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Can an interactive application be used to collect meaningful feedback from paediatric patients and their parents in a hospital setting?

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Cover Page Footnote

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Abstract

The objective of this study was to determine the acceptability of using an interactive application (Fabio the Frog) to understand the experiences and perspectives of children and parents/carers regarding their health care encounter for the purpose of quality improvement and consumer feedback. Children's perspectives of their healthcare were collected via the interactive application through the use of a validated survey, the Children's Perceptions of Healthcare Survey (CPHS). The acceptability of eliciting views from children and parents via an interactive application platform was collected using an additional survey designed for this purpose. Data were collected in two phases. Overall, healthcare experiences were found to be positive across key areas including communication, care delivery, hospital environment, and interaction with staff. The application was identified as easy and fun to use from the perspective of children (n=96) and parents/carers (n=79). Parents/carers also responded positively to the ease and enjoyment they observed when their child was using this tool. Staff appreciated that eliciting children's responses to their care helps to inform high quality care. The interactive application - Fabio the Frog - was a successful strategy for understanding children's experience across a range of ages, abilities and medical conditions. The study demonstrated the acceptability of an application as an engaging and valuable means to collect meaningful feedback from children and their families. Nevertheless, limitations were noted in the practicality of providing an application to patients in a busy clinical environment. Additionally, the authors recognise that a greater challenge lies in finding ways to incorporate feedback into improving the patient experience

Keywords

Pediatric patient experience, paediatric patient experience, patient experience survey, rights of children, Fabio the Frog, national paediatric toolkit

Introduction and Background

Client involvement in all levels of health care improves outcomes and quality of care¹. The United Nations Convention on the Rights of the Child (UNCRC) states that the views of children and young people should be considered in any decision that is likely to affect their wellbeing². In its 10 articles, the European Association for Children in Hospital³ has set down children's rights in hospital, emphasising the child's right to information and participation. The Charter on the Rights of Children and Young People in Healthcare in Australia states that 'Every child and young person has a right to: express their views, and to be heard and taken seriously' (p.7). This should be in all matters affecting them; and given due weight in accordance with the competence of the child or young person⁴.

Children represent a substantial proportion of individuals accessing both in-patient and out-patient health care, both in Australia and internationally⁵. Children's feedback and

involvement in decision making varies widely between health care facilities and contexts. The mechanisms of how best to collect the views and perceptions of children and their families interacting with health care systems is an emerging area of health care services research and scholarship.

Asking children, adolescents and their families' perceptions of their health care is a relatively new phenomenon. Historically children's opinions, views and perceptions of their care have not been sought due to an assumption that their cognitive maturity and ability to participate in research as rational subjects was not adequate to provide meaningful input⁶. Health services advocate that children's views are represented in health care research, however these views are seldom presented in the literature⁷. Facilitating opportunities for children and young people to be engaged in meaningful participation regarding their health care rather than imposing fixed plans and ideas based on well-intentioned adult perspectives, can have a real impact upon decisions made⁸.

Health services have not consistently involved young people or sought to explore the impact their involvement has on the quality of health care⁹. Furthermore, analysis of how that involvement occurs and under what circumstances, by whom and what training they might have on participation techniques is limited⁹. One of the challenges is how best to enable children to express their views to an adult researcher⁷. Children's perspectives regarding matters concerning them is gaining momentum within child research and is included in some key performance indicators¹⁰. Coyne conducted a review of the literature on children's participation in consultations and decision-making at a health service level and found there to be limited published literature reporting the actualisation of children's contribution to their health care¹¹. This finding would imply that the process of involvement may be problematic or under-valued. However, studies have demonstrated that children as young as three show understanding and knowledge regarding their health care condition, and that this can enable them to make better decisions¹². Hallstrom and Elander found that whilst children and parents were usually involved in the decision-making process they seldom made decisions themselves and even if they disagreed, the decisions were rarely reconsidered¹³.

In recent years there has been growing recognition of the value of collecting children's views, and technology offers new opportunities to collect information in a way that resonates with young people. For example, 'In my shoes' is an interactive computer-assisted interview tool which enables and supports children to verbalise their experiences and perceptions of health care¹⁴. The authors' feasibility study found that the majority (n=24; 91%) of pre-school aged children were able to complete the 17-39-minute interview and 96% interacted well with the software. Anecdotally, multi-modal forms can be a good vehicle to facilitate collection of data on paediatric patient experience, especially where the forms include animations or electronic games which involve video and sound.

In Pelander and Leino-Kilpi's study asking children the 'best and worst' things about their hospital stay, many responses, both 'best and worst' related to the availability or otherwise of activities, affording insight into a child's need for activities¹⁵. For example, one child identified that "You can't go walking... On the vomit ward you're not allowed to move outside your own room." This helps health services identify the importance of providing activities to help prevent boredom and enhance the child's hospital experience. Asking children directly contributes to a better understanding of their individual experiences and needs^{6,16}.

Proxies' views of children's health care experiences are not the same as the views of the children themselves. The literature reports two modes of investigation regarding children's experiences and perspectives. The first is a *child*

perspective which is characterised by the adults' (parents and/or carer) perspective of characteristics of the child's condition and experience of health care⁶. On the other hand, a child's perspective is "characterised by the child's insider perspective on the conditions, experiences, perceptions and actions, based on what he or she find as important. Both perspectives are required to perceive and encounter children as equal human beings" (p.100).

It remains common place that parental opinions of paediatric nursing care substitute the children's own perspectives¹⁵. However, parents' views may vary from those of the hospitalised child. For example, children with chronic conditions are frequent users of health care services, yet they are rarely included in service evaluation¹⁷. Farrant and Watson's study found adolescents agreed with their parents regarding what was important to them in terms of their health care providers but found that they were more critical overall than their parents¹⁸. "(T)he invisibility of children in official statistics and the lack of knowledge of children's and young people's perceptions among policy makers and service providers in areas such as health, education, social services and the legal system" has become an important focus for health providers and researchers alike¹⁹.

Based on this review the authors contend that there is a need for a collaborative, inclusive approach to understanding the paediatric patient experience which focusses on working 'with', rather than 'on' children and using such feedback to inform improvements. Seeking to investigate an effective platform to support such an approach, in 2016 a 12-month pilot project was launched to capture the health care experience of paediatric patients and their families at a regional health service in south-east Queensland, Australia, using a system developed in the United Kingdom, the National Paediatric Toolkit (Fabio the Frog).

Following a review of feedback methods worldwide, it was identified that where health services claim to gather feedback from children, it typically employs modified versions of adult paper surveys. Fabio the Frog was identified as a creative alternative.

Fabio the Frog was developed in conjunction with the patients and siblings of the Alder Hey Children's Hospital, Liverpool. It was designed to be inclusive of children as young as three, adolescents and those with special learning needs, sensory, visual or audio impairments. Fabio the Frog is an electronic application (app) that combines fun animations with a survey platform. The app is installed on electronic tablets that are provided to survey respondents. Staff can write and upload different surveys to the app and responses to survey questions are uploaded to a web portal from where staff can download reports. A range of survey question formats can be used, including multiple choice or open text response. The animations feature a character

called Fabio the Frog as well as numerous other animal characters and provide amusing distractions between survey questions. They can be turned off or on at the discretion of the survey respondent.

Methods

Objectives

The aim of the study was two-fold. The first objective was to determine the acceptability of the Fabio the Frog app in eliciting children and parent/carer perspectives of their health care; and the second objective was to implement the app with a validated instrument to collect the 'real time' experiences and perspectives of children and parents/carers of their health care encounter within the paediatric inpatient ward, outpatient department and emergency department.

Study site

This study was conducted within one hospital and health service in Queensland, Australia. It included the inpatient paediatric wards, the outpatient paediatric department and emergency department. The study site was the primary provider of child and adolescent health care services in the region, with over 75,000 recorded encounters with children aged 0-16 years in 2015/16.

Participants and recruitment

The study population included three groups. The first group comprised children and adolescents receiving health care or requiring hospital admission during the research study period. Inclusion in the study required they were aged between three and 17 years of age, willing and able (physically and mentally) to participate and had interacted with the Fabio the Frog app within the previous three months. Children excluded from the study were under the age of three and unable to understand English. The second group comprised parents and carers of children and adolescents receiving health care or requiring hospital admission during the research study period. Inclusion in the study required they were willing and able (physically and mentally) to participate, were the primary caregiver to a child experiencing a health care encounter and their child had interacted with the Fabio the Frog app in the last three months. Exclusion from the study was the inability to understand English.

As the perspective of health care professionals regarding the acceptability of the use and results of the Fabio the Frog app within the context of care giving is pertinent to the success of using the app, health care professionals employed within the nominated study sites constituted the final study population group. Inclusion in the study required the staff member to be employed in a department which has participated in the Fabio the Frog project during the implementation.

Children and parents were invited to participate by the nominated project officer (not providing direct clinical care) during their health care encounter, from April 2016 – January 2017. If the child and/or parent agreed to participate the project officer introduced a handheld device with the Fabio the Frog app loaded onto it and, where required, explained how to complete the survey.

Data collection and analysis

Demographic information regarding child age, gender, family type, parental education and number of children in the household were collected. For health care professionals, demographics included: profession, role, department where employed, and years of service.

A specific survey was developed to determine the acceptability of the e-device and Fabio the Frog app in eliciting the views of children and their parents and/or carers experience of their hospital and health care encounter.

If the child/adolescent had been admitted to the paediatric ward or had a hospital encounter in the emergency department which had a duration of more than two hours the "Children's perceptions of healthcare survey" (CPHS)²⁰ was used to collect data via the Fabio the Frog app. The CPHS is validated for use in the paediatric population, internal consistency reliability for the tool was high (child/adolescents: $\alpha = 0.84$ and parents: $\alpha = 0.86$), with no significant differences by child age or gender (20).

Data were then coded and entered into a statistical software program (SPSS version 24) for descriptive statistical analyses. Measures of central tendency were calculated, including frequency and percentage. Brief text responses were analysed using content analysis²¹ and key themes and concepts highlighted. Missing data were excluded from the analyses.

Ethical considerations

All aspects of this study were conducted in accordance with the National Health and Medical Research Council guidelines for human research²² [HREC approval number HREC/16/QRCH/97].

Results

Children's views

A total of 96 children participated, with the mean age 9.8 years, range 4-17 years. Fifty-three girls and 37 boys participated; with seven of the children identifying as Aboriginal while the remainder identified as non-Indigenous. Many of the children (57, 59%) stated they could independently complete the survey, however 27

Table 1: Acceptability of Fabio the frog (children)

Question	Responses (n)					
	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	Did not respond
Fabio the Frog application was easy to use	65	26	7	3	4	9
Fabio the Frog application is enjoyable to use	38	28	16	3	1	10
I liked the characters Fabio and his friends	31	27	17	7	5	9

Table 2: Acceptability of the Fabio program (parents)

Question	Responses (n (%))					
	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	Did not respond
Fabio the Frog application was easy to use	35	30	3	1	1	1
Fabio the Frog application is enjoyable to use	20	34	9	0	1	7
I liked the characters Fabio and his friends	19	25	17	1	0	9
My child required little assistance to use the tool	33	24	4	3	2	5
My child can easily use this tool	34 (48)	21 (30)	3 (4)	1 (1)	0 (0)	12 (17)
My child enjoyed answering the questions on this device	21 (30)	30 (42)	7 (10)	2 (3)	0 (0)	11 (15)

(28%) stated they needed some assistance, such as having the questions read to them. Most children agreed or strongly agreed when asked if they found the application easy to use and liked Fabio and cartoon character friends in the app. (Table 1).

Parents' views

A total of 71 parents / carers of children admitted to the paediatric inpatient ward participated in the survey evaluating the Fabio the Frog app for acceptability as a quality improvement mechanism. No parents of children who simply had an emergency department admission or outpatient's appointment participated in this arm of the project. Most parents identified as non-Indigenous (55;

77%), with four identifying as Aboriginal (6%) (12 participants did not specify). (Table 2)

Staff views

A total of 34 staff participated in the survey evaluating the acceptability of the Fabio the Frog app, all of which were nursing staff. Most of the respondents were registered nurses (26; 76%) working in the paediatric inpatient ward (32; 97%), with one participant working in the paediatric outpatient department. There was a wide distribution in years of practice since qualification within the nursing group with most having worked in their current position for 1-5 years (19; 56%). The Fabio the Frog app was overall positively received and viewed by the participants,

with the majority agreeing or strongly agreeing that information was provided to them on how to use the application (30; 80%).

Children’s views of hospital experience

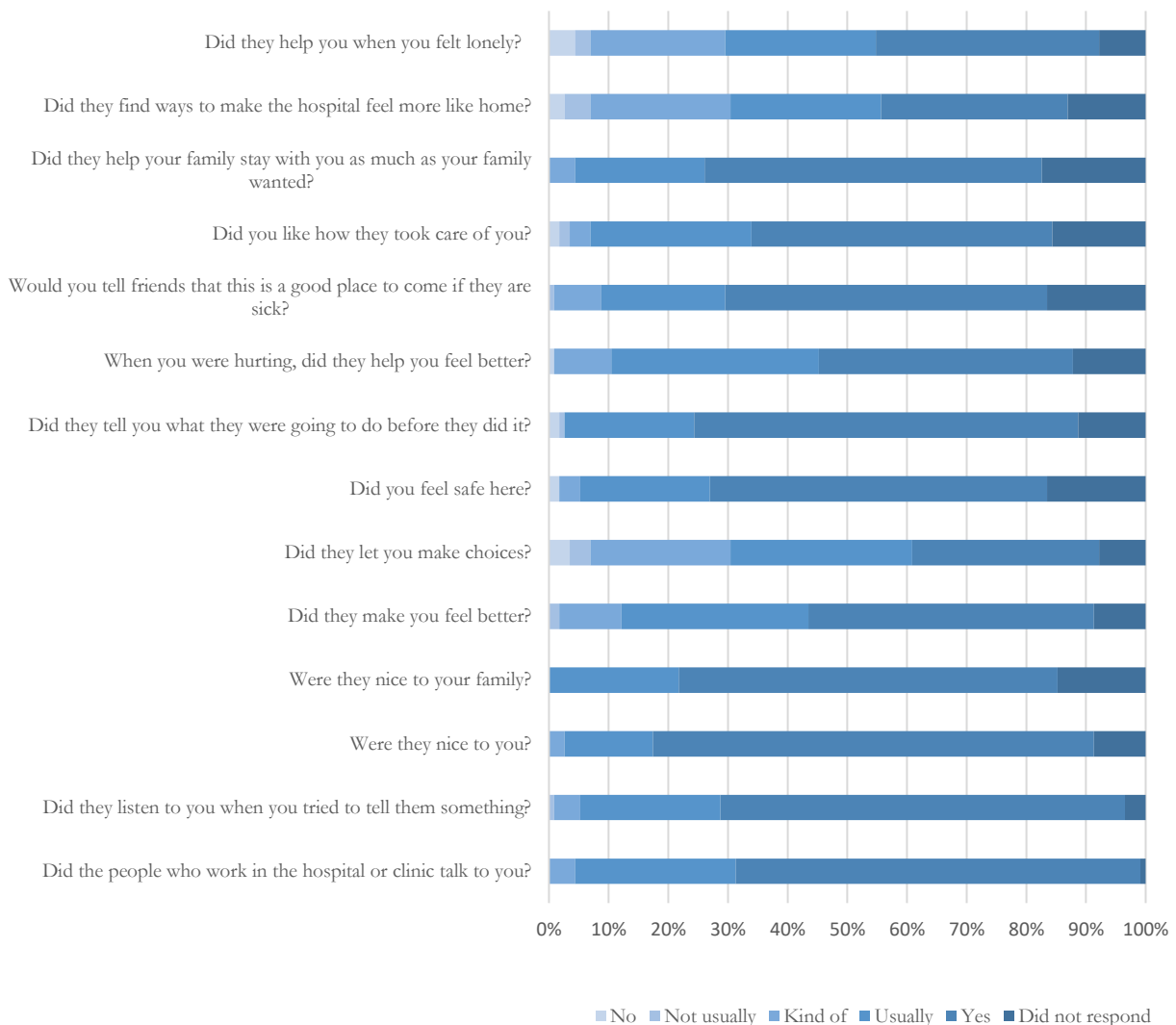
Children’s views of their own hospital experience were collected via the “Children’s perceptions of healthcare survey”²⁰; which was loaded onto the Fabio the Frog app. A total of 115 children participated, with the mean age being 12.25 years (range 4-17 years). Forty-seven boys and 65 girls participated (with three not disclosing gender). Eight participants identified as Aboriginal and the remainder as non-Indigenous. Many (37; 32%) participants had at least one sibling. Within the survey, children were asked to respond via a happy or sad face

demonstrating their view on the scale. Figure 1 presents a summary of these Likert scale results.

A free text question was asked within the survey “How did the hospital or clinic give you a chance to play or keep busy?” The dominant response to this question was “TV” (n=35). Occasional answers included: colouring-in; feeding the fish; playing video games, and a couple identified interaction with the school teacher and yoga therapist. Four children specifically wrote here that nothing was offered.

Children were also asked to identify the best and worst things about the hospital or clinic. Whilst three children identified the actual medicine, injury repair or getting better as the best thing, many children made comments

Figure 1. Children’s perceptions of healthcare survey



about the staff. Being kind, nice, friendly and listening without judgement were the key staff attributes valued by children in this study. Food was also listed as the 'best thing' as was the actual healing or health care process. Similarly, children were asked "The thing that's worst about the hospital or clinic is..." Interestingly 14 children stated 'nothing'. Key areas for comment included: painful procedures; waiting...; feelings during the night; staff attributes; and, facilities.

Discussion

This study identified that it is possible to use an app to collect the views and perspectives of children and their parents/carers with regards to their health encounter. Children engaged in answering the questions using the smiley face Likert scales, and the majority of those surveyed made comment in the free text sections. These responses provided understanding of how *they* perceived the best and worst elements of their health encounter as firsthand knowledge gathering. Parents also provided their perspective of the health encounter with their child, many indicating that they were happy with the care given. Furthermore, when asked about using an app, children and their parents/carers found this an acceptable tool to use.

The majority of children rated the tool easy and enjoyable to use, and they liked the characters of Fabio and his friends. Most parents/carers rated the tool easy and enjoyable to use. They also liked the characters of Fabio and his friends. Parents and carers strongly agreed (33; 46%) or agreed (24; 34%) that their child required little assistance in using the tool, and that their child could easily use the tool and enjoyed answering questions on the tool. Fifteen to 17% of parents did not respond to the ease or enjoyment of the tool, and 20% did not agree or strongly agree that their child required little assistance to use this tool.

Over 90% of staff believed parents could easily understand the information given to them about the project. Staff also agreed strongly (27, 80%) that it is important to elicit children's and parent/carer views and opinions regarding their health encounter through formalised feedback avenues, however almost one fifth did not respond to this question - reasons for this are unknown.

The implementation of an e-device with the Fabio the Frog app within paediatric health care marks a significant change in the way children and their families' views and perceptions about their health care experience are collected and can be used to inform improvements in service delivery. Where previous surveys were inwardly focussed often based on staff perspectives, or parent driven, Fabio the Frog provides a platform to reframe how care is approached. This creates a more inclusive approach that truly reflects the views and perspectives of children and adolescents. It empowers them to influence and

inform the care they receive. This in turn allows staff to reconsider the care they deliver, recognising opportunities exist to change care delivery to better reflect children's views.

This tool creates the opportunity to construct customised surveys tailoring the questions for a particular audience. This could include focus on children with diabetes, asthma or other lifestyle limiting conditions. Alternatively, customised surveys could focus on certain age groups, gender or an encounter in a particular department. It is suitable to use with children over three years and can also be adapted to survey parents and staff.

This study has addressed the challenge outlined by McTavish et al to identify ways for young people to express their views to an adult researcher and further supports the assertion that young people are capable of providing meaningful feedback⁷. The real challenge for paediatric health care lies beyond simply collecting views and perceptions. This study has identified a satisfactory method for collecting data, but care providers must learn and develop mechanisms to respond to these views and perceptions such that the patient experience improves. One method explored by the authors' hospital service has been a working group where hospital volunteers and staff review survey outcomes and identify actions for promoting success and improvements.

Limitations

A number of limitations have been identified during this project. The project officer was employed two days a week for 12 months, which constrained the necessary time to educate and support nursing staff about the tool. Staff who reported poor education or understanding of the tool generally worked on other days or shifts to that of the project officer. Nursing staff generally rated the importance of using the app low in comparison to the delivery of clinical care. There was no opportunity to enrol children outside of the project officer's work hours, and given the principal paediatric inpatient ward had a high admission and discharge rate the potential opportunity for greater enrolment numbers was lost. With only two hand held devices and four app licences available to use across five locations, it was difficult to allocate the devices equally. The majority of surveys were conducted at the principal hospital site, as the inpatient department had 20 funded beds, as opposed to a secondary one with six. The principal hospital site also had a high admission and discharge rate, therefore greater potential to survey a more varied population of children and adolescents.

Conclusion

A 12-month trial of the Fabio the Frog app created the opportunity for children, adolescents and their families to have a voice in directing their health care, based on their unique viewpoints and experiences. The positive response

from this pilot project clearly demonstrates that children value the opportunity to be included in a meaningful way in their care.

Fabio the Frog is a successful mechanism for understanding children's experience that is adaptable to use across a range of ages, abilities and medical conditions. Using this tool to investigate the experience from a child's viewpoint and in turn inform health care delivery fulfils the obligations of the Charter on the Rights of Children and Young People in Healthcare Services in Australia; for children have a right to express their views, be heard and taken seriously. The feedback received from this information will inform and influence ongoing quality improvement facilitating more uniform processes across the service as a whole.

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