Family satisfaction with care on the ICU: essential lessons for all doctors

In the intensive care unit (ICU), satisfaction with the care of their loved one impacts upon family members' psychological morbidity and maybe the health of patients afterwards. Enhancing family satisfaction is holistic and may impact on health throughout the hospital and beyond.

Business has long understood that customer experience is equally as important, if not more so, as the quality of their product. Consumers will forgive small deficiencies if the service is excellent and the brand enticing. Health relates to overall wellbeing and not just freedom from disease or infirmity. Nevertheless, health care traditionally emphasizes the latter, focusing on outcomes such as mortality and physical morbidity. Policy makers have highlighted the imbalance and tried to place patient experience at the core of what we do. Consumer-focused care has been emphasized in the UK by the Francis (2013) inquiry, Berwick (National Advisory Group on the Safety of Patients in England, 2013) report and the Care Quality Commission.

Patients exist within a wider social cohesion of family members and friends. Should we endeavour to improve family experience as well? Paediatrics has traditionally adopted a model of patient and family centric care. Undoubtedly, many clinicians who care for adult patients are concerned for the patient's family members, but family experiences are not widely recorded and receive little scrutiny. In intensive care units, where patients are often sedated, family satisfaction has been proposed as a surrogate for patient satisfaction and maybe an indicator of intensive care unit quality (Berenholtz et al, 2002). How important is family satisfaction? Is it a gauge for our compassion? Or is it something that impacts significantly upon the health of patients and their families and friends? (This article uses the word family to refer to the wider group of people that includes relatives, friends and anybody with a close social, emotional or supportive relationship with a patient.)

The aftermath of critical illness

Patient experience

Critical care patients experience an array of negative physical, emotional and cognitive effects. These are in addition to the underlying condition that led to their admission to the intensive care unit which may that have a significant impact upon their physical function or longevity (e.g. disfiguring surgery or new diagnoses of cancer, heart failure, respiratory failure, neurological injury or dialysis-dependent renal failure).

Owing to the severity of their illness and the need for mechanical ventilation, many patients are usually unconscious for a significant period of time and lack early memories. In fact, lack of recall of the entire admission has been reported in 23–45% of intensive care unit patients, with a dose-related correlation between sedative use and amnesia (Capuzzo et al, 2001). After sedative medications are discontinued, a syndrome of acute brain dysfunction termed intensive care unit delirium is often revealed. It is characterized by inattention, fluctuating mental status and an altered level of consciousness or disorganized thinking. It occurs in as many 60–80% of patients who are mechanically ventilated (Ely et al, 2004), and is a consequence of many factors that include the critical illness itself, withdrawal from sedative medications, polypharmacy of other medications, pain, altered bodily status and sleep deprivation. It is associated with poor recall and false, often distressing, memories (Jones et al, 2001; Wade et al, 2012). These may manifest as intrusive dreams or nightmares, hallucinations and paranoid delusions. Patients often know that the experiences are 'unreal' but state that they appear real when they occur. The incidence of these intrusive memories in survivors of a period of intensive care varies from 26–49%. Under-reporting as a result of anxiety at being perceived as having a mental illness has been cited as a potential reason for the large variation seen.

Cognitive dysfunction is associated with significant longer term morbidity in patients who survive their time on the intensive care unit. In one prospective cohort of 157 patients, 55% had some degree of psychological morbidity 3 months following discharge, 27% exhibited signs of post-traumatic stress disorder, 56% had depression and 44% had persistent anxiety (Wade et al, 2012). Psychological morbidity was related to the duration and type of sedation used and the incidence of delusional memories. Others have demonstrated that cognitive

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sequelae may persist for years after discharge, with patients demonstrating an acquired dementia that severely impacts on their quality of life (Hopkins and Jackson, 2006).

Significant muscular wasting and weakness (intensive care unit-acquired paresis) is common and a cause of major disability. It is a consequence of both neuropathy and myopathy. Severely affected patients may lose independent sitting balance and the ability to use their limbs for self care or standing. Rehabilitation is prolonged and results in more prolonged intensive care unit admissions and a longer duration of mechanical ventilation, which in turn leads to longer periods of sedation and the associated risks of cognitive dysfunction and delirium (Schweickert and Hall, 2007).

Several longitudinal studies demonstrate the significant and prolonged health impact of an episode of critical illness (O'Brien et al, 2006). This has been termed the post-intensive care syndrome by the Task Force of the Society of Critical Care Medicine.

Family experience

Psychological morbidity is not limited to patients but encompasses their families and friends. In an observational study of 76 patients, over 50% of family members of patients admitted to the intensive care unit demonstrated signs of depression and psychological illness (Perez-San Gregorio et al, 1992). The Task Force of the Society of Critical Care Medicine in the USA has adapted their post-intensive care syndrome acronym to represent the cluster of anxiety, depression, post-traumatic stress disorder and complicated grief as post-intensive care syndrome-family (PICS-F). Several international studies have been undertaken using well-established scoring systems for anxiety and depressive symptoms (Hospital Anxiety and Depression Scale, HADS) and post-traumatic stress (Impact of Events Scale) in families of critical care patients (*Table 1*). These studies demonstrate that the cluster of PICS-F symptoms tend to ameliorate over time, from admission to 6-month follow-up; however, without intervention, a high incidence of post-traumatic stress disorder remains. Depression and anxiety impair comprehension and decision-making. This should be considered as we involve families in discussions about end-of-life care (Pochard et al, 2001).

Why is family satisfaction important?

Surrogate marker of 'customer care'

Relatives can provide an account and opinion of the perceived quality health care in the absence of an account

Table 1. Prevalence of anxiety, depression or PTSD in families during admission, between 0–3 months and at follow-up (6 months) as measured using the Hospital Anxiety and Depression Scale or Impact of Events Scale

					Incidence (%)		
Study	Location	Study type	*n*		On ICU	0–3 months	6 months
Pochard et al (2001)	France	Multicentre observational	836	Anxiety	69	–	–
				Depression	35	–	–
				PTSD	–	–	–
Pochard et al (2005)	France	Multicentre observational	544	Anxiety	–	73	–
				Depression	–	35	–
				PTSD	–	–	–
Jones et al (2004)	UK	Control group of trial	46	Anxiety	61	62	24
				Depression	26	31	–
				PTSD	–	–	49
Azoulay et al (2005)	France	Observational	284	Anxiety	49	–	–
				Depression	20	–	–
				PTSD	33	–	–
Lautrette et al (2007)	France	Control group of trial	126	Anxiety	69	35	–
				Depression	67	29	–
				PTSD	56	36	–
Anderson et al (2008)	USA	Observational	50	Anxiety	42	21	15
				Depression	16	8	6
				PTSD	–	–	35

ICU = intensive care unit; PTSD = post-traumatic stress disorder.

from a patient who may be unable to do so for the reasons outlined above. Thus observations made by families and friends regarding the timeliness, completeness, concern and compassion with which care was given have been used in intensive care units as a measure of 'customer care' and the holistic nature of the care provided.

Patient experience

Maintaining a high level of family satisfaction may enhance patient experience later on in a patient's journey. During recovery, patients anchor on to 'significant others', usually family members, for assurance and a sense of reality (Morse, 1997). A poor family–clinician relationship or conflict may be perceived by and transferred to the patient.

Families as the primary source of care

In the paediatric population, patient- and family-centred care is based in part on an understanding that the family is the child's primary source of strength and support. Similarly following an adult's critical illness, families continue to support a patient physically, emotionally and financially following discharge. Many patients do not return to their previous occupations, and those that do take time and often modify their roles. Family members with post-traumatic stress disorder and poor satisfaction may be less able to participate in the care of their potentially severely disabled loved ones. The further disruption to family units and the demands upon health and social services could be considerable.

Account of events

Families provide an account of events to the patient upon his/her recovery. Similar to the provision of intensive care unit diaries, this helps patients to fill gaps in their memories and distinguish factual from delusional memories, or at least put delusional memories into context (Jones et al, 2001). It is hypothesized that this may reduce the incidence of longer term psychological morbidity and post-traumatic stress disorder.

Post-intensive care unit syndrome in families

Several factors have been identified that increase the risk of families developing PICS-F (Siegel et al, 2008; Lefkowitz et al, 2010; Davidson et al, 2012). These include the demographics of the family member, such as being young, female, having a pre-disposition to anxiety or depression, or being the spouse of the patient. Bereavement is considered to increase the risk of PICS-F, although not universally (Anderson et al, 2008). Other patient-associated risk factors include the suddenness of the illness and the perceived risk of death. These factors, apart from survival, can not be influenced by the critical care team.

By contrast, potentially modifiable factors that have been associated with PICS-F include low levels of social support, poor intensive care worker communication about anxiety and concerns, poor overall experience with care, a perception of lack of compassion or incomplete disclosure, and an incongruity between the family's desired participation in decision making and that permitted by the health-care team (Azoulay et al, 2005). Attempts to address these factors may reduce the incidence or severity of adverse long-term psychological effects. A diagnosis of post-traumatic stress disorder implies a significant impairment of a major domain of life activity such as work or social relations; the morbidity is great for the person and family.

Measuring family satisfaction

Several tools have been developed to quantitatively and qualitatively measure family satisfaction. However, as important as the tool is the context in which it is used. Reported family satisfaction is likely to differ over time. For example, immediately following discharge family may be relieved that the patient has survived and respond positively. By contrast, later on when there is concern about the prolonged recovery from critical illness, the family may respond differently. Similarly, social and cultural factors, that differ between and within families, are likely to impact upon an individual's expectations and thus his/her satisfaction.

Critical care family needs inventory

Developed in the 1970s, this tool measures the specific needs of family members of critically ill patients, using questions derived from a set of needs statements (Molter, 1979). Answers to these questions are rated using a Likert scale. A later adaptation combined these questions into five domains regarding the need for support, comfort, information, proximity and assurance (Leske, 1991). Its use in measuring family needs has been validated in several international studies (Bijttebier et al, 2000). Assurance and information support are key needs categories during the early post-admission period, with the most important need being 'to know the expected outcome' (Lee and Lau, 2003). Effective communication and information delivery by nurses and physicians reduces anxiety and increases satisfaction among families of critical care patients. If this involves multiple physicians and nurses then this may disrupt the continuity of the message (Johnson et al, 1998).

Critical care family satisfaction survey

The critical care family satisfaction survey is another self-reported measure. Devised in 2001 and then validated in a group of 2494 family members, it has 20 items separated into the same five subscales as the critical care family needs inventory: assurance (the need to feel hope for a desired outcome), information (the need for consistent and timely information), proximity (the need for patient contact), support (the need for resources and support systems) and comfort (the need for family members' personal comfort) (Wasser et al, 2001). A total overall score has been shown to be useful in quantifying and monitoring family satisfaction (Wasser et al, 2004), while subscale scoring is useful in researching met and unmet family needs.

Family satisfaction – intensive care unit

A third tool, the family satisfaction in the intensive care unit survey, was developed for assessing family satisfaction with care and decision making in the critically ill population and has been validated and refined for use through large multicentre cohort studies across North America (Heyland et al, 2002; Wall et al, 2007). It may have advantages over the critical care family needs inventory since meeting family needs may not necessarily guarantee high family satisfaction. Qualitative and thematic analysis of narrative responses can provide a valuable insight into an individual intensive care unit's performance (Henrich et al, 2011). A framework for using the family satisfaction in the intensive care unit survey in these initiatives on the intensive care unit has been produced (Wall et al, 2007). In this study of 539 family members, greater satisfaction was found in the family members of deceased patients, particularly in relation to decision making, communication, emotional support, respect and compassion. The family satisfaction in the intensive care unit survey is currently undergoing a robust evaluation in 20 intensive care units in the UK (FREE study, ISRCTN47363549).

Improving family satisfaction

What can we do better? The main themes that have emerged from the literature on how to improve the family experience include improving communication, the shared decision-making model with particular regard to end-of-life decisions, promoting coping mechanisms within families and the culture of the unit that ensures it is open and approachable to families.

Communication

Communication is one of the most important factors in reducing the psychological burden of intensive care unit admission on families. Poor satisfaction has been demonstrated when incomplete information is given to family members (Azoulay et al, 2005), when a lack of empathy is shown by physicians (Selph et al, 2008), and when the preferred level of family involvement is neither assessed nor adhered to (Gries et al, 2010). The use of formal methods of communication, the provision of consistent and reliable information, and rejecting the practice of withholding poor prognostic information from families as a way of maintaining hope have been shown to relieve conflict and family anxiety, and improve family satisfaction and cooperation (Schaefer and Block, 2009). A task force assembled by the American College of Critical Care Medicine and the Society of Critical Care Medicine (Davidson et al, 2007) highlighted this need for intensive care unit caregivers to receive training in communication, conflict management and meeting facilitation skills. Davidson et al (2007) suggest that intensive care unit staff should give families frequent updates, using terminology they understand, from consistent members of the team. Their findings have been supported by studies showing that family satisfaction increases when fewer clinicians and nurses are involved in the care of the patient and when physicians are more accessible to families, highlighting the importance of consistency of information delivery as key to improving family satisfaction (Fumis et al, 2008).

Shared decision-making model

In the UK, the Mental Capacity Act 2005 defines how we care for the many adult patients on intensive care units who lack capacity to make decisions about their health care (as a result of the administration of sedative medications or as a result of their illness). Outside the scenario where there is a power of attorney, decisions are the final responsibility of health-care professionals who must consider a patient's best interests. This may minimize the burden of decision making on families (Bijttebier et al, 2000; Azoulay et al, 2005) when they are emotionally and physically exhausted, find it difficult to retain or recall complex medical explanations, appropriately weigh the risks *vs* benefits of a particular treatment, or feel unable take responsibility for end-of-life decisions (Azoulay et al, 2005). Nevertheless, family discussions are important in assisting health-care professionals to make the 'best interests' evaluation. The discussions may enable clinicians to understand the likely patient perspective regarding a decision and they certainly help families understand the clinical situation. Indeed, many relatives prefer an active role in patient care and were less likely to be anxious and depressed than those taking a passive role (Anderson et al, 2009; Osborn et al, 2012).

Non-verbal information delivery

Family information leaflets can encourage a dialogue between the clinicians and the family, manage family expectations and improve family comprehension of treatment options and prognosis, allowing for greater participation in clinical decision making (Azoulay et al, 2002). Educational material combined with proactive end-of-life conferences decreased anxiety and depression and post-traumatic stress disorder symptoms in family members 3 months after death (Lautrette et al, 2007).

Changing the culture of an intensive care unit regarding families

Families are often dissatisfied when intensive care units impose restricted visitation policies (Roland et al, 2001). These policies are based on perceptions that this helps clinicians care for patients and that this translates into better clinical outcomes. A more patient- and family-centric approach may be better – families should have an intensive care unit orientation, be informed of intensive care unit routines, and have flexible, individualized visitation to facilitate family coping mechanisms with hospitalization (Jamerson et al, 1996). Flexible visitation has been shown to benefit patients as well as families without evidence that it increases stress in either group (Gonzalez et al, 2004). In fact, there is evidence that unrestricted visiting improves family satisfaction and decreases anxiety without leading to longer family visits (Berwick and Kotagal, 2004).

Other organizational changes can reduce family stress and improve satisfaction. Increasing family involvement in familiar aspects of patient care (e.g. movement exercises and simple patient care) has been promoted as a method to improve families' coping mechanisms with critical illness and to reduce family stress (Davidson et al, 2010). Structural changes within an intensive care unit that ensure better and more private waiting facilities will help families (Osborn et al, 2012; Jongerden et al, 2013).

Conclusions

The intensive care unit has been a focus of family satisfaction since patients are often unable to provide an account of events. By contrast, patient satisfaction is the key focus for ward-based health care. This division is artificial. Patient satisfaction is still paramount even when patients are unable to recall all of what happened. Their opinions about the aspects that they can remember, the eventual outcome and how they felt their families were supported is important. On the intensive care unit, there are psychological and social burdens upon families. These all exist, maybe some to a lesser degree, for families of patients across the hospital and even those treated in their homes.

Family satisfaction is more than a marker of the empathy and compassion with which care is delivered. Changes in practice that improve family satisfaction have the potential to significantly impact upon the health of our patients and their family members. While this remains unproven, is it not something that we would expect for our own loved ones if we were patients? **BJHM**

KEY POINTS

- The last two decades have seen the introduction of the patient-centred model of medical care.
- On the intensive care unit, family-centred care and family satisfaction has been considered as a surrogate measure, not only for patient satisfaction but also the quality of care received by the patient.
- Evidence suggests that maintaining high levels of satisfaction in families leads to reduced stress and post-traumatic stress disorder after discharge, whether the patient survives or not.
- Enhanced family satisfaction may also impact upon patient experience and outcomes.
- Several methods have been developed to measure family satisfaction, but measurement alone is insufficient. A cultural change putting patients' and families' priorities over those of the organization is key. Excellent communication, compassion, appropriately shared decision making, and the intensive care unit environment all impact on family satisfaction.
- Much of what applies on the intensive care unit applies to families of the patients we care for elsewhere in the hospital and even at home.

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