Excellence In Services International Conference
EISIC
Formerly Toulon-Verona Conference, founded in 1998

RETHINKING YOUTH ENGAGEMENT IN EVALUATING THE EXPERIENCE OF HOSPITALIZATION [1]

Ilaria Corazza[†]
Management and Healthcare Laboratory, Institute of Management and Department EMbeDS
Sant'Anna School of Advanced Studies (Italy)
ilaria.corazza@santannapisa.it

Veronica Spataro[†*]
Management and Healthcare Laboratory, Institute of Management and Department EMbeDS
Sant'Anna School of Advanced Studies (Italy)
veronica.spataro@santannapisa.it
[*]Corresponding author

Jan Hazelzet
Department of Public Health
Erasmus University Medical Center (Netherlands)
j.a.hazelzet@erasmusmc.nl

Manila Bonciani
Management and Healthcare Laboratory, Institute of Management and Department EMbeDS
Sant'Anna School of Advanced Studies (Italy)
manila.bonciani@santannapisa.it

Sabina De Rosis
Management and Healthcare Laboratory, Institute of Management and Department EMbeDS
Sant'Anna School of Advanced Studies (Italy)
sabina.derosis@santannapisa.it

[†]These are first authors of the present article, as they equally contributed to this work.

---

[1] IC and VS were responsible for performing the scoping review, by taking care of the methodology, formal analysis, data curation and visualization of results. All authors conceptualized the study. IC and VS wrote the original draft, with an important contribution from SDR with regards to the introduction and discussion sections of the article. All authors reviewed and made minor edits to the article. SDR and MB are project administrators and acquired funding for this research, namely the VoiCEs Project, co-funded by the European Union's Rights, Equality and Citizenship Programme (2014-2020) (REC-RCHI-PROF-AG-2020). The content of this document represents only the views of the authors and it is their sole responsibility, therefore the authors declare no conflict of interest.

Abstract

There is an intrinsic complexity in meeting the needs of users in healthcare services, therefore it is fundamental that they can contribute to processes of value co-creation through the lens of co-assessment and co-innovation. Nevertheless, most of the research on user experience does not focus on some specific users' groups, which may find it hard to provide their perspective.

This systematic scoping review aims at investigating the diversity of strategies and tools to directly involve children and adolescents in evaluating their experience of hospitalization services.

The authors used PRISMA methodology. The search algorithm included three components, respectively: patient experience as the object of research, paediatric patients as the target group of the study and hospitalization as the reference setting. The results were analyzed and summarized qualitatively. Starting from 261 articles, throughout the removal of duplicates and three screening phases, 19 studies were included in the final review.

Nine out of nineteen of the studies included in the final review were performed using a quantitative methodology and traditional methods. Our findings provide insights for future research aimed at defining innovative methods to collect paediatric patients' voices continuously and systematically for the sake of inpatient services quality improvement.

Keywords
user experience; user-reported experience; child user; adolescent user; healthcare service; scoping review

1. Introduction

User experience has been gaining momentum in both contemporary management practice and services research (McColl-Kennedy et al., 2015). Users play an active role and are nowadays considered as co-creators and ultimate determiners of value with respect to the services provided to them (Vargo and Lusch, 2008; McColl-Kennedy et al., 2015).

In the perspective of the service dominant logic (SDL), services are considered as always co-produced, particularly during the experience with the service (value-in-use) (e.g., Vargo & Lusch, 2016). The encounter between the provider and the users is the momentum of value co-creation, in the SDL approach. Medberg and Grönroos (2020) underline that service users tend to experience value-in-use in terms of service quality. Hence, measuring user-perceived service quality (Parasuraman et al., 1994), might be a good proxy for assessing value-in-use in service contexts (Medberg and Grönroos, 2020). The inputs and outputs of value creation actions, similarly to value-in-use, are incorporated in the conceptualization of value-in-experience, according to which value is the result of the efforts of value co-creation processes undertaken by different actors, also with regards to efforts on evaluation (Chen et al., 2012).

In this perspective, capturing the quality of services in the user perspective by the means of the experience with the service itself can be considered a powerful tool for: measuring value-in-use, co-creating value-in-experience and, prospectively, increasing the value for future users, by up-taking user data driven actions of service quality improvement.

In this sense, value co-creation can be referred to the processes through which the providers collaboratively, explicitly, and voluntarily engage with customers to create value (Prahalad & Ramaswamy, 2004).

This interest in user experience and in its potential impact on services quality applies also to the health sector, where the perspective of healthcare services users, including patients and caregivers, is a key indicator of healthcare services quality and becomes a crucial driver of healthcare services quality improvement (Bastemeijer et al., 2017; Jamieson et al., 2022).

Indeed, the quality of services, the experience, and the value created along the user journey among healthcare services are key to meet the needs and preferences of healthcare users and, consequently, increase the quality of healthcare services (Berry 2019).

As in other sectors, healthcare services' users can contribute to value co-creation in different ways, including co-assessing services and giving feedback to co-innovate them (e.g., Osborn et al., 2016).

Several scholars developed specific healthcare services' quality evaluation tools, with a particular focus on interpersonal and relational aspects (Dagger et al., 2007; Vinagre and Neves, 2008). This focus is appropriate in healthcare where high-contact and relation-intensive services are provided, mostly delivered through direct encounters and interactions between users (hereafter patients) and providers (hereafter healthcare professionals), and where patients are usually in conditions of information asymmetry with respect to the provider: patients depend on healthcare professionals' knowledge, skills, and competencies (Berry and Bendapudi, 2007; De Rosis and Barsanti, 2016; De Rosis et al., 2019). Such an imbalance in information and understanding, and a relative lack of consumer control, per-se creates consumer vulnerability among people receiving services (Echeverri and Salomonson, 2019). In addition, there are specific groups of users who suffer from an increased vulnerability, for various reasons, including the difficulties in providing their perspective and making their voice heard.

Nevertheless, most of the research on user – and especially patient - experience does not focus on these specific users' groups, which may find it hard to share their experience, evaluate the service quality and contribute to its improvement. Indeed, although some experiences are found in the literature, it emerges that one of these underrepresented groups consists of children and adolescent patients (e.g., O'Neill et al., 2018; Karisalmi et al., 2018).

Still, the experience of being hospitalized represents a very delicate moment for everyone but this is especially true for health-related vulnerable children and adolescents (e.g., Boztepe et al., 2017). Although children are one of the most fragile segments of the population and the hospitalization experience can per se make them more vulnerable, usually hospitalized children do not have a chance to express an opinion about the care they received (O'Neill et al., 2018; Karisalmi et al., 2018).

Some studies on pediatric patients' reported experience during hospitalization exist, but they usually focus on the point of view of caregivers (e.g., Latour et al., 2010).

Directly collecting and reporting the children's voices would represent a fundamental step towards the improvement of children's rights, as well as of practitioners' attention on their young patients' rights.

There are experiences at the international level, but the authors did not identify a taxonomy reporting peculiar characteristic of such experiences. Some of the salient points identified as common to most of these results from the literature include dimensions of experience investigated, methods, principal respondent, languages available, and use of data.

The objective of this review is, therefore, to map the existing knowledge about the diversity of strategies and tools to directly involve children and adolescents in evaluating their experience of hospitalization services, with respect to these salient points, by focusing on those studies where the voices of children and adolescents are valued directly.

2. Methodology

According to the definition of "scoping review" provided by Pham et al. (2014) and Daudt et al. (2013), this review was intended to "map the literature" and "provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research", regarding the field of children's and adolescents' experience of hospitalization.

Moreover, to guarantee transparency and replicability in the methodology, the authors adhered to the "Preferred Reporting Items for Systematic Reviews and Meta-Analyzes" (PRISMA) guidelines (Page et al., 2021; Liberati et al., 2009). The search process and output, throughout the PRISMA approach, are presented in detail in the results section.

Finally, the themes emerged from the research products collected throughout the search process were analyzed and synthetized qualitatively and, particularly, with a narrative and anecdotal approach.

In further detail, the first activity concerned the definition of the search algorithm. Before this, it was decided to conduct the search of research products using Scopus, ISI Web of Science and PubMed. The selected search algorithm consists of three distinct components, namely the broad object of the research (i.e., patient experience, especially directly reported), the target group of interest for the research (i.e., pediatric patients, including both children and teenagers) and the specific reference setting (i.e., hospital stay).

Regarding the object of research, the terms selected were experience and reported experience as well as patient voice and centeredness, together with its version in American English. The authors deliberately chose not to include in the search algorithm the terms satisfaction to narrow the focus of the search on the specific concept of patient experience (Coulter et al., 2009). Therefore, the final version of the search algorithm was composed by the following keywords and phrases:

("patient experience" *OR* "patient reported experience" *OR* "patient w/5 voice*" *OR*
"patient centredness" *OR* "patient centeredness")
AND

(child* *OR* adolescent* *OR* teenager* *OR* "pediatric care" *OR* "pediatric patient*" *OR*
"paediatric care" *OR* "paediatric patient*")
AND
(hospitalization* *OR* "ordinary admission*" *OR* "hospital stay" *OR* "discharge from
hospital")

To narrow the set of search results, some limitations were adopted throughout the process, namely: articles, as the study type; 2011-2021, as period of publication, to restrict the focus on the most recent results produced, so to eventually identify also innovative experiences in terms of methodology and technologies used; and English, as the language of publication. Some studies were screened based on previous knowledge of authors about the topic, in addition to the products extracted by means of the above-mentioned search algorithm.

As far as it concerns the inclusion criteria, all papers evidently not complying with the search algorithm were left apart. More particularly:

- The studies consider only ordinary admissions as the setting of investigation;
- The focus of the analysis is specifically on patient experience: satisfaction and outcomes are acceptable if and only if associated with patient experience;
- The studies consider children and/or adolescents (<=18 years), and/or their caregivers, as the target group of investigation;
- The studies focus exclusively on the paediatric patients' experience of hospitalization reported either directly from the patients' point of view or indirectly on behalf of their caregiver. This means that, if the studies did not focus on children's perspectives and on their experience of hospitalization services, they were excluded.

3. Results

As shown in Figure 1, the selection process was conducted throughout three main phases.

The authors started from 257 products extracted from data banks and 4 additional papers based on authors' previous knowledge. Overall, 73 papers were removed as duplicates among the papers extracted from the data banks. The first phase was a screening of titles and abstracts. A total of 141 papers were excluded based on the above-mentioned criteria, 24 were included in the full text analysis, and 23 were assigned to a second phase of screening. This second phase was a screening of the papers fallen into the grey area, which means that it was not possible to understand if inclusion and exclusion criteria were fulfilled by reading only titles and abstracts. With respect to these studies, the authors read some sections more in depth, such as the introduction and discussion of the papers, although it was not necessary at this stage to read the papers integrally. Only 5 of the papers in the grey area were eligible to be included in the full text analysis. The third phase was a screening of the full papers kept for the final review (total of 29 articles), of which 10 were excluded. Therefore, the output of the search process consists of 19 articles.

Figure 1. PRISMA chart

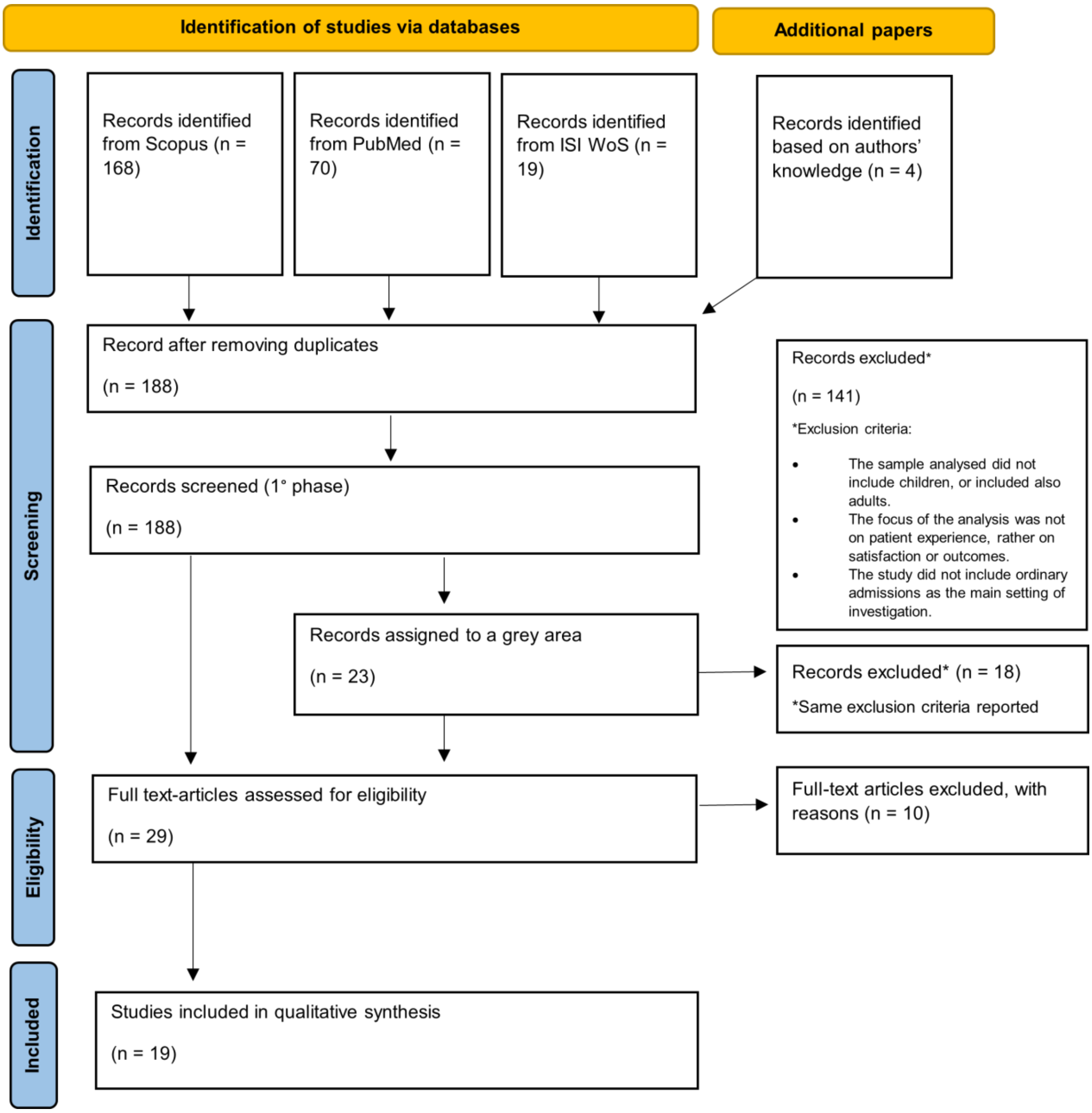

Table 1 reports the 19 papers that resulted from the final review phase. Each paper is associated respectively with the year of publication, the author(s) of the article, the title of the publishing journal, the title of the product and the country of origin.

Table 1. List of articles included in the final review

ID	Year	Authors	Journal	Title	Country
1	2021	Corazza et al.	BMC Health Services Research	Benchmarking experience to improve paediatric healthcare: listening to the voices of families from two European Children's University Hospitals	Italy and Latvia
2	2020	Chen et al.	Journal of Patient Experience	Association of Demographics and Hospital Stay Characteristics with Patient Experience in Hospitalized Pediatric Patients	USA

3	2020	Hawkins et al.	BMC Pediatrics	Patient and family experience with chronic transfusion therapy for sickle cell disease: A qualitative study	USA
4	2020	Karisalmi et al.	BMC Health Services Research	Measuring patient experiences in a Children's hospital with a medical clowning intervention: a case-control study	Finland
5	2019	Kaipio et al.	Improving Usability, Safety and Patient Outcomes with Health Information Technology	Development of the Patient Experience Questionnaire for Parents of Pediatric Patients (PEQP)	Finland
6	2019	Nordin et al.	Malaysian Journal of Computer Science	Game requirements gathering among hospitalised paediatric cancer patients: A thematic analysis	Malaysia
7	2019	Wu and Harrison	Journal of Eating Disorders	Our daily life was mainly comprised of eating and sitting:" A qualitative analysis of adolescents' experiences of inpatient eating disorder treatment in China	China
8	2018	Hargreaves et al.	Archives of Disease in Childhood	Children and young people's versus parents' responses in an English national inpatient survey	UK
9	2018	Peeters et al.	Journal of Adolescent and Young Adult Oncology	How Do Adolescents Affected by Cancer Experience a Hospital Environment?	Belgium
10	2017	Bruyneel et al.	European Journal of Pediatrics	Validation of the Child HCAHPS survey to measure pediatric inpatient experience of care in Flanders	Belgium
11	2017	Ehwerhemuepha et al.	Clinical Pediatrics	Clinical and Psychosocial Factors Associated With Patient Experience in Pediatrics	USA
12	2017	Wray et al.	Archives of Disease in Childhood	Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting	UK
13	2016	Dackiewicz et al.	International Journal for Quality in Health Care	Patient experience assessment in pediatric hospitals in Argentina	Argentina
14	2016	Kramer et al.	Journal of Critical Care	Noise pollution levels in the pediatric intensive care unit	USA
15	2016	Lerwick	World Journal of Clinical Pediatrics	Minimizing pediatric healthcare-induced anxiety and trauma	USA
16	2016	Wangmo et al.	Swiss Medical Weekly	Parents' and patients' experiences with paediatric oncology care in Switzerland: satisfaction and some hurdles	Switzerland
17	2015	Toomey et al.	Pediatrics	The development of a pediatric inpatient experience of care measure: Child HCAHPS	USA
18	2014	Sawyer et al.	Journal of Adolescent Health	A measurement framework for quality health care for adolescents in hospital	Australia
19	2012	Edge et al.	Diabetic Medicine	Care of children with diabetes as inpatients: Frequency of admissions, clinical care and patient experience	UK

Qualitative analysis

The qualitative analysis of the papers selected throughout the phase of the final review includes, as emerging themes, the dimensions and sub-dimensions of experience of care, the type of methodology of the study, the list of pre-existing sources of questionnaires and scales, the languages available in the studies, the administration times and data collection methods, and the level of patient engagement.

Dimensions of experience

To categorize the dimensions of experience, a careful analysis was conducted by considering the most important frameworks on user and patient experience. Particularly, we considered the patient-centeredness framework which, according to Picker Institute (2020), includes the following clear-cut principles: access to care; respect for patients' values, preferences and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity. In addition, in the research field of services quality, five dimensions of experience with healthcare services were identified: tangibles, reliability, responsiveness, assurance, and empathy (Parasuraman et al., 1985, Parasuraman et al., 1988). Despite its wide application, however, research showed that the latter five dimensions may not be universal across all kinds of services, and several different concerns have arisen around it so far (Llosa et al., 1998, Lassar et al., 2000, Ladhari, 2009). For this reason, the analysis was conducted flexibly, so to include what emerged from the analysis itself.

Following the above-mentioned process, the analysis of the papers showed the presence of eight macro-categories, namely:

- Hospital environment, meant as physical evidence of services provision, including physical facilities, appearance of spaces and staff, the equipment, and the layout of the facilities.
- Overall assessment, including the concepts of willingness-to-recommend and personnel evaluation.
- Communication, defined as the quality of interactions and relationships between the healthcare services providers and users (both paediatric patients and caregivers), such as responsiveness, courtesy and clarity of information received by the provider.
- Hospital admission and discharge, for example concerning the speed of processes.
- Emotions and feelings, intended as the providers' capacity to transfer confidence and trust to users, caring and attention towards everyone, and managing anxiety and fears.
- Pain management, in terms of support received and methods applied for pain relief.
- Involvement, of both patients and caregivers, throughout the care pathway of the patient.

The most frequently identified dimensions of experience investigated in the selected studies are, in order of relevance: 1) hospital and ward environment, mentioned in over 60% of studies included in the final review, for example in terms of appropriateness and comfort, 2) overall assessment that in some cases includes willingness-to-recommend the hospital and evaluation of services quality, and 3) communication that refers to clarity of requested information and capability of staff in dealing with patients and their caregivers, both mentioned in about half of studies included in the final review.

In addition, our analysis revealed that the studies focused also on other extremely important aspects of care-related experience, such as hospital admission and discharge (37%), emotions and feelings of patients and caregivers during the hospital stay (32%), pain management (21%) and involvement in the care process (11%).

Only five studies focus on specific treatments, investigating some of the over-mentioned aspects such as communication and involvement, related to the specific care condition, and other ones more specifically tailored to the studies, like psychological support, peer pressures and pharmaceutical adherence.

Each of the above-mentioned dimensions of experience includes different sub-dimensions. In the table below (table 2) the authors report some examples of these sub-dimensions.

Table 2. Examples of sub-dimensions of experience

Dimensions	**Examples of sub-dimensions**
Hospital environment	Age-appropriate environment Appearance Comfort Entertainment Quality of food
Overall assessment	Best practices Net promoter score Services quality Willingness-to-recommend
Communication	Attitude toward requests Courtesy of the staff Promptness in responding Respect and dignity Trust Understanding of health information
Hospital admission and discharge	Instructions given about how to care for children at home Speed of admission and discharge process
Emotions and feelings	Control and autonomy Experienced stress or psychological burden due to illness Fears and anxiety
Pain management	Pain relief Support
Involvement	Freedom of choices Shared decision-making Staff explanation of what will happen and how it will feel

Type of method and languages

The studies analyzed were performed using quantitative methods (63%) or qualitative methods (37%). Particularly, within the domain of quantitative methods, the approach adopted is the use of questionnaires, either pre-existing or developed *ad hoc*. In the former case, among the pre-existing sources found in the articles, there are the questionnaires from the Picker Institute, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), the Child HCAHPS, and the Measurement Model for the Pediatric Quality of Life Inventory (PedsQL™). In the latter case, it was found that in some cases they were inspired by already existing survey tools. On the other hand, concerning qualitative methods, the most used techniques are interviews, which are mainly semi-structured and, in minor part, unstructured. Other methodological approaches were also detected that are not based on the use of questionnaires and interviews as methods of investigation, but are aimed at the development of protocols, frameworks, or the validation of surveys.

When the articles are based on the development and use of questionnaires to be completed by patients and their families, the languages detected are British and American English, Spanish, Italian, Russian, Latvian, and Finnish. In the studies based on qualitative methods, the interviews were conducted by researchers in American English, Mandarin Chinese, and Swiss

German. Finally, the studies aimed at validating already existing questionnaires in other languages were found using as dissemination languages Spanish, Argentinian Spanish, and Flemish.

Administration method, times, and data collection

In terms of administration, the principal element of diversity among studies is the time of administration, namely during hospitalization (41%), after discharge (35%) or both (24%). Additionally, as it regards data collection, only few cases of electronic and digital methods emerged (29%), against more traditional ones (59%), for instance paper-based surveys (either in person or by mail), telephonic surveys or face-to-face interviews.
Table 3 provides further details on administration times and data collection methods, but it does not include the articles based on methods that do not foresee the use of questionnaires or interviews. For the sake of clarity, the first column of the table below illustrates the number of articles, characterized by the same type of data collection method and administration time.

Table 3. Administration and data collection methods

Number of cases	What	When	How
1	Interviews	After discharge	Not specified
2	Interviews	During hospitalization	Face-to-face
1	Interviews	During hospitalization	Face-to face/Video conferences
1	Interviews	During hospitalization/After discharge	Face-to-face
2	Survey	After discharge	E-mail/Mobile
3	Survey	After discharge	Ordinary mail
1	Survey	During hospitalization	Tablet
1	Survey	During hospitalization	Paper format
2	Survey	During hospitalization	Not specified
1	Survey	During hospitalization/After discharge	Tablet/Mobile
1	Survey	During hospitalization/After discharge	Paper format
1	Survey	During hospitalization/After discharge	Paper format/Ordinary mail

Patient engagement

The authors tried to identify who is the target of the investigation, who is the participant or respondent in the study, and whether the paediatric patient is expected to participate directly and without any support or interference by the caregiver. The qualitative analysis showed that in most cases the respondents or participants in the studies are the paediatric patients' caregivers. There is a relevant percentage of studies (26%) where the paediatric patients, both children and adolescents, are allowed to participate directly, however supported by a caregiver. Finally, there are few studies (21%), where the paediatric patients are shown to participate alone, and they are studies involving primarily adolescent patients (e.g., Wu and Harrison, 2019). Nevertheless, there is also a low percentage of articles, where the direct respondent or participant in the study is not clearly stated (11%). Table 4 shows for each paper included in the final review who is the principal participant in the study, as counterposed with the target of the study where, by target, it is meant the category to which the study is addressed. In addition, most of caregivers found in the analyzed studies are the parents of the paediatric patients.

Table 4. Principal respondent and target group of the studies

Principal respondent	Target group
Caregiver	Not specified
Caregiver	Not specified
Caregiver	Not specified
Caregiver	Caregiver
Caregiver	0-11 years old
Caregiver	0-17 years old
Caregiver	0-17 years old
Caregiver	0-26 years old
Caregiver and paediatric patient	Not specified
Caregiver and paediatric patient	0-16 years old
Caregiver and paediatric patient	8-15 years old
Caregiver and paediatric patient	9-17 years old
Caregiver and paediatric patient	0-18 years old
Paediatric patient	4-17 years old
Paediatric patient	8-16 years old
Paediatric patient	16-19 years old
Paediatric patient	14-25 years old
Not specified	Not specified
Not specified	13-19 years old

Focusing on the four cases where paediatric patients are both the principal respondents and the target of the studies, it emerged that two of them were about specific treatments, namely eating disorders and cancer (i.e. Wu and Harrison, 2019; Peeters et al., 2018), while the other two investigated, respectively, as dimensions of experience emotions and feelings, pain management and overall assessment (Karisalmi et al., 2020), and hospital environment, communication, emotions and feelings, and pain management (Wray et al., 2017). Specific focus emerged within the target group, such as based on different age classes. As possible examples, one article was found where the questionnaire includes filters to differentiate questions between different age classes of patients (Corazza et al., 2021), or designs (Wray et al., 2017), while Kaipio and colleagues (2019) diversify patient experience questionnaires according to the different phases of the patient journey.

4. Discussion

This article is the output of a scoping review aimed at extrapolating the state-of-the-art in the collection of experience measures related to hospitalization, with a specific focus on paediatric patients that are an underrepresented group in the literature.

Most of studies are based on a few recurrent sources (e.g., Child HCAHPS and Picker Institute) and directly use the original tool or refer to it to develop questionnaires *ad hoc*. As a direct consequence of this, the dimensions of experience more frequently found are those coming from the original sources, such as hospital environment, overall assessment, and communication.

Even if in most studies the target groups are children and adolescents, the principal respondents are caregivers, and more particularly parents. The few studies directly involving patients, as users of hospitalization services, are addressed to adolescents. Moreover, it is worth noticing that most studies in the final review used traditional administration and data collection methods, such as face-to-face interviews or paper-based questionnaires.

To enhance user’s direct participation, especially in the case of younger children, it would be useful to design tools that can be more effective for such specific targets in terms of child-friendliness, for example using gamification, cartoons or emojis. For instance, vignettes that are increasingly used as a research tool in qualitative and quantitative methods, were validated by research when respondents are children and adolescents; smiley scales have been used by health care researchers, to record, for example, pain levels of young patients (Levison and Bolgrien, 2020; O'Dell et al., 2021; Scott. 1997). It is known that in the literature there are numerous examples of the use of innovative methodologies based on digital tools using emoticons or gamification to involve children and young people in studies, not necessarily relative to hospitalizations (e.g., Nordin et al., 2019; Pennucci et al., 2018). Emojis are widely used for involving adolescents in surveys aimed at longitudinally assessing their mental health or for changing behaviors' initiatives (Eisele et al., 2021; Temkin et al., 2020; Van Dam et al., 2019). In De Rosis and colleagues (2020a), the survey targeted to adolescents included gamified questions, using the "this or that" approach and providing a final behavioral profile after the questionnaire completion.

Indeed, in terms of user-friendliness and child-oriented innovations, only one paper was found where emoticons are used to make survey questions more appealing for children (Karisalmi et al., 2020), while another one used diversified questionnaire layouts with animals for children and cartoon for adolescents (Wray et al., 2017).

Additionally, while some specific focus emerged within the target, such as based on different age classes, no specific focus was found relating to users' abilities, such as with respect to children with some kinds of physical and/or cognitive impairments.

Another crucial theme relates to the use of user-reported data for quality improvement, especially in health care (Corazza et al., 2021; De Rosis et al., 2020b; Corazza et al., 2019). As found in Bastemeijer et al. (2019), the use of patient reported data is deemed as essential for healthcare providers to undertake quality improvement actions. For example, one of the studies included in the final review focused on a specific problem that should be solved, namely eliminating noise sources (Kramer et al., 2016). Most of the studies identified do not present systematic and continuous experiences of data collection and use, but rather isolated experiments. However, for the sake of quality improvement, it would be essential to collect and employ user-reported data on a regular basis (De Rosis et al., 2020b; Coletta et al., 2019).

Another emerging issue concerns the lack of evidence on the positive effects related to the standardized use of tools among different services providers, especially in the perspective of data benchmarking. Among the articles included in the final review, only one study was detected where the survey was developed and implemented as a continuous and systematic management tool for quality improvement using a data return web platform in real time (Corazza et al., 2021).

5. Conclusions

This study is the first review explicitly aimed at exploring and analyzing methods and tools of user experience data collection and use, with specific reference to children and adolescents experiencing hospitalization services. The results presented here suggest that there is space for improvement in this field.

First, personalized and innovative tools for collecting children's and adolescents' voices on their experience should be designed, tested, and adopted to measure and monitor service quality as a key part of an internal marketing policy, for quality improvement actions and as a crucial management practice. The findings of this study suggest that, to improve the experience of paediatric patients with hospitalization services, it is important: 1) to develop more specifically tailored tools according to different age classes and needs of users of hospitalization services; 2) to implement business intelligence and business analytics methods with data reporting and visualization tools aimed at improving hospital management and health care services based on user data; and 3) to make the collection of children users experience of hospitalization more innovative by means of digital technologies and gamification techniques. Second, such methodologies would be aligned with Article 12 of the Convention on the Rights of the Child, according to which children's participation is the right of children to be listened to and taken seriously and it is defined by the Council of Europe (2012) as "individuals or groups of children having the right, the means, the space, the opportunity and, where necessary, the support to freely express their views, to be heard and to contribute to decision making on matters affecting them, their views being given due weight in accordance with their age and maturity". Its implementation in practice is needed in different settings, including health care. In this sense, it is fundamental "to provide children with the necessary information in accessible forms, as well as the time and space in which to participate safely and effectively" (Lansdown, 2011).

In terms of opportunities for further research, the authors suggest the refinement of the search algorithm, to expand the scope of this exploratory analysis. It could be also interesting to analyze in an in-depth qualitative fashion, good practices and experiences of data collection and use with reference to this specific vulnerable population, to identify and analyze key determinant factors.

6. References

Bastemeijer, C. M., Voogt, L., van Ewijk, J. P., & Hazelzet, J. A. (2017). "What do patient values and preferences mean? A taxonomy based on a systematic review of qualitative papers", *Patient Education and Counseling,* 100(5): 871–881.

Bastemeijer, C. M., Boosman, H., van Ewijk, H., Verweij, L. M., Voogt, L., Hazelzet, J. A. (2019). "Patient experiences: a systematic review of quality improvement interventions in a hospital setting", *Patient related outcome measures,* 10: 157-169.

Berry, L.L. and Bendapudi, N. (2007). "Health care: a fertile field for service research", *Journal of Service Research,* 10(2): 111–122.

Berry, L. L. (2019). "Service innovation is urgent in healthcare", *AMS Review,* 9(1–2): 78–92.

Boztepe, H., Çınar, S., Ay, A. (2017). "School-age children's perception of the hospital experience", *Journal of Child Health Care,* 21: 162–170.

Chen, T., Drennan, J., Andrews, L. (2012). "Experience sharing", *Journal of Marketing Management,* 28(13–14): 1535–1552.

Coletta, L., Murante, A.M., Nuti, S., (2019). "The continuous collection of user experience for timely addressing critical factors of the hospital journey", *Conference Proceedings "Excellence in Services" Perrotis College 22nd International Conference Thessaloniki (Greece).*

Corazza, I., Gilmore, K. J., Bonciani, M., De Rosis, S. (2019, September). "Building big data from experience: a new model for PREMs collection and utilization", In *Israel Journal of Health Policy Research, 8(1), Campus, 4 Crinan St, London N1 9xw, England: BMC.*

Corazza, I., Gilmore, K. J., Menegazzo, F., Abols, V. (2021). "Benchmarking experience to improve paediatric healthcare: listening to the voices of families from two European Children's University Hospitals", *BMC Health Services Research,* 21(1): 1-13.

Council of Europe. (2012). Council of Europe Recommendation on the participation of children and young people under the age of 18. Available at: https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168046c478.

Coulter, A., Fitzpatrick, R., Cornwell, J. (2009). *Measures of patients' experience in hospital: purpose, methods and uses*. London: King's Fund.

Dagger, T.S., Sweeney, J.C. Johnson, L.W. (2007). "A hierarchical model of health service quality: scale development and investigation of an integrated model", *Journal of Service Research,* 10(2): 123–142.

Daudt, H. M., van Mossel, C., Scott, S. J. (2013). “Enhancing the scoping study methodology: a large, inter-professional team’s experience with Arksey and O’Malley’s framework”, *BMC Medical Research Methodology*, 13(1): 1-9.

De Rosis, S., Barsanti, S. (2016). “Patient satisfaction, e-health and the evolution of the patient–general practitioner relationship: Evidence from an Italian survey”, *Health Policy*, 120(11): 1279-1292.

De Rosis, S., Pennucci, F., Nuti, S. (2019). “From experience and outcome measurement to the health professionals’ engagement”, *Micro & Macro Marketing*, 28(3): 493-520.

De Rosis, S., Pennucci, F., Noto, G., Nuti, S. (2020a). “Healthy living and co-production: Evaluation of processes and outcomes of a health promotion initiative co-produced with adolescents”, *International Journal of Environmental Research and Public Health*, 17(21): 8007.

De Rosis, S., Cerasuolo, D., Nuti, S. (2020b). “Using patient-reported measures to drive change in healthcare: the experience of the digital, continuous and systematic PREMs observatory in Italy”, *BMC Health Services Research*, 20(1): 1-17.

Echeverri, P. and Salomonson, N. (2019). “Consumer vulnerability during mobility service interactions: causes, forms and coping”, *Journal of Marketing Management*, 35(3–4): 364–389.

Gilmore, K. J., Corazza, I., Coletta, L., Allin, S. (2022). The uses of Patient Reported Experience Measures in health systems: a systematic narrative review. Health Policy.

Kaipio, J., Karisalmi, N., Hiekkanen, K., Stenhammar, H., Lahdenne, P. (2019, January). “Development of the Patient Experience Questionnaire for Parents of Pediatric Patients (PEQP)”, In *ITCH*, pp. 200-205.

Eisele, G., Vachon, H., Lafit, G., Tuyaerts, D., Houben, M., Kuppens, P., … Viechtbauer, W. (2021). “A mixed-method investigation into measurement reactivity to the experience sampling method: The role of sampling protocol and individual characteristics”.

Karisalmi, N., Stenhammar, H., Kaipio, J. (2018). “What constitutes the patient experience of children? Findings from the photo elicitation and the video diary study”, *Patient Experience Journal*, 5(2): 54-68.

Karisalmi, N., Mäenpää, K., Kaipio, J., Lahdenne, P. (2020). “Measuring patient experiences in a Children’s hospital with a medical clowning intervention: a case-control study”, *BMC Health Services Research*, 20(1): 1-12.

Ladhari, R. (2009). “A review of twenty years of SERVQUAL research”, *International journal of quality and service sciences*, 1(2): 172-198.

Lansdown, G. (2011). “A Framework for Monitoring and Evaluating Children’s Participation. A Preparatory Draft for Piloting”. Available at: https://resourcecentre.savethechildren.net/node/4733/pdf/4733.pdf.

Lassar, W. M., Manolis, C., Winsor, R. D. (2000). “Service quality perspectives and satisfaction in private banking”, *Journal of services marketing*, 14(3): 244-271.

Latour, J. M., Hazelzet, J. A., Duivenvoorden, H. J., van Goudoever, J. B. (2010). “Perceptions of parents, nurses, and physicians on neonatal intensive care practices”, *The Journal of Pediatrics*, 157(2): 215-220.

Levison, D., and Bolgrien, A. (2020). “Using cartoon videos to survey children and adolescents in the global south: A tanzanian example”, *Statistical Journal of the IAOS*, pp. 1-13.

Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P., ... Moher, D. (2009). “The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration”, *Journal of clinical epidemiology*, 62(10): 1-34.

Llosa, S., Chandon, J. L., Orsingher, C. (1998). “An empirical study of SERVQUAL's dimensionality”, *Service Industries Journal*, 18(2): 16-44.

McColl-Kennedy, J. R., Gustafsson, A., Jaakkola, E., Klaus, P., Radnor, Z. J., Perks, H., Friman, M. (2015). “Fresh perspectives on customer experience”, *Journal of Services Marketing*, 29(6–7): 430–435.

Medberg, G., and Grönroos, C. (2020). “Value-in-use and service quality: do customers see a difference?”, *Journal of Service Theory and Practice*, 30(4–5): 507–529.

O’Dell, L., Crafter, S., de Abreu, G., Cline, T. (2012). “The problem of interpretation in vignette methodology in research with young people”, *Qualitative Research*, 12(6): 702-714.

O'Neill, J., Reeks, G. R., Kearney, L. (2018). “Can an interactive application be used to collect meaningful feedback from paediatric patients and their parents in a hospital setting?”, *Patient Experience Journal*, 5(2): 69-75.

Osborne, S. P., Radnor, Z., Strokosch, K. (2016). “Co-Production and the Co-Creation of Value in Public Services: A suitable case for treatment?”, *Public Management Review*, 18(5): 639–653.

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... Moher, D. (2021). “The PRISMA 2020 statement: an updated guideline for reporting systematic reviews”, *BMJ*, 372(71): 1-9.

Parasuraman, A., Zeithaml, V.A., Berry, L.L. (1985). “A conceptual model of service quality and its implications for future research”, *Journal of Marketing*, 49(4): 41-50.

Parasuraman, A., Zeithaml, V.A., Berry, L.L. (1988). “SERVQUAL: A multiple-item scale for measuring consumer perceptions of service quality”, *Journal of Retailing*, 64(1): 12-40.

Parasuraman, A., Zeithaml, V.A. and Berry, L.L. (1994). “Reassessment of expectations as a comparison standard in measuring service quality: implications for further research”, *Journal of Marketing*, 58(1): 111-124.

Pennucci, F., De Rosis, S., Nuti, S. (2018). “Quando promuovere stili di vita sani diventa un’esperienza professionale per gli adolescenti: Il progetto beFood”, *Politiche Sanitarie*, 19: 10-22.

Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., McEwen, S. A. (2014). “A scoping review of scoping reviews: advancing the approach and enhancing the consistency”, *Research synthesis methods*, 5(4): 371-385.

Picker Institute (2020). *Impact report 2019-2020*. Available at: https://www.picker.org/wp-content/uploads/2021/01/Picker_Impact-Report-2020_Web_spreads.pdf.

Prahalad, C. K., and Ramaswamy, V. (2004). “Co-creation experiences: The next practice in value creation”, *Journal of Interactive Marketing*, 18(3): 5–14.

Scott, J. (1997). “Children as respondents: Methods for improving data quality”, *Survey measurement and process quality*, pp. 331-350.

Temkin, A. B., Schild, J., Falk, A., Bennett, S. M. (2020). “Mobile apps for youth anxiety disorders: A review of the evidence and forecast of future innovations”, *Professional Psychology: Research and Practice*, 51(4): 400.

Van Dam, L., Rietstra, S., Van der Drift, E., Stams, G. J. J., Van der Mei, R., Mahfoud, M., ... Reid, T. G. (2019). “Can an emoji a day keep the doctor away? An explorative mixed-methods feasibility study to develop a self-help app for youth with mental health problems”, *Frontiers in Psychiatry*, 10(593), 1-11.

Vargo, S. L., and Lusch, R. F. (2008). “Service-dominant logic: Continuing the evolution”, *Journal of the Academy of Marketing Science*, 36(1): 1–10.

Vargo, S. L., and Lusch, R. F. (2016). “Institutions and axioms: an extension and update of service-dominant logic”, *Journal of the Academy of Marketing Science*, 44(1): 5–23.

Vinagre, M.H. and Neves, J. (2008), “The influence of service quality and patients’ emotions on satisfaction”, *International Journal of Health Care Quality Assurance*, 21(1), 87–103.