

**The experience of decision making in the care of children with palliative care
needs: the experiences of Jordanian mothers**

Abstract

The purpose of this study is to explore the experience of decision making in the care of children with palliative care needs in Jordan, from the perspective of their mothers. This study employed a collective qualitative case study approach. Data were collected in three paediatric wards in a Jordanian hospital. Two data collection methods were employed: participant observation (197 observational hours) and (56) semi-structured interviews with (24 mothers, 12 physicians and 20 nurses). The findings show how Jordanian mothers seek to transfer the role of decision making to physicians, as they perceive themselves to be unable to make decisions about critical issues related to the treatment of their children. Mothers had a widespread apprehension of 'future guilt', especially when they feared that any decisions they might make could have an adverse impact on their children. Contrary to the predominant pattern, some mothers took a proactive approach towards decision making about their children's treatment. These mothers requested detailed information from primary physicians and sought out different sources of knowledge such as second opinions, reading online resources, or talking to other parents who had a child with similar circumstances. The study concludes that mothers prefer to involve physicians in decisions about their children's healthcare and treatment to eliminate their fear of probable future guilt; this modifies any tendency to autonomously decide for their children. These findings are underpinned by the Jordanian culture in which doctors' opinions are highly regarded.

Keywords: Paediatric palliative care, End Of Life, decision making, healthcare providers, children with life-threatening or life- limiting illnesses.

Introduction

Paediatric palliative care is defined as: "The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease" (World Health Organisation, 1998:8). Parental decision making is a critical component in the provision of paediatric palliative care and end of life care (Himmelstein & Hilden, 2004; Liben, Papadatou, & Wolfe, 2008; Mack et al., 2011). The decisions that parents face during the illness of their child range from decisions at the end of life such as do not resuscitate or do not intubate options (Carroll, Mollen, Aldridge, Hexem, & Feudtner, 2012), to decisions about life supporting care options such as whether the child should have a tracheostomy or additional surgery (Montagnino & Mauricio, 2004; Patel & Zdanski, 2009) or deciding whether to treat child in the home or the hospice (Whittle & Cutts, 2002).

Background literature review

Empirical evidence highlights several issues affecting the extent of parental involvement in the decisions of their children (Kilicarslan-Toruner & Akgun-Citak, 2013; Zwaanswijk et al., 2007). For instance, the severity of children's illnesses has been shown to influence the degree of parental involvement (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Gross & Howard, 2001; Kilicarslan-Toruner & Akgun-Citak, 2013; Pyke-Grimm, Stewart, Kelly, & Degner, 2006; Sullivan, Gillam, & Monagle, 2015). When decisions concern critical situations such as decisions about discontinuing treatment towards the end of life, the issues about parental involvement are complex (Sullivan et al., 2015). The literature demonstrates several psychological consequences such as pathological grief for parents who may be required to take the decision to allow their children to die (Caeymaex et al., 2013; Caeymaex et al., 2011; McHaffie, Lyon, & Hume, 2001).

The issue of who will be the ultimate decision maker remains a debatable issue in literature (Brinchmann & Vik, 2002; Caeymaex et al., 2011; Gillam, 2008). Parents' experiences and opinions related to who should be the ultimate decision maker in children's end of life care are ambivalent (Brinchmann & Vik, 2002; Caeymaex et al., 2011; Einarsdottir, 2009; Gillam, 2008; McHaffie et al., 2001; Pector, 2004; Vandvik & Forde, 2000). Although parents appreciate it when they are involved in health care decisions about their children (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Inglin, Hornung, & Bergstraesser, 2011), they show considerable variation regarding the type and degree of their involvement (Brinchmann & Vik, 2002; Caeymaex et al., 2011; Hsiao, Evan, & Zeltzer, 2007; Sullivan et al., 2015). Some studies show that parents perceive that health care professionals are the experts (Coyne, Amory, Kiernan, & Gibson, 2014; Zwaanswijk et al., 2007), while others show that parents wish to be the ultimate decision makers (McHaffie et al., 2001; Vandvik & Forde, 2000). Caeymaex et al. (2011) defined four models according to how parents perceive their role in the End Of Life decision-making process: shared decision making, medical, informed parental and

no decision. The most appreciated typology by parents is shared decision-making, as it appears to achieve a balance between seeking an active position in the care of their children and their fear of deciding wrongly and potential associated regret in the future (Caeymaex et al., 2011). This paper reports one aspect of a study conducted in Jordan, which sought to understand the experiences of mothers of children with palliative care needs about involvement in decision making which has not appeared in the Jordanian literature.

Materials and Methods

Study design

In this study, we employed a collective qualitative case study approach. The qualitative case study approach is usually used to understand and investigate in-depth phenomena, encompassing important contextual conditions (Lucka, Jacksonb, & Ushera, 2006; Salminen, Harra, & Lautamo, 2006; Stake, 2006; Yin, 2014). This study also adopted a collective approach of case study, in which a number of instrumental cases are examined in order to gain deep insights into a particular phenomenon. In collective case study research, each case is instrumental in getting a deep insight, but there will be an important coordination between the individual cases (Stake, 1995, 2006). In the present study, a collective design was adopted, as it speaks to the study questions, which investigate the phenomena of communication by investigating several cases rather than focusing on a case because of its particularity. Communications are context-based phenomena that are difficult to investigate if they are isolated from their original context (Baxter & Jack, 2008; Stake, 1995, 2006; Yin, 2012). The case study approach enabled capture of the multifaceted nature of the communications between children, their family carers and the health professionals who were the most involved in their care. The cases were chosen by identifying children first via the clinical staff and then building up a case around them, with participants included according to their caring relationship with the child. A typical case consisted of a child with palliative care needs; one or more family carers (e.g. mother, grandmother); one physician; one or more nurses.

Setting

This study was conducted at one public hospital in Amman, Jordan. The rationale for choosing this particular hospital as a study site was that it is one of the major public

hospitals in Jordan providing health services for a large and varied proportion of the population. The hospital includes three paediatric departments: the medical floor, surgical floor, and paediatric intensive care unit (PICU). All paediatric departments were considered in this study to increase the diversity of the case studies across the hospital context. The current hospital has no specialized palliative care unit for children. However, the departments receive children with conditions that are eligible for palliative care (Table 1).

Sampling

A purposeful sampling strategy was adopted to find children to build up the whole case (Merriam & Tisdell, 2015). The inclusion criteria adopted when recruiting the study participants were: children aged between 1-12 years old who were admitted to the hospital's paediatric units diagnosed with a condition eligible for palliative care. Although children were the centre of each case, they did not participate in interviews to avoid any potential harm to them (Ethical issues section). After identifying the children, the family carers who accompanied them during their admission to the hospital were identified and asked to participate in the study. In the current study, the mothers of such children were the main family carers. Finally, the most involved health care professionals in the care of the child were identified with the assistance of the mothers who agreed to participate in the study.

Access and Recruitment

To obtain and maintain access to the study participants, it was important to inform all professional gatekeepers about the research study, therefore with the cooperation of the head of medical and nursing departments of both floors, an announcement of the research study was placed on the bulletin board of each department, facilitating information for the health care providers. Moreover, an internal memo was sent to both medical and nursing staff on both floors. MA gave copies of an Arabic leaflet providing a

brief description of the study to the heads of both nursing departments; this was then disseminated amongst nurses assigned for admission rooms in both departments. Those nurses verbally discussed the study during the regular hospital policy identification session that is usually given for all new admissions.

Ethical considerations

Research ethics committee approvals were gained from the study hospital's dedicated committee. Mothers' informed written consent to participate in the interviews was sought. The consent forms were translated from English to Arabic to facilitate participant understanding. Participants were assigned pseudonyms to maintain anonymity. Data were saved on the personal computer of MA and password-protected to ensure data protection.

It is essential to weigh up the risks and benefits of interviewing children (Jokinen, Lappalainen, Merilainen, & Pelkonen, 2002) to protect them from any potential harm (Kennan, Fives, & Canavan, 2012). Although currently there is no consensus on including children in research, concerning their health and wellbeing (Helseth & Slettebø, 2004; Lambert & Glacken, 2011), according to the Declaration of Helsinki, research involving children should be limited, with special justification related to their health (World Medical Association, 2000).

In qualitative health studies, participants are usually asked to discuss specific topics, which rarely cause substantial harm. However, there remains potential for emotional and psychological risk during the research process (Helseth & Slettebø, 2004; Jokinen et al., 2002; Kankkunen, Vehvilainen-Julkunen, & Pietila, 2002). In the current study, interviewing children would have had the potential to cause them significant emotional harm, as the interviews might force them to recall painful memories and events, or discuss sensitive issues concerning death and end of life issues (Helseth & Slettebø,

2004). Therefore, we decided to avoid interviewing children in the current study in order to avoid any potential harm to these highly vulnerable children.

Data collection methods

Two data collection methods were employed: participant observation and semi-structured interviews with three categories of participants: mothers, physicians, and the nurses who cared for the children who are the centre of each case. In this paper, the qualitative interviews with mothers are reported and there is a focus on the theme of decision making.

Data analysis

This study used constant comparison to analyse the data – a method common to qualitative research, and one which is based on an inductive, comparative approach (Charmaz, 2014). The data results from the interviews were compared with the data results from observations (Ayres, Kavanaugh, & Knafelz, 2003). This comparison informed the next data collection, especially when certain information was missed. In order for the data collection to be simultaneous with data analysis, every data collection session was based on the initial analysis of the data gathered from the preceding observations and interviews (Bogdan & Biklen, 2011). In addition, the study objectives were continuously reviewed which helped the researchers to avoid being overwhelmed by the huge amount of data collected. Within-case and cross-case analysis were undertaken in accordance with Stake's (2006) recommendations. Within-case analysis focused on establishing the contextual background for every case (Creswell, 2013). This significantly protected the uniqueness of each case within its context and to be consistent with the case-study approach. Within-case analysis involved developing a detailed narrative for every case. Subsequently, cross-case analysis was undertaken to systematically extract the common themes and subthemes across all the cases to identify similarities, differences, and contradictions.

Study rigour

Trustworthiness of the findings was improved through prolonged engagement with the paediatric department of the hospital and MA's sustained observations of each case. MA spent around nine months (approximately 197 hours) observing to gain as full an understanding as possible of the phenomenon of communication in a paediatric setting. Furthermore, the credibility of the findings was improved using a peer debriefing technique (Lincoln & Guba, 1985). MA sent examples of the interview transcripts and field notes to the co-authors for further comments. Member checking was achieved by asking participants to read the transcripts of their interviews to confirm whether the words reflect what they intended to say (Shenton, 2004). Confirmability was improved in several ways, such as using triangulation, maintaining an audit trail and promoting reflexivity throughout the research process (Lincoln & Guba, 1985; Merriam & Tisdell, 2015).

Findings

The study yielded 15 cases (Table 2) with a total of 15 mothers participating in the study. As the focus of this paper is on the experience of mothers, mothers' demographical details are shown in Table 3. The majority of mothers were housewives, two of them school teachers, and one was a university student. Regarding education, the majority of the mothers finished primary or secondary school and then left school to take care of their children. However, three of them were graduates, and two of them had a higher diploma.

Study findings demonstrated several novel issues influencing the level of the mothers' involvement in decision making related to their children's illnesses. For example, the predominant Jordanian culture that trusts physician meant that mothers preferred to give their doctors a free hand in deciding the majority of decisions related to their children's health.

- *Make it the responsibility of the doctor*

The predominant pattern of the data shows that mothers preferred to give the doctor the major role in determining the major treatment options for their children. Although the responsibility for deciding about treatment options technically laid with the parents, as evidenced by the hospital policy relating to informed consent for all major procedures undertaken for children, in effect these mothers 'rubber-stamped' the treatment options determined by the physicians:

We do not like to take decisions ... from the beginning we know that his treatment is difficult ... we gave him [Dr. Raed] trust ... whatever he does with our child, we are satisfied (Firas's mother, Case 11: a 10 year boy with nephrotic syndrome).

One reason for this was that the majority of mothers had little confidence in their own ability to decide the best course for their children without the doctor's help. They perceived themselves to be lay people with insufficient medical knowledge, and they were extremely fearful of making decisions that might be less effective than the course recommended by the doctor. There is an underlying culture of trusting physicians in Jordan. On the whole, Qusai's mother trusted Dr Nihad to decide the best for her son, which did not contradict her thirst to know all of the details about her child's condition and progression. She followed Dr Nihad's advice for the majority of treatment options related to her son, as she perceived that the doctor knew the best course of action.

Similarly, Suha's mother mistrusted her ability to independently decide the best treatment options for her daughter, as she perceived the physicians to be more knowledgeable than her (Table 4). Suha's mother described how she insisted on understanding Suha's disease as soon as Suha was diagnosed with cerebral palsy. As soon as she knew that her daughter's disease was relatively rare, she tried to gain as much information as she could about it. She explained that the health professionals did not give her new information about the nature of her daughter's illness because she had already collected very detailed information. She sought to determine the specific category of Suha's disease, for example by re-reading books that she had studied when she was at the faculty a few years before. She was very curious about the degree of muscular dystrophy her daughter had, and because she had studied learning disabilities, she saw herself as having some knowledge about the disabilities her daughter might face. However, she underestimated her ability to decide independently from her daughter's physician perceiving that the doctor is more knowledgeable and she does not wish to decide against his opinion:

These are medical issues ... this means I cannot choose, but the doctor, as he sees my daughter's condition ... if he says a certain thing for her, shall I come and tell him "no, no"? ... No, it is difficult ... as based on how I evaluate

something, I do not know that much about it (Suha's mother, Case 14: a 12 month girl with cerebral palsy).

Conversely, the mothers of Baraa and Qusai did not accept the doctors' opinions absolutely; rather, they sought other resources to gain more information about some major decisions to decide the best course of action for their children. Qusai's mother sought the opinions of some friends and relatives about whether or not to go for kidney transplantation for her child in the future. Similarly, Baraa's parents asked Dr Raed to give them all of the details about Baraa's disease (End Stage Renal Disease). Although the parents mostly agreed with the specialist's opinion, the predominant pattern of trusting doctors was modified by the previous experiences of those mothers. Thus, Baraa and Qusai's mothers usually investigated the issue using different resources that they thought would help them to decide. In the main their disagreement with Dr Raed's opinion was fuelled by second opinions, such as other doctors, or trusted resources such as the parents of children with the same disease who had tried the same treatment. They refused several procedures when they were informed that they could be highly risky for Baraa's health:

For example, with Baraa, there were some conditions we intervened in based on some consultations ... so there were some procedures we refused ... so based on some people, they told us this procedure might be dangerous for him or something like that ... even when the doctor himself encouraged us to do it ... we refused (Baraa's mother, Case 15: a 3 year boy with end stage renal disease).

- *The fear of future guilt*

In addition to trusting the doctors, it seems that feelings of guilt that mothers anticipated they might get as a result of taking certain decisions related to their children's illness made the decision process more complicated. To some extent, the parents preferred to

agree with the doctors' opinions in order to avoid an additional burden if the decisions had negative outcomes. For example, Suha's mother wanted to do the best for her daughter before her death. Although she was not expecting a complete cure, she intended to do anything she could that might protect her from any expected self-blame. Therefore, she wanted to transfer the responsibility for the decision from herself to the physician.

This means I try to do everything and try to know if I did something incomplete or [there was] something that could be done and I did not do it (Suha's mother, Case 14: a 12 month girl with cerebral palsy).

In summary, it was clear that when the mothers had more information about the different disease options related to their children's illnesses, they had more capability and confidence to decide, but also to disagree with the doctors' opinions when they felt they needed to. This was clear with the mothers of Baraa and Qusai. Having collected as much information as possible about the different treatment options available for their children's conditions they were more proactive than the rest of mothers in deciding what they perceived to be best for their children's health.

Moreover, previous experience could make another contribution to the mothers' beliefs in their abilities to independently decide about the treatment of their children. Baraa's mother had previous experience, as this was her second child with the same illness. This could add another dimension to her confidence in her ability to independently decide whatever she thought suitable for her child. However, having more information about the treatment options for their children was not necessarily enough to guarantee the mothers' trust in themselves to make decisions for their children. Although Suha's mother was perhaps the most active in terms of collecting detailed information about her daughter's disease, her fear of the future guilt prohibited her from autonomously deciding the best for her daughter without an input from her daughter's doctors.

- *We do not have other options*

In a few cases, some mothers reported being compelled to choose some treatment options for their children simply because there were no alternatives. For example, Baraa's sister, Areej, who had died some years before had needed haemodialysis because of ineffective peritoneal dialysis; the health professionals informed Baraa's mother and her husband of the need to perform vascular access for Areej as a preparatory procedure before starting the haemodialysis. Given the risk of the operation to Areej's life because of the analgesia required, Areej's mother stated that this decision was very difficult for her and Areej's father. However, Areej's parents had no other options at that time, because the peritoneal dialysis was no longer beneficial. They felt that if she did not undergo the operation, Areej would be unable to have dialysis, and would die:

Yes, we signed [for vascular access operation for Areej] because if we left her, it would be the same as setting a time for [i.e. causing] the end of her life ... this means at the same time, that was like there was no way ... this means the peritoneal had no benefits ... we did not have any options except haemo [haemodialysis], so it was like we were compelled to do it, and that was what happened in reality (Baraa's mother, Case 15: a 3 year boy with end stage renal disease).

Baraa's mother felt that trying whatever treatment was available for her daughter was better than nothing. Similarly, the mothers of Mousa, Qasim, and Suha were always concerned about future guilt when trying to make decisions about any potential treatment or life-prolonging procedures that might help their child. They felt as if they would be responsible for their children's deaths if they did not decide on the one option available.

Discussion

This study shows that Jordanian mothers' experiences of decision making are shaped by several interrelating perceptions. Some of these were culturally situated and involved placing their trust in the physician and some were shaped by previous experiences. In each case however, an overriding concern was to avoid 'a fear of future guilt'. Jordanian mothers reported that the feelings of guilt they might have as a result of taking certain decisions made them hesitate to independently decide over the care options of their children especially with critical decisions at the end of life stage. Therefore, to some extent, mothers preferred to agree with doctors' opinions regarding the treatment options, so as to avoid the additional burden of future guilt they might experience if the decisions had negative outcomes. This conceptual category of 'fear of future guilt' has its transferability to other contexts, as evidenced by the resonance of this concept with international research (Caeymaex et al., 2013; Caeymaex et al., 2011), this was especially so if the decisions were major and contrary to the physicians' opinions. For instance, Caeymaex et al. (2013) found that parents perceived the decisions they took by themselves without discussion or counselling with medical team was correlated with severe grief in comparison with the other styles of decision making such as shared decision making.

A recent Australian study by Sullivan et al. (2015) investigated the experience of decision making among 25 bereaved parents in the end of life of their children who died as a result of a life threatening condition showed findings that are different to those from the current study. Parents who were active in the decision making for their children did not experience negative impact such as the feeling of guilt as suggested by the previously mentioned evidence (Caeymaex et al., 2013; Garel, Caeymaex, Goffinet, Cuttini, & Kaminski, 2011). Sullivan et al. (2015) explain that the appreciation the parents received after the death of their children by the hospital could be one reason for decreasing their feeling of guilt concerning their children's end of life decisions. However, there could be

other factors that affect parents' degree of involvement in their children's health treatment.

The underlying culture upon which these studies conducted could significantly affect parental perceptions toward their role in the medical decision making of their children (Gillam, 2008; Kilicarslan-Toruner & Akgun-Citak, 2013; Zwaanswijk et al., 2007). For example, Brazilian parents reported that their participation in decision-making process was limited and they were compelled to accept the treatments and interventions decided by the medical team. This could be due to the dominant culture in Brazil whereby physicians are held to have the required knowledge to make the best decisions (El Halal et al., 2013). The findings of the current study concur with El Halal et al. (2013) study as it shows that the Jordanian culture which trusts physician affects mothers' trust of their abilities to decide. The predominant pattern shows that mothers prefer to be supplied with information about the progress of their children rather than deciding over the best course of action for them.

The mothers who participated in the current study considered all treatment options that they thought might prolong their children's lives. The general principle the parents adopted was 'trying whatever is possible to preserve a child's life is better than nothing'. The literature reports similar findings (Carnevale et al., 2006; Gurková, Andračíková, & Čáp, 2015; Young, Dixon-Woods, Findlay, & Heney, 2002). Gurková et al. (2015) found that parents and doctors did not hesitate to try experimental treatment when conventional treatments failed. One parent in this study asserted the importance of ensuring that they tried everything that could be done for their child. Moreover, Bluebond-Langner, Belasco, Goldman, and Belasco (2007) found that none of the parents in their study (17 US, 17 UK) discontinued any supportive therapies, cancer therapies, or symptom-directed therapies. This is supported by the findings of Mack et al. (2008), in which several bereaved parents did not recommend the treatment of incurable cancer for other families despite their insistence that it be done for their children.

In addition, it seems that the severity of the child's illnesses affected parental decision-making roles. The predominant pattern in the current study that mothers found themselves being compelled to choose some options related to certain treatments for their children as they did not have several alternatives. A few of them felt that if they refused care for their children it was as if they had left their children to die. Similar findings were shown in previous works (Carnevale et al., 2006; Gross & Howard, 2001; Kilicarslan-Toruner & Akgun-Citak, 2013; Pyke-Grimm et al., 2006), which demonstrated that the severity of the children's illnesses affected parental decision-making roles.

The findings of this study have significant implications for clinical practice. In spite of the clear importance of parental involvement in the process of decision making related to their children's health, the fear of future guilt could be an obstacle for parent's desire to independently make decisions. It was clear in this study that mothers preferred to consult physicians in all decisions related to their children's health and this is supported by the dominant culture that appreciates the physicians' opinion regarding to the critical decisions of their children's health. Mothers who had the required knowledge about their children's conditions -which is essential in decision making- still hesitated to have independent decisions, but they wanted some input from their children's physician. This sheds the light on the importance of considering the fear of future guilt when aspiring to shared decision- making.

This study has several strengths, it is built on a qualitative case-study approach, which involved the study of cases within a real-life contemporary context or setting (Stake, 2006; Yin, 2014). In addition, as this study employed observation in addition to the semi-structured interview, it accomplished an in-depth understanding of the communication phenomenon being studied.

This study had several limitations that should be acknowledged. The period of observation varied significantly for each case study. MA spent several weeks performing data collection for some cases which enabled us to collect rich information. However, in

other case studies, MA spent a relatively short period observing them (a few hours) because of the difficulty of predicting the exact time of discharge, as well as some unexpected events, such as the death of one child who was at the centre of a case study. Therefore, more attention was given to some case studies than others, which might result in shedding more light on some issues and less on others.

Another limitation of the study was that we were unable to follow up with parents after the death of their children. Although one of the strengths of this study is using participant observation that captures current life events as well as the historical experiences gathered by interviewing participants, it did not capture the effect of the parents' decisions in the long run. However, the presence of some mothers who had more than one child with the same illness facilitated the investigation of their experiences of their deceased children and thus their change of perception was examined. This was especially so when they compared how they were before their child's diagnosis and their condition with the current children.

Conclusion

This study demonstrates that Jordanian mothers who felt less confident about their knowledge of their children's health gave the physicians the main role in determining major treatment options. The underlying Jordanian culture that trusts in physicians could play a significant role in the mothers adopting a passive role in decision making. The feeling of 'future guilt' also reduces parental desire to independently make decisions for their children. Therefore, the parents accepted all medical procedures that could help the child to survive even if they knew it could not be helpful. The findings of this study suggests encouraging the shared style of decision making which involves both parents and health care team to be involved in the process of decision making for children with palliative care needs.

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Conflict of interest

The authors have no conflicts of interests.

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