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Content validity of patient-reported measures evaluating experiences of the quality of transitions in healthcare settings—a scoping review

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Abstract

No reviews so far have been conducted to define the constructs of patient-experienced quality in healthcare transitions or to identify existing generic measures of patients' experience of the quality within healthcare transitions. Our aim was to identify domains relevant for people experiencing healthcare transitions when evaluating the quality of care they have received, map the comprehensiveness of existing patient-reported experience measures (PREM), and evaluate the PREMs' content validity. The method was guided by the Joanna Briggs Institutes' guidance for scoping reviews. The search was performed on 07 December 2021 and updated 27 May 2024, in the electronic databases Medline (Ovid), Embase (Ovid), and Cinahl (EBSCO). The search identified 20,422 publications, and 190 studies were included for review. We identified 30 PREMs assessing at least one aspect of adults' experience of transitions in healthcare. Summarising the content, we consider a model with two domains, organisational and human-relational, likely to be adequate. However, a more comprehensive analysis and adequate definition of the construct is needed. None of the PREMs were considered content valid.

Keywords Healthcare transitions, Patient-Reported Experience Measure, Patient Experience, Quality, Scoping Review

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Background

Care management encompasses evaluating individuals' needs and coordinating healthcare services; however, patients struggle with consistency and clarity in care management [1]. Patients' ability to navigate healthcare systems has implications for the outcome of their treatment [2, 3] such as functional ability [4], illness management [5], disease relapse [6], and quality of life [7], and patients experience navigation of healthcare services as burdensome [8]. Furthermore, healthcare structures which are difficult to navigate accentuate existing social inequities in healthcare [9] and people with poor health literacy are at higher risk of poor quality of care in healthcare transitions [10–12]. Because patients' experiences are associated with clinical effectiveness and safety [13], assessing patients' experiences with transitions in healthcare is important in determining the quality of healthcare delivery. Patient-reported experience measures (PREM) are intended to be reliable measures of the quality of healthcare services from patients' perspectives and may support evaluation of the effectiveness, safety, and efficiency of healthcare provision [14, 15]. However, validity and reliability criteria of PREMs are often inadequately investigated before clinical application of the PREMs, potentially leading to issues of responsiveness when applied in clinical trials [16].

Several reviews of instruments measuring patient experience of quality in healthcare transitions have been published [17–22]. In the systematic review by Berbee et al. [23] they aimed to identify and select an appropriate instrument for measuring the quality of integrated care for patients experiencing chronic illness, but identified no patient-reported experience measure that was comprehensive or relevant according to focus group interviews with the patients [17]. Concordantly, in a systematic review for evaluating patient satisfaction in healthcare settings integrating behavioural and medical health services, Black et al. [18] found that no PREM comprehensively captured all relevant aspects of the integrated healthcare experience [18]. In contrast, Weaver et al. [19] reviewed concepts, models, and instruments for understanding care continuity in mental health services and suggested a PREM suitable for self-reporting experiences with mental healthcare [19]. In 2011 Fiscella et al. [20] published a consensus of domains and measures suitable for patient-reported assessment of cancer navigation but also called for an instrument that covered all relevant topics [20]. Likewise, McMurray et al. [21] identified 25 instruments to assess patients' experience of rehabilitation services, but none comprehensively measured patient experience across the rehabilitative care continuum [21]. Following this, Quinn et al. [22] concluded that no instruments adequately assessed veterans' experience

with access and coordination across healthcare settings [22]. No reviews so far have identified a generic PREM that comprehensively measures patients' experience with the quality of healthcare transitions [17–22, 24, 25]. Therefore, there is a need to identify adequate concepts and measures that can target patient experienced transitions in healthcare.

The "COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN)" initiative was founded by a group of researchers with a mission to improve the quality of measurement of health outcomes [26]. The COSMIN group argues that content validity is the most important aspect of patient-reported measures [27]. Content validity refers to a patient-reported measure's relevance, comprehensiveness, and comprehensibility [28]. In other words, to evaluate whether the instrument provides an adequate reflection of the construct to be measured in the context [27]. Although there is some consensus on defining patient experience of healthcare transitions as a multidimensional concept consisting of human-relational and system factors, the conceptualizations found in existing reviews still lack clarity [17–22, 24, 25].

The overall scope of this review was to explore and define domains of the concept of patient-experienced quality in cross-sectoral care for generic patient populations. Further, to map existing methods for generically assessing the quality of transitions in healthcare settings (e.g. between municipality, general practitioner, and hospital). To achieve this, our objectives were:

1. What domains are considered relevant to measure for patients' experiencing healthcare transitions when evaluating the quality of care they have received?
2. What existing patient-reported experience measures attempt to measure patients' experience of transitions in healthcare settings?
3. Are any existing patient-reported experience measures adequate (relevant and comprehensive) reflections of patients' experience of transitions in healthcare settings?

Methods

The method of this scoping review followed the Joanna Briggs Institutes' (JBI) guidance for scoping reviews [29]. The article was outlined following JBI guidelines [29] supported by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist [30]. A pre-registered protocol, including aims, search strategies, and amendments made during the iterative review process [29], is available via Open Science Framework (OSF) [31]. The

research question was defined using the SPIDER-model (i.e., Setting, Phenomenon of Interest, Design, Evaluation, Research) [32]. The research question encompassed five concepts with predefined definitions and in- and exclusion criteria to ensure identification of eligible studies (Table 1).

Search

The search was performed on 07 December 2021 and updated 27 May 2024. The electronic databases Medline (Ovid), Embase (Ovid), and Cinahl (EBSCO) were chosen because they cover multiple research areas within healthcare. The search was developed in Embase and translated to Medline and Cinahl as recommended [35]. For the phenomenon of interest, we identified the Medical Subject Heading (MeSH) term “Patient Satisfaction”. Although we excluded studies reporting on patient satisfaction rather than patient experience, the terms have been used interchangeably, [21] and patient satisfaction thus seemed necessary to include in our search strategy. As the focus on patient’s experiences of coherent care seemed to have emerged around late 1990 and early 2000, [36] we searched for literature from 2000. The search strategy was developed from the predefined definitions and criteria with guidance from research librarians. An example of the search can be seen in Table 2 (see full search strategy in Supplementary material 1).

Selection of sources of evidence

Covidence (Veritas Health Innovation, Melbourne, Australia) was used to manage the duplication and screening process [37]. All studies were screened by two independent reviewers, and a total of seven reviewers participated in the screening process. To ensure calibration of the screening process, a consensus meeting was arranged

at the beginning of the process as in rapid reviews [38]. During the calibration sessions, in- and exclusion criteria were specified further than the a-priori defined criteria (Supplementary material 2).

In the full-text screening process, we experienced a larger number of articles than expected. In order to focus this review on the a priori defined aims, we decided to; I) report on intervention studies in an independent review, II) exclude mixed-methods studies and original qualitative studies, III) synthesize dimensions found in the included syntheses and reviews rather than report on the original studies. We decided to include syntheses and reviews because reports on qualitative studies were frequent, and relevant themes for patient-experienced quality of healthcare transitions had already been mapped in these meta-syntheses, integrative reviews, or scoping reviews.

Data charting process

A priori-defined data extraction templates were used and are available at OSF [39]. The data charting was done by one author (SW). The first 10 data extractions were validated independently by a research assistant (NH). The data charting table and process were adapted following the pilot extraction. The final data extraction tables are available in Supplementary materials 3 and 4.

Critical appraisal of individual sources of evidence

Although the JBI guidelines for scoping reviews do not warrant critical appraisal, [40] we critically appraised a selection of the most comprehensive PREMs according to the COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures [27, 41, 42] to assess content validity [27] (relevance, comprehensiveness, and comprehensibility) from patients’ perspectives

Table 1 Research Question Defined by the SPIDER^a-Model

	Concepts	Inclusion criteria	Exclusion criteria	
S	Setting	Transitions in healthcare settings	Patient transition between at least 2 healthcare settings (municipality, GP, hospital)	Single settings such as “In the primary care setting, at the hospital etc.”
PI	Phenomenon of Interest	Patient-experienced quality	Patients’ experiences were accounted for or assessed	Only healthcare personnel or relatives’ experiences were assessed
D	Design	Qualitative and quantitative research designs	Psychometric studies, qualitative studies, quantitative studies, syntheses/ reviews	Feasibility studies, study protocols, reports
E	Evaluation	PREMs ^b , patient accounts, narratives, attitudes, perspectives, and experiences of quality	Patient experience of healthcare provision [21, 33]	Patient satisfaction [34]
R	Research Type	Published, peer-reviewed research reporting data	Peer-reviewed, published studies	Conference abstracts and meeting notes

^a Setting, Phenomenon of Interest, Design, Evaluation, Research type

^b Patient-Reported Experience Measure

Table 2 Example of search syntax

	MEDLINE Ovid (Ovid MEDLINE(R) ALL)
1	"continuity of patient care"/ or patient discharge/ or patient handoff/ or patient transfer/ or retention in care/ or transitional care/
2	**"Delivery of Health Care, Integrated"/
3	(care adj2 continu*).ab,kf,ti
4	(care adj2 across adj5 sectors).ab,kf,ti
5	(care adj2 ?cross adj5 sector*).ab,kf,ti
6	(inter* adj2 sector* adj2 care).ab,kf,ti
7	(integrat* adj care).ab,kf,ti
8	(transition* adj2 care).ab,kf,ti
9	(coordinat* adj3 care).ab,kf,ti
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	exp Patient Satisfaction/
12	(patient* adj1 experience*).ab,ti
13	(patient* adj1 perspective*).ab,ti
14	(patient* adj2 view*).ab,kf,ti
15	(patient* adj2 attitude*).ab,kf,ti
16	(patient* adj2 satisf*).ab,kf,ti
17	(patient* adj2 involvement*).ab,kf,ti
18	(user* adj2 perspective*).ab,kf,ti
19	(user* adj2 view*).ab,kf,ti
20	(user* adj2 involvement*).ab,kf,ti
21	(user* adj2 attitude*).ab,kf,ti
22	(user* adj2 satisf*).ab,kf,ti
23	(user* adj2 involvement*).ab,kf,ti
24	(people* adj1 experience*).ab,ti
25	(people* adj1 perspective*).ab,ti
26	(people* adj2 view*).ab,kf,ti
27	(people* adj2 attitude*).ab,kf,ti
28	(people* adj2 satisf*).ab,kf,ti
29	(people* adj2 involvement*).ab,kf,ti
30	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 or 25 or 26 or 27 or 28 or 29
31	10 and 30
32	Limit 31 to yr= "2000-Current"

(See Supplementary material 5 for checklist). The critical assessment was done independently by two reviewers (SW, LM), and conflicts were discussed until a consensus was reached. When PREMs were mentioned in included publications but not available in the publication, references were followed to the original publications on that PREM.

Synthesis of results

We synthesized the data by; I) Summarizing themes identified in the qualitative syntheses and identifying relevant domains (Supplementary material 3 and Fig. 3); II) Identifying PREMs, assessing the PREMs phenomenon of interest, and categorizing and listing the items of

the relevant PREMs to assess comprehensiveness (Supplementary materials 4, 6 and Table 3); III) Assessing the content validity of the most comprehensive PREMs (items related to five or more themes) (Table 3). The process of synthesizing data is also described in Fig. 1.

Results

The search identified 20,422 records (Fig. 2), and 190 reports were included after the screening and selection process (Fig. 2). Reviewers had 70%-93% agreement. In addition to the regular selection process, first author SW divided the reports according to objectives 1 (27 reports) and 2 (163 reports, 35 reports excluded during data extraction, leaving 128 reports for inclusion). This was

Table 3 Comprehensiveness and Content Validity of Existing PREMs for Assessment of Patients' Experiences of the Quality of Transitions in Healthcare Settings

Themes relevant for measuring patient-experienced quality in healthcare transitions as identified in qualitative literature (objective 1) – n = number of items of PREM ^a for the named theme														
PREM	Patient-centeredness and individualized care	Effectiveness	Efficiency, coordination, and management	Timeliness	Equity	Caring attitude and compassion	Navigation, access, and availability	Responsibility	Relational continuity and relationship	Informational continuity	Communication and education	Caretakers and relatives	Articles referencing this PREM	Content Validity
ACSS-MH Alberta Continuity of Services Scale—Mental Health	6	3	9	2	2	8	8	4	5	2	2	2	Joyce 2010 [43], Fernandes 2020 [24], Weaver 2017 [19]	Adequate
CCAENA Questionnaire of Continuity between Care Levels	2		7	2		2	2		6	4	4	4	Aller 2013 [44], Vargas 2013 [45], Karam 2019 [46]	Inadequate
CCRQ Client-Centered Rehabilitation Questionnaire	8	4	2			2	4		1		6	4	McMurray 2016 [47]	Doubtful
CONTINUUM of care – User Measure	5	1	3	1		4	4		2	1	1		Rose 2009 [48], Fernandes 2020 [24], Weaver 2017 [19], Sweeney 2012 [49]	Doubtful
CPCI Components of Primary Care Index	3	1	3					1	6	2	2	2	Quinn 2017 [22]	Inadequate
CPCO Client Perception of Continuity Questionnaire	7	3	6	1		1	1	1	2	2	1	2	McGuiness 2003 [50], Quinn 2017 [22]	Inadequate
CQI Consumer Quality Index (Continuum of Care)		1	4	2		1	1		2	4			Berendsen 2009 [51], Williams 2013 [52], Kollen 2011 [53]	Doubtful
CTM Care Transition Measure	3		2							10			Acosta 2017 [54], Bakshi 2012 [55], Coleman 2005 [56], Shadmi 2009 [57], Mosalam 2014 [58], Hod 2020 [59]	Inadequate

Table 3 (continued)

Themes relevant for measuring patient-experienced quality in healthcare transitions as identified in qualitative literature (objective 1) – n = number of items of PREM ^a for the named theme														
PREM	Patient-centeredness and individualized care	Effectiveness	Efficiency, coordination, and management	Timeliness	Equity	Caring attitude and compassion	Navigation, access, and availability	Responsibility	Relational Continuity and relationship	Informational continuity	Communication and education	Caretakers and relatives	Articles referencing this PREM	Content Validity
DCCS Diabetes Continuity of Care Scale	7	6	4	6	3	8	8	5	3	4	4	1	Dolovich 2004 [60]	Doubtful
ECC Experienced Continuity of Care	2	2	5	2		1		2	4	1			Gulliford 2006 [61], Fillion 2012 [62]	Inadequate
HCCQ-Heart Continuity of Care Questionnaire	1	2	5				2	2	6	13			Hadjistavropoulos 2004 [63], Hadjistavropoulos 2008 [64], Kowalyk 2004 [65], Valaker 2019 [66], Riley 2007 [67]	Inadequate
NCQ Nijmegen continuity of care questionnaire	3		13					2	5	6			Cohen Castel 2018 [68], Hetlevik 2017 [69], Uijen 2012 [70], Fernandes 2020 [24], Weaver 2017 [19], Hopstaken 2021 [71], den Herder van der Eerden 2018 [72]	Doubtful
P3CEQ Person centred coordinated experience questionnaire	4	2	2			1		1	1	2			Lloyd 2019 [73], Sugavanam 2018 [74]	Adequate

Table 3 (continued)

Themes relevant for measuring patient-experienced quality in healthcare transitions as identified in qualitative literature (objective 1) – n = number of items of PREM ^a for the named theme														
PREM	Patient-centeredness and individualized care	Effectiveness	Efficiency, coordination, and management	Timeliness	Equity	Caring attitude and compassion	Navigation, access, and availability	Responsibility	Relational Continuity and relationship	Informational continuity	Communication and education	Caretakers and relatives	Articles referencing this PREM	Content Validity
PACIC Patient Assessment of Chronic Illness Care	10	2	2			1			2	3			Drewes 2012 [75], Berbee 2009 [23], Fernandes 2020 [24], Quinn 2017 [22], Cramm 2013 [77, 78], Bower 2018 [79]	Inadequate
PECQ Patient Experienced Continuity of care Questionnaire	4	1	2			1	2	1	1	2	5	1	Ljungholm 2024 [80]	Doubtful
PCAS The Primary Care Assessment Survey	4	2	2			1		1	1	1	11		Quinn 2017 [22], O'Malley 2009 [81]	Inadequate
PCCQ Patient Continuity of Care Questionnaire	7		6				5		6	2	12	2	Fillion 2012 [62], Quinn 2017 [22], Sisler 2012 [82], Carneiro 2016 [83]	Inadequate
PEICS Patient Experience of Integrated Care Scale	3	2	2				4				4	2	Joerber 2018 [84]	Adequate
PPCMC Patient Perceived Continuity from Multiple Clinicians		1	8					2		6	6		Haggerty 2012 [85], Quinn 2017 [22], Tremblay 2017 [86], Breton 2012 [87]	Doubtful
PPIC Patient Perceptions of Integrated Care	3		6	2			1	1	6	6	4		Kiang 2013 [88], Mohr 2019 [89], Fryer 2016 [90], Benzer 2019 [91]	Doubtful

Table 3 (continued)

Themes relevant for measuring patient-experienced quality in healthcare transitions as identified in qualitative literature (objective 1) – n = number of items of PREM ^a for the named theme														
PREM	Patient-centeredness and individualized care	Effectiveness	Efficiency, coordination, and management	Timeliness	Equity	Caring attitude and compassion	Navigation, access, and availability	Responsibility	Relational Continuity and relationship	Informational continuity	Communication and education	Caretakers and relatives	Articles referencing this PREM	Content Validity
SHEP Survey of Healthcare Experiences of Patients	5	1	2	2	2	2				5			Black 2021 [18], Fernandes 2020 [24], Quinn 2017 [22]	Inadequate
VANCOSS Veteran Affairs National Outpatient Customer Satisfaction	7	4	7	7	2	7			4	8	1		Black 2021 [18], Quinn 2017 [22]	Inadequate

^a Patient-reported experience measure

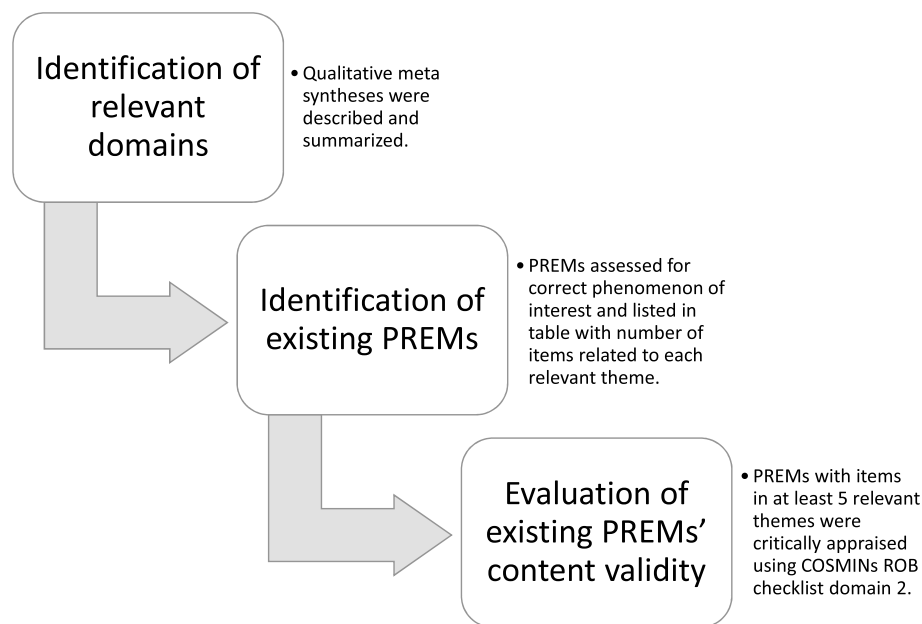


Fig. 1 Data Synthesis Process

done because the scientific methods for reports to answer objective 1 needed to be qualitative, and the methods relevant for answering objective 2 needed to be quantitative observational, development, or validation reports.

Relevant domains (Results for Objective 1)

For objective one, we included 27 reports (Supplementary material 7), [47, 92–117] which included: 10 (37%) systematic reviews, [47, 96, 98, 99, 102, 105, 107, 108, 110, 112] seven (26%) scoping reviews, [94, 100, 103, 109, 111, 114, 115] three (11%) meta syntheses, [92, 101, 113] three (11%) integrated reviews, [95, 97, 104] two (7%) narrative reviews, [117, 118] two (7%) qualitative reviews, [106, 116] that provided information on relevant domains and/or themes for assessing patients' experiences with care across healthcare settings. The number of identified themes ranged from two [94] to 13, [111] with most articles reporting three themes [96, 101, 113, 114, 117]. When summarizing and describing themes from the included reports, we found that the themes could be organized in two distinct domains; I) A system/organizational domain; II) A human-relational domain. Each of these domains encompassed six themes; thus, we identified 12 relevant themes as illustrated in Fig. 3.

The organizational domain included themes that had to do with delivery of healthcare services such as timeliness and efficiency [104, 106]. The human-relational domain was more about how services were delivered [107, 108]. We found that quality in care could not be measured without addressing concerns such as health

care providers caring attitudes or respect for patient preferences and informational needs [95, 115, 116].

Existing patient-reported experience measures (Results for Objective 2)

For objective two, we included 128 [17–22, 24, 25, 43–46, 48, 50–91, 119–160, 160–191] (Supplementary material 7) reports that described 113 unique PREMs (Supplementary materials 4 and 6). However, 83 (73%) PREMs were excluded during data extraction as they referred to other aspects of care quality than transitions between healthcare settings or otherwise deviated from our specified phenomenon (Supplementary material 6). The Consumer Assessment of Healthcare Providers and Systems (CAHPS) [192–195] questionnaires were most frequently referred to, [17, 18, 20, 22, 81, 119, 121, 123] but we did not find the items relevant according to the construct definition in objective 1. The two relevant PREMs that were most frequently referred to were Nijmegen Continuity Questionnaire [19, 24, 68–72, 172] and Patient Assessment of Chronic Illness Care (PACIC) [17, 22, 24, 75–77, 79, 196].

In the data extraction process, we identified different ways of formulating items. Some items were worded from a medical system perspective on quality i.e. “My physical pain was controlled as well as possible”, [197] whereas others were articulated from a patient-centred perspective i.e. “My treatment fits my needs” [43]. Yet, other items were specific to a certain contextual system infrastructure i.e. “The specialist makes out the first

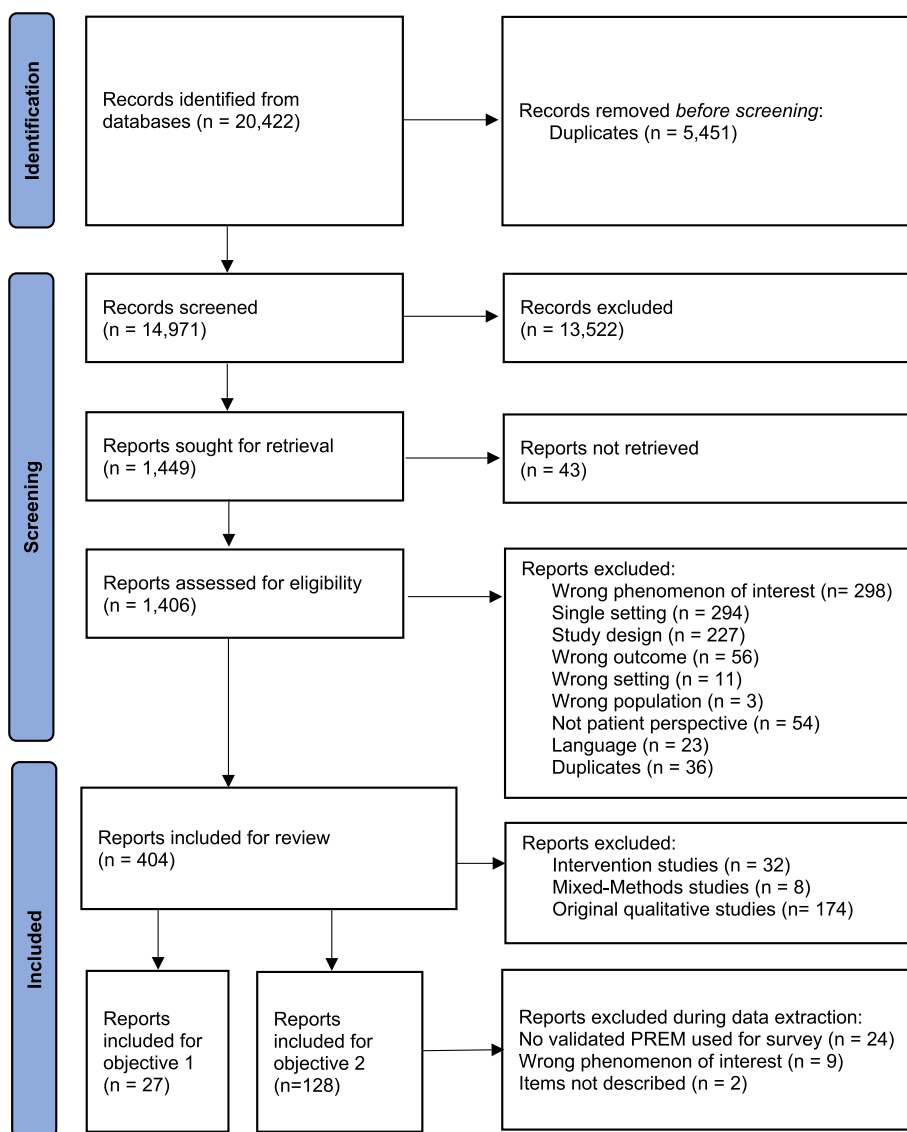


Fig. 2 PRISMA Flowchart

prescription for the treatment he/she prescribes me”, [44] or they were disease-specific [61]. However, we did identify PREMs with a more generic wording such as, “Were there times when you had to repeat information that should have been in your care records?” [198].

Adequate reflection of patients’ experience (results for objective 3)

We extracted 30 PREMs that pertained to patient-experience of quality of transitions in healthcare settings. To assess the relevance and comprehensiveness of the identified PREMs, the items of each PREM were plotted according to the 12 subthemes identified for objective 1 (Table 3). Twenty-two PREMs had items related to

at least five of the 12 subthemes (Table 3). To focus our review on the most comprehensive PREMs, we critically appraised the selected 22 PREMs. The Alberta Continuity of Services Scale – Mental Health (ACSS-MH), [43] the Person-Centered Coordinated Care Experience Questionnaire (P3CEQ), [74] and the Patient Experience of Integrated Care Scale (PEICS) [84] had adequate content validity, however, they were disease-specific and/or did not have items in all themes identified in objective 1 (Table 3). The remaining 17 PREMs had doubtful or inadequate content validity. Despite P3CEQ and PEIC having been adequately tested for content validity we do not find them comprehensive according to our conceptualization of the construct (Objective 1) and thus not content valid.

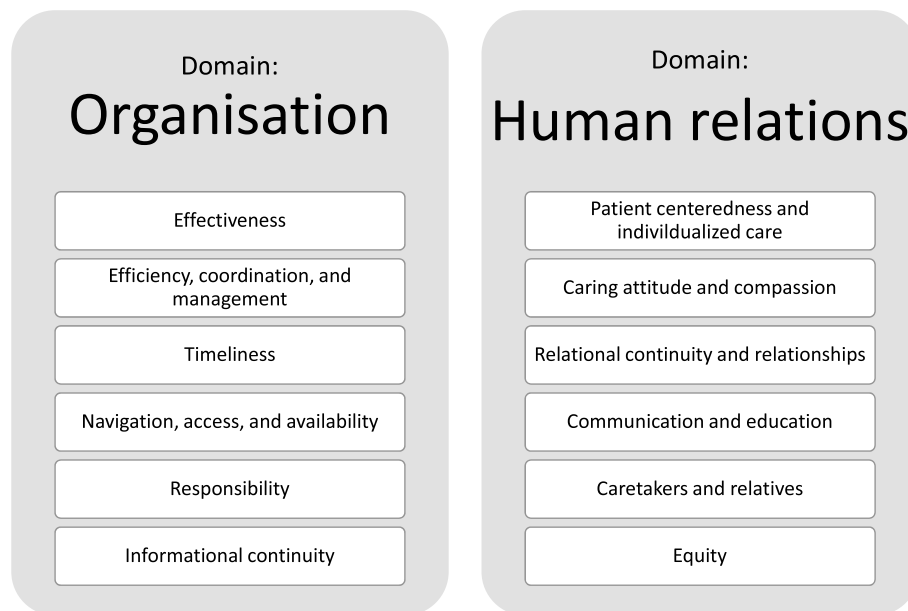


Fig. 3 Domains, Themes, and Items Relevant for Assessing Patients' Experiences of Pathways Across Healthcare Settings

Discussion

The overall aim of this scoping review was to define the concept of patient-experienced quality in healthcare transitions and map existing content valid PREMs relevant for measuring this concept. We found the construct of patient-reported experience of transitions in healthcare to consist of two domains – system/organization and human-relation. However, in summarizing the 27 qualitative reports for this review, we found some inconsistency and lack of clarity in the conceptualization and understanding of patient-experienced quality in healthcare transitions. Although some reports identified the construct of patient-experienced quality in healthcare transitions to consist of two main domains (organization and human-relational), [19, 20, 62, 102, 108, 115] others disagreed [95, 111] and leaned towards the Institute of Medicine's framework for quality with five or more domains [36]. The two-dimensional model is, however, supported by both qualitative conceptualization [102, 108, 115] and testing of measurement properties, [19, 20, 62] whereas the Institute of Medicine's framework is not. In addition to inconsistency in domains, there was a general inconsistency in the number and terminology for themes [94, 111] and formulation of items concerning patient-centeredness. [43, 197] As items in PREMs may be approached by respondents much the same as a dialogue, [199] we believe a person-centred approach to item formulation may provide the best opportunity for patients to assess quality of care appropriately. Several reports suggest further research into the conceptualization and understanding of

patient-experience with care transitions [94, 98, 110, 118]. Due to the variations in how the construct is defined, assessing the content validity of current PREMs becomes challenging [27, 28]. Therefore, we support the suggestion of further research into the conceptualization of patient-experienced quality in healthcare transitions.

We identified 30 PREMs that reflected at least one relevant aspect of the construct but none that were comprehensive reflections of generic patient populations' experiences of transitions in healthcare settings. This finding aligns with the conclusion of the included reviews of instruments [17–22, 24, 25, 62, 177]. It is surprising that we have not identified a content-valid PREM given the large number of reports (128) and unique PREMs (113) included. This may be associated with the lack of clarity in the construct of patient-experienced quality in healthcare transitions. In the future, a generic PREM should be developed to make cross-comparison between studies and healthcare organizations possible. A collective effort to test and use a generic PREM might also support further development and/or understanding of the construct. This, however, would entail a generic approach to item formulation, as seen in P3CEQ, [198] rather than a context-specific approach [44].

It may be a limitation in our study that our search was imprecise with the inclusion of patient satisfaction in the search terms. However, the sensitivity of our search originates from inclusion of patient satisfaction in the search terms, and we consider the strength of this sensitivity to outweigh the imprecision by securing a comprehensive

review. The comprehensiveness of our search resulted in a large number of records to be reviewed, and thus many reviewers to accommodate for time constraints. We attempted to compensate for a potentially low inter-rater reliability with calibration meetings. Despite of this, the number of reviewers may have been a limitation to the inclusion of all relevant, and only relevant reports. Furthermore, our pragmatic decision of excluding original qualitative studies from this review could have been a limitation to the comprehensiveness of our results. Incorporating the 24 qualitative reports has sufficiently advanced our comprehension of the existing literature to address objective 1. This is corroborated by the absence of new themes identified during data extraction from recent reports. The data extraction performed primarily by one reviewer may have caused some imprecision. However, as we have identified more PREMs than the included reviews of instruments, [17–22, 24, 25, 62, 177] this does not seem to be the case. While our scoping review does exhibit certain limitations, the thoroughness of our search and the inclusive methodology employed in comprehending and evaluating patient-experienced quality during healthcare transitions have nonetheless generated novel and significant insights.

CTM [56, 200] and PACIC [196] are widely used measures of patient-experience of transitions in healthcare settings and Nijmegen Continuity Questionnaire [70, 172] is often used for measurement of continuity. However, we found P3CEQ [73, 74], and PEICS [84] to have more adequately tested content validity for generic measurement of patient-experienced quality in healthcare transitions. With seventeen [73, 84] respectively twenty items for the questionnaires, we do not expect any one of them to be more challenging for participants to respond to. P3CEQ had been found to be difficult to use in an older population [164], but this is likely to be true for both questionnaires. The questionnaires have some overlap in themes and some differences. As P3CEQ has been more thoroughly tested using item response theory methods [73, 74, 191] we recommend the use of P3CEQ if the questionnaire has face validity for the intended purpose. We do still find though, that some items relating to kindness in care [95] are missing and that neither P3CEQ nor PEICS are comprehensive measures of patient-experienced quality in healthcare transitions according to the conceptualizations we have identified.

In light of our findings, it is plausible that items extracted from the most relevant and comprehensive PREMs, with a focus on generic formulations for infrastructure and disease, would reflect the construct of patient-experienced quality in healthcare transitions adequately. Furthermore, as there is some consensus that quality healthcare transitions occur when organisational structures are flexible and sensitive to patient preferences, [96, 101–104, 107, 114] it seems advantageous to apply this knowledge in item

extraction and/or formulation. As described, the construct seems to be unclear or imprecisely defined. Therefore, a process of extracting and/or formulating items should be undertaken systematically and iteratively with patient involvement and openness to re-evaluating the definition of the construct. A PREM revised by the outlined approach may support valid and reliable evaluation of the effectiveness, safety, and efficiency of healthcare provision.

With this scoping review we share an overview of available PREMs for assessment of patient-experienced quality of healthcare in pathways with transitions between settings. Our review may have implications for assessment of transitional care in the future, as we do not recommend continued use of CTM [56, 200]. Comprehensive and valid measurement of patients' experiences is pivotal to securing high quality, safe healthcare for patients with complex disease [1, 201] and we would welcome a collaborative, international effort to define the construct and further assess the existing PREMs or co-create a measure on the basis of the existing PREMs.

Conclusion

In the literature, we identified several conceptual models that referred to aspects of patients' experience with the quality of healthcare transitions. We consider a model with two domains likely to be adequate, however, a more comprehensive analysis and adequate definition of the construct is needed.

Thirty PREMs assessing at least one aspect of patients' experience of transitions in healthcare were identified. However, we did not consider any of the PREMs to be content valid to measure patient-experienced quality in healthcare transitions generically according to the conceptual models we identified. It is possible that items extracted from the identified questionnaires can be combined for a content-valid PREM. We call for further exploration into the construct of patient experience with healthcare transitions and testing of models to produce a content-valid PREM suitable for generic assessment of patients' experiences with the quality of healthcare transitions.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-024-11298-0>.

- Supplementary Material 1.
- Supplementary Material 2.
- Supplementary Material 3.
- Supplementary Material 4.
- Supplementary Material 5.
- Supplementary Material 6.
- Supplementary Material 7.

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Authors' contributions

SW devised the systematic search and review process, contributed substantially to the data extraction and mapping process, and revised the manuscript critically. SGR contributed substantially to the deviation of the systematic search and review process, and revised the manuscript critically. SMH contributed substantially to the deviation of the search and screening process and revised the manuscript critically. GZ and SRM contributed substantially to the review process and revised the manuscript critically. CBK contributed substantially to the data extraction and mapping process and with critical revision of the manuscript. CS, HHL, and LM made substantial contributions to conceptualisation, the systematic search and review process, the data extraction and mapping process, and critically revised the manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- Stewart A, MacIntyre G. Care management in the twenty-first century: Persistent challenges in implementation in the context of the emergence of self-care. *J Integr Care*. 2013;21:91–104.
- Freeman HP, Muth BJ, Kerner JF. Expanding access to cancer screening and clinical follow-up among the medically underserved. *Cancer Pract*. 1995;3:19–30.
- Egan M, Anderson S, McTaggart J. Community navigation for stroke survivors and their care partners: description and evaluation. *Top Stroke Rehabil*. 2010;17:183–90.
- Markle-Reid M, Fisher K, Walker KM, et al. The stroke transitional care intervention for older adults with stroke and multimorbidity: a multisite pragmatic randomized controlled trial. *BMC Geriatr*. 2023;23:687.
- Nielsen JD, Palshof T, Mainz J, et al. Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Saf Health Care*. 2003;12:263–72.
- Preen DB, Bailey BES, Wright A, et al. Effects of a multidisciplinary, post-discharge continuance of care intervention on quality of life, discharge satisfaction, and hospital length of stay: a randomized controlled trial. *Int J Qual Health Care*. 2005;17:43–51.
- Smidth M, Olesen F, Fenger-Gron M, et al. Patient-experienced effect of an active implementation of a disease management programme for COPD - a randomised trial. *BMC Fam Pract*. 2013;14:147.
- Walløe S, Beck M, Lauridsen HH, et al. Quality in care requires kindness and flexibility – a hermeneutic-phenomenological study of patients' experiences from pathways including transitions across healthcare settings. *BMC Health Serv Res*. 2024;24:117.
- Kvæl LA, Gautun H. Social inequality in navigating the healthcare maze: Care trajectories from hospital to home via intermediate care for older people in Norway. *Soc Sci Med*. 2023;333:116142.
- Adams RJ, Piantadosi C, Ettridge K, et al. Functional health literacy mediates the relationship between socio-economic status, perceptions and lifestyle behaviors related to cancer risk in an Australian population. *Patient Educ Couns*. 2013;91:206–12.
- Friis K, Vind BD, Simmons RK, et al. The relationship between health literacy and health behaviour in people with diabetes: a Danish population-based study. *J Diabetes Res*. 2016;2016:e7823130.
- Bo A, Friis K, Osborne RH, et al. National indicators of health literacy: ability to understand health information and to engage actively with healthcare providers - a population-based survey among Danish adults. *BMC Public Health*. 2014;14:1095.
- Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3:e001570.
- Weldring T, Smith SMS. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Health Serv Insights*. 2013;6:61–8.
- Jamieson Gilmore K, Corazza I, Coletta L, et al. The uses of patient reported experience measures in health systems: a systematic narrative review. *Health Policy*. 2023;128:1–10.
- Bull C, Byrnes J, Hettiarachchi R, et al. A systematic review of the validity and reliability of patient-reported experience measures. *Health Serv Res*. 2019;54:1023–35.
- Vrijhoef HJM, Berbee R, Wagner EH, et al. Quality of integrated chronic care measured by patient survey: identification, selection and application of most appropriate instruments. *Health Expect*. 2009;12(4):417–29.
- Black D, Held ML, Skeesick J, et al. Measures Evaluating Patient Satisfaction in Integrated Health Care Settings: A Systematic Review. *Community Ment Health J*. 2021;57:1464–77.
- Weaver N, Coffey M, Hewitt J. Concepts, models and measurement of continuity of care in mental health services: A systematic appraisal of the literature. *J Psychiatr Ment Health Nurs*. 2017;24:431–50.
- Fiscella K, Ransom S, Jean-Pierre P, et al. Patient-reported outcome measures suitable to assessment of patient navigation. *Cancer*. 2011;117:3603–17.
- McMurray J, McNeil H, Lafortune C, et al. Measuring patients' experience of rehabilitation services across the care continuum. Part I: a systematic review of the literature. *Arch Phys Med Rehabil*. 2016;97:104–20.
- Quinn M, Robinson C, Forman J, et al. Survey instruments to assess patient experiences with access and coordination across health care settings: available and needed measures. *Med Care*. 2017;55:S84–91.
- Berbee R, Steuten LMG, Vrijhoef HJM, Wagner EH. Quality of integrated chronic care measured by patient survey: Identification, selection and application of most appropriate instruments. *Health Expect*. 2009;12(4):417–29.
- Fernandes S, Fond G, Zendjidian XY, et al. Measuring the patient experience of mental health care: a systematic and critical review of patient-reported experience measures. *Patient Prefer Adherence*. 2020;14:2147–61.
- Perriman N, Davis D. Measuring maternal satisfaction with maternity care: a systematic integrative review. *Women Birth*. 2016;29:293–9.
- About the initiative • COSMIN. COSMIN. <https://www.cosmin.nl/about/>. Accessed 5 Jan 2024.
- Terwee CB, Prinsen CA, Chiarotto A, et al. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil*. 2018;27:1159–70.
- Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol*. 2010;63:737–45.
- Peters MDJ, Marnie C, Tricco AC, et al. Updated methodological guidance for the conduct of scoping reviews. *JBI Evid Synth*. 2020;18:2119–26.

30. PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation | Annals of Internal Medicine. <https://www.acpjournals.org/doi/10.7326/M18-0850>. Accessed 12 Jan 2023.
31. Tang L, Skou ST, Nissen N, et al. The Exercise First Research Program. 2020. <https://osf.io/v3ec5/>. Accessed 21 June 2023.
32. The SPIDER Tool for Qualitative Evidence Synthesis | NCCMT. <https://www.nccmt.ca/knowledge-repositories/search/191>. Accessed 16 Jan 2023.
33. Crow R, Gage H, Hampson S, et al. The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. *Health Technol Assess Winch Engl*. 2002;6:1–244.
34. Jenkinson C, Coulter A, Bruster S, et al. Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Qual Saf Health Care*. 2002;11:335–9.
35. Bramer WM, De Jonge GB, Rethlefsen ML, et al. A systematic approach to searching: an efficient and complete method to develop literature searches. *J Med Libr Assoc*; 106. Epub ahead of print 4 October 2018. <https://doi.org/10.5195/JMLA.2018.283>.
36. Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st century. Washington (DC): National Academies Press (US); 2001. <http://www.ncbi.nlm.nih.gov/books/NBK22274/>. Accessed 23 Jan 2023.
37. McKeown S, Mir ZM. Considerations for conducting systematic reviews: evaluating the performance of different methods for de-duplicating references. *Syst Rev*. 2021;10:38.
38. Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews - ClinicalKey. <https://www.clinicalkey.com/#/content/playContent/1-s2.0-S089543562031146X?returnurl=https%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS089543562031146X%3Fshowall%3Dtrue&referer=https%2F%2Fpubmed.ncbi.nlm.nih.gov%2F>. Accessed 2 Mar 2022.
39. Review_protocol_20220404.pdf. 2022. <https://osf.io/https://osf.io/zwh4>. Accessed 21 June 2023.
40. Peters MDJ, Godfrey C, McInerney P, et al. Best practice guidance and reporting items for the development of scoping review protocols. *JBI Evid Synth*. 2022;20:953–68.
41. Mokkink LB, de Vet HCW, Prinsen CAC, et al. COSMIN risk of bias checklist for systematic reviews of patient-reported outcome measures. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil*. 2018;27:1171–9.
42. Prinsen CAC, Mokkink LB, Bouter LM, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. *Qual Life Res Int J Qual Life Asp Treat Care Rehabil*. 2018;27:1147–57.
43. Joyce AS, Adair CE, Wild TC, et al. Continuity of care: validation of a self-report measure to assess client perceptions of mental health service delivery. *Community Ment Health J*. 2010;46:192–208.
44. Aller MB, Vargas I, Garcia I, et al. A tool for assessing continuity of care across care levels: an extended psychometric validation of the CCAENA questionnaire. *Int J Integr Care*. 13. Epub ahead of print 2 December 2013. <https://doi.org/10.5334/ijic.1160>.
45. Vargas I, Waibel S, Vazquez ML, et al. A comprehensive analysis of patients' perceptions of continuity of care and their associated factors. *Int J Qual Health Care*. 2013;25:291–9.
46. Karam M, Lambert A-S, Macq J. Patients' perceptions of continuity of care across primary care level and emergency departments in Belgium: cross-sectional survey. *BMJ Open*. 2019;9:e033188.
47. McMurray J, McNeil H, Lafortune C, et al. Measuring patients' experience of rehabilitation services across the care continuum. Part II: key dimensions. *Arch Phys Med Rehabil*. 2016;97:121–30.
48. Rose D, Sweeney A, Leese M, et al. Developing a user-generated measure of continuity of care: brief report. *Acta Psychiatr Scand*. 2009;119:320–4.
49. Sweeney A, Rose D, Clement S, Jichi F, Jones IR, Burns T, m.fl. Understanding service user-defined continuity of care and its relationship to health and social measures: a cross-sectional study. *BMC Health Serv Res*. 2012;12:145.
50. McGuinness C, Sibthorpe B. Development and initial validation of a measure of coordination of health care. *Int J Qual Health Care J Int Soc Qual Health Care*. 2003;15:309–18.
51. Berendsen AJ, Groenier KH, de Jong GM, et al. Assessment of patient's experiences across the interface between primary and secondary care: consumer quality index continuum of care. *Patient Educ Couns*. 2009;77:123–7.
52. Willems LM, Kwakkenbos L, Bode C, et al. Health care use and patients' perceptions on quality of care in systemic sclerosis. *Clin Exp Rheumatol*. 2013;31:64–70.
53. Kollen BJ, Groenier KH, Berendsen AJ. Patients' experiences with continuum of care across hospitals. A multilevel analysis of Consumer Quality Index Continuum of Care. *Patient Educ Couns*. 2011;83:269–72.
54. Acosta AM, Lima MADS, Marques GQ, et al. Brazilian version of the care transitions measure: translation and validation. *Int Nurs Rev*. 2017;64:379–87.
55. Bakshi AB, Wee SL, Tay C, et al. Validation of the care transition measure in multi-ethnic South-East Asia in Singapore. *BMC Health Serv Res*. 2012;12:256.
56. Coleman EA, Mahoney E, Parry C. Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Med Care*. 2005;43:246–55.
57. Shadmi E, Zisberg A, Coleman EA. Translation and validation of the care transition measure into Hebrew and Arabic. *Int J Qual Health Care J Int Soc Qual Health Care*. 2009;21:97–102.
58. Mosallam RA, Metwally S. Patients' views on the quality of transitional care at a health insurance hospital in Alexandria. *Egypt J Egypt Public Health Assoc*. 2014;89:74–80.
59. Hod R, Maimon O, Zimlichman E. Does Care Transition Matter? Exploring the Newly Published HCAHPS Measure. *Am J Med Qual*. 2020;35:380–7.
60. Dolovich LR, Nair KM, Ciliska DK, et al. The diabetes continuity of care scale: the development and initial evaluation of a questionnaire that measures continuity of care from the patient perspective. *Health Soc Care Community*. 2004;12:475–87.
61. Gulliford MC, Naithani S, Morgan M. Measuring continuity of care in diabetes mellitus: an experience-based measure. *Ann Fam Med*. 2006;4:548–55.
62. Fillion L, Cook S, Veillette A-M, et al. Professional navigation framework: elaboration and validation in a Canadian context. *Oncol Nurs Forum*. 2012;39(1):E58–69.
63. Hadjistavropoulos HD, Biem HJ, Kowalyk KM. Measurement of continuity of care in cardiac patients: reliability and validity of an in-person questionnaire. *Can J Cardiol*. 2004;20:883–91.
64. Hadjistavropoulos H, Biem H, Sharpe D, et al. Patient perceptions of hospital discharge: reliability and validity of a patient continuity of care questionnaire. *Int J Qual Health Care*. 2008;20:314–23.
65. Kowalyk KM, Hadjistavropoulos HD, Biem HJ. Measuring continuity of care for cardiac patients: development of a patient self-report questionnaire. *Can J Cardiol*. 2004;20:205–12.
66. Valaker I, Fridlund B, Wentzel-Larsen T, et al. Adaptation and psychometric properties of the Norwegian version of the heart continuity of care questionnaire (HCCQ). *BMC Med Res Methodol*. 2019;19:62.
67. Riley DL, Stewart DE, Grace SL. Continuity of cardiac care: cardiac rehabilitation participation and other correlates. *Int J Cardiol*. 2007;119:326–33.
68. Cohen Castel O, Dagan E, Keinan-Boker L, et al. Reliability and validity of the Hebrew version of the Nijmegen continuity questionnaire for measuring patients' perceived continuity of care in oral anticancer therapy. *Eur J Cancer Care (Engl)*. 2018;27:e12913.
69. Hetlevik Ø, Hustoft M, Uijen A, et al. Patient perspectives on continuity of care: adaptation and preliminary psychometric assessment of a Norwegian version of the Nijmegen Continuity Questionnaire (NCQ-N). *BMC Health Serv Res*. 2017;17(1):760.
70. Uijen AA, Schers HJ, Schellevis FG, et al. Measuring continuity of care: psychometric properties of the Nijmegen Continuity Questionnaire. *Br J Gen Pract J R Coll Gen Pract*. 2012;62:e949–57.
71. Hopstaken JS, van Dalen D, van der Kolk BM, et al. Continuity of care experienced by patients in a multi-institutional pancreatic care network: a pilot study. *BMC Health Serv Res*. 2021;21:1–9.
72. Den Herder-van Der Eerden M, Ebenau A, Payne S, et al. Integrated palliative care networks from the perspectives of patients: a cross-sectional explorative study in five European countries. *Palliat Med*. 2018;32:1103–13.
73. Lloyd H, Fosh B, Whalley B, et al. Validation of the person-centred coordinated care experience questionnaire (P3CEQ). *Int J Qual Health Care*. 2019;31:506–12.
74. Sugavanam T, Fosh B, Close J, et al. Codesigning a measure of person-centred coordinated care to capture the experience of the patient: the development of the P3CEQ. *J Patient Exp*. 2018;5:201–11.

75. Drewes HW, de Jong-van Til JT, Struijs JN, et al. Measuring chronic care management experience of patients with diabetes: PACIC and PACIC+ validation. *Int J Integr Care*. 2012;12:e194.
76. Glasgow RE, Wagner EH, Schaefer J, et al. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). *Med Care*. 2005;43:436–44.
77. Cramm JM, Nieboer AP. High-quality chronic care delivery improves experiences of chronically ill patients receiving care. *Int J Qual Health Care*. 2013;25:689–95.
78. Carryer J, Doolan-Noble F, Gauld R, et al. New Zealand patients' perceptions of chronic care delivery. *J Integr Care*. 2014;22:71–80.
79. Bower P, Reeves D, Sutton M, et al. Improving care for older people with long-term conditions and social care needs in Salford: the CLASSIC mixed-methods study, including RCT. *Health Serv Deliv Res*. 2018;6:1–188.
80. Ljungholm L, Årestedt K, Fagerström C, et al. Measuring patients' experiences of continuity of care in a primary care context-development and evaluation of a patient-reported experience measure. *J Adv Nurs*. 2024;80:387–98.
81. O'Malley AS, Cunningham PJ. Patient experiences with coordination of care: the benefit of continuity and primary care physician as referral source. *J Gen Intern Med*. 2009;24:170–7.
82. Sisler JJ, Taylor-Brown J, Nugent Z, et al. Continuity of care of colorectal cancer survivors at the end of treatment: the oncology–primary care interface. *J Cancer Surviv*. 2012;6:468–75.
83. Carneiro C, Ellis J, Singh S, et al. Patient and primary care practitioner confidence in and perceptions of cancer treatment transition and the shared care model of cancer care. *J Oncol Navig Surviv*. 2016;7:18–24.
84. Joobor H, Chouinard MC, King J, et al. The patient experience of integrated care scale: a validation study among patients with chronic conditions seen in primary care. *Int J Integr Care*. 2018;18:1.
85. Haggerty JL, Roberge D, Freeman GK, et al. Validation of a generic measure of continuity of care: when patients encounter several clinicians. *Ann Fam Med*. 2012;10(5):443–51.
86. Tremblay D, Roberge D, Touati N, et al. Effects of interdisciplinary teamwork on patient-reported experience of cancer care. *BMC Health Serv Res*. 2017;17:218.
87. Breton M, Haggerty J, Roberge D, et al. Management continuity in local health networks. *Int J Integr Care*. 12. Epub ahead of print 13 April 2012. <https://doi.org/10.5334/ijic.682>.
88. Kiang MV, Singer SJ, Friedberg MW, et al. Development and preliminary validation of the patient perceptions of integrated care survey. *Med Care Res Rev*. 2013;70:143–64.
89. Mohr DC, Benzer JK, Vimalananda VG, et al. Organizational Coordination and Patient Experiences of Specialty Care Integration. *J Gen Intern Med*. 2019;34:30–6.
90. Fryer AK, Friedberg MW, Thompson RW, et al. Achieving care integration from the patients' perspective: results from a care management program. *Healthcare*. 2016;4:36–44.
91. Benzer JK, Singer SJ, Mohr DC, et al. Survey of patient-centered coordination of care for diabetes with cardiovascular and mental health comorbidities in the department of veterans affairs. *J Gen Intern Med*. 2019;34:43–9.
92. Allen J, Hutchinson AM, Brown R, et al. User experience and care for older people transitioning from hospital to home: Patients' and carers' perspectives. *Health Expect Int J Public Particip Health Care Health Policy*. 2018;21:518–27.
93. Instituto Nacional de Cancerología E.S.E, Arias Rojas M, García-Vivar C, et al. The transition of palliative care from the hospital to the home: a narrative review of experiences of patients and family caretakers. *Investig Educ En Enferm*. 33. Epub ahead of print 15 October 2015. <https://doi.org/10.17533/udea.iee.v33n3a12>.
94. Asif M, Cadel L, Kuluski K, et al. Patient and caregiver experiences on care transitions for adults with a hip fracture: a scoping review. *Disabil Rehabil*. 2020;42:3549–58.
95. Beattie M, Shepherd A, Howieson B. Do the Institute of Medicine's (IOM's) dimensions of quality capture the current meaning of quality in health care? – An integrative review. *J Res Nurs*. 2013;18:288–304.
96. Boye LK, Mogensen CB, Mechlenborg T, et al. Older multimorbid patients' experiences on integration of services: a systematic review. *BMC Health Serv Res*. 2019;19:795.
97. Carpenter JG. Hospital palliative care teams and post-acute care in nursing facilities: an integrative review. *Res Gerontol Nurs*. 2017;10:25–34.
98. Davidson L, Scott J, Forster N. Patient experiences of integrated care within the United Kingdom: a systematic review. *Int J Care Coord*. 2021;24:39–56.
99. De Regge M, De Pourcq K, Meijboom B, et al. The role of hospitals in bridging the care continuum: a systematic review of coordination of care and follow-up for adults with chronic conditions. *BMC Health Serv Res*. 2017;17:550.
100. Foglino S, Bravi F, Carretta E, et al. The relationship between integrated care and cancer patient experience: A scoping review of the evidence. *Health Policy*. 2016;120:55–63.
101. Hestevik CH, Molin M, Debesay J, et al. Older persons' experiences of adapting to daily life at home after hospital discharge: a qualitative metasummary. *BMC Health Serv Res*. 2019;19:224.
102. Hohmann NS, McDaniel CC, Mason SW, et al. Patient perspectives on primary care and oncology care coordination in the context of multiple chronic conditions: A systematic review. *Res Soc Adm Pharm*. 2020;16:1003–16.
103. Lawless MT, Marshall A, Mittinty MM, et al. What does integrated care mean from an older person's perspective? A scoping review. *BMJ Open*. 2020;10:e035157.
104. Mayo SJ, Ajaj R, Drury A. Survivors' preferences for the organization and delivery of supportive care after treatment: An integrative review. *Eur J Oncol Nurs*. 2021;54:102040.
105. Oishi A, Murtagh FE. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals. *Palliat Med*. 2014;28:1081–98.
106. Piccenna L, Lannin NA, Gruen R, et al. The experience of discharge for patients with an acquired brain injury from the inpatient to the community setting: a qualitative review. *Brain Inj*. 2016;30:241–51.
107. Sampson R, Cooper J, Barbour R, et al. Patients' perspectives on the medical primary–secondary care interface: systematic review and synthesis of qualitative research. *BMJ Open*. 2015;5:e008708.
108. Scholl I, Zill JM, Härter M, et al. An integrative model of patient-centeredness – a systematic review and concept analysis. *PLoS One*. 2014;9:e107828.
109. Segan JD, Briggs AM, Chou L, et al. Patient-perceived health service needs in inflammatory arthritis: a systematic scoping review. *Semin Arthritis Rheum*. 2018;47:765–77.
110. Sibounheuang P, Olson PS, Kittiboonyakun P. Patients' and healthcare providers' perspectives on diabetes management: a systematic review of qualitative studies. *Res Soc Adm Pharm*. 2020;16:854–74.
111. Staniszewska S, Boardman F, Gunn L, et al. The Warwick patient experiences framework: patient-based evidence in clinical guidelines. *Int J Qual Health Care*. 2014;26:151–7.
112. van Servellen G, Fongwa M, Mockus DE. Continuity of care and quality care outcomes for people experiencing chronic conditions: a literature review. *Nurs Health Sci*. 2006;8:185–95.
113. Waibel S, Henao D, Aller M-B, et al. What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies. *Int J Qual Health Care*. 2012;24:39–48.
114. Youssef A, Chaudhary ZK, Wiljer D, et al. Mapping evidence of patients' experiences in integrated care: a scoping review. *Gen Hosp Psychiatry*. 2019;61:1–9.
115. Djukanovic I, Hellström A, Wolke A, et al. The meaning of continuity of care from the perspective of older people with complex care needs—a scoping review. *Geriatr Nur (Lond)*. 2024;55:354–61.
116. Joo JY, Liu MF. The experience of chronic illness transitional care: a qualitative systematic review. *Clin Nurs Res*. 2022;31:163–73.
117. Sanjida S, Garvey G, Ward J, et al. Indigenous Australians' experiences of cancer care: a narrative literature review. *Int J Environ Res Public Health*. 2022;19:16947.
118. Arias Rojas M, García-Vivar C. The transition of palliative care from the hospital to the home: a narrative review of experiences of patients and family caretakers. *Investig Educ En Enfermeria*. 2015;33:482–91.
119. Wells R, Breckenridge ED, Siañez M, et al. Self-Reported Quality, Health, and Cost-Related Outcomes of Care Coordination Among Patients with Complex Health Needs. *Popul Health Manag*. 2020;23:59–67.

120. Weinberg DB, Gittel JH, Lusenhop RW, et al. Beyond our walls: impact of patient and provider coordination across the continuum on outcomes for surgical patients. *Health Serv Res*. 2007;42:7–24.
121. Sequist TD, Von Glahn T, Li A, et al. Measuring chronic care delivery: patient experiences and clinical performance. *Int J Qual Health Care*. 2012;24:206–13.
122. Noel PH, Barnard JM, Barry FM, et al. Patient experience of health care system hassles: dual-system vs single-system users. *Health Serv Res*. 2020;55:548–55.
123. Mollica MA, Buckenmaier SS, Halpern MT, et al. Perceptions of care coordination among older adult cancer survivors: a SEER-CAHPS study. *J Geriatr Oncol*. 2021;12:446–52.
124. Kessing LV, Hansen HV, Ruggeri M, et al. Satisfaction with treatment among patients with depressive and bipolar disorders. *Soc Psychiatry Psychiatr Epidemiol*. 2006;41:148–55.
125. Ireson CL, Stutchfield FD, Slavova S, et al. Bridging the care continuum: patient information needs for specialist referrals. *BMC Health Serv Res*. 2009;9:163.
126. Hincapie AL, Slack M, Malone DC, et al. Relationship between patients' perceptions of care quality and health care errors in 11 countries: a secondary data analysis. *Qual Manag Health Care*. 2016;25:13–21.
127. Guilabert M, Martínez-García A, Sala-González M, et al. Results of a Patient Reported Experience Measure (PREM) to measure the rare disease patients and caregivers experience: a Spanish cross-sectional study. *Orphanet J Rare Dis*. 2021;16:67.
128. Collett GK, Durcinoska I, Rankin NM, et al. Patients' experience of lung cancer care coordination: a quantitative exploration. *Support Care Cancer*. 2019;27:485–93.
129. Burgers JS, Voerman GE, Grol R, et al. Quality and coordination of care for patients with multiple conditions: results from an international survey of patient experience. *Eval Health Prof*. 2010;33:343–64.
130. Bravi F, Ruscio ED, Frassoldati A, et al. Patient and health care professional perspectives: a case study of the lung cancer integrated care pathway. *Int J Integr Care*. 2018;18:7.
131. Bortoli A, Daperno M, Kohn A, et al. Patient and physician views on the quality of care in inflammatory bowel disease: Results from SOLLUTION-1, a prospective IG-IBD study. *J Crohns Colitis*. 2014;8:1642–52.
132. Boele F, Harley C, Pini S, et al. Cancer as a chronic illness: support needs and experiences. *BMJ Support Palliat Care*. 2019;14(e1):bmj.spcare-2019-001882.
133. Bentler SE, Morgan RO, Virnig BA, et al. The association of longitudinal and interpersonal continuity of care with emergency department use, hospitalization, and mortality among medicare beneficiaries. *PLoS One*. 2014;9:e115088.
134. Auerbach AD, Kripalani S, Vasilevskis EE, et al. Preventability and causes of readmissions in a national cohort of general medicine patients. *JAMA Intern Med*. 2016;176:484.
135. Andrew NE, Busingye D, Lannin NA, et al. The quality of discharge care planning in acute stroke care: influencing factors and association with postdischarge outcomes. *J Stroke Cerebrovasc Dis*. 2018;27:583–90.
136. Alsayali MM, AlSharif K, Al-Sahafi A, et al. Patients' satisfaction after primary health care centers' integration with Ministry of Health Hospitals. *Jeddah J Epidemiol Glob Health*. 2019;9:135–42.
137. Aller MB, Vargas I, Waibel S, et al. Factors associated to experienced continuity of care between primary and outpatient secondary care in the Catalan public healthcare system. *Gac Sanit*. 2013;27:207–13.
138. Badri MA, Attia ST, Ustadi AM. Testing not-so-obvious models of health-care quality. *Int J Health Care Qual Assur*. 2008;21:159–74.
139. Bentler SE, Morgan RO, Virnig BA, et al. Do claims-based continuity of care measures reflect the patient perspective? *Med Care Res Rev MCRR*. 2014;71:156–73.
140. Bentler SE, Morgan RO, Virnig BA, et al. Evaluation of a patient-reported continuity of care model for older adults. *Qual Life Res*. 2014;23:185–93.
141. Bull MJ, Luo D, Maruyama GM. Measuring continuity of elders' posthospital care. *J Nurs Meas*. 2000;8:41–60.
142. Castle N, Engberg J, Men A. Satisfaction of discharged nursing home residents. *J Appl Gerontol Off J South Gerontol Soc*. 2018;37:1225–43.
143. Chavez LM, Canino G, Shrout PE, et al. Psychometric evaluation of the Spanish version of CONNECT: a measure of continuity of care in mental health services. *Int J Methods Psychiatr Res*. 2007;16:23–33.
144. Clark K, Beatty S, Reibel T. Maternity-care: measuring women's perceptions. *Int J Health Care Qual Assur*. 2016;29:89–99.
145. Crump H, King J, Graham C, et al. Developing a User Reported Measure of Care Co-ordination. *Int J Integr Care*. 2017;17:4.
146. Eubank BH, Lafave MR, Mohtadi NG, et al. Validation of a tool to assess patient satisfaction, waiting times, healthcare utilization, and cost. *Prim Health Care Res Dev*. 2019;20:e47.
147. Fulton BR, Sternke EA, Ayala L, et al. Psychometric testing of a measure of patient experience in an ambulatory surgery setting. *J Ambulatory Care Manage*. 2019;42:27–36.
148. Graumlich JF, Novotny NL, Aldag JC. Brief scale measuring patient preparedness for hospital discharge to home: psychometric properties. *J Hosp Med*. 2008;3:446–54.
149. Haggerty JL, Burge F, Pineault R, et al. Management continuity from the patient perspective: comparison of primary healthcare evaluation instruments. *Health Policy*. 2011;7:139–53.
150. Husain A, Barbera L, Howell D, et al. Advanced lung cancer patients' experience with continuity of care and supportive care needs. *Support Care Cancer Off J Multinat Assoc Support Care Cancer*. 2013;21:1351–8.
151. Hwang JI, Chung JH, Kim HK. Psychometric properties of transitional care instruments and their relationships with health literacy: Brief prepared and care transitions measure. *Int J Qual Health Care*. 2019;31:774–80.
152. Ignatyev Y, Timm J, Heinze M, et al. Development and preliminary validation of the scale for evaluation of psychiatric integrative and continuous care-patient's version. *Front Psychiatry*. 2017;8:162.
153. Liu L-M, Liu M-T, Sun M-J, et al. Validity and reliability of the Chinese version of the partners at care transitions measure. *BMC Health Serv Res*. 2021;21:1284.
154. Malik N, Alvaro C, Kuluski K, et al. Measuring patient satisfaction in complex continuing care/rehabilitation care. *Int J Health Care Qual Assur*. 2016;29:324–36.
155. Masters S, Giles L, Halbert J, et al. Development and testing of a questionnaire to measure older people's experience of the transition care program in Australia. *Australas J Ageing*. 2010;29:172–8.
156. McAlister FA, Lin M, Bakal J, et al. The care transitions measure-3 is only weakly associated with post-discharge outcomes: a retrospective cohort study in 48,384 Albertans. *J Gen Intern Med*. 2019;34:2497–504.
157. Mira JJ, Nuno-Solinis R, Guilabert-Mora M, et al. Development and validation of an instrument for assessing patient experience of chronic illness care. *Int J Integr Care*. 2016;16:13.
158. Noest S, Ludt S, Klingenberg A, et al. Involving patients in detecting quality gaps in a fragmented healthcare system: development of a questionnaire for Patients' Experiences Across Health Care Sectors (PEACS). *Int J Qual Health Care*. 2014;26:240–9.
159. Oikonomou E, Page B, Lawton R, et al. Validation of the Partners at Care Transitions Measure (PACT-M): assessing the quality and safety of care transitions for older people in the UK. *BMC Health Serv Res*. 2020;20:608.
160. Parra-Vega I, Marques-Sanchez P, Pelayo-Teran JM, et al. Development and validation of a questionnaire for assessing patients' perceptions of interprofessional integration in health care. *J Interprof Care*. 2022;36(4):538–44.
161. Peabody M, Bradley KD, Custer M. Assessing the validity of a continuum-of-care survey: a rasch measurement approach. *J Appl Meas*. 2016;17:1–13.
162. Radwin LE, Cabral HJ, Seibert MN, et al. Patient-centered care in primary care scale: Pilot development and psychometric assessment. *J Nurs Care Qual*. 2019;34:34–9.
163. Ramond-Roquin A, Stewart M, Ryan BL, et al. The 'patient-centered coordination by a care team' questionnaire achieves satisfactory validity and reliability. *J Interprof Care*. 2019;33:558–69.
164. Reynolds J, Gadsby E, Rijken M, et al. Measuring older peoples' experiences of person-centred coordinated care: experience and methodological reflections from applying a patient reported experience measure in SUSTAIN. *Int J Integr Care*. 2021;21:1–17.
165. Rucci P, Fogliano S, Bravi F, et al. Validation of the Opportunity for Treatment In ONcology (OPTION) questionnaire measuring continuity of care. *Eur J Cancer Care (Engl)*. 27. Epub ahead of print 2018. <https://doi.org/10.1111/ecc.12765>.
166. Smith LFP. Postnatal care: development of a psychometric multidimensional satisfaction questionnaire (the WOMBPNSQ) to assess women's views. *Br J Gen Pract*. 2011;61:e628–37.

167. Soares JB, Nogueira MC, Fernandes D, et al. Validation of the Portuguese version of a questionnaire to measure Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease (QUOTE-IBD). *Eur J Gastroenterol Hepatol*. 2015;27:1409–17.
168. Sorra J, Zebrak K, Carpenter D, et al. Development and psychometric properties of surveys to assess patient and family caregiver experience with care transitions. *BMC Health Serv Res*. 2021;21:785.
169. Squitieri L, Tsangaris E, Klassen AF, et al. Patient-reported experience measures are essential to improving quality of care for chronic wounds: an international qualitative study. *Int Wound J*. 2020;17:1052–61.
170. Teale EA, Young JB. A Patient Reported Experience Measure (PREM) for use by older people in community services. *Age Ageing*. 2015;44:667–72.
171. Thompson R, Stevens G, Elwyn G. Measuring patient experiences of integration in health care delivery: psychometric validation of IntegRATE under controlled conditions. *J Patient Exp*. 2021;8:23743735211007344.
172. Uijen A, Schellevis F, Bosch W, et al. Nijmegen continuity questionnaire: development and testing of a questionnaire that measures continuity of care. *J Clin Epidemiol*. 2011;64:1391–9.
173. van Melle MA, van Stel HF, Poldervaart JM, et al. The transitional risk and incident questionnaire was valid and reliable for measuring transitional patient safety from the patients' perspective. *J Clin Epidemiol*. 2019;105:40–9.
174. Walker KO, Stewart AL, Grumbach K. Development of a survey instrument to measure patient experience of integrated care. *BMC Health Serv Res*. 2016;16:193.
175. Ware NC, Dickey B, Tugenberg T, et al. CONNECT: a measure of continuity of care in mental health services. *Ment Health Serv Res*. 2003;5:209–21.
176. Young JM, Walsh J, Butow PN, et al. Measuring cancer care coordination: development and validation of a questionnaire for patients. *BMC Cancer*. 2011;11:298.
177. Schick-Makaroff K, Karimi-Dehkordi M, Cuthbertson L, et al. Using patient- and family-reported outcome and experience measures across transitions of care for frail older adults living at home: a meta-narrative synthesis. *Gerontologist*. 2020;61:e23–38.
178. Volakakis N, Pylli M, Raftopoulos V, et al. Exploration of the factors that influence perceived quality of patient centered care among cancer survivors: a systematic review. *Eur J Oncol Nurs*. 2024;68:102503.
179. Yoshimura M, Sumi N. Measurement tools that assess the quality of transitional care from patients' perspective: a literature review. *Jpn J Nurs Sci*. 2022;19:e12472.
180. Van Roij J, Rajmakers N, Ham L, et al. Quality of life and quality of care as experienced by patients with advanced cancer and their relatives: a multicentre observational cohort study (eQuiPe). *Eur J Cancer*. 2022;165:125–35.
181. Liu LM, Zhuansun MY, Xu TY, et al. Measuring the quality of transitional care based on elderly patients' experiences with the partners at care transitions measure: a cross-sectional survey. *BMC Nurs*. 2024;23:172.
182. Chen CC, Cheng SH. Reexamining the association of care continuity and health care outcomes. *Am J Manag Care*. 2023;29:e242–9.
183. Arnold C, Hennrich P, Wensing M. Patient-reported continuity of care and the association with patient experience of cardiovascular prevention: an observational study in Germany. *BMC Prim Care*. 2022;23:176.
184. Kim SK, Hwang YS, Ock M, et al. Development of items for transitional care service and outcome indicators of discharged patients for improvement in quality of care. *J Korean Med Sci*. 2023;38:e246.
185. Seo AR, Kim BK, Park KS. Psychometric properties and effects on health outcomes of the Patient Assessment of Chronic Illness Care (PACIC) in Korean hemodialysis patients. *Healthcare*. 2022;10:1149.
186. Hennrich P, Arnold C, Koetsenruijter J, et al. Measuring continuity of ambulatory cardiovascular care: a cross-sectional study on the applicability of the Nijmegen continuity questionnaire in Germany. *BMC Health Serv Res*. 2022;22:1258.
187. Boyer L, Fernandes S, Brousse Y, et al. Development of the PREMIUM computerized adaptive testing for measuring the access and care coordination for patients with severe mental illness. *Psychiatry Res*. 2023;328:115444.
188. Sollid MIV, Slaaen M, Danielsen S, et al. Psychometric properties of the person-centred coordinated care experience questionnaire (P3CEQ) in a Norwegian radiotherapy setting. *Int J Qual Health Care J Int Soc Qual Health Care*. 2022;34:mzac067.
189. Vimalananda VG, Meterko M, Sitter KE, et al. Patients' experience of specialty care coordination: survey development and validation. *J Patient-Centered Res Rev*. 2023;10:219–30.
190. Rosenlund L, Jakobsson S, Lloyd H, et al. Measuring patient experiences of person-centred care: translation, cultural adaptation and qualitative evaluation of item candidates for use in England and Sweden. *Scand J Caring Sci*. 2022;36:235–44.
191. Rijken M, Close J, Menting J, et al. Assessing the experience of person-centred coordinated care of people with chronic conditions in the Netherlands: Validation of the Dutch P3CEQ. *Health Expect*. 2022;25:1069–80.
192. Hargraves JL, Hays RD, Cleary PD. Psychometric properties of the Consumer Assessment of Health Plans Study (CAHPS) 2.0 adult core survey. *Health Serv Res*. 2003;38:1509–27.
193. Platonova EA, Saunders WB, Warren-Findlow J, et al. Patient perceptions of patient-centered medical home characteristics and satisfaction with free clinic services. *Popul Health Manag*. 2016;19:324–31.
194. Dyer N, Sorra JS, Smith SA, et al. Psychometric properties of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) clinician and group adult visit survey. *Med Care*. 2012;50 Suppl:S28–34.
195. Hays RD, Berman LJ, Kanter MH, et al. Evaluating the psychometric properties of the CAHPS Patient-centered Medical Home survey. *Clin Ther*. 2014;36:689–696.e1.
196. Gensichen J, Serras A, Paulitsch MA, et al. The patient assessment of chronic illness care questionnaire: evaluation in patients with mental disorders in primary care. *Community Ment Health J*. 2011;47:447–53.
197. Cott CA, Teare G, McGilton KS, et al. Reliability and construct validity of the client-centred rehabilitation questionnaire. *Disabil Rehabil*. 2006;28:1387–97.
198. Lloyd H, Jenkinson C, Hadi M, et al. Patient reports of the outcomes of treatment: a structured review of approaches. *Health Qual Life Outcomes*. 2014;12:5.
199. Ash MG, Sturm T, editors. *Psychology's territories: historical and contemporary perspectives from different disciplines*. Mahwah: Lawrence Erlbaum Associates; 2007.
200. Coleman EA, Smith JD, Frank JC, et al. Development and testing of a measure designed to assess the quality of care transitions. *Int J Integr Care*. 2002;2:e02.
201. WHO. WHO global strategy on people-centred and integrated health services. WHO. <https://www.who.int/servicedeliverysafety/areas/people-centred-care/global-strategy/en/>. Accessed 3 May 2021.

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