

The family context of assent: Comparison of child and parent perspectives on familial decision-making

Abstract

Assent guidelines currently fail to include an assessment of a child's decision-making ability, experience, and interest. This paper summarizes a two-stage study exploring perspectives on children's decision-making power and ability within their family, as an indicator for overall decision-making readiness. Children desired to make some decisions but knew their parents held ultimate authority. Parents believed their children could make some decisions, and actively trained them through involvement in daily decisions. Researchers should strive to include children in enrolment decisions to some degree, based on a consideration of their expectations for involvement informed by their daily family context.

INTRODUCTION

In paediatric clinical research, the act of gaining a child's assent as a component of the enrolment process presents ethical dilemmas that must be addressed (Spencer, 2000). Children are not considered to have the necessary emotional and developmental capacities to provide fully informed consent; therefore, proxy informed consent is required from parents with additional assent from children when appropriate (Hickey, 2007). Assent is defined in the literature as "a child's affirmative agreement to participate in research" (Public Welfare, 2005). While it is generally agreed that some form of assent should exist (Capron, 2008), there is little consensus regarding how to determine when or in what manner an individual child should be asked to provide it (Canadian Paediatric Society, 2008; Kon, 2006). The need for appropriate approaches to assent has recently been restated and emphasized (Nuffield Council on Bioethics, 2015; Sibley and others, 2012; Sibley and others, 2016; Giesbertz and others, 2016; Wilfond and Diekema, 2012; Tait and Geisser, 2017), highlighting some of the most prevalent ethical issues related to assent as well as the need to examine myriad other influences on a child's competence, including age, past experience, general decision-making interest, and overall family dynamic.

The amount of decision-making authority that children have within their family can impact the development of their decision-making abilities and can shape their view of their individual rights, thus having a substantial influence on their ability to take part in the decision-making process for clinical research (Miller and others, 2004; Miller and others, 2008). Recent publications have analysed the ethical justification for assent, illustrating that engagement with a child participant as part of the enrolment process acknowledges the child's moral worth, while simultaneously helping to teach the child how to become a better decision-maker in the future. This is part of an overarching pedagogical process throughout a child's development, usually led by the parents within the context of daily family life (Sibley and others, 2016). The family context, therefore, is not only integral to the child's decision-making development, but also a key aspect of assent's ethical justification. Yet, current guidelines on assent neglect to mention the importance of considering a child's family context, instead focusing on an ideal age or competence level at which all children should be asked to provide assent.

Establishing a uniform assent process is clearly necessary, and should acknowledge specific family contexts as well as the evolving nature of a child's decision-making role within their family. To accomplish this, more research must examine children's daily decision-making, beyond purely the medical context. This paper summarizes the findings of a two-stage study that explores different perspectives on the decision-making power and ability of children aged 5-12 years old within their family lives. First, a series of focus groups were conducted with children, parents, and primary school educators. These results informed the development of a questionnaire study to examine key issues that emerged, including learning whether children want to be involved in specific decisions. The two-stage study design was planned in order to ensure that the questions posed in the questionnaire were both meaningful and appropriate to answer the research question. The views of both children and adults are reported, along with recommendations for future research and implications for child involvement in research enrolment proceedings.

METHODS

Study Design

Focus Groups

Focus groups were conducted with three different peer groups: children aged 5-12 years, parents of children aged 5-12 years, and primary school educators. Each focus group was led by a trained moderator and assistant moderator. Specific questioning routes were designed for each peer group, focusing on decision-making within a child's daily life, including what decisions a child makes, how the decision is made, what happens when the child and parents disagree, and whether the child has an interest in, or capacity for, increased autonomy. All questioning routes covered similar topics, however they were modified to account for the different perspective and age level of the group's members.

Questionnaires

The focus group analysis suggested that the pedagogical role of parenthood was an integral part of the children's decision-making development, and that children were allowed to make some, but not all, decisions in their daily lives, depending on the family, the child, and the decision's level of seriousness. Based on these findings, we developed questionnaires to quantitatively explore the dynamics of child decision-making within the family context. The questionnaire study consisted of complementary questionnaires delivered to parents and children aged 5-11 years. The age range was altered slightly to focus solely on children who were of primary school age. The questionnaires consisted of between 59 (parent) and 73 (child) questions, and covered multiple aspects of daily family life including health, family interactions, activities, food, and clothes.

Ethical approval for both studies was granted by the University of Oxford Social Sciences and Humanities Inter-Divisional Research Ethics Committee (SSD/CUREC1/10/403; SSD/CUREC1A/11/267).

Participants

Recruitment for both studies was achieved through in-person recruitment at local primary schools in Oxfordshire and direct mail-out to school parents as well as to staff members at the University of Oxford. Study participation was for the duration of the focus group discussion (1 hour) or completion of the questionnaire (20-40 minutes). Adult focus group participants received a £20 gift card to a local grocery store as compensation for their time. Adult questionnaire participants did not receive compensation as questionnaire completion was not anticipated to be time-consuming. Child participants in both studies received a certificate and stickers. Adult participants provided written consent. Consent for child participants included parental consent with verbal assent of each child verified by the study investigator and documented on the consent form.

Data Collection

The number of focus groups for each peer group depended on when saturation was achieved, meaning when no additional information was gained from the conduct of further focus groups. This was determined through an analysis of each focus group discussion upon its completion.

Based on the analysis of the focus group data, questionnaires were developed to explore a child's decision-making experience within several main categories of daily family life, including health, family interaction, activities, food, and clothes. Parent and child questionnaires were

complementary in order to create an accurate picture of each child's family decision-making experience. Adult participants were asked to complete a paper questionnaire. Child participants answered the questionnaire in individual or small group sessions with a member of the study team.

Analysis

Focus group transcripts were entered into NVivo 8 (QSR International) by the focus group moderator and a transcript-based thematic analysis was conducted, allowing themes to emerge from the text. All focus group discussions were coded by the same person in order to ensure consistency in the coding methods, however the coding definitions and any ambiguities were discussed with the entire research team throughout the coding process. Focus group discussions were coded and arranged into wider themes labelled with a descriptive statement (e.g. "my mum makes me"). Discussions were analysed first within each peer group, to identify the main themes that emerged and to determine whether saturation had occurred. Secondly, an analysis was conducted across peer groups to explore commonalities between themes, thus creating the 3 MetaThemes that will be discussed below.

Questionnaire data were entered into SPSS for analysis. Analysis of the questionnaire data examined total pooled child responses and total pooled parent responses, focusing on the individual questions within each peer group in order to identify any noteworthy trends.

RESULTS

Participants

Focus groups

Nine focus group discussions were conducted between December 2010 and February 2011, consisting of 45 participants within 5 child groups (23 participants), 3 parent groups (17 participants), and 1 primary school educator group (5 participants). Each group ranged in size from 3 to 7 participants, with an average of 5 participants per group (Figure 1). There were fewer educator groups than originally planned as no additional information was gained beyond what was already learned through the parent groups. Conversely, additional child groups were necessary to reach saturation. Participants in the child focus groups were placed in groups of similarly aged children to facilitate the discussion (median age=8 years old). Age was not collected from the adult participants. There were more female than male participants across all groups, however the distribution was closer to even among the child participants (60% female) than the adult participants (86% female).

Questionnaire

The questionnaire study enrolled 239 participants, representing 93 family groups: 93 parents and 146 children (Figure 1). 85 of the parent participants were female (91%), while the gender of the 146 child participants was evenly distributed (49.3% male, 50.7% female). The mean age of child participants was 7.82 years old, and the ages were approximately normally distributed. The majority of child participants (n=124, 84.9%) in this study lived in a household with two parents. Almost all child participants also lived in households with siblings (n=135, 92.5%). Therefore, the majority of child participants in this study lived in households with 2 parents and at least one sibling (n=119, 81.5%).

Focus Group Themes

Three main MetaThemes emerged from the focus groups, illustrating commonalities between the child and adult perspectives. These themes described the children's current decision-making status and main influences [MetaTheme 1], methods used to change decisions [MetaTheme 2], and the pedagogical nature of the family context [MetaTheme 3]. (Table 1)

The first MetaTheme portrays the present decision-making status of child participants, including the types of decisions they are allowed to make and the main influences on their decision-making development. Child participants stated that they did make some choices in their daily lives regarding clothes, food, and how they spent their free time [Theme 1.1: "I choose"]. Adult participants agreed that children make some decisions [Theme 1.2: "They do make decisions"]. However, the types of decisions varied substantially based on the individual child and family [Theme 1.3: "It depends on their personality"]. While the adult participants encouraged their children to make at least some decisions, they expressed a desire for authority over important choices with potential consequences, such as those related to the child's health and well-being, and they were aware that their children were not always receptive to this authority [Theme 1.4: "A decision you can't let them make"]. Most adult participants agreed that the two main influences on a child's maturity and decision-making ability were siblings and the school environment. Those children with older siblings were thought to be influenced positively in terms of their maturity, whereas those with only younger siblings might be influenced in the opposite direction. Parents with only one child believed their children were more mature since their main family interactions were with adults, thus increasing their exposure to mature behaviour and autonomous decision-making [Theme 1.5: "Child's place in the family"]. School was cited as a second key influence on a child's decision-making ability [Theme 1.6: "Starting school"]. Prior to beginning school, a child's family is the main influence on their world-view. Once at school they are influenced by teachers and other children. One educator observed that through school a child learns to negotiate their new role as a member of society rather than just their family.

The second MetaTheme describes methods used by children and adults when trying to change a decision within the family context. Parents discussed trying to push or coerce their children into agreeing to some decisions [Theme 2.1: "Try and push"], while children mentioned instances when their parents would make them do things [Theme 2.2: "My mum makes me"]. The children also gave examples of methods used to attempt to change their parents' minds, including nagging or begging [Theme 2.3: "Please please please"]. While these children stated that they generally accepted, and sometimes appreciated, their parents' decision-making authority, they also experienced frustration when they disagreed with the parental decision and were unable to change it, resorting to temper tantrums, yelling, and crying [Theme 2.4: "Scream and shout"]. In fact, every parent focus group mentioned the need to "choose your battles" when dealing with children [Theme 2.5: "Choose your battles"], representing a strategy to let children make some decisions, even if the parents disagreed with their choices, in order to conserve the authority necessary to enforce the decisions that they, as parents, deemed important.

The third MetaTheme pertains to the pedagogical role of parenthood. Participants discussed methods that they employ in their daily lives to teach children and to guide their decision-making. They stressed the importance of explaining decisions to their children [Theme 3.1:

“Explain why”], and recognized that their children welcomed parental input at least some of the time [Theme 3.2: “Pleased that someone will take that decision”]. Child participants also mentioned their interest in understanding why parental decisions were made [Theme 3.3: “Why”]. The majority of child participants articulated some doubt regarding their own capacity to make decisions [Theme 3.4: “I know I get some things wrong”], and many expressed satisfaction that their parents made some decisions with them or on their behalf [Theme 3.5: “Help me choose”; Theme 3.6: “Ask my mum”], while others admitted awareness of their parents’ viewpoint on important issues, having learned from past decision-making within their family [Theme 3.7: “My mum would be happy”]. Finally, parents discussed an important method for guiding their children’s decision-making [Theme 3.8: “The illusion of control”], by allowing the child to make a decision within a pre-selected range. This method was mentioned in every parent focus group and participants explained that it was employed in most aspects of their daily lives, from decisions about food to extracurricular activities. Interestingly, child participants appeared aware of this tactic, explaining that they often were provided limited options from which to choose [Theme 3.9: “Sort of choice”].

Questionnaire Results

Questions were divided into categories of daily family life, including health (doctors and dental hygiene), family interactions (bedtime, religion, chores, games), activities (media and socializing), food, and clothes, and were designed to elucidate who in the family makes these decisions, and whether they are enforced or negotiable.

Child Participants

Desire to choose

Children were asked “Would you like to choose...” for a range of questions related to daily life to ascertain whether these children had differing levels of interest in making decisions about specific subjects or if they wanted autonomy over everything. Their responses demonstrate that they did overwhelmingly want to make decisions, across almost all sectors of their life covered by this survey. (Table 2) However, they were happier to relinquish decision-making authority over some categories such as health (i.e. whether to go to a doctor), as opposed to other categories such as clothes (i.e. choosing what clothes to buy).

Current decision-making

Child participants were also asked who in their family generally made the decision for each subject area. The children were able to choose all applicable answers from the following possibilities: “parent/guardian”, “brother/sister”, “me”, and “other”. The only category where the majority of children felt that they alone made the decision was related to their activities, such as what games they played (50.3%). Across almost all other categories of family life, children reported a substantial amount of parental involvement in decisions, and over half of the participants stated that their parents alone made decisions related to health (87.5%), family interactions (54.2%), and meals (59.9%). These data would imply that, while the child participants may have believed they were involved in many daily decisions, they were also aware of their parents’ influence over most areas of their lives. (Table 3)

Decision-making assistance

At the end of the questionnaire children were asked three questions to determine their overall perspective on their decision-making experience and ability. They were first asked whether they thought that their parents or guardians let them make decisions. The vast majority (84.9%) answered that they believed their parents let them make at least some decisions within their daily lives. The children were then asked if they sometimes needed help making decisions and the majority admitted that “yes” they did need help (83.4%). Finally, those children who said that they sometimes needed help making decisions were asked what helped them make the decision. An overwhelming majority of the children chose “talking to parent/guardian” as one of their responses (86.8%) and well over half of the children chose “understanding the problem” (63.6%) (Table 4). The fact that most of the children admitted that they relied on their parents first and foremost to guide them in their decision-making implies that, in addition to recognising their parent’s authority within the context of their family, they depended on it.

Adult Participants

The parent questionnaire was composed of complementary questions to the child questionnaire, but for each topic parents were also asked questions to understand the overall dynamic within that family unit. For example, parents were asked whether their child was required to follow a specific decision as well as who in their family, if anyone, would enforce that original decision.

Required to comply

The series of questions regarding whether their child was required to do something was designed in order to determine how much control these parents regularly allowed their children to have over different parts of their life. Questions ranged from more serious subjects such as whether their child was made to go to the doctor when unwell to questions of a more social nature, such as whether their child was required to attend birthday parties if invited. In aspects of a child’s health and well-being or nutrition, the majority of parents responded that they “always” or “most of the time” required their children to comply (going to the doctor: 92.1%; bedtime: 97.9%; eating dinner: 93.1%). This is in contrast with questions about how children spent their time, where parents were more likely to respond that they “never” or only “sometimes” required their children to do something (attending birthday parties: 66.4%; playing games with family members: 74.8%).

Authority over decisions

In order to explore the parent’s perception of authority in their family, they were then asked who in the family would enforce specific decisions. They were given several possible answers (“me”, “other parent”, “child’s sibling”, and “other adult”) and were allowed to choose all applicable responses for each question. The vast majority of parents (over 80%) stated that only parents enforced decisions across all subject areas except for game playing when 32.3% of parents also included siblings.

Pedagogical role

Parents were asked several questions to explore their pedagogical role regarding decision-making (Table 5). Most parents (87.1%) reported that they “always” or “most of the time” explained their decisions to their child, while none of the parents responded “never”, clearly illustrating that the parents in this study actively taught their children about decision-making. Parents were also asked if they involved their children in decision-making for non-significant

versus significant decisions. While all of these parents reported involving their child to some degree in non-significant decision-making, 19.3% responded that they never involved their child in significant decisions, implying that these parents showed greater willingness to include their children when there were not large potential consequences associated with the decisions in question.

Parents were then asked if they thought their child needed help making decisions. The majority of parents responded “sometimes” (73.6%), and almost all of the remaining parents responded “most of the time” (20.7%), with only 5.7% responding “never”. None of the parents responded “always”, indicating that all participants in this study believed their children to be capable of making at least some decisions unaided (Table 5). As in the child questionnaire, parents were asked what helped their child make decisions and over 90% of parents responded with “understanding the problem” (92.9%) and “talking with parent” (92.1%) (Table 6).

Finally, when asked what methods they used to involve their children in decision-making, the most common answers were “negotiation” (64.3% for non-significant decisions, 62.5% for significant decisions) and “with limited options” (47.9% for non-significant decisions and 48.3% for significant decisions). These responses once again illustrate the pedagogical nature of childhood decision-making within the family unit: when involving children in the decision-making process, these parents were likely to provide their children with limited options from which to choose, or to discuss and negotiate the decision with the children, thus teaching them how the decision was made without burdening them with full decision-making responsibility.

Discussion

None of the child participants in either study expressed interest in making all decisions in their daily lives. They desired some measure of control, particularly over their activities, but also trusted their parents to make good decisions and, while they did not always agree, they were receptive at least some of the time to obtaining parental guidance. The children also appeared to be aware of their place within the hierarchy of their family context. This did not usually present a problem, however when confronted with a disagreement about a specific decision over which they were powerless to change, children in the focus group study shared that their only outlet was to express their frustration in the form of a temper tantrum. This finding is supported by previous research where children have reported feelings of anger or sadness when excluded from decisions, instead preferring the option of joint decision-making with their parents (Kelsey and others, 2007; Beresford and Sloper, 2003; Coyne, 2006; Sartain and others, 2000; Runeson, 2007). This willingness to accept parental assistance likely has the long-term effect of helping children develop decision-making skills.

Adult participants in both studies clearly believed that children were capable of making some decisions in their daily lives but were not yet ready for, nor interested in, full decision-making responsibility. Instead, they felt that children generally welcomed some input or authority from their parents. They also expressed a desire to help guide children’s decision-making without resorting to a strict enforcement that may cause arguments or rebellion. This guidance was regularly used within the family context to help refine their child’s decision-making skills by teaching them how a decision is made while still maintaining ultimate decision-making

authority. However, the specific opportunities for decision-making that these participants chose to provide were determined largely by individual parenting style.

Although the child and adult participants in these studies had different perspectives on child decision-making, their viewpoints were quite similar. Both groups believed that children did make some decisions in their daily lives, usually related to less serious decisions such as choices of food, clothing, or extracurricular activities. They also agreed that the children liked to be guided in some decisions by their parents. Parent participants often limited a child's choices, giving the child the "illusion of control" by allowing them to make a decision between specific pre-selected options. Children appeared to be aware of this limited choice, referred to in focus groups as "sort of choices", and were not necessarily unhappy about it. The benefits of this technique were threefold: the children believed they were making a decision and were content in their newfound independence; the children were practicing and improving their decision-making abilities; and the parent was satisfied that the children would be safe and avoid negative consequences since all available choices had already been pre-approved.

Both of these studies were vulnerable to potential biases, including selection, interviewer, and questionnaire biases. Participants were not recruited through random sampling, so it is possible that they differed meaningfully from those who chose not to participate. Interview bias could have affected responses in the focus groups and interviewer-administered child questionnaires, perhaps altering some answers. It is possible that the questionnaire design introduced additional biases. Many questions used an answer scale, and it is possible that choices such as "most of the time" and "sometimes" may have been interpreted differently by participants, or that respondents might have chosen an answer in the middle of the scale while avoiding the two ends ("always" or "never"). Questions with only two possible responses ("yes" or "no") may have introduced a bias of forced choice since respondents were forced to choose between two responses, neither of which may have been correct. Finally, the questionnaires were designed based on the focus group findings, so any bias from the focus groups could have been carried over into the questionnaires. While some potential biases were possible, these studies were of a strictly exploratory nature with no attempt to generalize results to a wider population. Instead, trends from the study data have been identified that may indicate areas for further research in a larger study.

CONCLUSIONS

These findings demonstrate that both child and adult participants view childhood as a time to develop decision-making skills and gradually adopt increasing decision-making authority. Furthermore, they illustrate that a child's family context can play a crucial role in the development of a child's decision-making abilities. Parent participants confirmed that they were responsible for enforcing most decisions within their families and that their children were usually required to acquiesce with their wishes. However, these parents actively taught their children how to make decisions by explaining their own decisions, providing their children with limited options from which to choose, and fostering discussion and negotiation about those decisions. Simultaneously, child participants both expected and desired guidance from their parents to be able to make many decisions. Given this reality in the context of their daily lives, it is unlikely that in the context of clinical research, these children would want full decision-making authority for such an important decision. The act of being included in the decision-making process while

under the overall guidance of their parents would emulate the environment to which they are accustomed, while simultaneously continuing to provide them with an opportunity to further develop their decision-making capacities.

While the results from these two studies cannot be generalised to a wider population, they do provide some indication that these trends may not be unique to these participants, and could be used in a critical assessment of the current assent process for paediatric clinical research. The results indicate that to meaningfully involve children in decision-making, some assessment of the family context should occur. Furthermore, they suggest that assent, understood partly as a pedagogical process, should strive to mirror a child's daily decision-making experience: involving a child in decision-making to some degree, based on their expectations of involvement in relation to their family dynamic. This interaction would be individual to each child, regardless of chronological age, and would be informed by their actual decision-making interest, level, and experience. The focus of assent would therefore shift from the solicitation of a specific answer from the child participant (e.g. "yes" or "no") to an overall, ongoing engagement with the child: listening, considering, and involving them in the entire decision-making process, to an extent that is appropriate to their ability to engage.

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