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Research article

A multicase study of prolonged critical illness in the intensive care unit: Families' experiences

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ABSTRACT

Background: It is widely acknowledged a critical illness is a stressful life event for not only the patient but also their family members; when an illness becomes prolonged, the impact is profound. It is suggested that as medical technologies advance, the number of days patients stay in an intensive care unit will increase. Therefore, it is important nurses understand how families experience a prolonged critical illness of their family member in an intensive care unit.
Objective: To explore the trajectory of a prolonged critical illness in the intensive care unit from the experiences of family.
Methods: A qualitative, longitudinal, multi-case design consisting of six cases from New Zealand intensive care units. Findings presented in this article only relate to the family's experiences, although patients and healthcare professionals formed part of each case. Data collection methods included observation, conversations, interviews and document review. Analysis was undertaken using thematic analysis, vignette development and trajectory mapping.
Findings: Relentless uncertainty dominated all phases of the trajectory for the family during a family member's prolonged critical illness in the intensive care unit. When faced with a critical illness, family shifted rapidly into a world of unknowns. Family worked hard to navigate their way through the many uncertainties that dominated each phase of their family member's illness.
Conclusions: Nurses need to understand the levels of uncertainty families endure in order to provide care that meets the philosophical underpinnings of family centred care.

Implications for clinical practice

- Knowledge of the family's experiences of a trajectory of a prolonged critical illness can assist nurses to understand the extended burden for this family group and to target interventions at specific problematic issues to improve experiences.
- The importance of nurses 'knowing' the family and the patient, as a dyad, throughout the illness trajectory is paramount for effective therapeutic relationships and individualised care.
- Nurses need to understand families' uncertainty and engage in information sharing more freely.
- Family assessment and documentation should be an on-going process throughout the patient's prolonged illness in an intensive care unit.

Introduction

It is acknowledged that a critical illness and admission to an intensive care unit (ICU) is a stressful experience for patients and close family; when an illness is prolonged, it becomes particularly arduous (Hickman and Douglas, 2010). An unintended impact of

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advances in acute critical care is the emergence of a new and growing cohort of patients with chronic critical illness (CCI), a complex illness with a multitude of physiological and psychological consequences, who require a prolonged ICU stay (Carson, 2012; Tilburgs et al., 2015). It is well known that family members of critically ill patients are at a high risk of anxiety and resulting conditions such as posttraumatic stress disorder (PTSD), depression and grief (Davidson, Jones, and Bienvenu, 2012). The impact of CCI on family members has been reported as substantial, with increased symptoms of depression, caregiver burden and decreased quality of life compared to short stay ICU patients' relatives (Hickman et al., 2012). When patients have CCI with multiple ongoing complications and problems family are exposed to an uncertain and slow trajectory (Hickman and Douglas, 2010; Nelson et al., 2010). During a prolonged critical illness, it is important nurses understand family members' experiences to meet families need as part of family-centred care. Family-centred care is based on the principles that the family are seen as an important component of nursing care with the patient (Mitchell and Chaboyer, 2010). There is great diversity in how 'family' is defined, in this study family are those who the patient describes as significant in their life.

Background

Family needs have been a focus of ICU research since the late 1970s, influenced by Molter's seminal study that resulted in the development of the Critical Care Family Needs Inventory (CCFNI) (Molter, 1979). Following that work, the needs of the family while their relative is in an ICU have been well documented including those of information regarding the patient's condition, being in close proximity, and the need for support, reassurance and comfort (Ågård and Harder, 2007; Hinkle and Fitzpatrick, 2011; Obringer et al., 2012; Olding et al., 2015; Wong et al., 2015). Olding et al. (2015) noted family presence within an ICU has been extensively researched, but their findings identified a relationship of passivity, with family viewed as visitors to the ICU, attendants at the bedside or witnessing invasive procedures on their family member, an approach that lacked partnership with healthcare professionals. However, in recent years, the concept of family-centred care has been introduced into ICUs, with family seen as a natural extension of the patient and therefore also the focus of care (Mitchell and Chaboyer, 2010; Mitchell et al., 2016).

ICU nurses play a key role in supporting family to provide them with a sense of security and to help them cope with experiences that families find disturbing (Hetland et al., 2017). When nurses demonstrate personalised care, compassion and positive attitudes towards family it significantly enhances their well-being (Blom et al., 2013; Frivold et al., 2015). Family also provides the link between the patient and the nurse because they offer the opportunity for nurses to know the patient as an individual (Wassenaar et al., 2014). Furthermore, family provide security, consolation and a link to reality that healthcare professionals cannot provide (Cutler et al., 2013; Engstrom et al., 2013; Wassenaar et al., 2014). The importance of family presence for the patients' well-being has been well established (Cutler et al., 2013; Engstrom et al., 2013; Wassenaar et al., 2014).

In the wider context, the highly technical acute care environment with dominance of the biomedical model of care which influences family experiences in the ICU, has not been extensively acknowledged within the literature (Olding et al., 2015). Although there is an expectation that nurses play a leading role in facilitating family-centred care in ICU, their ability to implement this model may be constrained in contexts where doctors maintain authority over patient care (Coombs and Ersser, 2004; Olding et al., 2015). These challenges can become more pertinent when a critical illness is prolonged. This was demonstrated by Roulin and Spirig (2006) who found nurses faced difficulties when caring for patients with CCI in a traditional ICU setting, partly related to organisational characteristics. Organisational characteristics included the loss of information over time, poor care coordination, and a focus on a fast-paced recovery rather than a slow rehabilitative care approach, factors which are also likely to influence negative family experiences (Roulin and Spirig, 2006).

It is estimated that as technologies advance, more patients will survive their initial critical illness, increasing the number of days patients stay in the ICU (Tilburgs et al., 2015). It is also suggested that patients with a CCI are a rapidly growing cohort who have survived their acute critical illness, but are left with ongoing organ dysfunction resulting in prolonged ICU stays of 15 to 60 days (Iwashyna et al., 2016; MacIntyre, 2012; Nelson et al., 2010; Wiencek and Winkelman, 2010). Internationally, patients with CCI comprise be 5 to 10% of the all ICU patients, yet represent 25 to 30% of the ICU bed days (Wiencek and Winkelman, 2010). Hence, the clinical progress for this cohort is relatively slow, making the ICU environment problematic (Roulin and Spirig, 2006). Several studies have shown that this group of patients have unpredictable trajectories, with repeated complications; these can result in a shift to a palliative care focus (Leung et al., 2016; Nelson and Hope, 2012). Hence, family needs are likely to differ; however there is limited literature that deals with their specific needs.

Literature from the United States of America (USA) on family needs when a patient has CCI highlighted that families have distinct characteristics and needs as the patient's CCI continues (Nelson et al., 2010; Wiencek and Winkelman, 2010). These needs included information about how the illness was expected to progress, the prognosis of being liberated from mechanical ventilation, the potential for further complications, pain and suffering, and expectations of the long-term effects of the illness on the patient (Nelson et al., 2005). However further research demonstrated that over 50% of these needs were not met to the family's satisfaction, with most receiving information about the need for a tracheostomy and its immediate implications, but limited information of the short and long-term consequences of CCI (Nelson et al., 2007).

Communication difficulties between healthcare professionals and family have been highlighted as problematic for patients with CCI, particularly in relation to treatment plans that meet individual goals and preferences (Camhi et al., 2009; Nelson and Hope, 2012). Challenges for healthcare professionals have been attributed to the unpredictable initial acute illness, where survival is doubtful, followed by the precarious course of the prolonged critical illness (Leung et al., 2015; Roulin and Spirig, 2006). These uncertainties challenge nurses' abilities to engage with family because of difficulties communicating expected outcomes, as nurses feel information could positively or negatively influence families' hope and cause distrust (Leung et al., 2015). It is important to understand the experience for family through the trajectory of a prolonged critical illness in the ICU, so interventions can be targeted to specific problems to improve patient and family outcomes. The purpose of this study, which forms one part of a larger study, is to explore the experiences of family of ICU patients with a prolonged critical illness.

Methods

This study use a qualitative, longitudinal, instrumental multicase study design, informed by the approaches of Stake (1995) and Merriam (1998) with the theoretical underpinnings drawn from chronic conditions research, including the trajectory framework of Corbin and Strauss (1988). Stake (1995, p2) defines case

study as a "*specific, and complex, functioning thing*", whereas Merriam (1998, p. 9) defines case study as "*... an examination of a specific phenomenon, such as a program, an event, a group, a person, a process, an institution or a social group*" As case study focuses on contexts as well as the case, it is useful for exploring phenomena within its real-life context. Although the case was important to this study, what was of upmost importance was the examination of a specific phenomenon performed within the real life context. Stake (2005) views case study as not a methodological choice but a choice of what to study, which for the family was their experiences throughout the trajectory.

As the aim of this study was to explore how the trajectory was shaped throughout the illness an instrumental approach within the larger study allowed the phenomena of interest the 'trajectory of a prolonged critical illness in the ICU' be understood within it real-life situation, allowing for a rich and holistic account of the experience.

Ethical approval

Ethical approval was granted by the New Zealand Health and Disability Ethics Committee (12/NTB/3). Each hospital also gave organisational approval, as did the senior clinicians within each ICU where data collection occurred. As the case that informed this study was the long-stay ICU patient throughout the trajectory of the prolonged critical illness in the ICU, consent was required from all participants that informed the case. Data collection occurred over a two-year period, with the researcher concentrating on one case at a time when the patient was in the ICU to ensure sufficient time to concentrate fully on data collection.

Family participants were provided with verbal and written study information and gave written consent. Informed consent was an on-going process throughout data collection because of continuing interactions and longitudinal data collection that occurred throughout the patient's stay in the ICU and after discharge.

It was acknowledged that family had many stressors confronting them; including fear of losing the patient and uncertainty of outcomes. It was important to ensure participating in this study was not an added burden. Therefore, ongoing dialogue was important to assess family needs and their understandings as the study progressed. Before this study commenced there was consideration of the potential outcomes that occur throughout the trajectory. Because long-term ICU patients have a high mortality rate, there was the potential the patient's treatment could change from cure to palliation. If patients in this study were to have their treatment changed to palliation, it was planned to seek sensitive and ongoing communication with the family for data collection to continue. If at any time family members showed signs of distress, a discussion about seeking the appropriate help was to occur. Each ICU where this study was conducted had a bereavement service for family of ICU patients, which could offer ongoing services if required. However, this never eventuated and all patients survived their ICU stay to hospital discharge.

Participants and setting

This study took place in four ICUs within the New Zealand public health system. Two were regional hospital ICUs, located in small cities, providing intensive care services at level II that receives both general surgical and medical admissions, and two tertiary-referrals ICUs in large metropolitan cities, providing comprehensive and specialised services of level III ICUs, that admitted patients for general as well as specialised surgical and medical care. All four sites had varying approaches to the management of this patient and family cohort.

As the phenomenon of interest in this study was the trajectory of a prolonged critical illness in the ICU, it was important to maintain data collection throughout the ICU inpatient stay to capture all the complexities that inform the experiences for the family in the ICU. Sixteen family members participated in this study, with between one and four family members per case. Family members included in this study were parents, adult children, spouses, nieces and siblings. As a potential to build a case around the trajectory of a prolonged critical illness in ICU, family recruited into this study were first identified as having a family member as an ICU patient is the larger study. They were first contacted via an ICU research nurse who informed them about the study and the potential for the ICU in-patient and any of their family to participate in. The inclusion criteria for the ICU inpatient were adults, admitted into an ICU for at least seven to ten days, were still dependent of life support and clinically appeared to be not eminently weaned from life support, had family that could provide consent, and who spoke English, six patients met these criteria. Their ICU length of stay ranged from 17 to 66 days, and reasons for ICU admission included respiratory failure, sepsis, and multi-trauma.

Data collection

Data were collected from family, from day seven of the ICU inpatients stay to discharge from ICU by the researcher, who attended the ICU weekly for a 48-hour period. Over this time a range of data collection methods were used. Methods included observation with field notes, in-depth interviews and conversations with family. Over the larger study six cases a total of 160 h was spent observing the ICU inpatient and their care in the ICU, which included observing the family during their time visiting the inpatient, interacting with nurses and family meetings with healthcare professionals. Once the patient was discharged to the ward and home, follow-up interviews were undertaken, with some family.

Short conversations with family members often occurred when they arrived for the day in the ICU, during periods in the waiting room or when they were with the ICU inpatient. Often short conversations were followed up with audio-taped interviews where issues could be explored in more depth. Some family members also texted the researcher with updates about the ICU inpatient and how they were feeling when the researcher was not present in the ICU.

The use of in-depth interviews, combined with periods of observation and short conversations, were invaluable to enrich the data and provide an increased depth of knowledge. Interviews became more focused as the study progressed, with issues identified in earlier cases explored in more detail. Family members participated more often in follow-up interviews, sharing their experiences as the patient's illness progressed and occasional telephone interviews were conducted in-between the researcher's visits.

Reflexivity was important throughout the data collection and analysis process. Familiarity can reduce researcher sensitivity to broader perspectives of experiences and behaviours, therefore the key to reflexivity is transparency of processes (Merriam, 1998). The clear identification of 'self' in the research was important, which started at the study's commencement with the use of field notes to capture observations, thoughts and ideas that could be reflected upon and explored further. Furthermore, field notes were important to record emotional reactions to events and observations so as not to influence data analysis. Case analysis meetings were important (Miles and Huberman, 1994) with all researchers to discuss the field notes, data, issues and interpretations that were puzzling, and to aid further analysis to understand each case in more depth.

Data analysis

Two phases of data analysis were undertaken; within case and cross case analysis (Stake, 2006). Within case analysis was undertaken with all of the data related to a single case. Firstly each case was entered into Dedoose Version 7.5.16 in chronological order, to facilitate how the case was initial described as the illness progressed and qualitative thematic analysis was informed by Boyatzis (1998). Data was also written up as vignettes to incorporate all participant groups, as well as trajectory mapping was undertake to produce a single map of each case with experiences of the patient, family and staff mapped individually and then against the key events in the patient's trajectory. Once each case was complete, including independent data and analysis review, cross case analysis was undertaken, with a focus on the themes related to the differences and similarities in experiences of participant groups across the six cases and in the development of cross-case trajectories. Collective vignettes were also developed to present common trajectories for individual participant groups across the cases.

Findings

Sixteen family members from six cases described their experiences throughout the trajectory of a prolonged critical illness in ICU. These family members viewed themselves as the primary support people for the patient throughout their illness, with some of these family members visiting every day, while others visited as often as their other everyday responsibilities allowed. Their experiences throughout the trajectory were informed by the severity of the ICU inpatients illness, compounded by multiple complications, a slow recovery and uncertainties about the future. The overarching theme of uncertainty portrayed their experiences throughout their family member's illness in the ICU, which varied according to the patients changing trajectory phases.

Being overwhelmed

For family, everyday life suddenly stopped when their family member was admitted to the ICU and their focus turned to the ICU inpatient. As they arrived at the hospital and the ICU and saw the patient for the first time they confronted reality with little understanding of what was happening. In fear, they watched the inpatients physiological struggle. As the ICU inpatient continued to deteriorate, many family assumed, and some were told by the ICU consultant, that the patient had a high probability of dying. For some families it was difficult to accept that the ICU inpatient could be so sick, however, as the patient deteriorated over hours to days, family faced the prospect of their death. These experiences were painful, and for some unbearable to talk about at times, but after some time or weeks to month's families were able to discuss these difficult experiences. These responses were recorded in field notes:

> "*Following the events of the previous week and the traumatic information that their family member could have died, they state they do not want to talk with me at this stage… they "feel raw and traumatised…and can't bear to talk at the moment"… and resurface that grief*". (Case 3, Field notes)

How news was delivered to family during the initial meeting with doctors was also described as a traumatic event for some family members. Although family acknowledged they needed accurate information, the lack of compassion shown by some doctors when delivering bad news was particularly distressing. These initial meetings with the medical team established the precedence for further interactions and set the tone for future meetings. Therefore, family dreaded talking with some doctors:

> "*They give the worst-case scenario all the time, so sometimes you dread talking to the doctors … they want to cover all bases and give you the worst-case scenario so you don't get your hopes up*". (Case 3, Daughter 1)

The ongoing updates from doctors about the patient's condition compounded families' feelings of uncertainty.

Living in an uncertain world

Despite the poor predicted outcomes, these patients survived their initial critical illness. Family experiences correlated with the patient's changing physiological and psychological condition. Initially, a sense of hope emerged as patients began to show signs of improvement, however, this quickly declined as the ICU inpatients physiological condition suffered complications, causing the family ongoing emotional upheaval and leaving them with immense feelings of uncertainty.

Families experienced great anticipation when the ICU inpatient reached a point of physiological stability and reduced sedation levels. A sense of optimism emerged, especially when patients opened their eyes. However, this also became an upsetting experience:

> "*When she did wake up and she had this look of …almost panic, she didn't know where she was… she didn't know who we were …we thought she hated us* [for not letting her die]". (Case 3, Daughter 2)

Families' experienced a significant amount of anguish during this period. Firstly, the suffering they saw as the patient endured treatments and interventions; secondly, seeing the patient daily did not get any easier; and thirdly, they wondered if the patient would be grateful to be saved, due to the potential for physiological impairments. Furthermore, they waited for the ICU inpatient to wake and show signs of improvement to relieve some of their own constant uncertainty.

The placement of a tracheostomy tube was another indicator to family of progress and meant the ICU inpatient had transitioned from a period of being critically ill to one of stability and progress, this in turn reduced their uncertainty:

> "*Putting the trachy in was huge for us, it was definitely a step forward we felt … just little bumps in the road like that, but positive bumps*". (Case 6, wife 2nd interview)

Their feelings of positivity were short lived as the ICU inpatients fragile physiological condition left them prone to sudden changes. Again, uncertainty consumed the family as they wondered how the trajectory would progress:

> "*First we thought 'he wouldn't come out of this'… then we think, 'oh he's on the improve', and then you see him again and you think 'no, he is not going to make it*". (C4, Father 2nd interview)

Family had no control over the ICU inpatients ongoing instability, and with the uncertainty from constant complications came again the fear of death. Living in a world confined by uncertainty made the family vigilant when visiting. They constantly looked for signs of deterioration and improvement; it was their only control to relieve their feelings of uncertainty. They employed a number of strategies for surveillance of the patient. They observed the patients skin colour, questioned the nurse, and tried to converse with them but when they are asleep, they worried:

"*It is a bit hard when you come in and [patient] is asleep and you can't talk to her…you just worry* [that something is wrong]". (Case 3, daughter 1)

Knowing the ICU inpatient so well, family noticed subtle cues to changes in their condition and physiological appearance during their surveillance. Family also noticed something was wrong prior to a severe complication; however, it was difficult to know if healthcare professionals had noticed the same changes in the patient's condition before the deterioration occurred.

Families asked nurses for information, mostly due to their experiences of negative information provided by doctors. Family built connections with some nurses, so when those nurses were on shift, there was a sense of relief that they would include them and meet their information needs. When there was a new nurse or a nurse who was not forthcoming with information, it increased the burden for the family as they tried to alleviate their uncertainty. However, if nurses were not forthcoming family did not push for information, as they did not want to take the focus of care from the patient.

Ongoing complications and uncertainty overwhelmed each family as the illness became so protracted and they tried to balance their family roles and their usual, essential daily activities. Many families had to return to employment or care of dependent family members. Family reported symptoms including, having trouble sleeping, lack of concentration and eating poorly, with constant uncertainty leaving them physically and emotionally exhausted. Adding to their burden was having to fit in with ICU routines or unexpected incidents with other patients that could result in extended periods of waiting to see their family member. Many nurses lacked knowledge of the family's individual needs and so individualised care for family was limited in relation to information exchanges and visiting schedules.

An altering uncertainty

As the ICU inpatient improved enough to be weaned off life sustaining technology and reached a point of stability, family saw positive and encouraging signs, and their uncertainty lessened, however this is short-lived. With the patient awake, their presence was needed now more than ever. For some family their uncertainty alters as they now begin worrying about how the patient would cope with the lasting disability and disfigurement that resulted from the critical illness:

"*I don't know how [family member] will handle the road ahead…I don't know how …I don't know if* [other family members] *will look after him…I don't know what life holds*". (Case 4, Sibling)

However, in all cases family wondered if patients would be able to return to their former lives in relation to being physically well enough to maintain their previous everyday life and work before their illness.

As the ICU inpatient became more aware they wanted their family close by. Family needed to balance their everyday commitments with the needs of their family member, who was trying to make sense of what had happened to them. At times, nurses suggested that family did not need to spend as much time with the patient and they should rest or spend time with other family. However, the predominant patient need at this point of their trajectory was to feel safe and family presence was of great importance to them.

Most families experienced their family member's transfer out of the ICU as a huge milestone. However, they remained uncertain and concerned due to the high possibility of severe disability and what their future life would be.

Uncertainty in a different location

As patients were transferred to wards uncertainty again resurfaced. Families realised the long journey ahead in terms of their family members physiological deconditioning and questioned whether they would return to their previous everyday life, work and health status, as well as how the patient would deal with knowledge of their critical illness.

Family were emotionally shattered and they just wanted the patient home without necessarily understanding the challenges that would bring. The cumulative effects of such prolonged stress for the primary family supporters was evident:

"*I'm worn out…I feel terrible and I have had enough of* [son's] *illness… it goes on and on and on…how will* [son] *work in the future and when he gets home, how will we cope?*" (Case 1, field notes)

As the patient's condition improved they wanted information about their illness. Family were again the link and spent much time telling them about their illness. This required a great deal of emotional work as family have to relive the experiences themselves and deal the emotions of their relative as they learn how sick they were:

"*We've done a lot of talking about it …in the early days …it was quite raw and emotional*". (Case 6, Wife 6th interview)

Moving on

Family moved on with differing thoughts about their future after a family member's prolonged critical illness:

"*I never lost faith that he would survive…I always felt myself on my own, I never felt that I would lose him even though we had those horrendous days…I never lost the faith that he would fight it*". (Case 6, Wife 6th interview)

However, for some family the consequences of surviving a prolonged critical illness was not so straightforward:

"*On bad days I wonder why the ICU saved him…he is just an invalid and all the family are suffering because of it*". (Case 4, Mother 3rd interview)

The significance of family for their family member's well-being throughout a prolonged critical illness was crucial:

"*I couldn't believe that I was in ICU … my family have stories to tell me but I can't remember…and I'm glad I can't remember…but all these stories to tell that I can't relate to … but one thing I know is my children have been there … standing by me with their love and prayers and cares*". (Case 3, Patient)

Discussion

As was illustrated throughout this qualitative study, the experiences for family during a family member's prolonged critical illness in an ICU were dominated by uncertainty, resulting in an extended period of stress. Using a prospective study design, we identified how uncertainty fluctuated throughout the family's trajectory, dependent upon the family member's physiological and psychological condition and needs. The concept of uncertainty has been defined within the nursing literature as a "*… perception of being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation*" (Penrod, 2001). This feeling of unease family felt through the trajectory of a prolonged critical illness related to the fact that there was a significant possibility that the patient

would not survive the initial critical illness, followed by the high probability of complications, and finally the potential for the patient to never regain or return to, their previous way of life. As uncertainty can be reduced or escalated through cognitive, emotional or behavioural reactions (Penrod, 2001) family worked hard to try and alleviate their level of uncertainty. Therefore it is important for nurses to appreciate how family work to alleviate this uncertainty.

Importantly, new understandings were developed by mapping the families experiences against the patient's trajectory in this study as it allows nurses to be better prepared to detail with the complexity of the illness and the effect it has on the family. Assessment of how family are managing the uncertainty experienced by nurses are fundamental to lessen the burden and work for the family as they journey through a prolonged trajectory in the ICU. A greater understanding of the specific needs for family at each stage of the trajectory is crucial to improve outcomes for patients and their family. Knowing family's concerns facilitates the opportunity for nurses to prompt family to share their thoughts about the patient's condition, which has been reported to increase a sense of control (Johansson, 2014).

Families have a moral, ethical, legal, and psychological requirement for information about their critically ill family member. However, many families reported bad experiences at some stages of the ICU inpatients trajectory about how information was delivered or difficulties they had gaining information from individual nurses and doctors. Despite the overwhelming amount of research demonstrating the need for families to receive open and honest communication it remains problematic (Olausson, Ekebergh, and Lindahl, 2012; Wong et al., 2015). Doctors have an ethical and moral obligation to be open and honest about the patient's prognosis, but family also want hope and empathy. Also, the negative view that some ICU nurses demonstrated at times in regard to information sharing with family, suggests they do not understand the philosophy of family centred care or its importance to family and patient outcomes.

The actual work family do, and the important contributions they make to the patient's care, are largely invisible in the literature. However, qualitative research by McAdams et al. (2008) demonstrated the many roles family have, which are not always recognised by nurses. Those roles consisted of active presence, patient protector, facilitator, historian, coach and voluntary caregiver. Families' multiple roles within the ICU was also a significant finding in this study, with those roles complicated by the long duration of the illness that resulted in emotional and physical exhaustion as family tried to juggle multiple roles. McKiernan and McCarthy (2010) also found family were continuously evaluating care, monitoring progress and potential outcomes; however their family participants were only interviewed within the first three to five days of admission. These findings are important to understand family's needs in the ICU and they are particularly important for the body of work of patients with CCI and their family, as patient stays are predicted to increase (Tilburgs et al., 2015).

Nurses are more likely to understand the individual needs of family, especially when the patients' recovery is long and complex, when there is continuation of carer as 'knowing' about the patient, means nurses will also know the family, their responsibilities, and can anticipate their needs. When a family members illness becomes prolonged, it is important for nurses to consider the family's everyday lives, but to also give on-going information about the next phases of the patient's illness and to facilitate the family's active involvement in their family member's care. We identified how a family's uncertainty was reduced or escalated specifically in relation to the patient's condition and interactions with healthcare professionals. Previous research has suggested family members' stress levels are influenced by the interactions they have with the patient and with healthcare professionals (Soderstrom, Savernan, and Benzein, 2006; Wong et al., 2015).

When family work in partnership with nurses they help with symptom assessment, improve patient safety, as well as improve the family's level of anxiety (Hetland et al., 2017). Within this study, family noticed physiological signs of potential deterioration and increased agitation of the patient before there was marked clinical deterioration. This has also reported in recent studies were family were vigilant, looking for physiological deterioration before it occurred and assessing the wellbeing of the patient (Coombs et al., 2016; Plakas et al., 2014). Therefore, when nurses work in partnership with family to assess the patients' wellbeing on a daily basis there is potential to improve patient safety, quality and delivery of care.

The significance for nurses to understand the family's levels of uncertainty at different stages of the trajectory and assessing family's specific needs at this time aligns with the philosophy of family-centred-care. The relationship between patient, family and nurse is based on collaboration and support (Mitchell et al., 2009), however, within the context of an ICU there are many barriers that have impacted on engagement with this model of care. Other studies have report the paternalistic attitude of the nurse, that they know what is best (McConnell and Moroney, 2015; van Mol et al., 2017), as well as the impact of the ICU environment (Hetland et al., 2017), and acuity of the patient (Hetland et al., 2017; McConnell and Moroney, 2015) as barriers.

The findings of our study have relevance to clinical practice by providing nurses with knowledge of the experiences of families during a family member's prolonged critical illness. ICU nurses are central to the provision of care to the patient and family at the bedside and therefore recommendations for practice are based on this view. The development of a philosophy of family-centred care needs to a core component of all ICU care, which when absent was pronounced in this cohort. Just as the nursing role entails constant assessment of the patient, families changing needs need reassessment. When illness is prolonged families must juggle their everyday lives therefore on-going assessment of the family needs to be part of care planning. Documentation should focus on common problems but also have scope to deal with family's individual needs. Ongoing education for ICU nurses should be targeted toward mitigating barriers and facilitation to implement family-centred care within the ICU context, as well as education on how to develop partnerships with families with improved communication and assessment processes. As an illness becomes prolonged, care for patients and their family should include steps to lessen the impact of environmental factors, such as lack of privacy, noise levels and ward routines that are not always conducive to family's routines and their involvement in patient care over a prolonged period, and therefore patient wellbeing.

Limitations

The limitations of this study relate firstly to the findings of qualitative case studies which are not generalizable, because no two social settings are the sufficiently similar. However, the rich descriptions and contexts can offer insights to inform practice.

Although this study may be viewed as small, because of the number of case, there were many participants who informed each case with many family participants interviewed multiple times, which added to the richness of data gathered. However, the family participants with a range of adult family roles, including parents, siblings, spouses and child, were no way representatives of the diversity of families or specific cultural factors related to family roles and responsibilities, which was the focus of this study.

Conclusion

Using a prospective qualitative case study method achieved the aim of understanding the experiences for family throughout a family member's prolonged critical illness in ICU. Knowledge of how experiences changes throughout the illness can assist nurses and educators to target their interventions and education to meet these needs. Our findings provide a foundation for further work to understand the significant needs of family of patients with a prolonged critical illness, which are compounded by the length of the illness and the major impact it has on the everyday life of family members. ICU nurses have a vital role to work with family to help them deal with the multiple roles they perform while burdened with uncertainty.

Conflicts of interest

None.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.iccn.2018.08.010.

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