

PARENTAL EXPERIENCES IN GIVING INFORMED CONSENT IN PEDIATRIC SURGERY: A CROSS-CULTURAL STUDY.

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ABSTRACT

Parents often express dissatisfaction with the way in which consent for their children to undergo surgery is obtained. Using England and Thailand as examples, this study illuminates parents' experiences of giving consent for their children to undergo surgery. This qualitative approach, semi-structured interview, was conducted with a purposive sample of 18 English and 12 Thai parents. The parents of both cultures perceived a lack of time and felt pressured to sign. Some lack of choice was caused by deference to medical authority and a lack of clear information. Purpose of the consent was perceived to be linked to misunderstanding about protection medical personnel from litigation. The position and the communication skills of the surgeon and system processes in the hospital environment dominated the consenting consultation in both cultures. Some nurses played an empowering role during the consenting process. These findings suggest that there is a need for education and guidance to ensure a shared decision-making approach. Recommendations made to improve the process of giving consent focus on making this a more person-focused process and taking account of the parents' individual viewpoint.

Key words: Parents' experiences, informed consent, pediatric surgery, and cross-cultural study.

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INTRODUCTION

The giving of consent for children to undergo surgery must be a central concern for all professionals working in this aspect of health care. Only competent individuals with full understanding of all relevant information can give informed consent, which needs to be obtained freely without coercion and which can be withdrawn at any time (Harth and Thong, 1995). However, parental consent for surgery is often given in distressing and emotionally difficult circumstances (Nwomeh et al., 2005) resulting in high levels of anxiety, nervousness and difficulties to concentrate. Especially anxiety has been linked to parents having incorrect or not well-understood perception (Woodward et al., 2004; Frank et al., 2007).

Parents of children undergoing surgery desire comprehensive information, and providing even highly detailed anesthetic risk information, should not amplify anxiety levels (Kain et al., 1997; Moss, 2000). However, concerns have been raised about too much or the wrong information increasing anxiety (Kai, 1996). In addition, Mason and Allmark (2000) reported that 59 of the 200 parents had given valid consent or refusal but the remainder had problems in one or more of the component areas (42 for competence, 43 for information, 44 for understanding, and 21 for voluntariness).

In methodological terms quantitative studies dominate the literature, employing standardized questionnaires, structured score-based interviews and randomized-controlled trials. None of the literature reviewed for this study offered parents a platform to divulge their experiences and views to understand the issue from their viewpoint. There is a dearth of data describing parents' experience of giving consent (Stenson et al., 2004), highlighting the need for this qualitative exploration.

The purpose of this study was to examine parents' experiences of giving consent for their children to undergo elective or emergency surgery in a developing and a developed country, both with healthcare systems that are free at the point of delivery and funded through taxation, with the aim to suggest improvements to existing consenting procedures in Western and Southeast Asian countries.

MATERIALS AND METHODS

This qualitative study was generated from two cultures of informants, Thai and English parents. Each data set was in the first instance analyzed on its own. The Thai analytical results and the relevant data were then translated into English. This translation occurred independently by each of the Thai members of the research team, who then agreed on a definitive translation. The English results were analyzed and then combined with the Thai results to generate initial codes, followed by searching, reviewing, defining and naming themes as the process of thematic analysis suggested by Braun and Clarke (2006).

Participants

The purposive sample comprised 18 parents whose children had undergone and recovered from surgery at a center for pediatric surgery in Eastern England, plus 12 parents at a regional hospital on the Eastern seaboard of Thailand. Most parents of the English sub-sample were white, but two were British-Indian. The Thais were all the same ethnicity. Five English and three Thai fathers participated, and the rest were mothers. All parents had given consent on behalf of their children. The children's age ranged from one day to 13 years, who had undergone surgery, including elective, minor and emergency surgery. Only parents whose child was not in a critical condition were approached face-to-face after their child had recovered from the anesthetic. The total sample of 30 was a compromise between the most likely number to achieve data saturation for subsequent analysis in term of a qualitative study, and a reasonable use of resources.

Ethical considerations

Ethical approval for this study was obtained from the Britain's Essex 2 Research Ethics Committee and the Research Ethics Committee of Burapha University, Thailand. All participants were informed about their right to participate or withdraw at any time without penalty. Participation was voluntary and anonymous. Written consent was obtained from the parents upon their agreement and willingness to participate.

Data collection and analysis

Semi-structured face-to-face interviews took place one week after the operation at the parent's home or the hospital ward, according to participant preference. Prior to data collection all interviewers discussed and agreed with the interview schedule and aligned their approach to the interviews. Any new topics introduced by participants were noted, and where relevant, incorporated in subsequent interviews within a modified interview schedule. All interviews, each lasting for up to 40 minutes, were audio-recorded, transcribed verbatim and analyzed using a thematic analysis approach (Braun and Clarke, 2006).

The initial data analysis occurred independently in Thailand and England. Once the Thai analytical results and data had been translated, the results of both sub-sets were jointly considered in detail by researchers on both sides. To ensure a thorough depth of understanding a process of peer-debriefing (Lincoln and Guba, 1985) was employed during these face-to-face meetings, where each side presented their results in turn to the other, challenging the presenters to explain how they had arrived at their conclusions. The final step of this process entailed the uniting and prioritizing of both sets of themes into the joint results.

RESULTS

Across both the Thai and English data sets all parents expressed a strong sense of responsibility and desire to ensure the child's well-being, this was their overarching priority and giving consent was a difficult, even daunting decision. Prior to giving consent all British and many of the Thai parents wanted to know all the information required and they normally received it.

Theme 1: A lack of time and no choice

The process of giving due consideration before consenting was important to parents, but it appeared that parents felt they were not generally afforded enough time. Although none of the children required immediate surgery, some parents felt that the urgency of the intervention forced their hand and did not allow them enough time to fully

consider the issue.

"My daughter was crying so hard and there were a lot of people, doctors, nurses and others. I had no time to think or hear anything, just did what the nurse told me. I signed my name for my child to get her broken arm fixed." [TH-12]

Even when children were undergoing planned elective surgery and consent was sought in an outpatient clinic, the process was perceived by parents as rushed. Here the large numbers of children queuing to see the surgeon created time pressure of a different sort.

"You seem to wait for a long time but you are with the surgeon a very short space of time, because they are very busy. It did seem really rushed." [UK-08]

This lack of time resulted in a number of parents not having their questions answered by health workers but still signing the form.

"I had given consent not having spoken to somebody in detail about the operation." [UK-11]

"The nurse asked me to sign the consent form at the nurse station. Actually I went to ask whether or not the anesthesia was risky to the child's brain. But she did not say anything. So, I walked back to my child's bed." [TH-01]

With potentially incomplete or only partially understood information and too little time to consider the issue, the consent given under these circumstances was clearly not informed.

Additionally, the finding showed that many parents perceived a lack of choice concerning the giving of consent. It appeared in a variety of guises and circumstances. Where surgery was presented as the only possible option, it was widely seen as making their decision to give consent easier.

"It was something that was a very easy decision to make. It was an important operation to have for his future so we had no hesitation to give consent for that." [UK-14]

"This was the case when the suggested surgery was the only treatment possible and when without surgery the child would have to stay in hospital, take medicine and not get better." [TH-01]

Theme 2: Submission to medical authority and disempowerment

In both sub-samples medical authority clearly existed, often expressed as trust in the skill and ability of the surgeon, and by extension, the surgical team and the hospital. This trust had been earned, either by having previously treated the same child, a sibling or other family members. Moreover, the parents' dependence on the surgeon and the resulting power imbalance, potentially combined with the real or perceived lack of time.

"I gave consent firstly because I trust the doctor. He has treated my child since the beginning and we feel confident with him." [TH-08]

"I felt the surgeon listened and decided and discussed the best option for my son. He made me feel comfortable and I trusted his ability." [UK-15]

"I felt just powerless and realized that I can't do anything myself." [UK-01]

"If I had not given my consent, they could not have done the surgery." [TH-01]

Although essentially similar, this issue of potential, real or perceived pressure to give consent appeared more pronounced in the Thai sub-sample, with parents repeatedly talking about feeling "forced to sign" [TH-09] or having to "to obey and sign" [TH-04]. Even when explanations were lacking, they:

"...did not dare to ask anyone.. [and the surgeon]...told us that this case needs surgery, and I have to sign the consent form. It seems like a force" [TH-01].

However, this power imbalance appeared more pronounced among the Thai participants, it was not unheard of by the British parents.

Theme 3: The purpose of consent

A significant minority of British parents viewed the need for a signed consent as a means of protecting the surgeon rather than the children, with some Thai parents believing that signing the consent would allow the surgeon to abdicate responsibility. In the British sub-sample the awareness of high profile litigation had resulted in an understanding acceptance that surgeons have to protect themselves because they:

"...get sued all the time for malpractice" [UK-02].

Those Thai parents who talked about this issue, on the other hand, believed contrary to Thai law that giving consent would protect the surgeons from any claims made following both potential complications and malpractice.

"Giving consent means that we will not claim, will not ask anything from the hospital. It protects the health care staff from being sued in case of something going wrong." [TH-02]

Theme 4: Nurses and the consent process

Nurses did not feature prominently in the data. Only one English parent [UK-02] mentioned nurses at all, but as not being involved in the consenting process. On the other hand, two Thai [TH-02, 08] parents described nurses explaining consent-related issues to them.

"The nurse gave a very good advice. She talked and explained. I asked and she explained and told about the consent, and showed me the form." [TH-08]

However, five Thai parents [TH-01, 03, 05, 10, 11] mention nurses asking or even telling them to sign a consent form without providing any explanations.

"She (a nurse) did not tell anything, just said you (mother) please sign the consent form. I did not read, but the nurse told me to sign, so I signed." [TH-05]

DISCUSSION

The study findings were similar to the shortcoming in the consenting process described by Mason and Allmark (2000). Not all parents were given all the information required, not all had fully understood the information and in some cases questions regarding the voluntariness of the consent arose. Many themes arising from this research related to perceive a lack of time and no choice, submission to medical authority and disempowerment, the purpose of consent, and nurses and the consent process.

A lack of time and no choice. The first major issue is the lack of time available for the consenting process. White (2004, p289) discussed the need for 'fluid dialogue' so that questions may be asked and answered freely. He asserted that time constraints could be a factor that restricts the building of a relationship of trust between those giving and seeking consent. The parents participating in this study did not stand alone in raising this issue. Woodward et al. (2004) reported that for most parents the consenting consultation had taken less time than they would have liked. Informing parents and gaining their consent to treatment might be regarded by some surgeons as something of a chore with the purpose to persuade a patient to sign a piece of paper (Woodward et al., 2004; Bristol Royal Infirmary Inquiry, 2001). However, valid consent may require not only that the parent is provided with comprehensive information but also given time to think issues over. On the other hand, pushing a parent into making a quick decision may well be coercive. Accordingly, the Department of Health (2001) encouraged parents to take as much time as they need.

The perceived lack of time was closely linked to a need for good communication and interpersonal skills in surgeons, which would enable them to use empathy and sensitivity, allowing them to gain

parental trust (Nwomeh et al., 2005). This trust was a key factor affecting the parental capacity to give informed consent (BRI Secretariat, 1999), without fearing that any questions they might have could be branded as inappropriate (Lashley et al., 2000). This would also remedy the emphasis by surgeons on the distancing aspects of consenting and move them towards the parental interpretation of the consent process as a drawing together and informed agreement between fairly equal partners (Alderson, 2006). It is a process that still has some way to go.

Submission to medical authority and disempowerment. Parents would normally allow surgeons to operate on their child once they understood the necessity of the treatment. At the extreme end of this behavior, parents had unquestioning trust into the surgeon's abilities. Given the potentially serious consequences of consenting for their child to have surgery, it could be assumed that parents would see it as their role to consider carefully whether or not to give consent. However, this was not always the case. Instead, many parents were willing to give consent even if they had not fully understood the information they have received (Campbell et al., 2004; Alderson, 1999). Similarly, studies by Zupancic et al. (1997) and Chappuy et al. (2006) concluded that when asked whether to volunteer their infant for a clinical trial, the majority of parents preferred the doctor to take as much responsibility for this decision as possible. However, similar findings have not previously been described in pediatric surgery settings. Whatever the motivation for this parental behavior, it does not free health professionals from explaining all relevant details in order to ensure parental understanding and offering informed consent.

A degree of dependence of patients on the surgeon is inherent in the nature of surgical problems. However, in this study this dependence was often compounded by a parental feeling of disempowerment that was most pronounced when there was potential, real or perceived pressure to consent. In its boldest form, some parents reported having been told to sign the consent form without being given information. This was supported by previous findings. During their child's acute illness, most parents experienced

feelings of helplessness (Kai, 1996) or of being helpless observers (Alderson et al., 2006). They were not able to act autonomously (Taylor, 1999) and at times their information requests were only partially fulfilled (Goore et al., 2001). System pressures do exist within the busy hospital environment but the need for full information on which parents can give consent cannot be negated to satisfy the needs of the system.

The purpose of consent. Both English and Thai parents referred the purpose of consent linked to incorrect understanding about protection the surgeon and medical personnel from litigation. Dealing with this issue would be best achieved by paying attention to the factors that re-enforce this negative perception, i.e., the perceived lack of time spent on the consent interview as well as feelings of disempowerment and of being pressured into signing the form. However, another equally disconcerting factor related to this wider issue is the role that some nurses play in gaining parental consent.

Nurses and the consent process. Nursing has claimed both advocacy and empowerment as part of its role (ICN, 2004). Both concepts aimed at maintaining and enhancing the patients' ability to keep control over their lives as much as is possible. However, by asking parents to sign a consent form for a procedure to be carried out by a surgeon without providing the information required to give informed consent, some Thai nurses failed to encourage their patients to speak up for themselves. However, there were no examples of nurses seeking consent in the UK which may reflect nurse's individual responsibility in the two countries.

The data demonstrated strong similarities between English and Thai parents. However, there were some differences. For example, the overtly elevated social status of the surgeon still persisted in the Thais to a larger extent than in the British parents. A number of Thai parents felt pressured to sign the consent and thought that the purpose of giving consent was to protect the surgeon. In a weakened form, all these issues appeared with British parents as well. The similarities derived from

two culturally different backgrounds, allowed two careful assertions. The love of parents and their commitment to their children's well-being span beyond cultural barriers.

CONCLUSION

Our results suggest that in both the European and Asian settings, the same issues concerning the giving of parental consent did occur. Causal mechanisms were multi-layered with parents experiencing a lack of time and choice as well as a power imbalance and pressure to consent to their child's surgery. Differences existed primarily in perceptions of the status of doctors. Similarly, nurses failed to empower their patients by not enabling them to make informed decisions. The outdated social order in hospital and inappropriate nurses' role can be changed through research, education and good practice guidance into a shared decision-making approach in which parents, nurses and medical personnel may be equally taking part in participation. Currently, issues surrounding consent remain unanswered.

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