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Haneen Ali

Auburn University, hba0007@auburn.edu

Astin Cole

Auburn University, abc0074@auburn.edu

Adam Sienkiewicz

Auburn University, ats0040@auburn.edu

Steffie Rosene

Auburn University, msr0022@auburn.edu

Reagan Shaffer

Auburn University, ras0049@auburn.edu

See next page for additional authors

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Authors

Haneen Ali, Astin Cole, Adam Sienkiewicz, Steffie Rosene, Reagan Shaffer, and Robert Thames

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Haneen Ali, *Auburn University*, hba0007@auburn.edu

Astin Cole, *Auburn University*, abc0074@auburn.edu

Adam Sienkiewicz, *Auburn University*, ats0040@auburn.edu

Steffie Rosene, *Auburn University*, mrs0022@auburn.edu

Reagan Shaffer, *Auburn University*, ras0049@auburn.edu

Robert Thames, *Auburn University*, ort0002@auburn.edu

Abstract

Accurate reporting of patient experiences is a crucial resource for hospitals engaged in patient-and-family-centered care (PFCC). However, studies suggest that most children do not respond to patient satisfaction surveys and are instead represented by their parents or guardians. This study reviewed instruments used to obtain feedback from children about their healthcare experiences for two purposes: 1) To understand the limitations of current tools and 2) To determine if creating a new instrument is necessary. A systematic review was performed on PubMed, Medline, CINAHL, and Web of Science to identify peer-reviewed questionnaires designed to collect children's healthcare experiences. Out of the 9,822 retrieved studies, 17 met the inclusion criteria. Among the seventeen studies, only one provided versions of the study for non-English speaking respondents. Only seven studies developed their questionnaires, nine studies used tools developed by other authors, and one study did not specify. Only 58.82% of the included studies collected both the child and their parents' responses, and the remaining 41.18 % collected data solely from the child. Lastly, the included studies relied too heavily on questions that required the child to recall detailed accounts of their hospital experiences, the quality of their hospital room, and the hospital equipment used in their treatment. The study finds that these questions not only led to mixed results, it also limited self-reporting. Further, the study acknowledges the need to develop a superior instrument that asks children for their perspective of their healthcare experiences in an age-appropriate and culturally accessible way.

Keywords

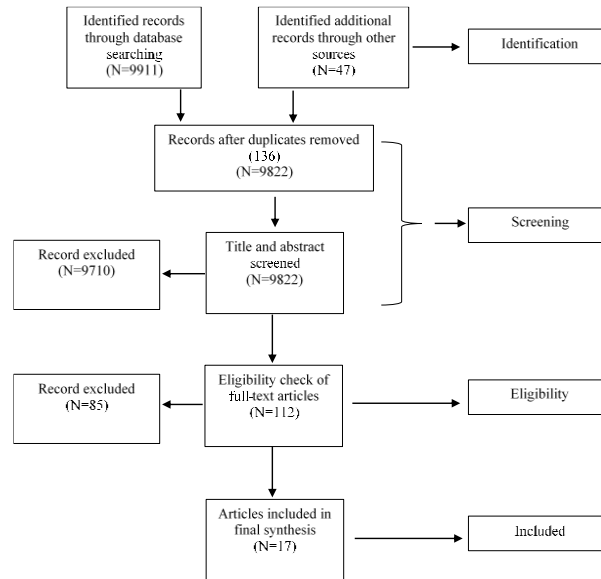
Hospitalized children, quality, feedback, experience, satisfaction

Introduction

Within the last decade, the United States (US) healthcare industry has seen a major push toward a value-based business model over the current volume-based (fee-for-service, FFS) model in place.¹ This value-based business model approach prioritizes focusing on the individual patient's unique needs and expectations, seeing them as stakeholders rather than a revenue stream from whom they can run unnecessary tests and treatments.^{2,3} This patient and family-centered care model (PFCC) therefore necessitated a shift from quantity-based financial incentives to performance incentives assessing levels of patient satisfaction.^{4,5} As a result, the study of patient experience is now a major component of insurance reimbursement as well as quality improvement (QI) projects within facilities.^{6,7} To quantify patient satisfaction as an indicator of the patient's overall experience, self-reporting tools are developed to assess the quality of their care received.⁸

Literature suggests that patient experience in the US is typically collected with survey data,^{6, 8-11} with the Hospital Consumer Assessment of Healthcare Providers Survey (HCAHPS) widely regarded as the industry standard.^{6, 9} Goldstein et al.¹⁰ writes that the HCAHPS was developed by the Agency for Healthcare Quality and Research (AHRQ) to use public reporting for three purposes 1) To produce comparable data on the patient's perspective on care that allow objective and meaningful comparisons among hospitals on domains that are important to consumers. 2) To create incentives for hospitals to improve their quality of care. 3) To increase the transparency of the quality of hospital care provided in return for the investment. The AHRQ has emphasized the use of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) to obtain patient experience. The data received from the HCAHPS is then analyzed and scored to determine how a facility or segment of the healthcare industry is performing.^{6, 9-10} As of 2013 under the Affordable Care Act (2010), these performance scores have been linked to Medicare

Figure 1. PRISMA flow diagram



reimbursement payments, with payment amounts changing according to the hospital's performance rates.¹⁰ As a result, hospitals under the PFCC model are found to have a vested interest in improving patient-reported experiences and outcomes.

The HCAHPS survey is currently offered to patients of all ages. There is one survey for adults (ages 18 and over) and one for children (ages 18 and under). For each respective survey, the patient provides answers to a set of questions asking about various aspects of their healthcare experience (such as food, level of care, facilities and equipment, staff responsiveness, etc.). However, there is one key difference in obtaining this information. When children are surveyed about their experiences, a parent or legal guardian is asked to fill in the answers and serves as a proxy for the child patient.^{12, 13} The survey ultimately falls short by allowing parents and legal guardians to speak for the child. A common belief is that children lack the perceptiveness, knowledge, experience, or maturity needed to answer questions on a complex subject such as their health and the day-to-day operations to care for them while hospitalized. It is also assumed that children are not cognitively mature enough to thoroughly reflect on their healthcare experiences, suggesting they cannot accurately score survey questions.¹⁴⁻¹⁵ However, it has been shown in the literature that children can express their perceptions and emotions, can understand and articulate the social consequences of having a chronic illness on everyday experiences, and can provide valuable feedback about their experiences, some as young as five years old.¹⁶⁻¹⁸ Research also suggests that children have different perceptions than their adult counterparts.¹⁹⁻²¹ These studies, therefore, suggest the need to re-imagine the way research in patient-

reported outcomes perceives and measures children's feedback. Further, the studies also suggest the need for hospitals to obtain direct child-patient feedback to ensure the integrity and accuracy of self-reported child-patient outcomes.

Conducting this systematic literature review is the first step of a project aiming to develop an age-appropriate instrument to obtain hospitalized children's experiences. Therefore, this study aims to systematically review the literature to identify all tools used to obtain direct feedback on children's healthcare experiences and to evaluate the quality and performance of these tools in measuring children's perceptions and experiences.

Methods

Search strategy

A systematic literature search was performed in PubMed, Medline, CINAHL, and Web of Science databases, from their inception up to May 2019. The goal of this search was to identify all tools which collected child-reported healthcare outcomes. The research was conducted using a set of keywords in all possible combinations, based on the consultation of an expert research librarian. Their primary role was to identify and list keywords, as well as provide general curation of the research tools reviewed. The keywords used included "children"; "quality"; "healthcare"; "feedback"; "satisfaction"; "hospitalized", and "experience". The search methodology and reported findings to comply with the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.²² (Figure 1). The search

results were then exported into EndNote citation manager and the duplicates were removed.

Article selection

The identification of relevant studies involved several steps. First, the searches were limited to peer-reviewed articles that sought children's perception of care and feedback. Specifically, the studies were assessed by the tools and methods used to obtain children's feedback and experience in healthcare. As the study seeks to identify gaps in scholarship related to US patient-reported outcomes, only peer-reviewed articles conducted in the US and published in English were included for this study. Further, to ensure that the systemic review reflects the most contemporary view of the topic, articles published before 1990 were excluded from this study. The initial search and screening criteria resulted in numerous articles from data sources such as PubMed, MEDLINE, Web of Science, CINAHL, and other sources. Second, duplicates were removed, and the remaining articles were further screened based on content via their description or abstracts. The remaining articles were then retrieved and reviewed to verify whether they met the criteria for acceptance. Finally, the studies were reviewed by the two authors independently, and the interrater reliability was calculated at 82% using Cohen's kappa.²³

Data collection

The information recorded from each article including the authorship, publication year, study outcomes, tools, design, settings, sample size, and age range were documented in Table 1 (Appendix). Additionally, from each article, the data was recorded by considering the concept measured, participants, items, domains, and scoring systems as documented in Table 2 (Appendix).

Quality assessment

The psychometric performance of each instrument employed in the selected studies was evaluated using the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) guidelines.²⁴⁻²⁶ The COSMIN checklist is a standardized approach for evaluating the methodological rigor of studies by analyzing the psychometric properties of its instrument. The psychometric data were recorded from each selected article and considered based on instrument type, purpose, strengths, and limitations. The study evaluated the overall strengths, limitations, reliability, internal consistency, validity, and feasibility of each instrument, which had been previously described by Rudmik et al.²⁷ These results, as well as summarized recommendations for each article, can be found in Table 3 (Appendix).

Results

Search results

A systematic literature search was performed in PubMed, Medline, CINAHL, and Web of Science databases, from 1990 up to May 2019. The search methodology and reported findings to comply with the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.²² Figure 1 displays the flow chart of the results of this study. The initial search strategy, after removing duplicates, resulted in a total of 9,822 abstracts that were identified, of which 3,506 abstracts were identified in PubMed, 3,130 in MEDLINE, 1,796 in the Web of Science and 47 articles were retrieved from other sources. The Interrater agreement for article selection was strong (Kappa, $\kappa = 0.82$).²⁸ Following a review of the abstracts, 112 articles were included for full-text review, and 17 articles were finally selected based on the inclusion criteria. The search result is displayed in Figure 1 and the summary of included studies is given in Table 1.

Table 1 shows that over the last two decades, there were only seventeen studies conducted in the US that utilized survey tools to capture the children's voices on their hospitalized experiences. Nine (52.94%) of the included studies used the tools developed by other scientists or organizations.²⁹⁻³⁷ Seven (41.18%) of the included studies used their developed tools.^{17,38-43} The remaining studies (5.8%) did not mention whether the authors used their developed tools or not.⁴⁴

Of the 17 studies, only 10 (58.82%) explicitly stated using reliability and validity testing. Further, five studies (29.41%) were identified as explicitly lacking reliability testing. In contrast, among the seven author-developed tools, all studies except one¹⁷ conducted a reliability and validity test. Of the nine articles that used tools developed by other scientists or organizations, only three studies conducted validity tests.^{29, 34-35} In contrast, seven studies which used tools developed by other authors claimed that the validations were performed in previous studies. The remaining studies (5.8%) did not conduct validity tests and did not justify this decision.⁴⁴ Research suggests that the settings of the study may vary based on the location, respondents, socio-economic factors, and demographic conditions.⁴⁵ Therefore, the study finds it advantageous to conduct the validation before starting with a new setting.⁴⁶⁻⁴⁷ Further, a lack of reliability and validation of survey tools ultimately limits their overall usability.

Among the included studies, only four (23.52%) considered readability while developing the tools for capturing the children's perceptions. Research suggests that surveys employing lower reading levels (fifth to sixth-grade) is more appropriate for children³⁰ However, thirteen (76.48%) of the articles failed to consider the

reading level during the child tool validation, which may also limit the wide acceptance of the studies. Additionally, policies regarding measures to reduce missing data were mentioned in only four (23.52%) of the included studies^{30,35,38,40}

Interviews were conducted in only six (35.29%) of the included studies, and among them, five (83.33%) of the studies used the appropriate methods and techniques to transcribe the interview.^{17,36,40-41,48} Further, among the included studies, eleven (64.71%) utilized pilot testing to increase the clarity and validity of the instrument items and content validity of interview questions.^{29,33-34,36,41-42,44,48}

Children's age was considered in only three (17.65%) of the included studies. These studies employed the following data collection processes: the school-agers coping inventory,³² reductionistic and constructionistic steps,⁴¹ and the Rasch measuring scale.³⁸ Further, only one (5.8%) study included versions of their instrument for non-English speaking respondents.³⁰ Lastly, among the included studies only one study appointed an expert as a consultant to assist in conducting the authors' study.

Instrument description

Ten (58.82%) of the included studies collected both pediatric patients' and their parents' proxy scores on the perceptions and satisfaction levels of children's hospitalized experiences, while the other seven articles measured only the children's voices on their hospitalized experiences. Uniquely developed questionnaires were used in seven (41.18%) of the included studies. Among the included studies, four studies used previously developed quality of life (QOL) questionnaires,^{33,35,38-39} one study used a child health questionnaire (CHO),³¹ one study used a youth client satisfaction questionnaire (YCSQ),⁴² three studies used an author-developed semi-structure interview,^{40-41,48} one study used consumer satisfaction questionnaire (CSQ),³⁷ one study used kid count questionnaire (KCQ),²⁹ one study used an open ended questionnaire,³² and the remaining studies used author developed survey questionnaires.^{17,30,34,43-44}

Quality assessment

The results of the psychometric properties, including strengths, weaknesses, and summaries of recommendations for each instrument employed in the selected studies, are presented in Table 3. In this study, interrater reliability, content and face validity, internal reliability, and respondents' recruiting processes were the main strengths of the selected articles. Conversely, the results found that demographic variations, lack of specific health status outcomes, small sample sizes, narrow research settings, lack of reliability and validity, brief interviews, cultural variations, measurement errors, and lack of generalizability were the main limitations of the reviewed articles. Generally, it is recommended to conduct

the applicable reliability and validity tests in future studies toward achieving the acceptance of employed tools, which would be used for capturing the voices of hospitalized children. Additionally, the sample sizes should be standardized to conduct the applicable statistical analysis and draw the proper conclusions.

Discussion

The results of this review demonstrate that relatively few studies were conducted with a research design intended to capture the children's direct feedback on their own experiences, while all studies reviewed considered to various degrees the parents' proxy voices. The reliability of child self-reports has long been an area of debate in clinical research since children are perceived as moving targets for measurements due to their constantly changing abilities and perceptions according to their stages of development.⁴⁹ For these reasons, traditional health and health-related quality of life measures have relied mainly on proxy-reporting by parents or guardians.⁵⁰ This sentiment can still be found in hospital settings, whereby studies observed that physicians might not ask child-patients about their experiences receiving healthcare because they do not trust the patient's ability to provide their feedback.^{29,38} As a result, the measuring and reporting of hospitalized children's feedback are still ambiguous, and the practices to achieve satisfaction for this population is still very limited. This gap in survey integrity runs counter to fundamental strategies in the PFCC model, which necessitates the use of accurate reports of patients' feedback to incorporate into future improvements. As a result, improving healthcare delivery to moving toward PFCC, requires that key factors such as patient engagement, patient needs and preferences, and using and understanding patient feedback are considered at every stage of human development.⁵¹⁻⁵⁴ While hospitals under the PFCC model strive to provide the highest quality of care, the continuing lack of direct child involvement in the development of their healthcare plans will likely lead to unintended gaps in healthcare services. Further, as the goal of AHRQ's HCAHPS for hospitalized children is to capture patient experiences, the study finds that by neglecting to incorporate direct children's feedback, the practice of allowing parents to fill the survey out for their child reduces the accuracy and the overall integrity of the self-reported data.

The study finds that professional organizations are aware of the benefits of capturing direct children's feedback. With one study stating that "The American Academy of Pediatrics and other pediatric organizations have long recommended involvement and direct questioning of children... especially those 4 years and older."⁴⁹ Despite these recommendations, parents are encouraged to complete HCAHPS for their child-patients. The study finds that one explanation for this gap in data collection

integrity may be that hospitals rely on the HCAHPS as both a survey instrument and performance measure. By linking scores to Medicare reimbursement, policymakers necessitated compliance with HCAHPS standards. Further, by allowing parents and guardians to complete self-reported surveys for child-patients, hospitals are incentivized to take “shortcuts” to assess child-patient experiences effectively. This not only encourages the use of parents to serve as proxy voices for self-reported surveys. It helps to diminish or discourage initiatives that capture child-patient experiences from their perspective. As a result, the study finds that continued reliance on parents or guardians as the proxy voice of children is counterproductive for PFCC culture, limiting our understanding of the child-patient. Therefore, it is imperative for the AHRQ and scholarship to re-evaluate their approach to assessing hospitalized children's feedback and for hospitals to re-examine the insights derived from children's feedback instruments that substitute direct feedback for proxy voices. Our study finds that there is a clear need for the development of age-appropriate instruments that capture the direct feedback of hospitalized children. However, we find that current surveys fall short in collecting meaningful feedback due to their lack of instruments aimed at children's perceptions. It is well supported by literature that children as young as five can express their perceptions and emotions as well as provide valuable feedback about their care experiences.^{11,16,18,49} Children have a unique awareness of their own experiences and can convey their thoughts if they are given the opportunity.^{17,32,34}

The analysis suggests that the included works stop short of providing a comprehensive study of children's perceptions in hospital settings. While construct validity plays a crucial part in their research's overall quality, another common denominator is the lack of developmentally competent research instruments. While many of the works included the use of Likert scales to simplify the data collection process,^{17,29-30,33-34,37,44} the analysis finds that the questions asked and the context presented was inappropriate given the age of the respondents. Younger children (age 7 and under) were observed to have difficulty remembering detailed accounts of their hospital experiences, particularly details related to the layout, unit name, and medical equipment related to their hospital stay.^{31-32,36} Many of the children observed could not recollect in detail the layout of their previous hospital visit. Further, while the children were able to understand the question, some of the same studies reported limited self-reporting.^{31,36} The analysis concludes that these studies relied too heavily on younger children's memory rather than engaging the respondents' overall understanding of their hospital experiences..

A crucial factor in capturing direct children's feedback is understanding that the goals and perceptions of a child-patient should not be assumed to be the same as that of

their parent or guardian. By developing studies that rely on detailed accounts of objective resources and processes, such as the level of sophistication of medical equipment,³² or even hospital staff, and physicians' performance,¹⁶ the research inherently excludes measures which reflect child-patient satisfaction based on the personal experience of the child. Due to the overreliance on the proxy voice of parents/guardians to assess child-patient feedback, the questions that the observed child-patient instruments employ are ultimately based on the administrative goals set by the hospital, which in turn are based on the expectations of adults.^{13,50,55-56} While child-patients certainly want clean bathrooms and quality healthcare delivered, their satisfaction may not be directly associated with objective cleanliness or quality of the hospital environmental conditions but rather on how well the hospital environment allows them to cope with their discomfort, fears, or anxiety related to their healthcare delivery. As a result, child-patient survey instruments and interviews should be created to target what the child associates with hospitals and their overall first impressions of their hospitalized experience. Future studies must incorporate a comprehensive questionnaire that asks children about the objective quality indicators and subjective, personal circumstances, such as questions related to fears, anxiety, and boredom. Further, successful studies will include an interviewing tool, as well as pilot testing, to strengthen the context of the child's narrative and test the overall design's validity.

Conclusion

We found that only half of the studies reviewed conducted a comparative analysis to check if there were any differences between the children's and their parents' perceptions of the children's hospitalized experiences. Significant differences were found across multiple different domains already supported by the literature. These differences in parents' and children's perceptions indicate the importance of accounting for the children's feedback on their own experiences for further healthcare development. Because the HCAHPS does not require direct child-patient feedback and allows the use of parents and guardians a proxy voice, the study concludes that the tool overall is limited in its ability to assess and interpret child-patient satisfaction. Further, the majority of the instruments reviewed did not provide multiple versions of their survey to account for variations in cognitive development and language (with none providing them simultaneously). The study finds that overall, the current survey instruments appear limited in their ability to engage with, as well as in their ability to reflect the inherent differences of child-patient experiences in hospital settings. As a reporting tool that serves as a key hospital performance measure, this flaw in survey design can hinder US hospitals' ability to develop and implement meaningful programs designed to improve hospitalized

children's feedback. In the future, the authors will investigate to what degree parents' and children's perceptions of quality of care differ, uncover the quality measures from children's perceptions, and eventually develop an effective and efficient tool that engages and captures rather than tests children on their experiences in an age-appropriate and culturally accessible way.

References

- Conrad DA, Vaughn M, Grembowski D and Marcus-Smith M (2015) Implementing value-based payment reform: A conceptual framework and case examples. *Medical Care Research and Review* 73(4): 437-457.
- Porter ME (2009) A strategy for health care reform--toward a value-based system. *The New England Journal of Medicine* 361(2): 109-112.
- Michael PE and Teisberg EO (2006) *Redefining Health Care: Creating Value-Based Competition on Results*. Harvard Business Review Press.
- Burwell SM (2015) Setting value-based payment goals — HHS efforts to improve U.S. health care. *New England Journal of Medicine* 372(10): 897-899.
- Groves P, Kayyali B, Knott D and Kuiken SV (2003) The 'big data' revolution in healthcare: Accelerating value and innovation. Available at: www.mckinsey.com/industries/healthcare-systems-and-services/our-insights/the-big-data-revolution-in-health-care (Accessed 9 October 2019)
- Zgierska A, Rabago D and Miller MM (2014) Impact of patient satisfaction ratings on physicians and clinical care. *Patient Preference Adherence* 8: 437-446.
- Bruin DSR, Baan CA and Struijs JN (2011) Pay-for-performance in disease management: a systematic review of the literature. *BMC Health Services Research* 11: 272-272
- Reid RJ, Coleman K and Johnson EA (2010) The Group Health medical home at year two: cost savings, higher patient satisfaction, and less burnout for providers. *Health Affairs* 29(5):835-843.
- Berenson RA, Pronovost PJ and Krumholz HM (2013) Achieving the potential of health care performance measures. Robert Wood Johnson Foundation.
- Goldstein E, Farquhar M, Crofton C, Darby C and Garfinkel S (2005) Measuring hospital care from the patients' perspective: an overview of the HCAHPS Hospital Survey development process. *Health Services Research Journal* 40(6 Pt 2): 1977-1995.
- Ygge BM, Arnetz JE (2001) Quality of pediatric care: application and validation of an instrument for measuring parent satisfaction with hospital care. *International journal for quality in health care* 13(1):33-43.
- Ryan RM and Deci EL (2000) Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*. 55(1): 68-78.
- Grimaldi Capitello T, Fiorilli C, Placidi S, Vallone R, Drago F and Gentile S (2006) What factors influence parents' perception of the quality of life of children and adolescents with neurocardiogenic syncope? *Health and Quality of Life Outcomes* 14: 79-79.
- Bjertnaes OA, Sjetne IS and Iversen HH (2012) Overall patient satisfaction with hospitals: effects of patient-reported experiences and fulfilment of expectations. *BMJ Quality & Safety* 21(1): 39-46.
- Okan O, Lopes E and Bollweg TM (2018) Generic health literacy measurement instruments for children and adolescents: a systematic review of the literature. *BMC Public Health* 18(1): 166.
- Cremeens J, Eiser C and Blades M (2006) Characteristics of health-related self-report measures for children aged three to eight years: A review of the literature. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation* 15(4): 739-754.
- Lindeke L, Nakai M and Johnson L (2006) Capturing children's voices for quality improvement. *MCN: The American Journal of Maternal Child Nursing* 31(5): 290-295; 296-297.
- Olson LM, Radecki L, Frintner MP, Weiss KB, Korfmacher J and Siegel RM (2007) At what age can children report dependably on their asthma health status? *Pediatrics* 119(1): 93-102.
- Hadley EK, Smith CAM, Gallo AM, Angst D and Knafel K (2008) Parents' perspectives on having their children interviewed for research. *Research in Nursing & Health* 31(1): 4-11.
- Christian BJ, Pearce PF, Roberson AJ, Rothwell E. (2010) It's a Small, Small World: Data Collection Strategies for Research with Children and Adolescents. *Journal of Pediatric Nursing: Nursing Care of Children and Families*. 25(3):202-214.
- Stanley JT and Isaacowitz DM (2011) Age-related differences in profiles of mood-change trajectories. *Developmental Psychology* 47(2): 318-330.
- Moher D, Liberati A, Tetzlaff J, Altman DG and The PG (2009) Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLOS Medicine* 6(7):e1000097.
- Belur J, Tompson L, Thornton A and Simon M (2018) Interrater reliability in systematic review methodology: Exploring variation in coder decision-making. *Sociological Methods & Research* 0049124118799372.
- Makoul G and Clayman ML (2006) An integrative model of shared decision making in medical encounters. *Patient Education and Counseling* 60(3): 301-312.
- Pusic A, Liu JC and Chen CM (2007) A systematic review of patient-reported outcome measures in head and neck cancer surgery. *Otolaryngology--Head and*

- Neck Surgery: Official Journal of American Academy of Otolaryngology-Head and Neck Surgery 136(4): 525-535.
26. Mokkink LB, Terwee CB and Patrick DL (2010) The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation* 19(4): 539-549.
 27. Rudmik L, Hopkins C, Peters A, Smith TL, Schlosser RJ and Soler ZM (2015) Patient-reported outcome measures for adult chronic rhinosinusitis: A systematic review and quality assessment. *The Journal of Allergy and Clinical Immunology* 136(6):1532-1540.
 28. McHugh ML (2012) Interrater reliability: The kappa statistic. *Biochemia Medica* 22(3): 276-282.
 29. Lindeke L, Fulkerson J, Chesney M, Johnson L, Savik K (2009) Children's Perceptions of Healthcare Survey. *Nursing administration quarterly* 33(1):26-31.
 30. Boss EF, Thompson RE (2012) Patient experience in outpatient pediatric otolaryngology. *The Laryngoscope* 122(10):2304-2310.
 31. Panepinto JA, O'Mahar KM, DeBaun MR, Loberiza FR, Scott JP (2005) Health-related quality of life in children with sickle cell disease: child and parent perception. *British Journal of Haematology* 130(3):437-444.
 32. Board R (2005) School-age children's perceptions of their PICU hospitalization. *Pediatric nursing* 31(3):166-175.
 33. Weaver MS, Darnall C, Bace S, Vail C, MacFadyen A, Wichman C (2017) Trending Longitudinal Agreement between Parent and Child Perceptions of Quality of Life for Pediatric Palliative Care Patients. *Children (Basel, Switzerland)* 4(8).
 34. Chesney M, Lindeke L, Johnson L, Jukkala A, Lynch S (2005) Comparison of child and parent satisfaction ratings of ambulatory pediatric subspecialty care. *Journal of Pediatric Healthcare: Official Publication of National Association of Pediatric Nurse Associates & Practitioners* 19(4):221-229.
 35. Varni JW, Burwinkle TM, Seid M, Skarr D (2003) The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambulatory pediatrics: the official journal of the Ambulatory Pediatric Association* 3(6):329-341.
 36. Hatt SR, Leske DA, Castaneda YS, et al (2018) Patient-derived questionnaire items for patient-reported outcome measures in pediatric eye conditions. *Journal of AAPOS: The Official Publication of the American Association for Pediatric Ophthalmology and Strabismus* 22(6):445-448.e422.
 37. Simonian SJ, Tarnowski KJ, Park A, Bekeny P (1993) Child, parent, and physician perceived satisfaction with pediatric outpatient visits. *Journal of Developmental and Behavioral Pediatrics* 14(1):8-12.
 38. Hatt SR, Leske DA, Castaneda YS, et al. (2019) Development of Pediatric Eye Questionnaires for Children With Eye Conditions. *American journal of ophthalmology*. 200:201-217.
 39. Angeles-Han ST, Griffin KW, Harrison MJ, et al. (2011) Development of a vision-related quality of life instrument for children ages 8-18 years for use in juvenile idiopathic arthritis-associated uveitis. *Arthritis care & research* 63(9):1254-1261.
 40. Moses T (2011) Adolescents' perspectives about brief psychiatric hospitalization: what is helpful and what is not? *The Psychiatric quarterly* 82(2):121-137.
 41. Schmidt C, Bernaix L, Koski A, Weese J, Chiappetta M, Sandrik K (2007) Hospitalized children's perceptions of nurses and nurse behaviors. *MCN The American journal of maternal child nursing* 32(6):336-342; quiz 343-334.
 42. Shapiro JP, Welker CJ, Jacobson BJ (1997) The Youth Client Satisfaction Questionnaire: development, construct validation, and factor structure. *Journal of clinical child psychology* 26(1):87-98.
 43. Kaplan S, Busner J, Chibnall J, Kang G (2011) Consumer satisfaction at a child and adolescent state psychiatric hospital. *Psychiatric services (Washington, DC)* 52(2):202-206.
 44. Magaret ND, Clark TA, Warden CR, Magnusson AR, Hedges JR. (2002) Patient Satisfaction in the Emergency Department—A Survey of Pediatric Patients and Their Parents. *Academic Emergency Medicine*. 9(12):1379-1388.
 45. Cummins S, Curtis S, Diez-Roux AV, Macintyre S. (2007) Understanding and representing 'place' in health research: A relational approach. *Social Science & Medicine*. 65(9):1825-1838.
 46. Caussade S, Ortúzar JdD, Rizzi LI, Hensher DA. (2005) Assessing the influence of design dimensions on stated choice experiment estimates. *Transportation Research Part B: Methodological*. 39(7):621-640.
 47. Forza C. (2002) Survey research in operations management: a process-based perspective. *International Journal of Operations & Production Management*. 22(2):152-194.
 48. Hatt SR, Leske DA, Wernimont SM, Birch EE, Holmes JM. (2017) Comparison of Rating Scales in the Development of Patient-Reported Outcome Measures for Children with Eye Disorders. *Strabismus*. 25(1):33-38.
 49. Riley AW. (2004) Evidence that school-age children can self-report on their health. *Ambulatory pediatrics: the official journal of the Ambulatory Pediatric Association*. 4(4):371-376.
 50. Theunissen NCM, Vogels TGC, Koopman HM, et al. (1998) The proxy problem: child report versus parent report in health-related quality of life research. *Quality of Life Research*. 7(5):387-397.

51. Newell S, Jordan Z (2015) The patient experience of patient-centered communication with nurses in the hospital setting: a qualitative systematic review protocol. *JBI database of systematic reviews and implementation reports* 13(1):76-87.
52. McMillan SS, Kendall E, Sav A, et al. (2013) Patient-Centered Approaches to Health Care: A Systematic Review of Randomized Controlled Trials. *Medical Care Research and Review*. 70(6):567-596.
53. Grol R, Wensing M, Eccles M, Davis D. (2013) *The Implementation of Change in Health Care*.
54. Moreau A, Carol L, Dedianne MC, et al (2012) What perceptions do patients have of decision making (DM)? Toward an integrative patient-centered care model. A qualitative study using focus-group interviews. *Patient education and counseling* 87(2):206-211.
55. Davis-Kean PE (2005) The influence of parent education and family income on child achievement: The indirect role of parental expectations and the home environment. *Journal of Family Psychology* 19(2): 294-304.
56. Upton P, Lawford J, Eiser C. (2008) Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation*. 17(6):895-913.

Appendix

Table 1. Summary of included studies

Authors	Study outcomes of interest	Tools/ Instruments	Design of study	Settings of study	Sample size	Age range	Year
Moses ⁴⁰	Patient satisfaction	Semi-structured interview	Cross-sectional	Community hospital settings	80 (Children Only)	13-18	2011
Shapiro et al ⁴²	Patient satisfaction	Youth client satisfaction questionnaire	Cross-sectional	Community clinical settings	150 (Child-parent pairs)	11-17	1997
Kaplan et al ⁴³	Patient satisfaction measurements	Survey instrument	Cross-sectional	Hospital settings	166 (Children) 114 (Parents)	6-17	2011
Angeles-Han et al ³⁹	Reliability, and validity of the survey instrument	Pediatric Quality of Life Inventory (PedsQL)	Cross-sectional	Clinical settings	120 (Children Only)	8-18	2011
Simonian et al ³⁷	Patient satisfaction	Child satisfaction questionnaire (CSQ)	Cross-sectional study	Hospital clinic setting	55 (Child-parent pairs)	Children (6-14) Mother (24-44)	1993
Varni et al ³⁵	Reliability, and validity of the survey instrument	Pediatric quality of life (PedsQL)	Cross-sectional study	Mailing settings	20031 (Children Only)	2-18 (Children)	2003
Hatt et al ³⁶	Healthcare quality of life	Semi-structured interview	Cross-sectional study	Clinical settings	328 (Child-parent pairs)	0-17 (Children)	2018
Panepinto et al ³¹	Healthcare quality of life	Child health questionnaire (Child-form-87) Child health questionnaire (Parent-form-28)	Cross-sectional study	Inpatient hospital setting	53 (Children) 95 (Parents)	5-18 (Children)	2005
Board ³²	Hospitalized children's experiences	Open-ended questionnaire Child drawing	Cross-sectional study	Inpatient hospital setting	21 (Children Only)	7-12	2005
Schmidt et al ⁴¹	Hospitalized children's perceptions of nurses	Semi-structure interview	Cross-sectional study	Inpatient hospital setting	65 (Children Only)	5-18	2007
Hatt et al ³⁸	Pediatric eye-related quality of life	Quality of Life	Cross-sectional study	Inpatient clinical settings	444 (Children) 446 (Parents)	0-17 (Children) >21 (Parents)	2019
Lindeke ¹⁷	Hospitalized children's perceptions	Survey Instrument	Longitudinal study	Inpatient hospital setting	120 (Children Only)	4-20	2006
Lindeke et al ²⁹	Reliability, and validity of the survey instrument	Kids Count Survey	Cross-sectional study	Inpatient pediatric unit	237 (Children Only)	5-15	2009
Weaver et al ³³	Healthcare quality of life	Quality of Life	Longitudinal study	Outpatient & inpatient medical settings	10 (Children Only)	5-18	2017
Boss & Thompson ³⁰	Healthcare quality of life	Survey Instrument	Cross-sectional study	Otolaryngology outpatient unit	44,010 (Children Only)	0-17 18-90	2012
Magaret et al ⁴⁴	Comparing patient satisfaction with their parent/guardian	Survey Instrument	Cross-sectional study	Pediatric emergency department	101 (Children Only)	5-7 Adult	2002
Chesney et al ³⁴	Comparing patient satisfaction with their parent/guard	Survey Instrument	Cross-sectional study	Pediatric outpatient clinic	115 (Children Only)	4-9	2005

Table 2. Instruments administered to assess the pediatric patient's satisfaction

Authors	Instrument	Instrument description				
		Concept	Participants	Domains	Items	Scoring system
Moses ⁴⁰	Semi-structured interview	Patient satisfaction measurements	Children	-	3	Numeric scoring system.
Shapiro et al ⁴²	Youth client satisfaction questionnaire	Patient satisfaction measurements	Children	-	5	Numeric Likert scale
Kaplan et al ⁴³	Survey instrument	Patient satisfaction measurements	Children Parents	-	28	Five-point Likert's scale
Angeles-Han et al ³⁹	Pediatric Quality of Life Inventory (PedsQL)	Validity and reliability of a novel questionnaire	Children	-	23 (8-15 years) 26(16-18 years)	A four-point Likert scale was used.
Simonian et al ³⁷	Child satisfaction questionnaire (CSQ)	Child satisfaction measures	Children Mother	-	15 (Children) 20 (Mother)	Five-point and six-point Likert scale were used.
Varni et al ³⁵	Structured questionnaire	Health-related quality of life (HRQL)	Children Parents	4	23	Three-point Likert scale and five-point Likert scale were used.
Hatt et al ³⁶	Semi-structure interview	Health-related quality of life (HRQL)	Children Parents	-	12	The interviewees' responses were coded by using NVivo 10 software (QSR International, Doncaster, Australia).
Panepinto et al ³¹	Child health questionnaire (Child-form-87) Child health questionnaire (Parent-form-28)	Health-related quality of life (HRQL)	Children Parents	12 (Children) 14 (Parents)	87 (Children) 28 (Parents)	Mean and standard deviation for continuous variables with a 95% confidence interval and proportion for categorical variables.
Board ³²	A structured questionnaire	Hospitalized children' experience	(Board, 2005; Weaver et al., 2017) Children	-	9	SCSI scale (1-52) for content validity Clatworthy et al. (1999a) proposed scale (1-10) for drawing content
Schmidt et al ⁴¹	Semi-structure interview	Hospitalized children' experience	Children	-	16	The data were analyzed by using reductionistic and constructionistic steps proposed by Knafl and Webster (1988)
Hatt et al ³⁸	Eye related quality of life	Assessment of eye-related quality of life.	Children Parents	4	40	Rasch measuring scale
Lindeke ²⁹	Open-ended questionnaire	Hospitalized children' experience	Children	0	3	Basic content analysis techniques (Weber)
Lindeke et al ¹⁷	Children' Perception of Healthcare Survey	Patients satisfaction with outpatient care	Children Parents	2	14	Each item was scored from sad (no.1) to happy (no. 5) through a numerical Likert scale.
Weaver et al ³³	Quality of life survey	Quality of life for pediatric patients	Children	4	23	Likert scale (0-100) was used to convert the patients' evaluation.
Boss & Thompson ³⁰	Press Ganey Medical Practice Survey	Health care quality	Children Adult	6	29	A Likert scale from 1(very poor) to 5(very good) was used.
Magaret et al ⁴⁴	Survey	Satisfaction of pediatric patience	Children Parents	0	27	A six-point Likert scale was used.
Chesney et al ³⁴	Survey	Patients satisfaction with outpatient care	Children Parents	0	12	A five point Likert scale from 1 (No) to 5 (Yes) was used.

Table 3. Qualitative summary of psychometric properties

Authors	Instrument	Type of Instrument	Purpose	Strength	Limitations
Moses ⁴⁰	Semi-structured interview	Measures of pediatric patients' satisfaction	Pediatric patients' satisfaction	<ul style="list-style-type: none"> • Thematic analysis • Validity by Kappa scores • Pilot testing • Face-to-face interview • Missing value 	<ul style="list-style-type: none"> • Long time interview (2 h) • Limited questions
Shapiro et al ⁴²	Youth client satisfaction questionnaire (YCSQ)	Measures of youth patients' satisfaction	Youth patients' satisfaction assessment	<ul style="list-style-type: none"> • Pilot testing • Test-retest • Internal reliability • Validity • Employing several strategies in the interview • Readability 	<ul style="list-style-type: none"> • Recruitment failures • Telephone interview rather than a written instrument
Kaplan et al ⁴³	Survey instrument	Measures of pediatric patients' satisfaction	Patients' satisfaction assessment	<ul style="list-style-type: none"> • Reliability • Sample size • Pilot testing 	<ul style="list-style-type: none"> • Content validity • Readability • Response rate
Angeles-Han et al ³⁹	Pediatric Quality of Life Inventory (PedsQL)	Health-related quality of life (HRQL)	Validity and reliability of a novel questionnaire	<ul style="list-style-type: none"> • Validity • Reliability • Readability • Pilot testing • Sample size 	<ul style="list-style-type: none"> • Validity and reliability limited to a particular age group (8-18) • A high rate of missing data
Simonian et al ³⁷	Child satisfaction questionnaire (CSQ)	Measures of child satisfaction	Development of a measure for pediatric patient satisfaction	<ul style="list-style-type: none"> • Pilot investigation • Likert scale measurement • Readability 	<ul style="list-style-type: none"> • Lack of reliability • Lack of construct validity
Varni et al ³⁵	Structured questionnaire	Pediatric quality of life (PedsQL)	Determination of feasibility, reliability, and validity of the 23-item PedsQL	<ul style="list-style-type: none"> • The items for each of the forms are essentially identical • Electronic data system • Internal reliability • Construct validity • Missing values were accounted 	<ul style="list-style-type: none"> • Lower response rate • Lack of causal associations • Lack of objective measures
Hatt et al ³⁶	Semi-structured interview	Health-related quality of life (HRQL)	Development of a comprehensive list of potential questionnaire items by identifying the specific HRQOL	<ul style="list-style-type: none"> • Patient-derived questionnaire • Patient-reported outcome measures • Sample size • Independent reviewers for coding 	<ul style="list-style-type: none"> • Heterogeneous population • Lack of Qualitative thematic approach to reviewing interview text • Lack of content validity of interview questions
Panepinto et al ³¹	Child health questionnaire (Child-form-87) Child health questionnaire (Parent-form-28)	Health-related quality of life (HRQL)	Exploration of health-related quality of life (HLQL) reported by both parents and children	<ul style="list-style-type: none"> • Children and their parents have a similar perception of children's physical well being • Evidence on the relationship between parent & child perception of HRQL 	<ul style="list-style-type: none"> • Demographic variables were not comparable between the two groups. • Lack of specific health status outcomes • Lack of self-reported feedback of children who were less than 10 years. • The child version survey was longer than the parent.
Board ³²	Open-ended questionnaire	Content analysis techniques	Exploration of PICU hospitalized school-age children	<ul style="list-style-type: none"> • Interrater reliability • Focus on school-age children's recollection of their PICU experience • Both positive and negative recollection of participants • A great deal of exposure of participants 	<ul style="list-style-type: none"> • Recollections were not very detailed • Small sample size • Lack of recollection of medical equipment

Table 3. Qualitative summary of psychometric properties (cont'd.)

Authors	Instrument	Type of Instrument	Purpose	Strength	Limitations
Schmidt et al ⁴¹	Semi-structure interview	Content analysis techniques	The measurement of hospitalized children's perception of nurses.	<ul style="list-style-type: none"> • Involvement of content and method experts • Content validity • Trustworthiness of data • Children hold high regards to nurses 	<ul style="list-style-type: none"> • Participants were recruited from only one hospital • Children's fear during admission were not acknowledged • Novice research interviewers
Hatt et al ³⁸	Eye-Related Quality of Life Questionnaire	Eye related quality of life	Development of a Pediatric Eye Questionnaires and to assess the eye-related quality of life of pediatric patients.	<ul style="list-style-type: none"> • Item reliability • Patient-driven concern • Respondents from a diverse cohort 	<ul style="list-style-type: none"> • Underrepresented certain socioeconomic and cultural groups • Coexisting systemic health conditions of some respondents
Lindeke ¹⁷	Open-ended questionnaire	Content analysis techniques	Extraction and comparison of collected data across the groups	<ul style="list-style-type: none"> • Clearly defined purpose • Basic content analysis techniques • Internal reliability • Overall consistency of quality of life across the domains • Convenience and ease of administration 	<ul style="list-style-type: none"> • Construct validity • Reliability of tool • Small sample size • Quantitative data • Short interview (5-10 minutes) is not sufficient to obtain patient' feedback holistically • Recruiting process of respondents was not specified • Children's range was considered (4-20 years) where the upper range exceeds the limit (18 years).
Lindeke et al ²⁹	Children Perception of Healthcare Survey	Healthcare survey of children perception	Improvement of healthcare quality by analyzing the different domains, which are related to the healthcare system.	<ul style="list-style-type: none"> • Internal reliability • Face validity • Wide range of respondents • Measures of respondents' score • Content validity • Recruiting process of respondents 	<ul style="list-style-type: none"> • Children age group • No specific tool for 4-7 years' kids • Criterion validity • A small number of survey items • Same tool for all aged respondents
Weaver et al ³³	Quality of life survey	Patient Quality of Life Measurement Model	Evaluation of quality of life of pediatric patients	<ul style="list-style-type: none"> • Clearly defined the purpose • Time interval in survey execution • Six domains of survey tool • Specified the respondent' age limit 	<ul style="list-style-type: none"> • The reliability of tool • Survey design • Very small sample size (10 respondents out of 87 patients) • Content validity • Structural validity • Time interval was not mentioned • Generalizability
Boss & Thompson ³⁰	Press Ganey Medical Practice Survey	Press Ganey Medical Practice Survey	Measurement of patient's experience of an outpatient clinic	<ul style="list-style-type: none"> • The objectives defined clearly • Accessibility for non-English speakers • Large sample size • Sub-groups of respondents • Cross sectional patients' level analysis 	<ul style="list-style-type: none"> • Demographic information: Income, education of parents, race, etc. • Content validity • Internal consistency • Readability grade • Measurements of Errors

Table 3. Qualitative summary of psychometric properties (cont'd.)

Authors	Instrument	Type of Instrument	Purpose	Strength	Limitations
Magaret et al ⁴⁴	Survey	Survey Questionnaire	To compare the overall patients' satisfaction level	<ul style="list-style-type: none"> • Clearly defined the objectives • Wong-Baker FACES Pain Rating Scale • Large sample size • Respondents' recruitment process was specified • Specified children' age range 	<ul style="list-style-type: none"> • Survey reliability • Content validity • Criterion validity • Cultural validity
Chesney et al ³⁴	MacMaster Survey	Survey Questionnaire	Comparison of perceived satisfaction levels between parents & children regarding child's hospital stay	<ul style="list-style-type: none"> • Five-point Likert scale • Internal reliability • Content validity 	<ul style="list-style-type: none"> • The research lacks discussion on the effect environment, access to resources, and education have on a child's hospital experience. • Sampling diversity • Time interval was not present • Biasness