TITLE

FAMILY-CENTRED CARE – A WAY TO CONNECT PATIENTS, FAMILIES AND NURSES IN CRITICAL CARE – A QUALITATIVE STUDY USING TELEPHONE INTERVIEWS.

SUMMARY

Objectives

This study sought to describe families' experiences of providing physical care to their critically ill relatives with bed-side nurses' support.

Methods

A qualitative research design was used and telephone interviews were conducted with ten family members. The interviews were analyzed using content analysis where data were grouped around central, recurrent ideas. A purposeful sample of family members who had performed care for their sick relative were drawn from a critical care unit in a large tertiary hospital in Australia.

Findings

The data revealed three main themes in relation to the family members' perceptions of providing some fundamental care to their sick relative. The three themes included: (1) 'Enacting Care'; (2) 'Connecting with Sick Relatives' and (3) 'Partnering with Nurses'.

Conclusions

This study demonstrates that family members of critically ill patients enjoyed participating in their relatives' care and critical care nurses supported them in individualising the care. They felt useful and it improved communication and facilitated close physical and emotional

contact with their relative. This partnership approach successfully incorporated family members into the daily care for their sick relative and connects patients, families and nurses in critical care within this Family-Centred Care model of care.

INTRODUCTION

In recent years there has been a movement to promote patients as partners in the care nurses and other health professionals provide (Sahlsten et al., 2007) yet patients' conditions may actually preclude or limit their active participation. As a result, proponents of such a partnership approach include the family as a natural extension of the patient, with family centred care increasing in popularity. Family-Centred Care (FCC) is a philosophy of care that sees the unit of care as the patient and their family rather than having the patient as the sole focus of care (Henneman and Cardin, 2002; Webster and Johnson, 1999). It is seen as a way to optimise patient and family outcomes through a collaborative partnership process with families, patients and healthcare services (Institute for Family-Centered Care, 2008). Some areas of nursing such as palliative care and care of the sick child (Just, 2005; Shields and Tanner, 2004) have embraced the family within the model of patient care, however, there is a lack of literature on families' perspective of FCC interventions in adult ICUs. Families of intensive care patients have been known to want to be physically close to their critically ill relatives for decades and to appreciate communication opportunities with the nursing and medical team (Molter, 1979). As ICU nurses strive to improve the care they deliver it is crucial to remember that family members' needs are both relevant and important aspects of the care they deliver.

However, how best to do this is unknown as there is limited understanding of families' perceptions of being partners in care in a critical care environment. As part of a larger FCC project (Mitchell et al., 2009) in an Intensive Care Unit (ICU) this study examined family members' perceptions of partnering with their relative's bed-side nurse in providing

individualised fundamental care and as such adds to the limited knowledge about family participation in care in a critical care setting.

Background

Caring for a patient who is in a critical care setting is complex and demanding. The nursing issues involve not only the multifaceted patient care issues but also the complexity that the patient's family can add to the situation. Family members are, however, recognised as legitimate recipients of nursing care (Crunken, In Press; Fowlie et al., 2000; Australian College of Critical Care Nurses, 2002) as they provide ongoing care and support to the patient along with patient advocacy and frequently, consent for treatment (Szalados, 2007). It is therefore important to assess how best to meet the needs of families and facilitate their inclusion into the critical care environment. It has been widely reported that having access to the patient is a primary need for family members of critically ill patients along with the need for assurance and the need for information (Leskie, 1991). One model of care that promotes patient access and family/staff communication and information sharing is Family-Centred Care.

Family-Centred Care

FCC is a model of care that is based on the principle that one's family is the single most important aspect of one's psychological and physical health (Shields and Tanner, 2004; Bruce et al., 2002; Williams, 2005) and has three key elements – mutual respect, collaboration and support (Hutchfield, 1999). In a FCC approach, the family is seen as an

important component of nursing care and along with the patient is a focus of care. FCC aims for a partnership between patients, families and health care providers (Institute for Family-Centered Care, 2008) and incorporates an holistic care which includes planning, delivery, and evaluation of patient healthcare. As with all models of care, FCC is best implemented when a whole of ward approach is taken, however, it is undeniable that the relationship between the family and the bed-side nurses is the essential element of FCC. This relationship is based upon mutual respect, collaboration and support for the family and patient (Hutchfield, 1999). Respect is the process of acknowledging and valuing individuals; collaboration is the act of partnering in health care options and support, pertains to acknowledging and assisting with someone's needs (Mitchell et al., 2009; Shields and Tanner, 2004). Although FCC model is able to be adapted to all areas of nursing (Shields et al., 2007) its effectiveness has predominantly been examined in paediatric settings (Coyne, 2007; Galvin et al., 2000; Shields and Tanner, 2004) which are arguably of limited use for the adult acute care setting due to the fundamental differences in these two clinical environments. Understanding the effectiveness (or otherwise) of FCC as a model of care is limited and thus requires further examination.

A meaningful perspective of care evaluation is from the viewpoint of the recipients of care. Client satisfaction, including both patients and their family, presents a genuine and justifiable measure of evaluation. Clients' level of satisfaction with care is an important health care outcome as it provides an indicator of the quality of care they experience

(Ekwall et al., 2008; Howard et al., 2005; Leiblum et al., 2008) and helps direct future practice change.

This paper describes families' experiences of providing physical care to their critically ill relatives (ICU patients). We have previously reported other results from this trial of FCC (Mitchell et al., 2009). A family member was defined as an individual who visited and had a sustained direct relationship with the patient. Ethical approval was received prior to the commencement of the project from the hospital and university ethic committees and the project was conducted in accordance with the National Health and Medical Research Council guidelines.

METHOD

Telephone interviews using qualitative analysis were used to develop an understanding of family members' experience of participating in the care of their relative, an ICU patient (DeSantis and Ugarriza, 2000; Graneheim and Lundman, 2004). FCC surveys were also used to capture data and these results are reported elsewhere ((Mitchell et al., 2009). The interviews allowed for open and free discussion of thoughts by participants and provide rich data which are not possible when using surveys (Polit and Beck, 2007). While some consider telephone interviews to be an inferior method of qualitative data collection due to the lack of data emanating from body language (Rubin H. and Rubin I, 1995; Sturges and Hanrahan, 2004), others suggest that quality data can result from telephone interviews as participants feel more relaxed and able to speak openly about the situation than may occur in face-to-face interviews (Yin, 2009).

Site and sample

The setting for this study was a large, tertiary adult critical care unit in Australia. A purposive sample of ten participants who assisted in their relative's care as part of a larger study, were invited to participate in telephone interviews. A broad selection of participants was sought. Males and females, young and old and those with relatively little and a lot of experience in providing physical care to their family member were invited. Family members were excluded if they were under 18 years of age, or were unable to speak or read English as translation services were not available. Potential participants were asked by the unit's research nurse if they would be willing to be contacted by the chief researcher for a telephone interview. If they consented to this, they were asked for a telephone number and suitable time for the interview to take place. Inclusion criteria for this sample included the need for the family member to have performed some type of care for their relative whilst in ICU and access and availability for a telephone interview. Examples of the types of care family members became involved in included mouth and oral care, massage and bed baths.

Data collection and analysis

One telephone interview per participant was conducted by the chief investigator who worked in the university sector and was a Visiting Scholar in the unit. She did not participate in any patient care in the unit and had no previous contact with the participants prior to their telephone interview. The interviews took place over a period of six months. A set of questions were asked with the aim of gaining more understanding of the family

member's experience of providing care for their relative. Participants were asked nine questions and were encouraged to comment about any aspect of the caring they did for their relative or associated factors. These questions included the following:

1. What is your relationship with the patient?
2. What type of care are you providing for your relative?
3. How important is it to you to be included in your relative's care?
4. How did helping your relative, or performing the care, make you feel?
5. Did you feel you had the support you needed to do this?
6. What sort of a contribution did you feel you made?
7. How helpful did you feel?
8. Do you have any other comments to make?
9. Would you recommend all families be given this option?

Individual verbal consent was obtained prior to the commencement of the interview, with written consent already received by these participants for the larger study.

Detailed verbatim notes were taken of these interviews and field notes were made immediately following each interview by the researcher who conducted all interviews. The interviews were analyzed using content analysis where data were grouped around central, recurrent ideas (DeSantis and Ugarriza, 2000; Graneheim and Lundman, 2004; Yin, 2009). This occurred by way of the two researchers (the interviewing researcher and other team member) reading each transcript and associated field notes several times to gain an understanding of each participant's comments. Team meetings then occurred to develop

emerging themes in an iterative and recursive manner by discussing and developing data codes. That is, quotes from the interviews were coded using a participant number. The researchers searched for meaningful units, firstly within each participant's responses and then across the data from all ten respondents. Constant comparison was used as a way to condense and describe the core meaning from the interviews (Graneheim and Lundman, 2004). The researches discussed different alternatives in order to develop consensus. They looked for deviant cases where a participant's experience contradicted the experience of the majority of participants and where appropriate reasons for this were discussed. Similar ideas were then organized into themes or categories to represent a manifestation of the content of the interviews (Graneheim and Lundman, 2004). The findings were not returned to the participants for verification as it was considered to be intrusive to follow up with these family members, when some had their relative die in ICU.

FINDINGS

Ten family members were selected and consented for telephone interviews. However, one participant declined their consent at the time of interview due to the deterioration in his wife's condition. A further family member was approached and consented resulting in ten interviews. The telephone interviews took between six and fifteen minutes and were conducted at a time set by the participant. All except for one interviewee was female. The one male family member was the partner of the patient. Half were partners, four were daughters of either their mother (3) or their father (1); one was the mother of the patient who was her son (Table 1). All family members interviewed provided care each time they

visited (when appropriate) which varied from relatively simple procedures such as eye care and hand and foot massage to more complex and demanding care such as hair washing and bed baths. The patients' aged ranged from 20 to 78 years of age (median = 51.6 years). The reason for their admission included cardiac conditions (three patients), trauma (three patients), respiratory (two patients), renal (one patient) and one was admitted for sepsis.

Table 1. – Family Member's Sex & Relationship to Patient – near here please

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	Family Member	Patient
	Frequency	Frequency
<u>Sex</u>		
Female	9	4
Male	1	6
<u>Relationship</u>		
Daughter	4	
Partner	5	
Mother	1	
Total	10 (100%)	10 (100%)

Upon examination of the data following the tenth interview it was evident that no new data were emerging. This assessment was enhanced by the fact that the same person conducted

all of the interviews and field notes and transcribed the notes. At the completion of the tenth interview, with no new data emerging, it was decided that the sample size was adequate. The data from the ten interviews revealed three themes in relation to the family members' experience of providing some fundamental care to their sick relative in ICU. The three themes included: (1) 'Enacting Care'; (2) 'Connecting with Sick Relatives' and (3) 'Partnering with Nurses' and collectively provide an understanding of the experiences of family members who provide care to their critically ill relative. Each cared for their relative in a way that was individualised to their situation which was considered an essential component of the families' experiences and is in accordance with a FCC approach.

Theme One: 'Enacting Care'

Family members were visiting their relative during the acute phase of their critical illness which frequently comes unplanned or unexpected. Some struggled with the situation as they grappled with conflicting feelings of helplessness and also a need to be involved and useful. Participants spoke of how performing some fundamental care enabled them to demonstrate that they cared deeply for their sick relative. One participant linked providing the care with her ability to demonstrate love and attachment to the patient:

"It's wonderful [the study]. I've had my children in hospital and know how ...you feel closer and we show love that way. The family is very important to me, we're very close. The project's wonderful". (Participant 8)

Having an ability to be involved in providing patient care that was structured around the patient and family member allowed them to feel more helpful and part of the situation. This provided them with a focus and purpose which they found to be very beneficial. One family member said:

“[I feel] a lot more useful...not helpless...not in the background all the time....something useful.”

(Participant 1)

In addition to being seen as helpful and a way to demonstrate caring by the primary family member delivering the care, a daughter of a patient shared how providing care also helped her elderly father who was having difficulty coming to terms with his wife's illness. It provided the daughter with the opportunity to include her father in the process of caring and in doing so assisted her father to adapt in a positive way to the illness situation.

“We didn't feel so useless... helping her... not standing back... it's a place where we have no control, so it helped. Dad's done it too... it makes him feel useful, not just sitting in the background. He can't handle the tubes - this is good to do something.” (Participant 4)

Thus, participants appeared to link the provision of physical care to the act of caring. That is, by assisting nurses with patient care, participants felt as if they were demonstrating to

themselves that they cared for their family member. The hands-on activity provided them with this opportunity and an ability to select the type of care they either knew their relative would like them to do, or that they felt comfortable doing. The next theme demonstrates another viewpoint of the caring as it focuses on the psychological benefits experienced by family members and patients.

Theme Two: 'Connecting with Sick Relative'

The act of helping with the physical care of their relative had particular benefits for some family members who considered it provided them with much more than the physical act of providing the fundamental care. It provided an emotional link and psychological benefit for both their relative and themselves, which distinguishes this theme from the 'Enacting Care' theme. Providing care not only gave the family members a way to access the patient's world and positively contribute to their level of comfort and wellbeing, it also allowed patients to feel a personal connection with their family members. For example, Participant 5 said:

"I feel that he gives us a sign that he is aware of us being there and it must be horrific for him ... I feel that I can give comfort to him."

A patient's wellbeing was felt to be enhanced when the daughter of another patient indicated that the act of rubbing cream into her mother's hands, elbows, ears and shoulders provided more for her mother than the simple physical act of moisturising her skin. She said:

“[Performing the care was] a great contribution to her wellbeing, we can’t communicate with Mum, she’s not talking, tactile touch is so important” (Participant 10).

The importance that family members are permitted to be involved in a critical illness situation and part of fundamental care was thought to be very positive for the welfare of the patient. A daughter of one of the patients thought that her provision of care to her father would psychologically be of benefit to him:

“[I] hoped he was more at ease knowing that we were doing things for him.” (Participant 8)

A common thread in this theme was the benefit of physical contact on an emotional and physical level that may only be seen with one’s close family who may be best placed to provide some of the care for a sick relative. The implication is that one’s family knows how this should be done and highlights the benefit of having a caring model that includes the family in caring for the patient. One participant, who was the patient’s fiancée, exemplifies this when she said:

“[I felt] better being able to touch... reassurance for both of us...He was fading in and out all the time but being there and being able to do things was great. I was by his side....He’s a very private person....He’d be mortified to think others would be caring and

*doing everything for him. It was great I could do it –
he's a one woman man.” (Participant 2)*

Thus, this second theme appeared to reflect a two way sharing between family members and critical care patients. In essence, the physical acts of mouth care and skin moisturising allowed not only families to connect with patients; it also allowed patients to connect with family members. A psychological mutual benefit can be seen in the family members' responses. The third theme helps to explain and understand from the family members' perspective the necessary logistics of the introduction of such an initiative in an ICU environment.

Theme Three: 'Partnering with Nurses'

The final theme evolved from participants' comments where it was very evident that they considered they were very much in a shared partnership with the bed-side nurses. Participants identified that they could not perform the care without the nurse's help which was they said was readily forthcoming. The need for help from the nurses facilitated them getting to know each other better. One recognized that providing some of the care was complex but with the nurse's support it was possible. She said:

*“Ahhhhhh.....yes, it's difficult ...don't want to hurt
him. Nurses helped a lot. [They] held his arm up for
me so I could bathe him”. (Participant 2)*

The flexibility and approach by the nurses to individualise the care options and patient/family situation was viewed positively by family members. One commented that the nurses did not put any pressure on them to perform any care but offered them the opportunity.

“Oh yes, I could do as little or as much as I wanted to.”

(Participant 3)

Of particular note, the initiative of families providing some care to their sick relative was thought to have helped with improving communication with the nurses. Communication is thought to be an essential element in meeting families’ needs and is therefore of particular importance in a family centred care initiative. One participant said:

“It made it a lot easier to talk to the nurses after that – I really felt I could talk to them, not just sit in the corner and keep out of the way”. (Participant 10)

In summary, this third theme demonstrates that families can collaborate with nursing staff in order to provide patient care. Having the opportunity to select the type of care delivered was important to the family members. The partnering with nursing staff allowed families to feel better able to communicate more broadly with the nurses.

The three themes of ‘Enacting Care’, ‘Connecting with Sick Relative’ and ‘Partnering in Care’ give an insight into important aspects of providing care to one’s critically ill relative in an ICU from the perspective of family members. They felt closer emotionally and physically to their sick relative and enjoyed the experience. The

nurses' ability to engage and support family members also promoted improved communication and an ability to relate to the staff.

DISCUSSION

Family members are, and will remain, an important part of patients' acute illness phase. It is therefore crucial for nurses to investigate and understand how to best include and involve families in a positive and beneficial way. With a FCC approach, families can be included in the care and the resultant partnership can be mutually beneficial (Mitchell et al., 2009). This study examined the family members' experiences of providing some care to their critically ill relative with the bed-side nurse's support.

During the telephone interviews family members clearly articulated that it was very important to them to be able to perform care for their relative. Close physical contact with the sick critically ill patient is a primary need for family members (Molter, 1979) and providing care necessarily facilitated this. A characteristic of human nature seeks to nurture, to provide comfort and to acknowledge someone's worth. A number of the participants said that by providing care they were demonstrating these characteristics of their love for the patient. Some believe that nurses have a responsibility and need to give permission and invite family members to be part of the caring team as this is frequently seen as the nurses' domain in acute-care adult settings (Davidson et al., 2007; Williams,

2005). This occurred in the current study as the nurse invited and supported family members in the care giving.

These invitations were appreciated by the participants who felt they were somewhat powerless and lacked a sense of control. This is not an unusual experience for families in acute illness situations (Davidson, 2009; Fontana, 2006) and it has been suggested that by providing specific activities families can regain some sense of control (Arockiasamy, 2008). The family member's involvement improved communication with the nurses as they felt more of a part of the situation, to the extent that they felt they were allowed to stay when previously they may not have been. Although good communication has been documented as a primary need for critical care family members for decades (Molter, 1979), both family members and nurses report this remains poorly done (Hughes et al., 2005). This project supports the assertion that involving family members in patient care enhances nurses' ability to communicate effectively and thus improve patient outcomes (Williams, 2005). Geller et al. (2008) claim that not only will patients benefit from a partnership in care model but also the nurse who can experience reduced feelings of burnout and more personal meaning from their work. The benefit to both patient and family member was also evident in the 'Connecting with Sick Relative' theme.

Connecting emotionally with the sick patient was important to the participants and providing physical care supported this connection. The 'emotional roller coaster' of critical illness adds stress to family members who attempt to cope with the demands of the

situation (Olsen et al., In Press). Including family members in patient care is one way to improve coping mechanisms with these stressful illness situations as it is thought to assist with families' response to the illness (Just, 2005). Current study family members were very clear that they liked being part of the project as they stated it helped them with a number of aspects of the critical illness situation. Other studies have reported similar positive findings. In a Canadian study, family members of critically ill patients stated how they liked being active and being able to participate by being involved in giving some care (Vandall- Walker et al., 2007). This enabled them to be physically close and touch their relative which helped them to connect and show their love. An holistic view of caring accepts this notion of spirituality and existential connection with a loved one. The nurse/family member relationship will further support holistic nursing as the nurse develops an understanding of the family's unique perspective in the illness situation (Johnson et al., 2009; Meiers and Brauer, 2008).

Getting to know the nurses was important to the family and they enjoyed the closer relationship that evolved from the partnership in caring. Critical care patients' families can be instrumental in ensuring continuity of care during illness and recovery (Hook, 2006), which may include a number of health care providers in both the acute and community settings (Barbetti and Choate, 2003). Many in the health professions recognise that providing stability across an illness trajectory is complex, problematic and frequently not done well (Beaulieu et al., 2009). This further supports the need to partner with family members in real ways from the first acute phase onwards. By involving and informing

family members there is the capacity for them to be ready and confident to provide the support needed.

Together, these findings suggest that providing care can transcend physical boundaries incorporating an existential domain, by promoting reciprocity between patients and family members and by promoting collaboration with nursing staff. When families provide physical care, they are actually 'doing more' than just the 'doing of care' as it allows them to show they care about (or care for) their loved one. It provides them with a vehicle to connect with the patient on an emotional or existential level. The provision of care also brings about a sense of partnership with the nursing staff who also provide physical care. There is the notion that when you provide physical care you are actually demonstrating a 'caring for' and 'about' the patient.

Limitations

There are several limitations to this study that have to be acknowledged. First, despite trying to ensure gender balance, only one male participated in the study. It may be that other themes would have emerged if more males were included in the study. However, the care giving role has traditionally been assumed by females, which may be one reason why more women agreed to participate in the study than men. Second, member-checking was not performed. Some researchers consider member checking may confuse rather than confirm an issue because the findings, such as the themes that emerged from this study, reflect integration of all data and not just that particular participant (Angen,

2000; Morse, 1994). Third, this study examined family members' experience of their participation, but did not include either the patient's or the nurse's experience. These other two perspectives should be considered in future research.

CONCLUSIONS

In conclusion, this study demonstrates that family members of critically ill patients were willing to participate in patient care. Further, this participation allowed families to connect with both patients and nurses. The project had the bed-side nurse invite and support family members in their participation of individualised fundamental care for their critically ill relative. The interviewed family members identified that by performing care they felt useful and it improved communication and notably, it facilitated close physical and emotional contact with their relative. Three themes emerged and included (1) 'Enacting Care'; (2) 'Connecting with Sick Relatives' and (3) 'Partnering with Nurses'. Family members considered they were 'doing more' than just the 'doing of care' as it allowed them to show they 'care about' and 'care for', their loved one. Universally, participants described being well supported by the nursing staff who allowed the family member to select the level and complexity of care provided. The cooperation of the bed-side nurse is essential to the success of this FCC approach, thus their enthusiasm and support is critical.

This study provides insight into the benefits of offering family members the opportunity of providing some care to their relative at a time nurses may not normally consider appropriate or of benefit. This partnership approach successfully incorporated family

members into the daily care for their sick relative and shows support for further exploration of promoting family/nurse partnering in other ward areas within a FCC model of care.

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Conflict of interest

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