/
- 21 Goals/
- 22 ((make or making) adj3 decision*).tw,kf.
- 23 ((share* or joint* or collaborat* or mutual* or transition* or discharg*) adj2 (decision* or negotiat* or plan*)).tw,kf.

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- 24 ((patient* or client* or carer* or care giv* or caregiv* or family or families or provider* or clinician* or health professional* or medical professional* or clinician*) adj3 (decide or deciding or decision* or participat* or preferenc* or choice* or choos* or autonom* or engage* or involv* or agency or value* or expect* or desire* or attitud*)).tw,kf.
- 25 (patient centered or patient centred or client centered or client centred).tw,kf.
- 26 (individuali#ed adj2 care).tw,kf.
- 27 (decision* adj2 support*).tw,kf.
- 28 ((goal* or priorit*) adj3 (care* or set or sett*)).tw,kf.
- 29 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
- 30 exp Aged/
- 31 Geriatrics/
- 32 (aged or senior* or elder* or geriatric* or gerontolog*).tw,kf.
- 33 (old* adj3 (age* or people or peoples or person or persons or men or women or man or woman or adult* or patient* or client*)).tw,kf.
- 34 30 or 31 or 32 or 33
- 35 Caregivers/
- 36 Family/
- 37 Adult Children/
- 38 Spouses/
- 39 Parents/
- 40 Friends/
- 41 ((nonprofessional* or non professional* or informal or unpaid or volunteer* or relative or relatives or peer or peers or spous* or parent or parents or father or fathers or mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or brother* or sibling* or offspring or son or sons or daughter* or adult child*) adj3 (help* or care or caring or support* or aid or aids or aided or aiding or assist* or succor*)).tw,kf.
- 42 (care giv* or caregiv* or carer* or family or families).tw,kf.
- 43 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42

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44 exp Health Personnel/

45 exp Health Occupations/

46 (provider or providers or professional or professionals or practitioner or practitioners or clinician or clinicians or specialist or specialists or doctor or doctors or physician or physicians or nurse or nurses or social worker or social workers or physiotherapist or physiotherapists or therapist or therapists or case worker or case workers or manager or managers or pharmacist or pharmacists or dietician or dieticians or nutritionist or nutritionists or coordinator or coordinators or discharge planner or discharge planners or transition planner or transition planners).tw,kf.

47 44 or 45 or 46

48 13 and 29 and 34 and 43 and 47

EMBASE search strategy

1 patient care planning/

2 clinical handover/

3 aftercare/

4 transitional care/

5 hospital discharge/

6 (care adj3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or path* or coordinat*)).tw,kw.

7 ((patient* or client*) adj3 (transiti* or transport* or transfer* or handoff* or hand off* or discharge*)).tw,kw.

8 ((optimal or ideal or plan or plans or plann*) adj2 (transiti* or transfer* or handoff* or hand off* or discharge*)).tw,kw.

9 (aftercare or after care).tw,kw.

10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9

11 exp decision making/

12 clinical decision making/

13 patient participation/

14 patient preference/

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- 1
2
3
4 15 decision support system/
5
6 16 ((make or making) adj3 decision*).tw,kw.
7
8 17 ((share* or joint* or collaborat* or mutual* or transition* or discharg*) adj2
9 (decision* or negotiat* or plan*)).tw,kw.
10
11 18 ((patient* or client* or carer* or care giv* or caregiv* or family or families or
12 provider* or clinician* or health professional* or medical professional* or
13 clinician*) adj3 (decide or deciding or decision* or participat* or preferenc* or
14 choice* or choos* or autonom* or engage* or involv* or agency or value* or
15 expect* or desire* or attitud*)).tw,kw.
16
17 19 (patient centered or patient centred or client centered or client centred).tw,kw.
18
19 20 (individuali#ed adj2 care).tw,kw.
20
21 21 (decision* adj2 support*).tw,kw.
22
23 22 ((goal* or priorit*) adj3 (care* or set or sett*)).tw,kw.
24
25 23 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
26
27 24 exp aged/
28
29 25 geriatrics/
30
31 26 gerontology/
32
33 27 (aged or senior* or elder* or geriatric* or gerontolog*).tw,kw.
34
35 28 (old* adj3 (age* or people or peoples or person or persons or men or women or man
36 or woman or adult* or patient*)).tw,kw.
37
38 29 24 or 25 or 26 or 27 or 28
39
40 30 caregiver/
41
42 31 caregiver support/
43
44 32 family/
45
46 33 adult child/
47
48 34 spouse/
49
50 35 parent/
51
52 36 ((nonprofessional* or non professional* or informal or unpaid or volunteer* or
53 relative or relatives or peer or peers or spous* or parent or parents or father or
54 fathers or mother or mothers or friend or friends or neighbo?r or neighbo?rs or

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sister* or brother* or sibling* or offspring or son or sons or daughter* or adult child*) adj3 (help* or care or caring or support* or aid or aids or aided or aiding or assist* or succor*).tw,kw.

37 (care giv* or caregiv* or carer* or family or families).tw,kw.

38 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37

39 health practitioner/

40 exp health care personnel/

41 (provider or providers or professional or professionals or practitioner or practitioners or clinician or clinicians or specialist or specialists or doctor or doctors or physician or physicians or nurse or nurses or social worker or social workers or physiotherapist or physiotherapists or therapist or therapists or case worker or case workers or manager or managers or pharmacist or pharmacists or dietician or dieticians or nutritionist or nutritionists or coordinator or coordinators or discharge planner or discharge planners or transition planner or transition planners).tw,kw.

42 39 or 40 or 41

43 10 and 23 and 29 and 38 and 42

CINAHL Plus search strategy

S1 (MH "Continuity of Patient Care")

S2 (MH "Transfer, Discharge")

S3 (MH "Hand Off (Patient Safety)")

S4 (MH "Patient Navigation")

S5 (MH "After Care")

S6 (MH "Transitional Care")

S7 (MH "Patient Discharge") OR (MH "Discharge Planning")

S8 TI (care N3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or path* or coordinat*))

S9 AB (care N3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or path* or coordinat*))

S10 TI ((patient* or client*) N3 (transiti* or transport* or transfer* or handoff* or hand off* or discharge*))

S11 AB ((patient* or client*) N3 (transiti* or transport* or transfer* or handoff* or hand off* or discharge*))

S12 TI ((optimal or ideal or plan or plans or plann*) N2 (transiti* or transfer* or handoff* or hand off* or discharge*))

S13 AB ((optimal or ideal or plan or plans or plann*) N2 (transiti* or transfer* or handoff* or hand off* or discharge*))

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- 1
2
3 S14 TI (aftercare or after care)
4 S15 AB (aftercare or after care)
5 S16 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12
6 OR S13 OR S14 OR S15
7
8 S17 (MH "Decision Making") OR (MH "Decision Making, Shared") OR (MH "Decision
9 Making, Patient") OR (MH "Decision Making, Family") OR (MH "Decision Making,
10 Ethical") OR (MH "Decision Making, Clinical")
11 S18 (MH "Patient Centered Care")
12 S19 (MH "Patient Preference")
13 S20 (MH "Decision Support Systems, Clinical") OR (MH "Decision Support Techniques")
14 S21 (MH "Goals and Objectives") OR (MH "Goal-Setting")
15 S22 TI ((make or making) N3 decision*)
16 S23 AB ((make or making) N3 decision*)
17 S24 TI ((share* or joint* or collaborat* or mutual* or transition* or discharg*) N2
18 (decision* or negotiat* or plan*))
19 S25 AB ((share* or joint* or collaborat* or mutual* or transition* or discharg*) N2
20 (decision* or negotiat* or plan*))
21 S26 TI ((patient* or client* or carer* or care giv* or caregiv* or family or families or
22 provider* or clinician* or health professional* or medical professional* or clinician*)
23 N3 (decide or deciding or decision* or participat* or preferenc* or choice* or choos* or
24 autonom* or engage* or involv* or agency or value* or expect* or desire* or attitud*))
25 S27 AB ((patient* or client* or carer* or care giv* or caregiv* or family or families or
26 provider* or clinician* or health professional* or medical professional* or clinician*)
27 N3 (decide or deciding or decision* or participat* or preferenc* or choice* or choos* or
28 autonom* or engage* or involv* or agency or value* or expect* or desire* or attitud*))
29 S28 TI (patient centered or patient centred or client centered or client centred)
30 S29 AB (patient centered or patient centred or client centered or client centred)
31 S30 TI (decision* N2 support*)
32 S31 AB (decision* N2 support*)
33 S32 TI ((goal* or priorit*) N3 (care* or set or sett*))
34 S33 AB ((goal* or priorit*) N3 (care* or set or sett*))
35 S34 TI (individuali?ed N2 care)
36 S35 AB (individuali?ed N2 care)
37 S36 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR
38 S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35
39 S37 (MH "Aged+") OR (MH "Aged, 80 and Over+")
40 S38 (MH "Geriatrics")
41 S39 (MH "Gerontologic Care")
42 S40 TI (aged or senior* or elder* or geriatric* or gerontolog*)
43 S41 AB (aged or senior* or elder* or geriatric* or gerontolog*)
44 S42 TI (old* N3 (age* or people or peoples or person or persons or men or women or man or
45 woman or adult* or patient* or client*))
46 S43 AB (old* N3 (age* or people or peoples or person or persons or men or women or man
47 or woman or adult* or patient* or client*))
48 S44 S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43
49 S45 (MH "Caregiver Support")
50
51
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- 1
2
3 S46 (MH "Family")
4 S47 (MH "Adult Children")
5 S48 (MH "Spouses")
6 S49 (MH "Parents")
7
8 S50 TI ((nonprofessional* or non professional* or informal or unpaid or volunteer* or
9 relative or relatives or peer or peers or spous* or parent or parents or father or fathers or
10 mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or brother*
11 or sibling* or offspring or son or sons or daughter* or adult child*) N3 (help* or care or
12 caring or support* or aid or aids or aided or aiding or assist* or succor*))
13
14 S51 AB ((nonprofessional* or non professional* or informal or unpaid or volunteer* or
15 relative or relatives or peer or peers or spous* or parent or parents or father or fathers or
16 mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or brother*
17 or sibling* or offspring or son or sons or daughter* or adult child*) N3 (help* or care or
18 caring or support* or aid or aids or aided or aiding or assist* or succor*))
19
20 S52 TI (care giv* or caregiv* or carer* or family or families)
21 S53 AB (care giv* or caregiv* or carer* or family or families)
22 S54 S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53
23 S55 (MH "Health Personnel+")
24 S56 TI (provider or providers or professional or professionals or practitioner or practitioners
25 or clinician or clinicians or specialist or specialists or doctor or doctors or physician or
26 physicians or nurse or nurses or social worker or social workers or physiotherapist or
27 physiotherapists or therapist or therapists or case worker or case workers or manager or
28 managers or pharmacist or pharmacists or dietician or dieticians or nutritionist or
29 nutritionists or coordinator or coordinators or discharge planner or discharge planners or
30 transition planner or transition planners)
31
32 S57 AB (provider or providers or professional or professionals or practitioner or practitioners
33 or clinician or clinicians or specialist or specialists or doctor or doctors or physician or
34 physicians or nurse or nurses or social worker or social workers or physiotherapist or
35 physiotherapists or therapist or therapists or case worker or case workers or manager or
36 managers or pharmacist or pharmacists or dietician or dieticians or nutritionist or
37 nutritionists or coordinator or coordinators or discharge planner or discharge planners or
38 transition planner or transition planners)
39
40 S58 S55 OR S56 OR S57
41 S59 S16 AND S36 AND S44 AND S54 AND S58
42
43

PSYCinfo search strategy

- 44
45
46 1 "continuum of care"/
47
48 2 client transfer/
49
50 3 aftercare/
51
52 4 hospital discharge/
53
54 5 discharge planning/
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3
4 6 (care adj3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or
5 path* or coordinat*)).tw.
6
7 7 ((patient* or client*) adj3 (transiti* or transport* or transfer* or handoff* or hand off*
8 or discharge*)).tw.
9
10 8 ((optimal or ideal or plan or plans or plann*) adj2 (transiti* or transfer* or handoff*
11 or hand off* or discharge*)).tw.
12
13 9 (aftercare or after care).tw.
14
15 10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
16
17 11 decision making/
18
19 12 client participation/
20
21 13 client centered therapy/
22
23 14 client attitudes/
24
25 15 decision support systems/
26
27 16 goals/
28
29 17 goal setting/
30
31 18 ((make or making) adj3 decision*).tw.
32
33 19 ((share* or joint* or collaborat* or mutual* or transition* or discharg*) adj2
34 (decision* or negotiat* or plan*)).tw.
35
36 20 ((patient* or client* or carer* or care giv* or caregiv* or family or families or
37 provider* or clinician* or health professional* or medical professional*) adj3 (decide
38 or deciding or decision* or participat* or preferenc* or choice* or choos* or
39 autonom* or engage* or involv* or agency or value* or expect* or desire* or
40 attitud*)).tw.
41
42 21 (patient centered or patient centred or client centered or client centred).tw.
43
44 22 (individuali#ed adj2 care).tw.
45
46 23 (decision* adj2 support*).tw.
47
48 24 ((goal* or priorit*) adj3 (care* or set or sett*)).tw.
49
50 25 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
51
52 26 aging/
53
54 27 geriatrics/
55
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3
4 28 gerontology/
5
6 29 (aged or senior* or elder* or geriatric* or gerontolog*).tw.
7
8 30 (old* adj3 (age* or people or peoples or person or persons or men or women or man
9 or woman or adult* or patient* or client*)).tw.
10
11 31 26 or 27 or 28 or 29 or 30
12
13 32 caregivers/
14
15 33 family/
16
17 34 adult offspring/
18
19 35 spouses/
20
21 36 parents/
22
23 37 ((nonprofessional* or non professional* or informal or unpaid or volunteer* or
24 relative or relatives or peer or peers or spous* or parent or parents or father or fathers
25 or mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or
26 brother* or sibling* or offspring or son or sons or daughter* or adult child*) adj3
27 (help* or care or caring or support* or aid or aids or aided or aiding or assist* or
28 succor*)).tw.
29
30
31 38 (care giv* or caregiv* or carer* or family or families).tw.
32
33 39 32 or 33 or 34 or 35 or 36 or 37 or 38
34
35 40 exp health personnel/
36
37 41 (provider or providers or professional or professionals or practitioner or practitioners
38 or clinician or clinicians or specialist or specialists or doctor or doctors or physician
39 or physicians or nurse or nurses or social worker or social workers or physiotherapist
40 or physiotherapists or therapist or therapists or case worker or case workers or
41 manager or managers or pharmacist or pharmacists or dietician or dieticians or
42 nutritionist or nutritionists or coordinator or coordinators or discharge planner or
43 discharge planners or transition planner or transition planners).tw.
44
45
46
47
48 42 40 or 41
49
50 44 10 and 25 and 31 and 39 and 42
51

AgeLine search strategy

52
53
54
55 S1 (((DE "Transition") OR (DE "Discharge Planning")) OR (DE "Patient Discharges"))
56
57
58
59
60

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- 1
2
3 S2 TI (care N3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or
4 path* or coordinat*))
5
6 S3 AB (care N3 (plan or plans or plann* or contin* or transiti* or transfer* or journ* or
7 path* or coordinat*))
8
9 S4 TI ((patient* or client*) N3 (transiti* or transport* or transfer* or handoff* or hand
10 off* or discharge*))
11
12 S5 AB ((patient* or client*) N3 (transiti* or transport* or transfer* or handoff* or hand
13 off* or discharge*))
14
15 S6 TI ((optimal or ideal or plan or plans or plann*) N2 (transiti* or transfer* or handoff*
16 or hand off* or discharge*))
17
18 S7 AB ((optimal or ideal or plan or plans or plann*) N2 (transiti* or transfer* or handoff*
19 or hand off* or discharge*))
20
21 S8 TI (aftercare or after care)
22
23 S9 AB (aftercare or after care)
24
25 S10 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9
26
27 S11 (DE "Decision Making") OR (DE "Individualized Care")
28
29 S12 TI ((make or making) N3 decision*)
30
31 S13 AB ((make or making) N3 decision*)
32
33 S14 TI ((share* or joint* or collaborat* or mutual* or transition* or discharg*) N2
34 (decision* or negotiat* or plan*))
35
36 S15 AB ((share* or joint* or collaborat* or mutual* or transition* or discharg*) N2
37 (decision* or negotiat* or plan*))
38
39 S16 TI ((patient* or client* or carer* or care giv* or caregiv* or family or families or
40 provider* or clinician* or health professional* or medical professional* or clinician*)
41 N3 (decide or deciding or decision* or participat* or preferenc* or choice* or choos*
42 or autonom* or engage* or involv* or agency or value* or expect* or desire* or
43 attitud*))
44
45 S17 AB ((patient* or client* or carer* or care giv* or caregiv* or family or families or
46 provider* or clinician* or health professional* or medical professional* or clinician*)
47 N3 (decide or deciding or decision* or participat* or preferenc* or choice* or choos*
48 or autonom* or engage* or involv* or agency or value* or expect* or desire* or
49 attitud*))
50
51 S18 TI (patient centered or patient centred or client centered or client centred)
52
53 S19 AB (patient centered or patient centred or client centered or client centred)
54
55 S20 TI (decision* N2 support*)
56
57 S21 AB (decision* N2 support*)
58
59 S22 TI ((goal* or priorit*) N3 (care* or set or sett*))
60
S23 AB ((goal* or priorit*) N3 (care* or set or sett*))
S24 TI (individuali?ed N2 care)
S25 AB (individuali?ed N2 care)
S26 S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR
S21 OR S22 OR S23 OR S24 OR S25
S27 (((DE "Old Old") OR (DE "Older Adults")) OR (DE "Frail Elderly")) OR (DE
"Geriatrics")) OR (DE "Gerontology")
S28 TI (aged or senior* or elder* or geriatric* or gerontolog*)
S29 AB (aged or senior* or elder* or geriatric* or gerontolog*)

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- 1
2
3 S30 TI (old* N3 (age* or people or peoples or person or persons or men or women or man
4 or woman or adult* or patient* or client*))
5
6 S31 AB (old* N3 (age* or people or peoples or person or persons or men or women or man
7 or woman or adult* or patient* or client*))
8
9 S32 S27 OR S28 OR S29 OR S30 OR S31
10
11 S33 (((((DE "Caregivers") OR (DE "Family Assistance")) OR (DE "Adult Children")) OR
12 (DE "Spouses")) OR (DE "Parents")) OR (DE "Friends")
13
14 S34 TI ((nonprofessional* or non professional* or informal or unpaid or volunteer* or
15 relative or relatives or peer or peers or spous* or parent or parents or father or fathers or
16 mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or brother*
17 or sibling* or offspring or son or sons or daughter* or adult child*) N3 (help* or care
18 or caring or support* or aid or aids or aided or aiding or assist* or succor*))
19
20 S35 AB ((nonprofessional* or non professional* or informal or unpaid or volunteer* or
21 relative or relatives or peer or peers or spous* or parent or parents or father or fathers or
22 mother or mothers or friend or friends or neighbo?r or neighbo?rs or sister* or brother*
23 or sibling* or offspring or son or sons or daughter* or adult child*) N3 (help* or care
24 or caring or support* or aid or aids or aided or aiding or assist* or succor*))
25
26 S36 TI (care giv* or caregiv* or carer* or family or families)
27
28 S37 AB (care giv* or caregiv* or carer* or family or families)
29
30 S38 S33 OR S34 OR S35 OR S36 OR S37
31
32 S39 DE "Health Personnel" OR DE "Hospital Personnel" OR DE "Institutional Personnel"
33 OR DE "Nurse Practitioners" OR DE "Nurses" OR DE "Nurses Aides" OR DE
34 "Pharmacists" OR DE "Physician Assistants" OR DE "Physicians"
35
36 S40 TI (provider or providers or professional or professionals or practitioner or practitioners
37 or clinician or clinicians or specialist or specialists or doctor or doctors or physician or
38 physicians or nurse or nurses or social worker or social workers or physiotherapist or
39 physiotherapists or therapist or therapists or case worker or case workers or manager or
40 managers or pharmacist or pharmacists or dietician or dieticians or nutritionist or
41 nutritionists or coordinator or coordinators or discharge planner or discharge planners
42 or transition planner or transition planners)
43
44 S41 AB (provider or providers or professional or professionals or practitioner or
45 practitioners or clinician or clinicians or specialist or specialists or doctor or doctors or
46 physician or physicians or nurse or nurses or social worker or social workers or
47 physiotherapist or physiotherapists or therapist or therapists or case worker or case
48 workers or manager or managers or pharmacist or pharmacists or dietician or dieticians
49 or nutritionist or nutritionists or coordinator or coordinators or discharge planner or
50 discharge planners or transition planner or transition planners)
51
52 S42 S39 OR S40 OR S41
53
54 S43 S10 AND S26 AND S32 AND S38 AND S42
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Supplementary File 2. Breakdown of factors influencing transition planning and decisions by record.

	Institutional Priorities and Requirements	Resources	Knowledge	Risk	Group Structure and dynamic	Health and support needs	Personality, preferences and beliefs
Ayele (2019)	X	X	X				
Bailey (2016)		X			X		
Bull (1996)	X	X	X		X		
Bull (2001)	X	X	X		X	X	X
Congdon (1994)		X			X		
Dill (1995)	X	X		X	X	X	X
Durocher (2017a)	X	X	X	X		X	
Durocher (2017b)			X	X	X		X
Durocher (2018)		X		X		X	X
Efraimsson (2003)	X		X		X		X
Efraimsson (2006)						X	X
Gladden (2000)	X	X	X			X	
Hedberg (2008)	X	X				X	X
Hicks (2012)	X	X	X	X	X	X	X
Jeffs (2017a)			X			X	
Jeffs (2017b)		X	X		X	X	
Jewell (1993)		X	X		X	X	
Magilvy (1991)		X				X	
Magilvy (2000)	X	X	X				X
McWilliam (1992)		X			X		X
McWilliam (1994a)	X	X	X		X		
McWilliam (1994b)					X		X
Palonen (2016)	X	X	X		X		
Poole (2014)		X	X	X	X	X	X
Popejoy (2011)		X			X	X	X
Rhynas (2018)		X		X		X	X
Robinson (2012)	X	X	X		X	X	X
Slatyer (2013)	X		X		X		
Toscan (2012)	X	X	X		X		
Toscan (2013)	X		X		X		
Trigg (2018)		X	X			X	X
Wells (1997)	X	X	X			X	
Wells (2002)			X		X		
Jenkins (2000)		X		X		X	X

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Mead (2005)	X	X			X	X	X
Smallegan (1981)		X				X	X
Stolee (2019)	X	X	X		X		
Toles (2012)			X			X	X
Toles (2016)			X		X	X	

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Supplementary File 3. Main findings related to transition planning and decision-making.

Author (Year)	Aim	Participants	Main settings	Major findings related to transition planning and decision-making
Ayele (2019)	To understand the role of perceived costs in decision making about post-acute care around the time of hospital discharge.	S (n=34) C (n=23) P (n=45)	Hospital >> SNF	<ul style="list-style-type: none"> Perceived costs of post-acute care had an important impact on transition decision-making. Insurance coverage and perceived costs of care constrained transition options and decisions. Some hospital professionals changed their treatment recommendations based on the patients' insurance coverage.
Bailey (2016)	To explore the experiences of patients with advanced COPD and lung cancer, their carers and their health professionals following emergency admission to the hospital.	S (n=39) C (n=20) P (n=50)	Hospital >> Home	<ul style="list-style-type: none"> During recovery, decisions were made by hospital staff and not communicated with patients or family. Caregivers were often excluded from planning, and information about care was often conveyed inaccurately, or was vague and confusing. There was a lack of continuity in care where information was not transferred successfully between the hospital and community, and patients often reported waiting for updates on their care plans.
Bull (1996)	To describe the nature of the difficulties encountered by elders and family caregivers following hospitalization, and identify the system constraints encountered in	S (n=25) C (n=253) P (n=38)	Hospital >> Home (or other community setting)	<ul style="list-style-type: none"> Communication gaps existed between health professionals, older adults and families. This resulted in problems with care and conflicting information being presented to the older adult and their caregiver. Health professionals reported having inadequate time for discharge planning and felt pressure from insurance companies to discharge quickly. Older adults and families were typically not involved in discharge planning and as a result often left the hospital with inadequate information.

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	planning for discharge.			<ul style="list-style-type: none"> Rural areas had less resources available for the transition, so professionals needed to expend extra effort to arrange care.
Bull (2001)	The purpose of this study was to identify the components of effective discharge planning for elders and factors that impede planning.	S (n=2) C (n=1) P (n=21)	Hospital >> Home; Nursing home	<ul style="list-style-type: none"> A ‘proper’ discharge relies on strong communication and trust between members of the multidisciplinary team, the patient, their family and the community professionals. Discharge planning involves four key stages: (a) getting to know the patient; (b) setting a discharge date; (c) getting ready to go home; and (d) making the transition. Older adults and families were not always included in discharge planning and were purposefully excluded when the professionals thought the decision would upset them. In these cases, plans often had to be revised.
Congdon (1994)	To gather information about the hospital discharge experience from elderly patients, their family members and nurses.	S (n=8) C (n=8) P (n=8)	Hospital >> Home or nursing home	<ul style="list-style-type: none"> Perceived readiness for discharge varied between participants, with patients believing they were ready, family members believing the patient was not ready, and nurses feeling uncertain. Family support was a key determinant in the discharge destination of the patient. The availability of family support resulted in patients’ transfer to homes in the community, rather than nursing homes. Decisions were made by the health professionals without the participation of patients and families. Some patients and families found ways to normalize their lack of involvement.
Dill (1995)	To augment current critical examinations of the principle of autonomy in medical decision making.	S (n=3+) C (n=3+) P (n=NA)	Hospital >> Home or Nursing home	<ul style="list-style-type: none"> Those who can authorize decisions are not always those involved in the planning. Health professionals planned multiple discharge options, regardless of patient and family preferences, so that once a decision was made they could act quickly. Patients’ decisional capacity was questioned when their views conflicted with the views of health professionals.

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Durocher (2017a)	To examine how the intersection of various influences on the process of discharge planning and how these may lead to unintended outcomes.	S (n=5) C (n=7) P (n=8)	Hospital >> Home	<ul style="list-style-type: none"> • Health professionals established recommendations for discharge prior to family conferences. There was pressure on patients and families to meet these timelines. • Discharge planning began on admission: some older adults and family members felt rushed and pressured to make decisions without sufficient information. • Health professionals often prioritized safety over peoples' preferences and values; however, older adults expressed little concern over their safety.
Durocher (2017b)	To examine social and political influences affecting perspectives and practices associated with discharge planning with older adults.	S (n=5) C (n=7) P (n=8)	Hospital >> Home or unspecified	<ul style="list-style-type: none"> • All participants expected that as older people aged they would experience a loss of agency and reduced participation in decision-making. This lack of autonomy over decision-making was sometimes not a choice. • Health professional participants privileged their own knowledge and expertise when determining the best course of action and privileged safety over all other factors influencing the decision. • Family conferences did not encourage older adults' contributions. Plans reflected the health professionals' beliefs rather than the patients' goals.
Durocher (2018)	To discern relational approaches adopted by families in planning for the discharge of older adults from inpatient settings and to explore how such approaches may inform practice in	S (n=3) C (n=5) P (n=NA)	Hospital >> Rehabilitation >> Retirement Home or Home	<ul style="list-style-type: none"> • In this study, older adults either shared decision-making authority with their caregivers, or deferred it. • In some cases, caregivers questioned the older adults' decisional capacity. • Transition decisions required compromise from the older adults and caregivers who may have different preferences and beliefs.

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	discharge planning with older adults.			
Efrainsson (2003)	To illuminate and describe the phenomenon of power as it appeared in a discharge planning conference.	S (n=1) C (n=3) P (n=3)	Hospital >> Nursing home	<ul style="list-style-type: none"> This case study showed that in the discharge planning conference, the institutional frame was privileged over the client frame. At the conference, the hospital staff occupied most of the speaking time, often talking about the patient in the third person. The patient found the conference to be valuable; however, often lacked information on the transition options available and were unsure of how to obtain this information.
Efrainsson (2006)	To describe how patients, relatives, and healthcare professionals deal with the variety of problems and responsibilities that occur in discharge planning conferences and especially how they managed to do this given the institutional frame that surrounds the meeting.	S (n=8) C (n=8) P (n=23)	Hospital >> Home; nursing home	<ul style="list-style-type: none"> There was a clear discrepancy between the ideological intent of the discharge planning conference and its actual realization. Multiple challenges emerged during discharge planning, particularly when patient and family preferences did not align with institutional routines and professional judgements. Patients and families needed fight to achieve their transition goals; however, if their transgressions were too obvious they were at risk of not being taken seriously.
Gladden (2000)	To describe the process of decision-making used by older adults, their	S (n=13) C (n=8) P (n=11)	Hospital >> Home; nursing home or basic care facility	<ul style="list-style-type: none"> Patients and families perceived that they had little control over information exchange and transition decision-making. Patients and families were sometimes reluctant to seek information, and health professionals admitted to

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	families and care providers during admission into a discharge from subacute care settings.			<p>withholding information to reduce stress and anxiety for the patient.</p> <ul style="list-style-type: none"> Patients, family members and health professionals felt mistrust towards one another, questioning the information provided and subsequent decisions.
Hedberg (2008)	To illustrate how stroke survivors, their relatives, and different professionals participated and interacted in care-planning meetings when negotiating the stroke survivors' health and further needs of support from the health and social system	S (n=14) C (n=26) P (n=41)	Hospital or Rehabilitation Centre >> Not reported	<ul style="list-style-type: none"> Health professionals took up more of the discourse time in care planning meetings than patients and family members. Communication during the care planning meetings could be broken down into two main activities: the 'assessment process' and the 'decision-making process'. Communicative alliances between different stakeholder groups in the care planning meetings were important in advancing with a decision. Alliances between patients and caregivers were particularly important for increasing patients' opportunities to influence decisions. When relatives were absent, there was an increased risk that the patients' perspective would not be taken into account.
Hicks (2012)	This paper examines the autonomy, choice, options and power in healthcare decision making for older people.	S (n=6) C (n=5) P (n=49)	Hospital >> Rehabilitation hospital >> Home	<ul style="list-style-type: none"> Health professionals may question clients' choices when they do not align with their own. This can result in the choice being perceived as 'risky'. The older adult in this study learned over time that she did not have the freedom to choose among the different options, as she had limited resources and many 'options' were determined to be unrealistic or risky. The client felt limited control over the decision, rather it was borne by the health professionals and the institution.
Jefferies (2017a)	To explore the perceptions of patients, their	S (n=13) C (n=9) P (n=50)	Hospital	<ul style="list-style-type: none"> Patients and caregivers described being unaware of their transition plan. Professionals were often uncertain

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	caregivers and healthcare professionals associated with the exchange of information during transition from hospital to rehab.		>> Rehabilitation Hospital	<p>whether the transition plan had been communicated to patients.</p> <ul style="list-style-type: none"> • Professionals withheld details of the plan from patients and caregivers until they knew what would be happening. • Overall, professionals led decision-making about transitions and patients and caregivers had limited involvement and knowledge of the plans.
Jeffs (2017b)	This study was undertaken with the aim of gaining insight into the nature of caregiver involvement in care transitions of patients being transferred from two acute care hospitals to a rehab hospital.	S (n=13) C (n=9) P (n=50)	Hospital >> Rehabilitation Hospital	<ul style="list-style-type: none"> • Caregivers in this study were actively involved in the patient's transitional care, but were not actively engaged by health professionals. • Caregivers advocated on behalf of the patient, provided care, and helped to organize the transitions. • Patients and caregivers expressed concern that had the caregivers not been included in transition planning, the patient would not have understood the plan and their needs may not have been met.
Jenkins (2000)	To investigate how a range of care arrangement decisions for frail older unmarried women are made.	S (n=11) C (n=9) P (n=6)	Hospital >> Home; nursing home	<ul style="list-style-type: none"> • Family members played a central role in decision-making for care arrangements. • In some cases, the unavailability of family members resulted in the older women preferences for care arrangements not being followed. • Care arrangement decisions changed, often repeatedly, as their needs fluctuated.
Jewell (1993)	To establish areas of concern and importance to all those involved in, and affecting the	S (n=4) C (n=2) P (n=26)	Hospital >> Home, rest home, or nursing home	<ul style="list-style-type: none"> • Discharge in this study was viewed as an ongoing process that began upon admission. • It was unclear if the patient and family were identified as team members during discharge planning and decision-making. Although staff implied this was the case, patients and families demonstrated non-involvement.

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	discharge of patients.			<ul style="list-style-type: none"> Community personnel were also not involved in the planning, which created challenges and discontinuity in care.
Magilvy (1991)	To discover the process of admission and transition of older adults to home care following hospital discharge, or during periods of illness.	S (n=13) C (n=~13) P (n=47+)	Hospital >> Home	<ul style="list-style-type: none"> Patients transitions sometimes did not account for all of their care needs, or their living situation. Family members played a crucial role in facilitating the transition, by gathering information on available services. Community planners indicated that sometimes transition planning had not occurred, and they received patient referrals with little or no plan.
Magilvy (2000)	To examine the health care transition experiences of older adults, families and health care providers in a longitudinal rural ethnography.	S & C (n=49) P (n=113) O (n=13)	Various institutional and community transitions	<ul style="list-style-type: none"> In many cases, family members were left alone to discover appropriate resources. Staff sometimes lacked knowledge of community services, making transition decisions more challenging. Patients and family members often not included in decision-making and didn't understand what was happening to them. Families experienced uncertainty over the best living arrangement for their loved one.
McWilliam (1992)	To describe hospital discharge as experienced by a group of elderly patients.	S (n=12) C (n=12) P (n=62)	Hospital >> Home	<ul style="list-style-type: none"> Patients' mindset and attitudes towards ageing impacted the transition planning. All patients deferred decision-making to health professionals. Role confusion among health professionals led to social problems during discharge. Confusion existed between hospital staff and community staff. Physicians often did not attend family conferences where decisions were made. Communication challenges created problems for discharge, resulting in delay and confusion.
McWilliam (1994a)	To explore and describe factors	S (n=21) C (n=22)	Hospital >> Home	<ul style="list-style-type: none"> Professionals in the rural and urban settings made decisions with limited involvement from patients and

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	other than medical condition and treatment which shaped the quality of discharge experiences of older patients.	P (n=127) O (n=23)		<p>families. This led to learned helplessness from the patients.</p> <ul style="list-style-type: none"> • Patients, families and professionals often lacked an understanding of the roles of others (e.g., the social worker, community care staff), which complicated decisions. • Patients, families and professionals complained about inadequate discharge teaching.
McWilliam (1994b)	To explore factors other than medical condition and treatment which contributed to discharge experiences of rural and urban patients.	S (n=21) C (n=22) P (n=127) O (n=23)	Hospital >> Home	<ul style="list-style-type: none"> • Patients with a positive mindset achieved control over their own care after discharge and remained successfully autonomous. • In many cases, patients were comfortable deferring to professional authority. Professionals often adopted a paternalistic approach to treatment and decisions. • The more negative a patient's mindset was, the more compromised their autonomy.
Mead (2005)	To explore the decision-making process regarding retention or transfer of persons with dementia.	S (n=23) C (n=20) P (n=19)	Assisted living facility >> Multiple	<ul style="list-style-type: none"> • Facility managers made relocation decisions, often based on perceptions of the facility's culture, the specific care requirements related to dementia and the role of the family. • Problematic behaviours (e.g., wandering) from patients influenced their admission and possible relocation from the facilities. • Family members and residents had varied involvement in decision-making, including the process and timing and ultimate placement decision.
Palonen (2016)	To describe the experiences of emergency department service users and nurses regarding older	S (n=7) C (n=5) P (n=15)	Hospital >> Home	<ul style="list-style-type: none"> • Family members were sometimes expected to support decision-making when the patients and staff views were different. • Nurses in the study sometimes saw family involvement as a nuisance and challenge.

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	peoples' discharge education.			<ul style="list-style-type: none"> The nurses encouraged family involvement in decision-making and viewed them as a resource in certain situations. Patients did not feel the family members should be left responsible to make decisions about discharge.
Poole (2014)	To understand how, on medical wards, judgements about capacity and best interests with respect to going home are made for people with dementia and how decision-making around hospital discharge for people with dementia and their families might be improved.	S (n=29) C (n=34) IP (n=35)	Hospital >> Home or care home	<ul style="list-style-type: none"> Patients who were judged to have capacity were discharged home, and all those without capacity went to care homes. Patients' capacity fluctuated over time, and so decisions needed to be made at the right time. Perceptions of risk had a clear influence on assessments of capacity. If a person disagreed with the care team or wanted to make a decision that was viewed as "unsafe", they were likely to be determined to lack capacity. One narrative frequently dominated the decisions, and so any doubts about the patient capacity meant they might be disbelieved.
Popejoy (2011)	To examine decisions made by hospitalized older adults, families and care providers about hospital discharge.	S (n=13) C (n=12) P (n=7)	Hospital >> Home, nursing home	<ul style="list-style-type: none"> Many older adults in this study didn't even consider a destination other than home. This option was more feasible when older adults were cared for by a spouse, rather than adult children. Some older adults made discharge plans alone and did not disclose their care needs to their children so they did not burden their family. Professionals had the task of reconciling differing opinions within families. Sometimes they were unable to change the minds of older adults and families who were resolute in their plans.

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Rhynas (2018)	To gain understanding of the decision-making processes involved in the discharge of people admitted to hospital from home and discharged to a care home.	S (n=10) C (n=NA) P (n=NA)	Hospital >> Care home	<ul style="list-style-type: none"> • Absence of a family member in discharge planning resulted in limited consideration for patient preferences. In some cases, patients felt powerless to make decisions. • Admission was often seen as the last straw for family members, who tried to rationalize their care home placement decisions. Often, families had difficulty reconciling the patients' current care needs with their expressed preferences. • Professionals often used the language of risk to justify a care home discharge. This language objectified the individual's circumstances and excluded the individual from decision-making
Robinson (2012)	To identify key elements, from multiple perspectives, that influence the success of transition experienced by nursing home residents when they required transfer to a hospital emergency department.	S (n=7) C (n=20) P (n=44)	Nursing home >> Hospital >> Nursing home	<ul style="list-style-type: none"> • Having knowledge of the patient increased professionals' confidence in the transfer decision. When personal knowledge of the patient was not available, the transition was negatively affected (e.g., family absent). • All stakeholder groups viewed family involvement as an important element for transitions. Families often filled the gaps, and were essential for successful transitions. However, health professionals and families sometimes clashed in what they believed were the best interests for the patient. • Emergency departments were under pressure to discharge patients as soon as possible.
Slatyer (2013)	To explore the perceptions of older patients who re-presented to hospital within 28 days of discharge,	S (n=12) C (n=15) P (n=35)	Home or residential care >> Hospital >> Home or residential care	<ul style="list-style-type: none"> • Patients and families had difficulty recalling their communication with health professionals during admission. This resulted in them being discharged without awareness of their care and treatment needs. • Most patients and families trusted the professionals to make decisions.

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	their family caregivers, and care providers.			<ul style="list-style-type: none"> Families often involved in the decision to return to the hospital or to go see a general practitioner.
Smallegan (1981)	To gather information on the factors affecting decisions to admit a patient to a nursing home.	S (n=9) C (n=14) P (n=11)	Hospital; Home >> Nursing home	<ul style="list-style-type: none"> Roughly half of the people admitted to the nursing home agreed they had a role in decision-making. However, in most cases, transition to the nursing home occurred when there were no other options available. In most cases, participants had no satisfactory options other than admission. Patients and their adult children were the most prominent decision-makers, and others were mostly consulted about the decision.
Stolee (2019)	To identify and conceptually organize the domains relevant to improving care transitions of older patients with hip fracture, so as to inform future ToC interventions.	S (n=23) C (n=19) P (n=92)	Multiple >> Multiple	<ul style="list-style-type: none"> System constraints (e.g., rushed discharges) impeded transitions. Family members were interested in being involved in the care, but were not always included due to conflicting responsibilities and other contextual factors. Strong working relationships between professionals from the sites (as well as professionals, patients and families) helped to foster trust and ease transition.
Toles (2012)	To describe transitional care provided by existing staff in an skilled nursing facility and to explore the influence of staff interaction strategies on the	S (n=3) C (n=2) P (n=20)	Skilled nursing facility >> Home	<ul style="list-style-type: none"> Family members were not consistently involved in care. In some cases, the staff were responsible for preparing the patient and family to go home both in terms of ensuring necessary skills and also building confidence. Staff used three main interaction strategies to support transitional care: 1) creating connections with patients and families to integrate their preferences into the plan; 2) uncovering and relaying new information needed; and 3) engaging patients and families in problem solving conversations.

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	delivery of transitional care.			
Toles (2016)	To describe how organizational structures and staff interactions are used by existing skilled nursing facility staff to deliver transitional care services.	S (n=3) C (n=2) P (n=49)	Skilled nursing facility >> Home	<ul style="list-style-type: none"> • Staff often did not engage family caregivers and sufficiently prepare them for the transition. • In one facility, various meetings were held with staff, the patients and/or family to decide the patients care needs. Not all facilities had a care planning meeting with the patient/family, and in one facility, the meeting was 2 days before the patient returned home. • Communication challenges emerged in some facilities, for e.g. in one case the care coordinator planned the discharge date but the occupational therapist and physician were not aware that it was pending.
Toscan (2012)	To investigate care coordination for older hip fracture patients from multiple perspectives to determine the core factors related to poorly integrated care when patients transition from one care setting to another.	S (n=6) C (n=6) P (n=18)	Hospital >> Multiple (Home; Inpatient rehabilitation; Long-term care)	<ul style="list-style-type: none"> • Breakdowns in communication occurred between health professionals, making it difficult to make transition plans. Caregivers were even further removed from the flow of information. • Patients did not feel central to their own care and expressed lack of involvement in decision-making. • Professionals felt pressured to prioritize system needs (e.g. early discharge) over the needs of their patients. Patients felt rushed to recover and make decisions, and sometimes learned of decisions without remembering conversations about them.
Toscan (2013)	To explore the experience of transitional care over the complete care trajectory for a single hip fracture patient,	S (n=1) C (n=2) P (n=10)	Hospital >> Rehabilitation hospital >> Assisted living facility >> Home	<ul style="list-style-type: none"> • The patient and family felt left out of the decision-making processes around the transition. They also did not always know who to direct questions to. • Professionals felt that the health care system's focus on discharge-centred care planning added pressure to initiate transitions early. Their discharge options were also restricted by the facilities' admission criteria.

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	from multiple perspectives.			<ul style="list-style-type: none"> • Privacy barriers made communication between the facilities and family difficult.
Trigg (2018)	To compare how people use quality information to choose residential care providers in England, the Netherlands, and Spain.	S (n=83) C (n=49) P (n=38)	Multiple (hospital, home) >> Care home	<ul style="list-style-type: none"> • The most important information influencing decisions was that gathered during visits. • Many of the decisions about transition were made with or on behalf of the older adult. Few residents were involved in both the decisions to move into residential care, and the selection of provider. Families and professionals felt that decisions needed to be taken away from the senior as they were not aware of their reduced ability to live independently. • In some cases, choices were restricted and so the quality information (e.g. care home indicators) provided was redundant.
Wells (1997)	To study the process of decision making for elderly patients over the total course of their hospital stay and the consequences of that process.	S (n=31) C (n=22) P (n=23)	Hospital >> Multiple (Home; residential care; chronic care; convalescence)	<ul style="list-style-type: none"> • Discharge decision making often took place early in the patients' hospital stays, when the patient's condition was still fluctuating. Patients and families were only included sporadically. Decisions often had to be revised as the patient's condition progressed. • Decisions were not tied to the patient's condition, but rather to their social situation (e.g., living arrangements, age of caregiver, etc.) • Institutional priorities (e.g. get the patients out) were often emphasized over the patients' interests, and families were pressured to accept the first place that became available.
Wells (2002)	To evaluate the process and impact of the Integrated Model of Discharge Planning.	S (n=48) C (n=~8) P (n=NA)	Hospital >> Home	<ul style="list-style-type: none"> • At both hospital sites, patients were involved in most of time discharge planning, and families were involved around 40% of the time. • Community professionals were not always involved in discharge planning.

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				<ul style="list-style-type: none"> Most patients and families were satisfied with the discharge process, and a few felt they were told to go before they were ready.
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S= Senior or Older Adult; C = Caregiver; P = Provider or Health Professional

For peer review only

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

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2-3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	3
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3-4
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	4
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	4
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	4-5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	18
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	NA



SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	4-5
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	5; Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	4
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	NA
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Suppl Files 2-3
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	5-9
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	5-9
Limitations	20	Discuss the limitations of the scoping review process.	11-12
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	12
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	12

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

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

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

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

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

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).



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