

Patient experience surveys for children's community health services: A scoping review

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Abstract

Patient experience surveys have a user focus and measure the quality of person-centered health care for hospital inpatients and consumers of community health services, providing a governance process to evaluate the quality of care and to action improvement. Experience of care has been described as effective communication, respect and dignity, and emotional support. Measurement criteria for these domains are not standardised leading to inconsistent reporting of patient experience. The objective of this scoping review was to synthesise evidence for measuring experience of care in children's community health services using the Joanna Briggs Institute framework for scoping review method. Three parent-reported surveys met the inclusion criteria, 50 survey items were assessed by expert reviewers for fit to domains of health care experience. Conceptual domains of parent experience in children's community health services included respect and dignity, effective communication, and emotional support. A gap was identified in that few items in identified surveys measured emotional support. This contribution will promote consistent reporting of health care experience, informing policy and practice for person-centered health care.

Keywords

Parent, Community Health, Measure, Experience, Respect.

Background

Patient and consumer experience surveys are used to measure the quality of person-centered health care, specifically the interactions between health care providers and the people who receive care (Kruk et al., 2018; Larson et al., 2019). In children's health services person-centered care includes parents or carers, who are responsible for the fundamental decision-making and ongoing care of children (Australian Commission on Safety and Quality in Health Care, 2018: [ACSQHC]). For this reason, parents will ideally be given an opportunity to provide feedback, incorporating parent and child experience of care in community health services (ACSQHC, 2018). Engagement of families with community health services includes universal services that provide care for well infants and children, and services that provide targeted or specialist care (Ridgway et al., 2020; Glasgow et al., 2017). Outcomes of health care experience include health and safety outcomes, satisfaction with care, and continuing engagement with the health service (Larson et al., 2019).

As an outcome measure, experience of care surveys provide transparency and a governance process to identify concerns, action improvement, and benchmark across services (Larson et al., 2019; Harrison et al., 2017). In contrast, patient satisfaction surveys measure a different underlying concept of person-centered care, an evaluation of care interpreted through the consumer's own values and expectations. Interpretation of patient satisfaction requires caution because responses are more subjective than responses for experience of care (Larson et al., 2019). High quality care is primarily measured by user experience (Kruk et al., 2018), with a consistent positive association being demonstrated between experience of care and health and safety outcomes (Doyle et al., 2013).

Two World Health Organization (WHO) quality of care frameworks for child and family care conceptualise experience of care as 'respect and dignity,' 'effective communication,' and 'emotional support.' The "framework for maternal and newborn health" (Tunçalp et al., 2015),

and the “framework for improving the quality of paediatric care” (World Health Organization, 2018) each apply to community health services. Consistent with these frameworks, domains of ‘respect’ and ‘communication’ are commonly identified in the literature (Gardner et al., 2015; Kruk et al., 2018; Larson et al., 2019; Taylor et al., 2018). This aligns the core principle that person-centered care is respectful, given with effective communication in partnership with parents and children (Larson et al., 2019; Ridgway et al., 2020). A third domain of ‘emotional support’ is identified in the WHO quality of care frameworks. There is some overlap between these three domains, these are discussed beginning with respect.

Respect is defined as “the common thread” of person centered care, placing family needs and values at the center of care, actively engaging the family in decision making and care (WHO, 2018: 18). Dignity and preferences of children and families are respected, privacy and autonomy given, care is given without discrimination, confidentiality maintained, and children’s rights are protected and fulfilled (Kruk et al., 2018; Larson et al., 2019; WHO, 2018). Families are empowered when they partner in care, and when health care providers are attentive (De et al., 2014).

‘Effective communication’ is defined in the WHO quality of care framework as understanding what is happening and what to expect, knowing health care rights, and meaningful participation (Tunçalp et al., 2015; WHO, 2018). Effective communication empowers families by giving timely updates, giving an opportunity to ask questions, and including them in decision making (Harrison et al., 2017). Parents identified that provision of adequate information was a key to being included in the care of their unwell children (Roden, 2005; Harrison et al., 2017). In one qualitative study with parents of unwell children, a common thread was evident between communication, respect, and emotional support, with a focus on communication. Parents valued communication that was respectful and showed an understanding of the emotional stress

associated with having an unwell child (Roden, 2005). In contrast, Kruk et al. (2018) included clear communication within the domain of 'respect.'

'Emotional support' was defined in the WHO framework for improving quality of care for children (2018) as care that is sensitive to the needs of children and their families, and strengthens capacity. For parents of unwell children it was important that health professionals provided adequate emotional support, and were able to empathise with the distress and worry that they faced concerning the care of their child (Harrison et al., 2017). This focus on empathy also overlapped with the domain of communication (Harrison et al., 2017). Emotional support may be most succinctly defined as contributing to a person's "feelings of security, knowing, value as a person, and connection to others" (Williams et al., 2017: 2). Interpersonal interactions used to provide emotional support have been found to increase a person's feelings of personal control and their associated state of emotional comfort (Williams and Irurita, 2006).

Within the WHO quality of care framework, the three domains that represented experience of care formed part of the process of care, but not the whole (Tunçalp et al., 2015). Experience of care measures the interpersonal process of care (Larson et al., 2019). Processes of care that are not classified as interpersonal included human and physical resources, evidence based practices, and information and referral systems (Tunçalp et al., 2015). The overlap between these processes with interpersonal processes was not identified, for example, the provision of an interpreter may relate to effective communication. Similarly, 'access' to the physical location of community health services is an issue that affects continuing engagement with care providers for many families (Gardner et al., 2015).

Gardner et al. (2015) conducted a scoping review of patient experience surveys for primary and community health care services and found that experience of care data was not routinely collected by community health services. Nine of 95 identified surveys were included for analysis, identified surveys were mostly specific to primary care (general practice or dental care). In an

international analysis and review of quality of care, Kruk et al. (2018) identified a lack of consistent experience reporting. The authors reported “vast blind spots” in experience of care measures, calling for “fewer, but better, measures” to build consistent reporting at subnational and national levels (Kruk et al., 2018: e1197). In response to these identified gaps, we conducted a preliminary scoping search for systematic or scoping reviews to identify surveys used to measure experience of care in children’s community health services (Nelson et al., 2020). No scoping or systematic review was identified to meet the objective to synthesise the evidence for measuring experience of care in children’s community health services.

Aim

To identify surveys available for measuring experience of health care in children’s community health services.

Method

The *a priori* protocol followed the Joanna Briggs Institute (JBI) framework for scoping review method (Peters et al., 2017). The JBI scoping review framework is congruent with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018). The nine-step framework identified by Peters et al. (2017) was followed and the scoping review was preregistered (Nelson et al., 2020). An expert panel and stakeholders were consulted throughout the research (Peters et al., 2017).

Step 1. Review question. The research question and objectives were defined, guided by the inclusion criteria, ‘population,’ ‘concept’ and ‘context’ (Peters et al., 2017; Tricco et al., 2018). Population included children or parents who attended community health services. The concept was experience of health care in the context of children’s community health services. The term ‘patient experience’ was used in the title, research question and objectives consistent with Gardner et al. (2015) and Harrison et al. (2017).

Step 2. Inclusion criteria. Articles were included for review if they aligned with the following criteria: Surveys specific to the population of parents and children who access children's community health care services. Concept is parent and child experience of health service delivery; in the context of health care provided by nurses, paediatricians, and allied health providers including integrated care. Exclusion criteria of surveys in the context of mental health, general practice, dental service provision. Evidence sources included meta-analysis, systematic reviews, primary research studies, and grey literature studies sourced through health care networks in Australia.

Step 3. Data search, selection, extraction, and presentation of the evidence. The search process occurred in three phases. 1) A search in Medline and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) using the terms 'child OR parent' AND 'community health' AND 'questionnaire OR survey OR measure OR reliable' AND 'experience OR respect.' The search fields included title, abstract and search terms, these were identified through keyword searches (National Library of Medicine, 2019). Search terms were consistent with groups identified by Gardner et al. (2015), population, setting, type of tool, and outcome. Following analysis of text in the title, abstract, keywords, or Medical Subject Heading (MeSH) terms of identified articles, search terms were revised. A second search using the revised search terms included Medline, CINAHL, Cochrane databases, PsychInfo, and Scopus. An additional search in CINAHL used MeSH terms 'child OR pediatrics AND community health services OR child health services AND health care surveys AND patient satisfaction OR respect.' Limits to the first and second search were: Jan 2010 to June 2020, English language, and human. A third search was conducted to source primary surveys, including grey literature, specifically health service documents identified through manual search and government sources. The authors of each identified primary survey were contacted for further information or for permission to cite the question set. Permission was given to cite the question set for two surveys (Rossiter et al.,

2019; Dunst et al., 2006), and to cite one question from each subscale for the third survey (King et al., 2004).

Steps 4 to 6. Summary of search strategy, evidence selection, and extraction. The search strategy is presented in summary form along with a PRISMA flow chart. Search results were managed using EndNotex9 reference management software. Text words in the title and abstract were reviewed independently by two reviewers (HN and CP), a third reviewer was included when consensus was not met (AM). To identify studies that met the criteria for evidence the full text was screened by two reviewers (HN and CP) against the inclusion criteria, the narrative of inclusion and exclusion criteria were documented. Data from full text articles that met the pre-specified inclusion criteria were extracted in table form (Nelson et al., 2020).

Steps 7 to 9. Analysis of the evidence, presentation of results and summary. Scoping reviews aim to identify available knowledge and do not routinely assess reviewed studies for bias or methodological quality, outcomes may however, be implicit within the concept (Peters et al., 2017). To meet the research objectives a quantitative deductive content analysis was used to assess the fit of each identified survey question (or item) into domains of experience of care (Elo and Kyngäs, 2008). An *a priori* framework of 'respect and dignity,' 'communication,' and 'emotional support' was used (Larson et al., 2019). Additional domains were considered using inductive analysis. This analysis was undertaken by two people with expertise in survey design and validation (AW and CB) and one person with expertise in health service leadership (KM). Three expert reviewers were included to give triangulation of data analysis (Carter et al., 2014). Each expert reviewed survey questions independently, convergence of the data enhanced trustworthiness of the research findings (Carter et al., 2014). Data was managed using NVivo 11 qualitative data analysis software. Results are discussed in relation to the implication of the scoping review for policy and practice pertaining to measurement of experience of care in

children's community health services. An overall conclusion and implications for research findings is presented.

Results

After duplicates were removed, 248 articles were identified through electronic data search. Screening of titles and abstracts resulted in identification of seven articles that met the criteria for full review, a further nine articles were identified through manual search. Three of these articles were the primary source of a survey specific to child or parent experience of care provided in children's community health services and were included for review of the survey (see Figure 1). Of the remaining 13 articles, eight referred to the primary source directly or indirectly but were not the primary source. Primary sources were identified and six were excluded based on the following criteria: three were specific to General Practice (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002; Stewart et al., 2007; Agency for Healthcare Research and Quality, 2020), one was a duplicate and one was a clinical tool (Elwyn et al., 2013).

INSERT FIGURE 1. ABOUT HERE

Figure 1. Prisma flow chart of literature search

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Three surveys were identified that met the inclusion criteria (see Table 1). First the Child Health: Researching Universal Services (CHoRUS) online survey was developed in Australia, questions were informed by thematic analysis of focus group discussions with consumers, and refined after pilot testing (Rossiter et al., 2019). There has been no psychometric validation (email communication, Rossiter, 10th June 2020). The qualitative analysis explored consumer experiences of universal child and family health services for families with children aged from birth to five years across Australia. Service providers were nurses and general practitioners

(Hesson et al., 2017). Thematic analysis identified four themes; 'accessible services,' 'timely information,' 'non-judgemental interactions,' and 'ongoing and trusting relationships with health care providers.' These themes are reflected in the 13 survey items listed by Rossiter et al. (2019).

Second, the Family-centered Practices Scale (FPS), developed in the United States of America (USA), is part of a set of instruments to evaluate preschool program quality and impact in family resource centers and homes (Dunst et al., 2006). The preschool programs were for children with and without developmental disability or delay. The combined question set measures family support, parent self-efficacy and confidence, and child behaviour and function. An overview of the psychometric validation of the set of instruments is reported in a technical manual (Dunst et al., 2006). There are three variations of the FPS, with 8, 12 and 17 items, answered on a five-point scale 1 (*never*) to 5 (*all of the time*). Validation of the FPS began with principal components analysis. Two domains of family-centered practice were identified; 'relational practice,' and 'participatory practice.' The model fit was not given. Factor loadings were provided for the 8 item, 12 item, and 17 item versions of the survey. All factor loadings were above .6 for the 8 and 12 item versions. On the 17 item version the factor loading of "sensitive to my families cultural/ethnic background" was .328 (relational indicator), and "Involves me in decision making" was .474 (participatory indicator) (Dunst et al., 2006: 108). The corrected Cronbach's alpha for each scale, if the item was removed, was consistently above .879 on the 12 and 17 item version, and above .671 for the 8 item version (Dunst et al., 2006: 107).

Third, the Measure of Processes of Care (MPOC-20) was developed in Canada to measure parent perception of family-centered care in services for children with chronic physical and health conditions (King et al., 2004). Family-centered care was defined as recognising the expertise of parents in understanding the needs of their child, supporting parents in making decisions, and promoting partnership between parents and care providers (King et al., 2004).

The original 56-item question set was generated through review of the literature and focus group discussion with parents of children with physical disability (King et al., 2004). The MPOC-20 was adapted from this set using an iterative process of principal components analysis, model fit was not reported. The five subscales were; 'enabling and partnership,' 'providing general information,' 'providing specific information,' 'coordinated and comprehensive care,' and 'respectful and supportive care.' In a second phase of the study, the MPOC-20 was answered by a new sample of parents of children of all ages, newborn to early adult. The stem question was "to what extent do people who work with your child," each question was answered on a seven-point scale 1 (*not at all*) to 7 (*to a very great extent*) (King et al., 2004: 38). Internal consistency and construct validity were demonstrated, Cronbach's alpha of the five subscales ranged from .83 to .90. The MPOC-20 is licensed with a license able to be purchased from CanChild (<https://www.canchild.ca/en/shop>) (email communication, B. Featherston, 8th June 2020).

A total of 50 items were identified in the three surveys. Each item was analysed for fit to domains of experience of care by three expert reviewers. Reviewers had the option to classify items outside of the *a priori* framework. This option was not used; each item was classified into one of the domains 'respect and dignity,' 'effective communication,' or 'emotional support.' Due to licensing restrictions, results are presented for a subset of the identified survey items in Table 2. Items of the CHoRUS Survey were distinctly allocated to a single domain of care by the three expert reviewers, with one exception. The item "Listened to me" was allocated by two reviewers to 'respect and dignity' and by one reviewer to 'effective communication.' One reviewer suggested the item could also fit in the domain of 'emotional support.' This is similar to allocation for the FPS item "Listens to my concerns or requests," allocated by two reviewers to 'respect and dignity' and by one reviewer to 'emotional support.' The FPS has two domains, 'relational indicators,' and 'participatory indicators.' Items of the 'relational indicator' scale were

predominately classified into the domain 'respect and dignity;' there was some overlap with 'emotional support.' Four items from the 'participatory items' scale were consistently categorised by the three expert reviewers; two items into the domain 'effective information,' two items into the domain 'respect and dignity' (e.g. "Involves me in decision making"). Fifteen of the MPOC-20 items were allocated by at least one expert reviewer to the domain of "effective communication." This included one item from the 'respectful and supportive care' scale.

INSERT TABLE 2 ABOUT HERE

Expert review of the items specific to community based health services for children demonstrated a conceptual framework consistent with the WHO quality of care framework, with three domains of experience of care. Five items only were allocated by all three expert reviewers to the domain 'emotional support,' four of these items were from the CHoRUS survey, and one from the FPS.

Discussion

Three surveys were identified to measure experience of health care in children's community health services. The CHoRUS online survey measures parent experience of child and family health services in Australia (Rossiter et al., 2019). The Family-centered Practices Scale was developed in the USA to measure family centered experience of preschool program quality for children with and without developmental disability or delay (Dunst et al., 2006). The MPOC-20 was developed in Canada to measure the experience of parents of children with disability (King et al., 2004). The implications for policy and practice pertaining to measurement of experience of care in children's community health services are discussed.

Patient outcome measures have a user focus, and are ideally designed with consumers to measure what matters most to service users (Kruk et al., 2018; Gardner et al., 2015; Harrison et al., 2017). The CHoRUS online survey and the MPOC-20 were based on focus group

discussions with consumers, recognising parents as the experts of their experience. Respect is demonstrated by involving people and communities in their own care and in the design of measures to evaluate care (ACSQHC, 2018). It is important that health care providers generate knowledge on the experiences of care that are valued by children and families through reliable measurement, as this provides transparency to reporting (WHO, 2018). The outcomes inform policy and practice, and transparent reporting demonstrates where interventions have translated to improvement (WHO, 2018). The transparency afforded by accurate measurement will promote respectful care, effective communication, and health care in which the best emotional and physical outcomes are achieved for children and their families. The benefit of improved health outcomes will extend from individual family's and health services to national and international systems of policy and practice. For this benefit to be fully realised, a distinction must be made between user satisfaction and user experience surveys. User experience surveys must be reliable and accurate, reflecting the actual quality of interpersonal care.

The WHO quality of care frameworks identified three overarching domains of experience of care (Tunçalp et al., 2015; WHO, 2018). These domains of 'respect and dignity,' 'effective communication,' and 'emotional support' are not consistently included in measures of patient experience. Consistent methods of measurement are required to identify issues relevant to experience of care at a service level or across broader systems related to care delivery, including national policy (Harrison et al., 2017). Each of the three surveys identified in this scoping review measured a different aspect of children's community health service delivery. Although the population and setting of each survey was different, the domains of health care experience identified by expert reviewers were consistent with those named in the WHO quality of care framework (Tunçalp et al., 2015). However, five items only were allocated by all three expert reviewers to the domain 'emotional support.' This identified a knowledge gap in measuring parent and child experience of emotional support in children's community health

services. More research attention is recommended to fill this gap. Taken together, our findings suggest that the three overarching domains of experience of care may be relevant across children's health services and potentially to adult experience of health care. This framework will contribute to consistent measurement and reporting of experience of care (Kruk et al., 2018).

Limitations of this scoping review are that consensus was not reached by the expert reviewers who identified individual survey items into domains of care. This is consistent with the overlap in care domains identified in the background review. It is also consistent with increase of emotional comfort experienced by adult patients who perceived that staff were competent in their work, and who felt informed and received adequate information (Williams and Irurita, 2004). Further research is recommended to confirm the transferability of the conceptual model to child and family health care in inpatient and community settings.

Implications for practice

Parent and child experience of interpersonal care in community health services underlie their continuing engagement and ongoing health outcomes. Practitioners will support this by giving care that is respectful, partnering with the family in effective communication, and providing emotional support in a way that builds family capacity and sense of worth. This study will promote consistent reporting of health care experience, informing policy and practice for person-centered health care.

Conclusion

Three surveys were identified that measure experience of care in children's community health services. Each survey measured a different aspect of care. These were parent experience of universal child and family health services, family centered experience of preschool program quality for children with and without developmental disability or delay, and the experience of parents of children with disability. Using a deductive approach, expert reviewers allocated each survey item within three *a priori* domains of care, 'respect and dignity,' 'effective

communication,' and 'emotional support.' A gap was identified in that some items were not consistently allocated to the same domain, suggesting that each domain of user experience is not clearly demarcated. Moreover, few items measured experience of emotional support. More research is recommended to clarify the concepts in order to improve consistent measurement. Accurate and consistent measurement of health care experience is necessary to ensure that the best care is continually given to children and their families, to increase safety, and to increase parent engagement with health services.

References

- Agency for Healthcare Research and Quality (2020) *CAHPS Clinician & Group Survey*. Available at: <https://www.ahrq.gov/cahps/surveys-guidance/cg/index.html>.
- Australian Commission on Safety and Quality in Health Care (2018) *National Safety and Quality Health Service Standards: User guide for acute and community health service organisations that provide care for children*. Sydney: Australian Commission for Safety and Quality in Health Care.
- Carter N, Bryant-Lukosius D, DiCenso A, et al. (2014) The use of triangulation in qualitative research. *Oncol Nurs Forum* 41(5): 545-547.
- De S, Tong A, Isaacs D, et al. (2014) Parental perspectives on evaluation and management of fever in young infants: an interview study. *Archives of Disease in Childhood* 99(8): 717.
- Doyle C, Lennox L and Bell D (2013) A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. 3(1): e001570.
- Dunst CJ, Trivette CM and Hamby DW (2006) *Technical manual for measuring and evaluating family support program quality and benefits*. Asheville, North Carolina: Winterberry Press.
- Elo S and Kynäs H (2008) The qualitative content analysis process. *J Adv Nurs* 62(1): 107-115.
- Elwyn G, Lloyd A, Joseph-Williams N, et al. (2013) Option Grids: Shared decision making made easier. *Patient Education and Counseling* 90(2): 207-212.
- Gardner K, Parkinson A, Banfield M, et al. (2015) Usability of patient experience surveys in Australian primary health care: a scoping review. *Australian Journal of Primary Health* 22(2): 93-99.
- Glassgow AE, Martin MA, Caskey R, et al. (2017) An innovative health-care delivery model for children with medical complexity. *Journal of Child Health Care* 21(3): 263-272.
- Harrison R, Walton M, Manias E, et al. (2017) Patients' experiences in Australian hospitals: a systematic review of evidence. *Australian Health Review* 41(4): 419-435.
- Hesson A, Fowler C, Rossiter C, et al. (2017) 'Lost and confused': parent representative groups' perspectives on child and family health services in Australia. *Australian Journal of Primary Health* 23(6): 560-566.
- King S, King G and Rosenbaum P (2004) Evaluating Health Service Delivery to Children With Chronic Conditions and Their Families: Development of a Refined Measure of Processes of Care (MPOC-20). *Children's Health Care* 33(1): 35-57.
- Kruk ME, Gage AD, Arsenault C, et al. (2018) High-quality health systems in the Sustainable Development Goals era: time for a revolution. *The Lancet Global Health* 6(11): e1196-e1252.
- Larson E, Sharma J, Bohen MA, et al. (2019) When the patient is the expert: measuring patient experience and satisfaction with care. *Bulletin of the World Health Organization*. DOI: <http://dx.doi.org/10.2471/BLT.18.225201>. 563-569.
- Medical Home Initiatives for Children With Special Needs Project Advisory Committee (2002) The Medical Home. *Pediatrics* 110(1): 184-186.
- National Library of Medicine (2019) *Medical Subject Headings*. Available at: <https://www.nlm.nih.gov/mesh/meshhome.html> (accessed 15th May 2020).
- Nelson HJ, Mörelius E, McKenzie K, et al. (2020) Patient experience surveys for children's community health services: A scoping review. *OSF Preregistration osf.io/bj5wf* 30 July 2020 ed.
- Peters MDJ, Godfrey C, McInerney P, et al. (2017) Chapter 11: Scoping reviews. In: Aromataris E and Munn Z (eds) *Joanna Briggs Institute Reviewer's Manual*. JBI.

- Ridgway L, Hackworth N, Nicholson J, et al. (2020) Working with families: A systematic scoping review of family-centred care in universal, community-based maternal, child, and family health services. *Journal of Child Health Care* 0(0): 22.
- Roden J (2005) The involvement of parents and nurses in the care of acutely-ill children in a non-specialist paediatric setting. *Journal of Child Health Care* 9(3): 222-240.
- Rossiter C, Fowler C, Hesson A, et al. (2019) Australian parents' experiences with universal child and family health services. *Collegian* 26(3): 321-328.
- Stewart AL, Nápoles-Springer AM, Gregorich SE, et al. (2007) Interpersonal processes of care survey: patient-reported measures for diverse groups. *Health services research* 42(3 Pt 1): 1235-1256.
- Taylor A, Grant J and Grande ED (2018) Australian Hospital Patient Experience Question Set field testing and statistical analysis: Technical report. Adelaide, SA, Faculty of Health Sciences, University of Adelaide.
- Tricco AC, Lillie E, Zarin W, et al. (2018) PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 169(7): 467-473.
- Tunçalp Ö, Were WM, MacLennan C, et al. (2015) Quality of care for pregnant women and newborns-the WHO vision. *Bjog* 122(8): 1045-1049.
- Williams AM and Irurita VF (2004) Therapeutic and non-therapeutic interpersonal interactions: the patient's perspective. *J Clin Nurs* 13(7): 806-815.
- Williams AM and Irurita VF (2006) Emotional comfort: the patient's perspective of a therapeutic context. *Int J Nurs Stud* 43(4): 405-415.
- Williams AM, Lester L, Bulsara C, et al. (2017) Patient Evaluation of Emotional Comfort Experienced (PEECE): developing and testing a measurement instrument. *BMJ open* 7(1): 1.
- World Health Organization for Economic Cooperation and Development, and the World Bank, (2018) *Delivering quality health services: A global imperative for universal health coverage*. Geneva.

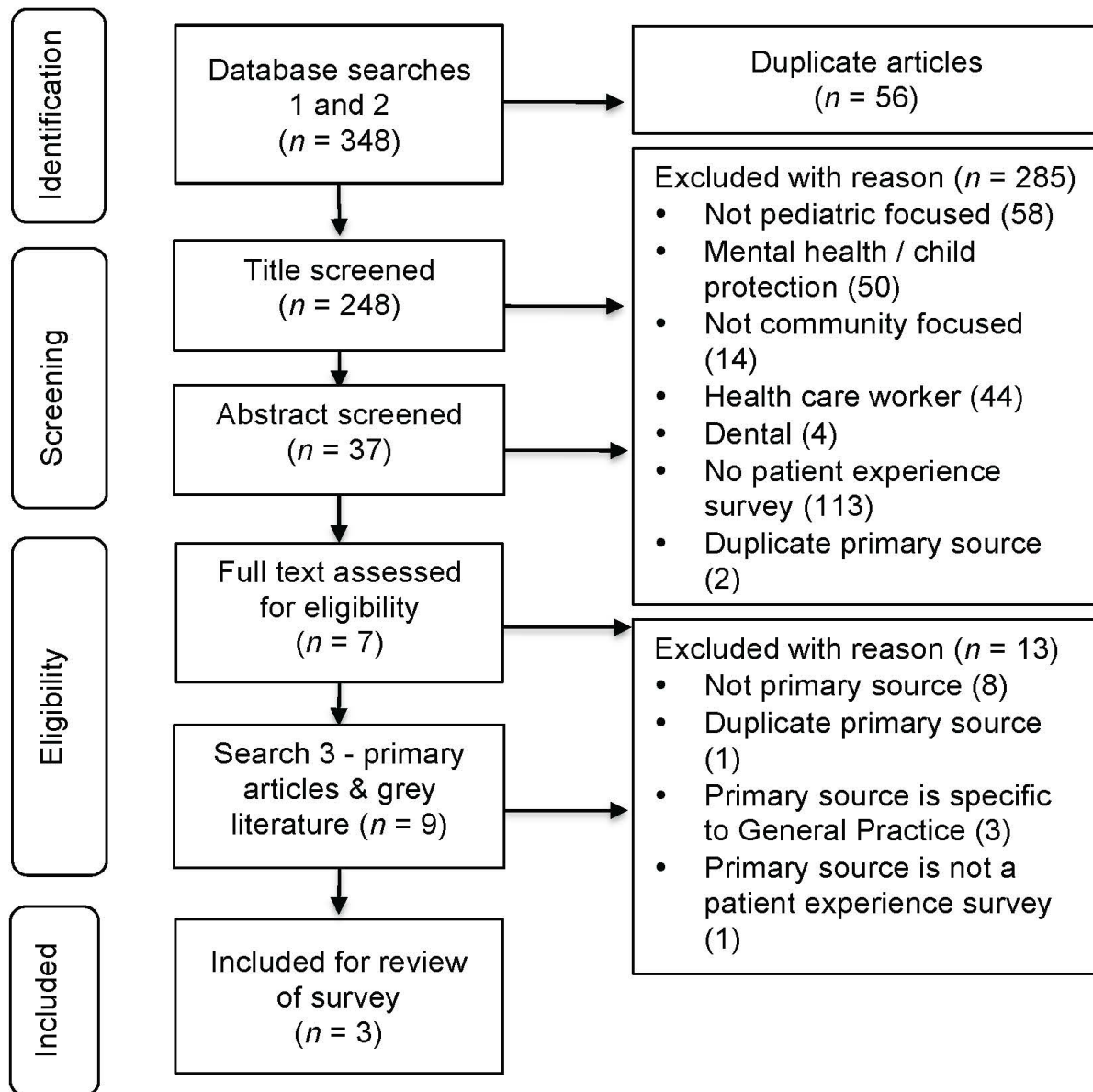


Figure 1. Prisma flow chart of literature search

Table 1. Data extraction instrument.

Article title	Australian parents' experiences with universal child and family health services	Technical manual for measuring and evaluating family support program quality and benefits.	Evaluating health service delivery to children with chronic conditions and their families: Development of a refined Measure of Processes of Care (MPOC-20)
Authors	Rossiter C, Fowler C, Hesson A, Kruske S, Homer C, Kemp L and Schmied V	Dunst CJ, Trivette CM and Hamby DW	King S, King G and Rosenbaum P
Year of publication	2019	2006	2004
Country and community health context	Australia, a range of service providers including community child health nurses.	USA, one of a set of surveys used to evaluate an early childhood and family support program from 1990 to 2004.	Canada, parent experience of family-centered care in services for children with disability and chronic conditions.
Number of participants and age of children	719 parents of children aged 0-5 years	1100 parents of infants, toddlers and preschool children enrolled in the family support program. Eighty percent of children were aged between 1 and 5 years.	Phase 1. Retrospective, 1011 parents of children of all ages who participated in prior studies related MPOC-56. Phase 2. New sample of 494 parents of children from rehabilitation and community care access centers. Children aged between newborn to early adult.
Research objectives	"To examine the experiences of families with young children across Australia in accessing and receiving health care for well children, parenting support and advice from a range of providers" (Rossiter et al., 2019: 321)	Using family-centered practices to provide support and resources that strengthen family capacity and assist families to achieve their desired outcomes.	To shorten the MPOC from 56 items to 20 items.
Research questions	"How do families around Australia experience the primary-level services they use for child and family health (CFH) and parenting support? Do they feel that CFH services are accessible, reliable and meeting their needs?" (Rossiter et al., 2019: 322)	The technical manual presents an overview of measures used in 18 studies, the reference for the primary study was not sourced.	Research questions were not stated - properties of the 20-item MPOC were examined using retrospective data collected on the MPOC-56 version. Phase 1. Assessment of reliability and validity of MPOC-20. Phase 2. Adaptation of the response scale and assessment of reliability and validity of revised version using an independent sample.
Inclusion / exclusion criteria			
Population	Parents of children aged under 5 years who access Child and Family Health services in Australia.	Parents of infants and preschool aged children with or without disability.	Parents of children with disability or chronic health conditions.
Concept	Parent experience of health	Parent experience of family	Parent experience or satisfaction with family

Context	service delivery. Maternal and child health service provision.	support. Practitioner relational and family-centered participatory help giving practices. Participatory includes involving family in decision-making and collaboration to help family obtain desired resources and build capacity.	centeredness of care. Care related to specific behaviours of health professionals.
Outcomes			
Number of items in survey	13 items in the published article.	Three variations of the survey; 8, 12 and 17 items.	20 items.
Psychometric validation	"The survey was developed specifically for this project, based on earlier qualitative work with parent representatives as part of the CHoRUS research (Hesson et al., 2017). It was pilot tested" (personal communication, email, C. Rossiter, 10th June 2020).	Principal components analysis resulted in 2 subscales: relational indicators, participatory indicators. Model fit was not given. Factor loadings >.6 on the 8 and 12 item version. In 17-item version the factor loading of "sensitive to my families cultural/ethnic background" = .328 (relational), and "Involves me in decision making" = .474 (participatory).	5 domains: Enabling and partnership $\alpha = .87$; Providing general information $\alpha = .90$; Providing specific information $\alpha = .83$; Coordinated and comprehensive care $\alpha = .84$; Respectful and supportive care $\alpha = .90$. Correlations between domains ranged between .56 to .87 showing intercorrelatedness of domains. Validity testing showed that the measure was consistent regardless of the age or diagnosis of the child.

Note. This table presents Step 6 of the scoping method, the extraction into table form of data from full text articles that met the pre-specified inclusion criteria.

Table 2. Classification of identified survey items into domains of experience of care by three expert reviewers.

	Respect and dignity	Effective communication	Emotional support	Other
CHoRUS survey (Rossiter et al., 2019) Stem: Please score the following statements about your most recent visit to... (1=not at all true, 5=very true).				
Listened to me	2	1	"Could fit here"	
Respected my knowledge of my child	3			
Gave me consistent and useful information		3		
Supported and encouraged me			3	
Family-centered Practices Scale (Dunst et al., 2006) Stem: The clinician				
Listens to my concerns and requests (RI)	2		1 and "Could fit here"	
Works together with me based on mutual trust and respect (RI)	3			
Presents all the options about available supports and resources			3	

(RI)				
Helps me be an active part of getting desired resources and support (PI)	1	1	1	
Provides me the information I need to make good choices (PI)		3		
Involves me in decision making (PI)	3			
MPOC-20 (King et al., 2004) (https://www.canchild.ca/en/shop) Stem: To what extent do the people who work with you child...				
Provide opportunities for you to make decisions about treatment? (EP)	2	1		
Provide enough time to talk so you don't feel rushed? (RSC)	1		2	
Plan together so they are all working in the same direction? (CCC)	2	1		
Tell you about the results from assessments? (SI)		3		
Have information available about your child's disability (e.g., its causes, how it progresses, future outlook)? (GI)		3		

Note. Family-centered Practices Scale: Relational indicator (RI); Participatory indicator (PI). MPOC 20: Enabling and partnership (EP); Respectful and supportive care (RSC); Coordinated and comprehensive care (CCC); Providing general information (GI); Providing specific information (SI).