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The Patient's Voice: Development of an Adolescent Hospital Quality of Care Survey (AHQOCS)

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ABSTRACT

Purpose: To develop an adolescent determined hospital quality of care survey.
Background: Adolescents do not currently evaluate their quality of hospital care. Hospital satisfaction surveys are mailed following discharge to parents, and parental input may not reflect adolescent perception.
Design and methods: This exploratory, descriptive study utilizing Q-sort methodology, investigated 60 adolescents/young adults' (ages 12–21) perception of hospital care. A comprehensive, peer-reviewed journal search conducted 1998–2017 explored adolescent perception of hospital care. Themes emerging from adolescent's perception of care were developed into 56 statements for relevance sorting.
Results: Excellent content validity of the care domains was established at 0.982 (utilizing the universal agreement). After placement of all 56 cards, items were correlated in order to reveal similarities in perspectives. Items of greatest importance to adolescents included 'able to tell the doctor what was wrong with you', 'having family stay', 'trust in nurse to take care of you', 'able to ask the doctor to explain what they said', 'nurse clearly told you what would happen to you', and 'a clean room'. Little variation in response occurred across the variables of age, gender, length of stay, or diagnosis.
Conclusions: Given the opportunity to relate autonomously to health services, adolescents are able to determine quality preferences and should be contributory in determining hospital care.
Practice implications: Based on adolescent preferences demonstrated in this study, satisfaction with pediatric care delivery should be improved with attention tailored to adolescent wishes.

Adolescents do not currently evaluate their quality of hospital care. Generally parents evaluate quality of pediatric hospital care in the United States. Following discharge, mailed surveys called the Child Hospital Consumer Assessment of Healthcare Providers and Systems (Child HCAHPS) assesses the experiences of pediatric patients (17 years and younger) and their parents or guardians with inpatient care (CAHPS Hospital Survey, 2018). This survey is similar to the Adult Hospital Survey, which asks adult inpatients age 18 and older about their experiences (CAHPS Hospital Survey, 2018). Both the adult and child versions of HCAHPS provide similar measures of patient experience and include communication with doctors and nurses, communication about medicine, hospital staff responsiveness, cleanliness and quietness of hospital environment, an overall rating of the hospital, and willingness to recommend the hospital.

While questions pertaining to the child/adolescent are asked on the Child HCAHPS, the questions are framed from the parent's perspective. For example the instructions for survey completion direct the parent with questions such as "during this hospital stay, how often did your child's nurses explain things in a way that was easy for your child to understand?" This type of questioning still frames the questions from the perception of the adult. In addition, these types of questions are positioned on the survey between questions asking the parent their experiences. Furthermore, a pediatric hospital usually encompasses pediatric patients to age 21, particularly if the adolescent has a chronic condition.

Prior research, using hypothetical situations has demonstrated that adolescents and parents hold vastly differing opinions regarding medical care (Brody, Scherer, Annett, Turner, & Dalen, 2006). Few published studies exist on the adolescent's perceived quality of care in a hospital. Previous attempts to include the adolescent's voice following hospitalization have been compromised by low response rate from families, even lower response rates from adolescents, and parents who chose to complete the adolescent-specific surveys (Battrick & Glasper, 2004). Furthermore, comparison of perceptions of care between parent and adolescent was not possible as responses from parents' surveys did not link to that of their adolescent (Battrick & Glasper, 2004). Therefore, parents' evaluations of their adolescent's care may not accurately reflect their children's perceptions of care.

Qualitative studies have determined that adolescents are well able to discern quality (Moules, 2009). In a study using vignettes that were

Abbreviations: AHQOCS, adolescent hospital quality of care survey; QOC, quality of care.

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developed based upon a child recovering from surgery with *hospital naïve* children aged nine to 14, children and adolescents were able to rank order, best and worst aspects of care, along with reason for choice (Moules, 2009). Characteristics in order of importance evolving from these vignettes shown to children and young adolescents included good technical skills, friendly staff, respect, explanations, and choice. Quality was defined as "something to do with identifying the things that went well for them and the reasons why this was so" (Moules, 2009, p.329). Although children and young adolescents did not recognize respect, they did recognize disrespect, which they described as "being treated like I was stupid", "being ignored", and "being patronized" (Moules, 2009, p. 329).

Despite many parents and healthcare providers tending to question whether adolescents have the capacity to make rational decisions regarding their care, and whether choices should be offered (Hill, Davis, Prout, & Tisdall, 2008; Mårtenson & Fägerskiöld, 2007), the previous findings demonstrate that children and young adolescents are quite vocal when opportunities to speak and be heard are present. These findings also demonstrate that adolescents are able to evaluate abstract components of quality of care in addition to concrete elements of décor and food (Moules, 2009). Furthermore, the ethical implication of the adolescent having an *invisible* role during hospitalization, when their presence is the reason for the event is unjustified. A hospital setting places adolescents in a powerless position because of their illness and lack of control over what is happening to them (Lerwick, J. L, 2016).

Adolescents' rights have been ratified worldwide. The United Nations Convention of the Rights of the Child (1989) is the most widely accepted human rights treaty in which 'Respect for the Views of the Child' include the right of the child to say what they think should happen when adults make decisions that affect them. Children should also have their opinions listened to and considered by adults, and be involved in decision-making appropriate to the child's level of maturity (Article 12). Given the opportunity to relate autonomously to health services, adolescents may feel encouraged to take an active role in their healthcare as they mature into adulthood.

Modifications to pediatric nursing care are often dependent on parental proxy survey results, without adolescent opinion regarding their quality of care. Therefore, it is of significance to develop an adolescent hospital quality of care survey with which to elicit adolescent perception of care, capitalizing on the abilities and rights of adolescents.

The purpose of this study is to develop an adolescent quality of care survey to administer to adolescents on their last day prior to discharge, while the adolescent is present in the hospital. To capture accurately the adolescent's perspective, the survey development design was driven by themes emerging from qualitative literature using adolescent comments. This study presents how direct quotes from adolescents' in a qualitative literature review were developed into four domains, each with 14 statements of perceived important quality items. The four domains of the scale included: environmental comfort, physical and psychological comfort, dignity and respect, and autonomy. Statements were assessed for readability ease, and content validity was established. Utilizing Q methodology and a Q-sort board (Fig. 1), each adolescent determined their extent of agreement on whether the item reflected greatest importance in their care. Following placement of the 56 statements, items were correlated to determine similarities in perspective. Twenty-six statements were kept for future survey development.

Literature review

An extensive review of the literature explored adolescent perception of hospital quality. This comprehensive search, conducted with a university research librarian consultation in selection of search terms and search strategy, included the limiters of scholarly journals/peer reviewed research studies published 1998–2017. Search terms included: child, adolescent, teen, youth, young adult, perspective, decision-making, communication, voice, views, experience, participation, satisfaction, interview, involvement, good nurse, quality improvement, hospital, quality of care, quality of nursing care, and quality of healthcare in varying combinations. A total of 1849 articles were returned from the databases CINAHL, Medline, and PsycINFO. Abstracts were scanned for relevancy, duplicates deleted, and 44 full text articles were reviewed. The criteria used for inclusion was that the study was qualitative, written in English, and included comments from adolescents age 12 years and older if their care was received in a pediatric facility.

The quality of the 44 studies was evaluated based on partial criteria developed by Lincoln and Guba (1985) by the researcher. *Confirmability* included actual interview questions with the researcher describing steps in the data collection in sufficient detail. *Dependability* was determined by verbatim quotes from the participants which supported the themes. *Transferability* was analyzed and deduced that the findings could be transferred to another setting. Very few articles utilized all qualitative research strategies based on Lincoln and Guba (1985) such as *peer debriefing* or *member checking.* However, most themes were recurring and occurred across multiple studies, despite qualitative method of data collection utilized. This further narrowed the number of studies to 21. Reference lists of the studies were reviewed for relevance, and further articles were read. These 21 studies were then organized into a research table with columns for author, date of study, and country where study was performed, title of the study, sample size, age, setting, design utilized, and direct quality comments from adolescents. From this table four central themes emerged. Fourteen recurring comments from adolescents across the studies were then developed under each of the four themes into statements that were written at the third grade reading level for ease of understanding (Table 2).

Five studies took place in the United States, four each in Ireland and The Netherlands, three in England, two in Canada, and one each in Poland, Sweden, and Switzerland. Settings for data collection varied across inpatient hospitals, subspecialty clinics, outpatient areas, schools and the home. Methods of data collection included questionnaires with free text, unstructured interviews, semi-structured interviews, focus groups, telephone interviews, web-based surveys, vignettes, and observations. Despite the variance in global location, health care facility, and method of data collection, the central themes identified by adolescents crucial to their care included environmental comfort, physical and psychological comfort, dignity and respect, and a need to exercise autonomy.

Environmental comfort

Adolescents in these studies made few comments about their environment. Scant comments included their basic needs of food (Battrick & Glasper, 2004; Lindeke, Nakai, & Johnson, 2006), comfort of facilities (Lindeke et al., 2006), and amusement activities (Schmidt et al., 2007). However, it appeared that interpersonal virtues noted in several studies contributed greatly to the environmental atmosphere and comfort (Battrick & Glasper, 2004; Byczkowski, Kollar, & Britto, 2010; Lindeke et al., 2006; Moules, 2009; Schmidt et al., 2007). Unfriendly staff were considered rude, unkind and impersonal (Moules, 2009). Poor eye contact or a lack of verbal interaction was not valued when the nurse was present in the room (Schmidt et al., 2007). Previously hospitalized adolescents or those with chronic conditions identified more nurse behaviors and the importance of acknowledgement as an individual.

Physical and psychological comfort

A general topic across studies was the technical skill of nurses related to interventions to relieve pain (Britto et al., 2004; Byczkowski et al., 2010;Moules, 2009; Schmidt et al., 2007). A 17-year-old boy, during a semi-structured interview discussing perception of nurses and nurse behavior, implied that the expertise and behavior of the nurse played a role in pain inflicted when he commented: "poking me for an

Fig. 1. Q-Sort board with courtesy and respect domain displayed.

IV if they're doubtful they can get it in the first place. If they are really good at it and they are confident, I don't mind (Schmidt et al., 2007, p. 339). Adolescents also wanted truthful responses "when they said it wouldn't hurt, it didn't" (Schmidt et al., 2007, p. 340). Physical comfort further extended to the noise level at night. Trying to sleep with fewer interruptions brought forth comments such as "don't wake us up at ungodly hours" (Schmidt et al., 2007, p.341) and "sometimes they make you get up in the middle of the night" (Lindeke et al., 2006, p. 293). Similarly, adolescents commented on disturbed sleep by the early doctor visits, "people are always coming in the morning" (Lindeke et al., 2006, p.294). Complaints of nurses talking loudly disturbed sleep for some children (Battrick & Glasper, 2004). Psychological comfort was described as trust in the nurse to take care of them, and responding to the call light provided a sense of security (Schmidt et al., 2007).

Dignity and respect

Many adolescents spoke of not being told what would happen to them (Battrick & Glasper, 2004; Fletcher et al., 2011), not being informed (Lambert, Glacken, & McCarron, 2008; Ruhe et al., 2016; Schmidt et al., 2007), and having things done to them with brief or no explanation (Coyne & Gallagher, 2011). Adolescents desired understandable answers to their questions (Al-Yateem, Docherty, & Rossiter, 2015; Britto et al., 2004; Byczkowski et al., 2010; Konstantynowicz, Marcinowicz, Abramowicz, & Abramowicz, 2016). They wanted age appropriate communication (Al-Yateem et al., 2015; Fletcher et al., 2011; Koller, Nicholas, Gearing, & Kalfa, 2010). Statements derived from the literature included the avoidance of "big" words (Coyne & Gallagher, 2011, p. 2339). Other suggestions included avoidance of medical jargon (Konstantynowicz et al., 2016; Ruhe et al., 2016). Professional competence extended to nurses' knowledge and explanation about their condition and the medications they took (Coyne, 2006), as well as the preferred method of taking their medications (Ruhe et al., 2015: Schalkers, Dedding, & Bungers, 2014). Respecting privacy took on several meanings to adolescents ranging from physical privacy, confidentiality when asking intimate questions and space for phone conversations (Battrick & Glasper, 2004; Byczkowski et al., 2010; Lindeke et al., 2006; Schalkers et al., 2014; Schmidt et al., 2007; van Staa, 2010). Communication with nurses actively listening to the adolescent surfaced in many studies with requests for viewpoints and concerns taken seriously (Al-Yateem et al., 2015; Britto et al., 2004; Byczkowski et al., 2010; Schmidt et al., 2007; van Staa, 2010). Adolescents expected the nurse

to respond when they pressed the call bell, acknowledged "Asked questions about me, talked to me, treated me like a person" (Schmidt et al., 2007, p. 340), and spoken to appropriately "They treat me like a child … I hate that" (Al-Yateem et al., 2015, p. 261)

Autonomy

Many adolescents described a need for self-determination with a desire to participate in their own care. They preferred explanations of care directly to them instead of their parents, and a dislike of being asked their opinion and then the parent being asked the same thing (Britto et al., 2004; Coyne, 2006; Coyne & Gallagher, 2011; Schalkers et al., 2014). Comments of feeling insignificant from a 14 year old included "It made me feel a bit … a slight bit … like a piece of machinery actually, they weren't actually talking to *me* …I thought hey I'm the patient here, talk to me, *explain* what you are going to do" (Coyne, 2006, p. 66). In a similar manner, a 17 year old commented, "I used to get so irritated when doctors addressed my parents instead of me, with me just sitting there!" (van Staa, 2010, p. 459). Some adolescents thought that they had a lack of choice with preferences ignored (Coyne & Gallagher, 2011; Moules, 2009; Schalkers et al., 2014).

Limitations to literature review

Limitations to this review included the lack of truly open-ended questions to illicit unbiased responses. Many of the interview questions reflect items of quality considered important to an adult, which may not necessarily reflect a younger person's needs. Very few of these adolescents had chronic illnesses requiring frequent hospitalizations. Greater experience with the hospital may illicit far greater depth in understanding the views of adolescents. Further limitations include the use of descriptors like younger child or older child, which make it difficult to discern the age of the child making comments. Many studies incorporated a large range of ages and many did not separate out developmental stages in the child's responses. Therefore, a gap exists in uncovering adolescents' true perception of the most important quality of care needs.

Methods

Design

This exploratory, descriptive study utilizing Q-sort methodology, considered 60 adolescents/young adults, age 12 to 21, perception of hospital care. Fifty-six statements based on the literature themes were developed into four domains of environmental comfort, physical and psychological comfort, dignity and respect, and autonomy. Each domain included 14-hospital quality of care statements derived from the literature. Along with these statements developed from the literature, additional safety items were included such as checking the adolescent's armband and observation of hand washing, extending the Joint Commission patient safety goals to identify patients correctly (NPSG.01.01.01) and prevent infection (NPSG.07.01.01; Hospital National Patient Safety Goals, 2017).

Development of the quality of care items

Five experts determined content validity of the four domains at the item level and scale (a pediatric clinical nurse specialist, a pediatric nurse practitioner, and three adolescents). Experts were defined in this study as pediatric nurses with experience in hospitalized pediatric patients and adolescent patients with previous hospital experience. Clarification and revision of eight of the 56 statements with unanimous consensus occurred prior to establishment of validity with inclusion of Microsoft word readability statistics (Table 2). A 4-point relevance scale quantified content validity, where (1) denoted not relevant, (2) somewhat relevant, (3) quite relevant, and (4) highly relevant. A rating of (3) or (4) for each item determined the proportion of experts agreeing the item was relevant (thereby dichotomizing the scale into relevant and not relevant). For each item, the item CVI (I-CVI) was computed as the number of experts giving a rating of (3) or (4), divided by the number of experts. For example, an item rated as quite relevant or highly relevant by four out of five experts would have a rating of 0.8. Fifty-five of 56 items received either a (3) or a (4) by all five experts (I-CVI of 1.0), with one item scoring somewhat relevant by one expert (I-CVI of 0.8). Therefore the mean of the 56 item statements received a positive endorsement of 0.996 (Table 1).

The scale (S-CVI), defined as the proportion of items with a quite relevant/very relevant rating by all five experts was 0.982 (utilizing the universal agreement with 55 statements of 56 items agreed as relevant by all five experts; Table 1). For a scale to be judged as having excellent content validity according to Lynn (1986), the items should meet the criteria of 1.0 with three to five experts, and the scale 0.9 or higher. This scale therefore had excellent content validity.

Reading level of statement cards

Using Microsoft word readability statistics of Flesch-Kincaid the following grade level and readability calculates as follows (Table 2). Test of the document readability statistic determines the US school grade reading level. A scoring of 3.0 denotes that a typical third grader can understand the document. Readability ease is based on a 100-point scale, the higher the score, the easier it is to understand. The total scale had a reading level of grade 2.4 and readability ease of 92.

Q-Sort board

Q methodology is a research method for discerning differences among individuals and group perceptions (Brown, 2004), and provides a "systematic and rigorously quantitative means for examining human subjectivity" (McKeown & Thomas, 1988). The fourteen boxes depicted force the adolescent to determine how important they perceive each quality item (Fig. 1). The Q-sort board and Q methodology was developed utilizing criteria based on Brown (2004).

Statements were rank ordered about the topic of quality of care from the individuals' point of view. The adolescents placed 14 cards with statements into five columns from each of the four domains onto a Q-sort board in order of perceived importance to hospital QOC (least important scored a negative −2, less important −1, neutral 0, more important scored a positive +1, and most important +2). Each domain utilized color-coded cards with numbering on the back for ease of data collection and Velcro to assist placement. The Q-sort board and statement cards for the four domains utilized materials designed for cleaning between patients. In summary, the author took 56 statements from the literature; split into four domains with 14 questions per domain, and through adolescent perception of importance reduced the items to a manageable survey length. Items scoring positively were retained and those scoring in the negative discarded.

Setting

Recruitment of participants occurred from three medical/surgical units in a pediatric Magnet® hospital in Central Florida, USA. The average length of stay on these units is four days.

Adolescents were approached in their private hospital room for study inclusion during their last day prior to discharge. Institutional Review Boards approved this research as Exempt and the study was granted a waiver of documented consent.

Table 1
Rating of 56-item scale by five experts: items rated 3 or 4 on a 4-point relevance scale.

Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Number in agreement	Item CVI
1	X	X	X	X	X	5	1.00
2	X	X	X	X	X	5	1.00
3	X	X	X	No	X	4	0.80
4–56	X	X	X	X	X	5 × 53	1.00 (X 53)
							Mean I-CVI = 0.996
Proportion							S-CVI/UA = 0.982
Relevant	1.00	1.00	1.00	0.98	1.00		Mean expert proportion = 0.996

Sample

Prior to study recruitment, four adolescents with hospital experience piloted the four domains to determine ease of use utilizing a Q-sort board (Fig. 1). The study population included a purposeful total sample of 60 adolescents/young adults age 12–21 years ($m = 16$). Selecting 12 as the minimal age criteria follows the fourth stage of Jean Piaget's cognitive developmental theory (Wadsworth, 2004). This stage of formal operation begins to emerge at age 12 and continues into adulthood. At this age, adolescents develop the ability to think about abstract concepts. These skills include logical thought, reasoning, decision-making, and systematic planning. Selecting 21 as the upper age follows the American Academy of Pediatrics (AAP) Policy Statement, which defines adolescence as ages 12–21 years of age. AAP previously published in 1988, and affirmed in 2012 a statement that identified the upper age limit at 21, noting that exceptions exist to include the pediatrician and family agreement to an older age, especially in regards to a child with special healthcare needs (Hardin & Hackell, 2017). The selection of 60 adolescents was determined from previous literature where 12–60 participants completed a Q-sort (Cairns, 2012; Roberts, Hargett, Nagler, Jakoi, & Lehrich, 2015; Webler, Danielson, & Tuler, 2009) with the higher number selected to include a representative set of participants with several variables of gender, age, length of hospital stay, and type of illness.

Inclusion criteria included that the adolescent was English speaking and had experienced at least one overnight stay in the hospital on a pediatric medical/surgical unit. Exclusion criteria included an inability to read at a third grade level, and any physical or mental inability to place cards on the Q-sort board.

Procedures

Adolescents completed the study in their hospital room on their last day prior to discharge, and identified by age and discharge status by charge nurses. Both participants and parents received an information sheet. Adolescents under the age of eighteen assented, with verbal permission from parent, while adolescents age eighteen and older verbally consented to the research. Prior to the Q-sort, adolescents read a couple of sentences of material at the third grade reading level to establish reading and comprehension ability. Adolescents completed the Q-sort and demographic form with an average time of 15 min. Data collected were anonymous with no patient identifiers. Parents and other visitors in the room were asked to refrain from suggesting placement of cards on the Q-sort board. Following agreement to participate, the adolescent received a $5 Walmart gift certificate.

The PI, who has no direct care of the participants, was the sole data collector. Adolescents completed a brief demographic form to include their age, gender, length of stay, reason for hospitalization, and prior hospitalization status using the self-report form. Following completion of the demographic form, adolescents placed 14 cards into five columns from each of four domains on the Q-sort board in order of perceived importance to hospital quality of care (Appendix A). Following placement of all four domains, adolescents were asked whether they had suggestions for additional statements. None were forthcoming as they perceived the 56 statements covered the most important aspects in their care.

Data analysis

After placement of all 56 cards by the 60 adolescents, items were correlated in order to reveal similarities in perspective, those deemed as least important discarded and 26 items were retained. The variables age, gender, length of stay, and whether the reason for admission was for an acute or chronic condition were further analyzed for similarities or differences in quality perception. Top scoring items in order of importance grouped by age, gender, length of stay, and whether the admission was for an acute or chronic condition are shown in Appendix B.

Results

More females participated in the study ($n = 36$), than males ($n = 24$; Demographics Table 3). Adolescents were grouped into two age categories, 12–16 years ($n = 34$), and 17–21 years ($n = 26$) in order to determine if there were differences in perception of care between the varying developmental stages of early to late adolescence. The median length of stay was 4.2 days, with less than or equal to 3 days ($n = 29$), and equal to or >4 days ($n = 31$). Finally, hospitalization was grouped by acute illness ($n = 43$), and chronic illness ($n = 17$) in order to

Table 2
Readability statistics of scale using Microsoft Word Flesch-Kincaid.

Domains	Flesch-Kincaid Grade Level	Flesch Reading Ease
Environmental comfort	3.2	80.2
Physical/psychological	1.9	98.0
Dignity and Respect	3.1	83.8
Autonomy	3.0	93.7
Total scale	2.4	92.0

Table 3
Demographics.

		N	Percent
Gender			
	Male	24	33.3%
	Female	36	66.7%
Age ($m = 16$ years)			
	12-16 years	34	56.7%
	17-21 years	26	43.3%
Length of stay ($m = 4.2$ days)			
	≤3 days	29	48.30%
	≥4 days	31	51.70%
Hospitalization			
	Acute	43	71.70%
	Chronic	17	28.30%

analyze data across variables to determine if perception of quality of care differs across acute and chronic illnesses (Appendix B). Acute illnesses included anemia, appendicitis, cellulitis, dehydration, fracture, GI disorders, hyponatremia, infection, joint effusion, ovarian cyst, overdose, pneumonia, spinal cord injury, stomatitis, and weight loss. Chronic illnesses included asthma, Crohn's disease, cystic fibrosis, diabetes mellitus, seizures, and spina bifida.

Environment of care domain

In descending order, the **most important quality aspects** were 'having family stay', 'a clean room', 'friendly staff', 'staff that were easy to talk to', and 'comfort of room' (Appendix A).

Physical and psychological comfort domain

In descending order, the **most important quality aspect** was 'trust in the nurse to take care of you'. 'Nurses wash or foam their hands to keep you safe from germs', 'nurse gave you medicine when needed' 'doctors wash or foam their hands to keep you safe from germs', 'nurse was truthful about things done to you that would hurt', and the 'skill of nurse taking your blood (little pain, did it quickly)' completed the items considered most important (Appendix A).

Dignity and respect domain

In descending order, the **most important quality aspects** were 'nurse and doctor clearly told you what would happen to you', 'doctor listens to you', 'being told what your medicine was for', 'understood what your doctor said', 'nurse listens to you', and 'understood what your nurse said' (Appendix A).

Autonomy domain

In descending order, the **most important quality aspects** were 'able to tell the doctor what was wrong with you' and 'able to ask the doctor to explain what he/she said'. This was followed by 'able to ask the nurse what he/she said', 'able to tell the nurse how much you hurt', 'able to ask questions', and 'questions about you were directed to you (not just your parents)' (Appendix A).

Discussion

General observations of card placement concluded that females tended to change their placement of cards, whereas males usually placed their cards one time. Both the autonomy and the dignity and respect domains took longer to select and place in the appropriate Q-sort boxes. A few mothers required reminders to not help with card placement.

Environment of care domain

As found in previous studies (Byczkowski et al., 2010; Moules, 2009), interpersonal attributes such as friendly staff were important to adolescents and scored high in this study. Both questions 'friendly staff' and 'staff easy to talk to' scored the same. These questions will be combined for the survey as many adolescents thought they reflected the same attribute. In contrast to the literature, some aspects of the environment scored low in this study. Unlike adult hospital quality of care surveys, the taste of the food was unimportant. However, adolescents wanted a 'clean room' that was 'comfortable'. This is also a new finding. The literature contains scant references to room attributes. Although 'enough alone time if you needed it' scored in the negative, this question will be included on the survey as 12–16 year-old males thought this important and less males than females completed the research (24:36). Interestingly males scored 'having family stay' fourth in order of importance, whereas the categories of female, age, length of stay, and type of illness selected this statement as first or second in importance. Although 'having family stay' will not be included in the final survey, it was included in the Q-sort as a hypothesized survey validation item. It was hypothesized that adolescents would want family present.

Physical and psychological comfort domain

Trust in the nurse scored utmost and far higher than that of other items in the physical and psychological domain. This finding is interesting given that adolescents are poised ready to move to the adult healthcare world and trust has been determined as the most important quality of care theme in the adult population surveys. A 14-year-old and 16-year-old female commented that the physical and psychological domain questions were very important. Although 'skill of the nurse starting your IV' scored in the negative (little importance), this statement will be included because 17–21 year-old males thought this important, with less males than females completing the research (24:36). Furthermore, there may be variance on who draws blood samples and who inserts the IV, as well as confusion over the custom of drawing blood through an IV catheter as opposed to a vein. Participants in previous studies have noted the importance of IV insertion skills (Schmidt et al., 2007). In keeping with Schmidt and colleagues, adolescents in this study wanted truthful responses to painful procedures. Questions pertaining to both doctors and nurses washing or foaming their hands also scored as highly important. This is a new finding from previous literature. Perhaps adolescents today are more in tune with germs than their predecessors.

Dignity and respect domain

As previously discussed, placement of the statements in this domain took longer than the first two domains. Remarks from several females' ages 12 through 19 included comments such as "these are so difficult … all questions are so important". As validated by many studies in the literature review, adolescents clearly wanted to know what would happen to them (Battrick & Glasper, 2004; Coyne & Gallagher, 2011; Fletcher et al., 2011; Lambert, et al., 2008; Ruhe et al., 2016; Scmidt et al., 2007). Furthermore, in keeping with the literature, adolescents want understandable answers to their questions and for doctors and nurses to listen to them (Al-Yateem et al., 2015; Konstantynowicz et al., 2016). Communication in this study extended to explanation of their medication needs.

Autonomy domain

The autonomy domain requiring multiple revisions to reflect adolescents' perception of items considered most important in their care. Several adolescents had difficulty prioritizing their needs. Adolescents selection of 'questions about you were directed to you (not just your parents)' scored in the positive in this study and mirrored preferences in much of the literature (Britto et al., 2004; Coyne, 2006; Coyne & Gallagher, 2011; Schalkers et al., 2014; van Staa, 2010). Independence extended to the statements 'you feel able to ask questions', 'you feel able ask the doctor [or nurse] to explain what he or she said', and 'you feel able to tell the nurse how much you hurt'. Topping their list of priorities was 'you feel able to tell the doctor what was wrong with you'. Although 'doctor included your ideas to get better' and 'you feel able to take part in plans for going home', scored negatively, both questions will be included as adolescents with chronic illnesses and males scored in the positive. Patients with chronic illness as opposed acute illness were represented in the study (17:43), and males to females (24:36). Adolescents with chronic illnesses may have experienced multiple hospitalizations and often have extensive knowledge of their health status, and what works better for them. Therefore, they may want to contribute suggestions more, feel validated for those suggestions, and feel more

engaged with the course of their treatment and care, than their peers with little reference to hospitalization.

Incidental findings

Following completion of card placement, many adolescents spontaneously remarked how much they enjoyed contributing to this study. They appreciated participation in selecting items of greatest importance to them during a hospital stay. Comments from adolescents included "thank you for asking *me* what *I* think is important" (15-year-old female). Comments from two 16-yesr-old females included "I like when doctors look you in the eye" (following placement of the card 'questions about you were directed to you and not just your parents'), and "I like this … this is *really* important to ask the teenager what they think is important".

Likewise, anecdotal comments from caregivers indicated that they too appreciated their adolescent's input in care. Comments included "it's so important to ask the teenagers this" (mother of 16-year-old male), "I think it's very important to ask young people about their care" (mother of 15-year-old female). One mother of a 15-year-old female stated, "This is the best thing that happened to her in here", while another mother of a17-year-old male remarked, "wow, I had never thought about this perspective" [asking the adolescent]. A general theme emerged where adolescents in isolation felt lonely and bored, despite availability of Child Life Specialists, supports findings from previous literature (Austin, Prieto, & Rushforth, 2013; Russo, Donnelly, & Reid, 2006).

Practice implications

Pediatric nurses may change practice in how they deliver care based on items deemed most important to adolescents' perception. For example, adolescents should be directly asked questions regarding their condition and directly told what their medications are for. They should be encouraged to ask questions in order to verify that they understand what will happen to them, feel that they are listened to, and perceive their responses are validated.

Limitations

A possible limitation to this study may include data collection from three medical surgical units within only one hospital, utilizing a limited number of participants. Further limitations may include the use of statements drawn from all qualitative articles, with limited ability to evaluate for rigor. However, following placement of the 56 cards, adolescents were asked if there were any other statements that they would like to include which had been omitted and they were unable to offer suggestions. Furthermore, results from the small pilot with four previously hospitalized adolescents were almost identical to the results from the 60 adolescents. This furthers validity of the measure.

Future research

This resulting 26-item survey will be distributed to 260 adolescents in a further study following IRB approval, using exploratory factor analysis to determine factor structure using $|0.40|$ cutoff. Cronbach's alpha will assess internal consistency reliability for item and total scale. If alpha is <0.70, item analysis will be performed to improve internal consistency of reliability.

Conclusion

This is the first phase in the development of an adolescent hospital quality of care survey. As demonstrated, adolescents despite variance in age, gender, length of stay, and reason for hospitalization given the opportunity relate well to determining quality items important in their hospital care. Furthermore, close similarities in the most important aspects of quality of care remain constant across variables. These statements of perceived importance of care differ somewhat from the Agency for Healthcare Research and Quality Child HCAHPS questions mailed following discharge to parents of hospitalized adolescents (CAHPS Hospital Survey, 2018). As parents probably complete the mailed Child HCAHPS survey, it may not truly capture the adolescent's perspective of their hospital quality of care. Many items determined by adolescents as highly important in this study mirror findings from the literature. Development of this survey begins to uncover the meaning of the most important aspects of care in descending order of importance from the adolescents' perspective.

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Declaration of competing interest

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