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Balancing professional tension and deciding upon the status of death: Making end-of-life decisions in intensive care units

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Abstract

This study investigated how intensivists make decisions regarding withholding and withdrawing treatment for patients at the end of their lives. This involved completing in-depth interviews from two sites of the South of England, United Kingdom by twelve intensivists. The data collected by these intensivists were analysed using thematic analysis. This resulted in the identification of three themes: intensivists' role, treatment effectiveness, and patients' best interest. Transcending these were two overarching themes relating to the balance between quantity and quality of life, and the intensivists' sense of responsibility versus burden. The results are considered in terms of making sense of death and the role of beliefs in the decision-making process.

Keywords

decision-making, end of life, intensive care medicine, intensivist, thematic analysis, withdrawing treatment, withholding

Introduction

According to the Department of Health (2008), 58 per cent of all the deaths in the United Kingdom happen in hospitals and many patients die in intensive care units (ICUs) and internationally the mortality rates in ICUs range from 15 to 25 per cent (Azoulay et al., 2009; Intensive Care National Audit and Research Centre (ICNARC), 2014; St Ledger et al., 2013; The Intensive Care Society, 2014). The role of intensive care has rapidly expanded over the last 20 years, with critical care staff being involved not only in the care of critically ill patients within the ICU but also of those on general wards before and after their critical illness and even following discharge. Patients in ICUs have care delivered by a multidisciplinary team (MDT; Seale, 2006) consisting of physicians with training in intensive care and other specialities, nurses, physiotherapists and dieticians; care is individualised to each patient's needs. A wide range of some of the most technologically advanced and specialised equipments are also available, with the potential to sustain life even in extreme situations such as multiple organ failure (Curtis and Vincent, 2010). Nonetheless, the responsibility for patient care decisions predominantly lies with the 'intensivists' who have specialised in the care and treatment of critically ill patients. In 2000, the Department of Health (2000) published Comprehensive Critical Care, which detailed the role of the critical care doctor (1) to avert admission by identifying patients who are deteriorating and instituting treatment early or by ensuring timely admission to an area where they can be treated to ensure the best outcome, (2) to support the continued recovery of previously critically ill patients discharged to the ward and after discharge from hospital and (3) to share critical care expertise and experience. Accordingly, the role of intensivists is highly demanding,

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with many expressing significant difficulty with complex decisions. Two such complex decisions concern whether or not to withhold treatment from a patient who is not currently being treated in the ICU and, second, whether or not to make the transition from a focus on the cure of the illness to the comfort of the patient throughout the dying process (Kübler et al., 2011). This is particularly pertinent given that there remain no standardised guidelines regarding decisions to admit to intensive care (versus withholding intensive care treatment) or for dealing with end-of-life decision-making (Leadership Alliance for the Care of Dying People, 2014; Liverpool Care Pathway (LCP), 2014; Pattison, 2006). It is also pertinent given the ongoing debate concerning the relative importance of quality of life versus quantity of life that is ever present both in the media and in the medical literature (Delamothe et al., 2014; Shipman et al., 2008).

Understanding the factors that influence intensivists' decisions is therefore key to improving the overall functioning and delivery of critical care within the ICU setting, and research has identified a role for their demographics, experience, personality and attitudes (Curtis and Vincent, 2010; Hinkka et al., 2002; Oberle and Hughes, 2013; Phua et al., 2015). These will now be considered.

In terms of demographics, studies indicate that physicians' decision-making processes relate to their age, marital status, gender, speciality and religion. For example, Hinkka et al. (2002) investigating physicians' decisions to forgo life-sustaining treatments (LSTs) in terminal care reported that young and female practitioners were more influenced by family appeal and that while younger physicians were more likely to continue most interventions, female physicians were more likely to continue treatments such as supplementary oxygen but not X-rays. Furthermore, oncologists were more likely to discontinue more of the suggested interventions than all other specialities. Similarly, Baggs et al. (2007) reported that whereas medical specialists spent more time with patients and their family to talk through their options and preferences, surgeons spent much less time in discussion yet seemed to continue a focus on cure for longer. Research has also identified a role of professional experience, suggesting that less experience is associated with simpler decisions, a perception of 'seeing a situation too clearly' and a greater willingness to provide treatment (Giannini et al., 2003; Jensen et al., 2013). Research has also explored the role of religion and ethical values but has produced contradictory results. For example, whereas Wenger and Carmel (2004) found that Catholic physicians were less likely to withhold or withdraw treatment compared to those who had no religious affiliation, Sprung et al. (2007) suggested that Catholic physicians were more likely to withdraw treatment than they were to withhold it. Furthermore, physicians who are Jewish or Greek Orthodox have been shown to withhold more often, while Catholics and Protestants tend to withdraw more often (e.g. Curtis and Vincent, 2010; Seale, 2010; Vincent, 1999, 2001). Nevertheless, as argued by Curtis and Vincent (2010), these differences may also be related to resource availability as well as religion or culture per se.

Some studies also show a role for the medical practitioners' personality in end-of-life decision-making. For example, Poulton et al. (2005) reviewed the end-of-life decisions that physicians had made for the past 3 years and measured their personality using the Myers–Briggs (personality) Type Indicator (Clack et al., 2004). The results indicated that those physicians who had made more end-of-life decisions than expected, using medical norms, had higher scores on the 'judging/perceiving' scale.

A final factor influencing decision-making is the physicians' attitudes to end-of-life care (Cook et al., 2003; Elstein and Schwarz, 2002; Thompson et al., 2004). Consistent with this, some research has explored the beliefs of those making end-of-life decisions and the ways these attitudes may influence the decision-making process. Mainly this has focused on attitudes to LSTs with research, showing that while withdrawal and withholding of LSTs are legally and ethically equivalent (British Medical Association [BMA], 1999; General Medical Council, 2010), most physicians believe that it is worse to withdraw a treatment once it has started rather than to withhold it in the first place (Christakis and Asch, 1993, 1995; Solomon et al., 1993).

Other studies have explored attitudes to the role of advance directives, in general, indicating considerable variability with only 6 per cent of Finnish physicians compared to a third of American physicians having completed an advance directive themselves (Mebane et al., 1999; Voltz et al., 1998).

Decision-making, however, reflects a complex array of beliefs other than just those relating to the higher level debates of ethics and can be seen as highly subjective with beliefs and emotions influencing all stages of the process. This is in line with theories of clinical decision-making which highlight a key role for health professional's beliefs in the development of an initial hypothesis, the ways in which they search for evidence and the mechanisms involved in deriving a final treatment plan (Chapman and Elstein, 2000; McWhinney, 1973; Newell and Simon, 1972). It also reflects the large volume of research across a number of domains highlighting a role for health professional's beliefs in decisions relating to diverse issues such as blood pressure management, antibiotic prescription, obesity management, smoking cessation and writing a sick note (see Ogden, 2012 for a review). To date, however, both the complex subjectivity of end-of-life decisions and the role of the beliefs of intensivists working in ICUs remain unexplored. This subjectivity is the focus of this study.

Research focusing on those working in end-of-life care therefore indicates that decision-making relates to a number of demographic factors and personality. Some studies also indicate a role of beliefs and a consideration of higher level ethical issues. In line with theories of clinical decision-making and

research across a number of other domains, it is likely, however, that the decision-making process concerning end-of-life care is more complex than previous research suggests and that there is a strong role for the intensivist's own beliefs, emotions and attitudes at all stages of the care process. Nevertheless, little research has addressed the impact of such subjectivity on the decisions made in ICU to date.

This study aimed to explore the issues that intensivists consider when making decisions concerning the withholding and withdrawing of treatment for patients at the end of their lives. A qualitative research approach was applied in order to ascertain how the intensivists perceived their own decision-making processes and to explore the involvement of subjectivity.

Methods

Participants

A total of 11 male and 1 female intensivists aged from 31 to 65 years were recruited purposively from two hospitals in South-East England. Inclusion criterion was 'currently being employed as an intensivist working in an ICU department'.

An invitation letter and an information sheet were sent to the director of each hospital, who contacted intensivists working within their trust to inform them about the study. Participants were encouraged to contact the researcher directly with any queries and to arrange a time for a face-to-face interview.

Interview

Semi-structured interviews were conducted by the primary investigator (E.K.) in a quiet room in the hospitals, in an attempt to explore and comprehend the processes that intensivists follow when making decisions regarding the withholding and withdrawing of treatment for patients at the end of their lives. The interview guide included questions on the nature and implementation of decisions within the ICU and between the different members of staff. These questions allowed for an understanding of the processes that are followed in each department in general, which staff members were responsible for what issues and who was usually involved in the decision-making. Next, the intensivists were asked to describe a recent or memorable case of a patient's end-of-life care that they were involved in, with a specific focus on the decisions that they made. Finally, the interviewer asked about the impact that the decision-making had on the intensivists themselves.

Procedure

Before deciding to take part in the interview, the participants had the chance to read through the information sheet and signed the consent form before the interview began. All interviews were audio-recorded and lasted between 30 and 80 minutes. Favourable ethical approval was obtained from the Faculty of Arts and Human Sciences Ethics Committee at the University of Surrey (1005-PSY-14).

Analytic strategy

All of the interviews were transcribed verbatim. Thematic analysis was used to analyse the data (Braun and Clarke, 2006). According to the guidelines, transcripts were first read and annotations were made (Willig, 2008). The transcripts were read and re-read to ensure familiarity with the data. For each interview, a coding sheet was used, which contained all possible themes and sub-themes. Relevant quotes from each interview were placed under each theme on the coding sheet. With continuous reference to each interview, comparisons were made across the various themes. A final table of themes and their sub-themes was constructed and the verbatim transcripts were re-read to ensure the themes were a true representation of the original data. Throughout the write-up process, themes and sub-themes were adjusted and illustrative quotes were identified. This analysis process involved close discussion between authors, and although transcripts were not independently coded, all codes, themes and sub-themes were discussed and changed as a result of this discussion.

Results

The intensivists discussed how they made end-of-life decisions for their patients. The analysis indicated that their thinking processes were affected by three key themes: (1) the intensivist's role, (2) treatment effectiveness and (3) the patients' best interest.

The analysis also indicated that two different tensions transcended the transcripts to form two overarching themes. The first tension related to a balance between intensivists' capabilities to prolong patients' lives, on one hand, and the patient's quality of life, on the other hand. The second tension reflected intensivists' difficulty to find a balance between their sense of responsibility and their perception of the burden that accompanies end-of-life decision-making. These themes will now be described and illustrated with exemplar quotes.

Theme 1: intensivists' role

Intensivists described the importance of different aspects of their role in terms of responsibility and burden, the necessity of some degree of 'professional detachment' and the importance of an evident level of confidence when making end-of-life decisions. Furthermore, they mentioned the significance of sharing their responsibility and burden with other intensivists or healthcare professionals and, finally,

re-established their role by claiming the ultimate responsibility of the decision as their own.

My role. Intensivists perceived the end-of-life decision-making and the consequential burden that accompanied this decision as an inclusive aspect of their role – and therefore not the responsibility of the patient's family:

> I don't see myself as God […] that's what I do for a living, I evaluate life and death … (Mark)

Intensivists often felt that the patients and their family expected them to have a 'magic wand' that they can wave and cure their patients. Most of the participants also mentioned a need to feel 'comfortable in their own mind' when they make end-of-life decisions, despite the fact that 'intensive care medicine is an art from – not an absolute science'. In order to do this and maintain a good professional identity, the intensivists felt they should always try to maintain some degree of 'detachment', in a way that they are 'sympathetic and empathetic' without 'breaking down in tears' but also not forgetting that having 'bits of tubing sticking out of your body isn't normal':

> I try to be [detached] as much as I am able to, because I am a human with emotions. (Peter)

Sharing my role. All of the intensivists shared the decisions around end-of-life care with other members of the MDT. However, the definition of an MDT was not the same between hospitals or even intensivists. Some intensivists would consider their ICU colleagues and the medical doctors as an MDT; some would also include the nurses and other healthcare professionals, while others would also involve the patient when they had the capacity to take part in the process as well as the family. Aside from the assembly of the MDT, they all preferred to work as a team as a means to 'share the responsibility' and burden of their role and increase their confidence that 'they are not going out on a limb':

> So that's why you never do it in isolation … […] So you share the burden but also you try and make sure you don't make a mistake. (John)

Sometimes the intensivists would refer to some of their colleagues, who 'actively avoid' making end-of-life decisions, considering this to be both unprofessional and 'cowardly'. This theme also arose by most of the intensivists as a statement of dissatisfaction of the perception that their non-ICU colleagues view them as 'end-of-life opinions'. Physicians from other specialities are perceived to refer their critically ill patients to the intensivists to make life-or-death decisions.

Re-establishing my role. After negotiating, first, their role in end-of-life decision-making and, second, who should have the responsibility and/or the burden that follows it, the intensivists re-constructed the image of themselves as those who have the authority to make decisions:

> I certainly listen to them, but ultimately it's my decision. (Jack)

Intensivists perceive their medical colleagues from other specialities as verifying and reinforcing their status as ultimately responsible for end-of-life decision-making.

This first theme refers to the intensivists' negotiation of their role in terms of what is their responsibility, their burden, the significance of a degree of confidence and professional detachment when making end-of-life decisions, their need to share it and, finally, the reclaiming of their role and everything that accompanies it.

Theme 2: treatment effectiveness

The intensivists elaborated upon the effectiveness of the available treatment in the ICU: the therapeutic interventions, the evolution of critical care medicine and the potential for 'futile' treatment and how this evolved over time.

Therapeutic interventions. Many of the participants discussed how therapies have advanced and the consequent options for prolonging life:

> … We can in critical care, with our … kidney machines and our drugs for the heart and the ventilators – we can keep people alive, 'inverted commas'… (Alex)

Evolution of critical care medicine. Most of the intensivists also observed a difference between the ways in which critical care is delivered now compared to some years ago. Specifically, some of them suggested that the criteria that indicated the admissions in the ICU have changed over time and conditions that were once considered to be fatal are now seen as treatable:

> We admit people we would never have admitted five or ten years ago, who are very very sick, who are very unwell before they even come to the hospital, whose likely outcome is either death or very limited life existence if they possibly get out of hospital. (Tom)

This has contributed to the development of a higher level of expectations on part of patients and their family:

> I think the expectations of healthcare have definitely changed over the years and certainly we've met people who do ITU now who you know, I have more end-of-life decisions to make now than I ever did before because of the expectations of the patients. Nobody is allowed to die anymore. […] Everybody has to die in a hospital bed and if possible in an ITU bed, or at least with an ITU consultant making the decision about who died and who doesn't. (Mark)

This process of the evolution of medicine was seen as having 'pushed the boundaries' between life and death, and many intensivists reported finding it much more difficult to recognise when an end-of-life situation was occurring, sometimes at the expense of the patient's quality of life:

> It's impossible to tell which ones are gonna get better and which ones aren't at the very beginning, so you offer everybody treatment. (John)

Futility and burden of treatment. The participants mentioned that sometimes, despite their efforts and the available equipment, patients die and the treatment that was offered might have been unpleasant. There is therefore a 'burden of treatment' that has to be taken into account when making end-of-life decisions:

> … Some of the things we do to patients do cause harm by the nature, you know, they're invasive and they will have complications, they can cause pain. And if those treatments are not going to affect the outcome, then potentially they are morally wrong to do. (Anthony)

Therefore, when making an end-of-life decision, the intensivists have to consider the costs and benefits of offering a treatment:

> Disease is a burden but treatments can be a burden as well. It can be quite overwhelming for some patients, that they don't want at the end of their life to be having doctors pulling and prodding them or poking them and sticking lines in them. (Kate)

Thus, the intensivists referred to the effectiveness of treatment with regard to the availability of the ICU equipment, the evolution of critical care medicine throughout the years, the potential futility of treatment and the burden that follows it.

Theme 3: patients' best interest

All of the intensivists mentioned their concern for patients' best interests, with a focus on the patients' capacity to participate in their end-of-life decision-making, the protection of their dignity throughout the dying process, the intensivists' identification with the patient and the importance of respect. At times, considering each of these best interests was problematic, as they could be in conflict with each other. Furthermore, although intensivists described attempting to consider the patient's wishes, often through consulting the family, this was hindered by the patient's health status.

Capacity. A major sub-theme that was also discussed among all of the participants was the capacity of the patients to make decisions – a trait that usually patients who are hospitalised in this setting are lacking. However, the ethical issues that emerged regarding this matter were whether or not the intensivist is – or should be – considered capable of making an end-of-life decision for a patient when they cannot communicate their preferences:

> When patients lose that capacity, effectively, all the decisions you're making are potentially in their best interest. All the information you're gathering from the family and from your colleagues, you're trying to make the best determined judgment. (Anthony)

Patient's dignity. Another matter that emerged and appeared to be important for the intensivists was the retention of patient's dignity regarding the dying process:

> When it comes to withdrawing care, I am focusing on what we perceive will be the manner in which the patient will die. So if it's potentially painful, providing pain relief; if there'll be agitation, providing sedation and reduction of anxiety: To provide dignity. (Peter)

Conversely, when the patient's or the family's wishes opposed the intensivists' perception of dignity, they would set aside their own views and follow their desires instead:

> We knew it [resuscitation] wouldn't help him and potentially would lose dignity from the dying process – which I'm sure it did but that's what he wanted, that's what his wife wanted so that's what we did. (Jack)

Identification. Moreover, the intensivists would often identify with the patients or their family and would make an assessment based upon this:

> Would I be doing it any different if it was my mother or brother or sister or my direct relative? (Alex)

Respect. Intensivists also considered the patients' best interests in terms of showing respect for them in terms of a number of different issues. For some this included respecting their religion:

> Myself and a couple of other colleagues […] trying to explain to them that it's a treatment [Cardiopulmonary Resuscitation] we wouldn't recommend or wanted to give. But they [the family] had a religious belief that if you didn't attempt all possibilities, then that is kind of against their belief and they were absolutely resolute in that sort of thing. You can either go completely against them and then if you do that, then it will affect the way they remember their loved one's death. (Richard)

Many also emphasised the need to respect the patient's family:

> 'There's no right or wrong answer to this but you can always stay with your loved one or you can say your goodbyes and

> come back later, or you can just not come back and see them after they've died – it's entirely up to you. You do exactly the way that you want to do it as a person, as an individual or as a family'. If the family's not ready then I'll give them more time – often at this stage it's about treating the family. (Mark)

One of the most interesting aspects that emerged was the amount of significance that the intensivists accredited to the dying process. Specifically, a very humanistic approach was evident among all of the interviews, with great respect to a natural, comfortable and peaceful 'journey from life to death' when that was possible:

> For withdrawing care, the considerations then are how best to minimize discomfort and pain and suffering for the patient. And to minimize stress for the family. And effectively, to give them a nice death. (Peter)

Overall, the intensivists' end-of-life decision-making was influenced by their perception of their role, of the treatment effectiveness and of the patients' best interests. Throughout all of the interviews, transcending these themes were often (1) the struggle to balance the ability to prolong life versus the quality of life they could provide and (2) the intensivists' perceived responsibility versus their perceived burden.

Overarching themes

The balance between quantity and quality of life. Through the interviews, intensivists seemed to have an inner struggle: to either make a decision aiming to prolong patients' life or give them a short but quality existence.

To answer to that dilemma, intensivists reflected upon the definition of the term 'quality of life':

> If you can't interact with your surroundings, if you've got no way of experiencing, do you really exist? […] Who's right, who's wrong? No-one's right or wrong are they? (John)

Based on that perception, they then attempted to weigh the pros and cons of each situation and through their own personal values and experiences, to select the best course of treatment:

> I may be making a valued judgment about quality of life, [but what] may seem terrible to me, actually may be fine from the patient's point of view. But if there's a dramatic change from where they were before, then I'm asking the question as to whether or not we should be going on with treatment. Because I think it's pointless just keeping people going without any possibility of a quality of life at the end of it. […] I accept that it is an intuitive assessment. […] Striving for your patient having some quality of life rather than just quantity … (Matt)

In conclusion, the intensivists' experiences have taught them that often, when life is prolonged, death is also prolonged – a result that is met with discontent:

> Most of the time [when prolonging life], it's just that sense that we are not achieving anything. […] [We are] continuing to maintain the patient's bodily functions. (Alex)

The balance between responsibility and burden. What was also evident among the interviews was the intensivists' struggle to cope with their responsibility as those who are expected to make important decisions in difficult matters and 'fix' their patients:

> My burden to bear because it's my job – I'm the doctor, I'm the patient's doctor, I have to make the decision. (Lewis)

At the same time, they attempt to also cope with the burden of this decision-making process:

> You have to make them [the decisions] and live with that. Because sometimes you accept a patient who is not actually appropriate for intensive care, and then you're accepting a whole load of additional problems that you might not have needed to. On the other hand, you'd feel terrible if you did not accept somebody who actually had a potential for recovery. (Matt)

Finally, there is always the possibility that intensivists' decisions are wrong, which results in them questioning their own abilities and subsequently ruminate over their decisions:

> If I think I'm making the right decision … I feel 'Good, I've done my job well'. [If not], you have doubts about the wisdom of your decision. That can be difficult because then it plays on your mind. (Matt)

Discussion

This study aimed to explore the ways in which intensivists make end-of-life decisions for their patients, with a particular focus on their beliefs, emotions and the subjective aspects of the process. Participants first referred to their role, which often included making end-of-life decisions. In addition, however, they also described the uncertainty associated with these decisions which was often a great burden for them. In order to resolve the inner conflicts arising from this, the intensivists described discussing their cases with an MDT. This reflects the work of Seale (2006) who emphasised the input of the MDT and showed that despite regional variations in interdisciplinary collaboration (Curtis and Vincent, 2010), UK intensivists tended to discuss their thoughts with their colleagues (Pugh et al., 2009; Seale, 2006). In this way, the responsibility and burden of decisions are both shared and 'reinforced' by the authority of another experienced clinician. However, in line with Jensen et al. (2013), the participants also placed the ultimate judgement and principal responsibility of end of life upon the intensivists, re-establishing their role as 'gatekeepers' between life and death. Accordingly, intensivists show beliefs about the

need to both share and own the responsibility for their decisions.

The interviewees also commented on the effectiveness of treatment. The rapid evolution of technology and treatments in ICU were seen to have transformed critical care over recent years. But all these weren't seen in a positive light, and the intensivists described how this had increased patient's and their family's expectations of the ICU. Furthermore, they felt that this had pushed the boundaries between life and death, making them hard to distinguish. Finally, they believed that the changing nature of the treatments they had to offer made the decision-making process more complex and difficult for them as they were sometimes offering treatments which were unpleasant and could make death worse rather than making life better, in line with Moller (1990). Accordingly, their judgements about which care to offer were influenced by their beliefs about the value of new interventions, the extent to which they were influenced by the expectations of others and how they viewed the process of death.

All intensivists also highlighted a need to consider the patient's best interest to evaluate whether they had the capacity to answer, to protect the patient's dignity, even if at times these best interests were in conflict with each other and to show a degree of identification with the patients. This is embedded within their strong sense of respect towards the patient, their family, religion and, ultimately, towards death. It also supports previous studies which have highlighted the ways in which those working in ICUs consider the larger ethical questions surrounding end-of-life care as a means to a good death for their patients and a peaceful memory for their family (e.g. Christakis and Asch, 1993, 1995; Solomon et al., 1993). Furthermore, it reflects the words of Baggs et al. (2007), indicating the degree of time intensivists spend with family and on the decision-making process.

Transcending the interviews were two overarching themes relating to two key tensions. The first reflected the tension between the quantity and quality of a patient's life and an ongoing struggle to decide whether and when to prolong life and avoid death. This can be seen to be present in the intensivists' need to share their decisions with others, their ambivalence about treatment effectiveness and their desire to respect the patient and consider their best interests. This tension reflects the two conflicting roles of the intensivists: to treat patients or to provide them with a good death (Johnson et al., 2000). Second, the results also illustrated a tension between a sense of responsibility versus the burden of their role which was reflected in the concerns about their role as a doctor, the sense of futility and burden offered by new technologies and a desire to address the patient's best interests even if they were in conflict with each other. In this study, participants struggled with both these tensions which were central to ways in which they reflected upon their role and the decisions they had to make. Therefore, although the primary role of the intensivist is to 'fix' patients, there comes a point when a teleological shift is made towards palliative care. This is therefore not a complex decision-making process but also a negotiation within their own sense of professionalism regarding whether the time of death has now arrived based on the 'practical certainty' they have (Ridley and Fisher, 2013) and whether they can manage the burden of such a choice. As Freckelton and Petersen (2006) propose, 'Prolongation of life … does not mean the mere suspension of the act of dying, but contemplates, at the very least, a remission of symptoms enabling a return towards a normal, functioning integrated existence'.

Conclusion

The results therefore indicate that the decision-making processes involved in an ICU are influenced at all stages by the intensivist's beliefs about their role as a doctor and a sense of responsibility which needs to be both shared and owned, beliefs about changes in treatment effectiveness and the impact upon patients, beliefs about the patients best interest and a focus on respect. Their decisions also reflected an ongoing balance and struggle between the quantity versus quality of life and the sense of responsibility versus burden of their role. Accordingly, in line with theories of clinical decision-making, research across a number of health domains decisions concerning end-of-life care appears to be similarly subjective and influenced by personal beliefs and emotions (Chapman and Elstein, 2000; McWhinney, 1973; Newell and Simon, 1972). Furthermore, these beliefs and emotions are ever changing and dynamic as the intensivists negotiate their position on critical life-changing issues.

These results have implications for the health and well-being of both the patients and the intensivists. In terms of patients and their families, although it may be initially worrying to recognise that the decisions being made about their health care while in ICU are subjective and influenced by a number of factors other than medical guidelines, it may also be reassuring to realise that intensivists are making compassionate and individually tailored decisions by drawing upon a number of sources of information and considering both immediate and higher level ethical issues. In terms of intensivists, recent research indicates that this medical speciality experiences high levels of work stress and burnout (e.g. see Reader et al., 2008 for a review). This study suggests that the need to make such complex decisions on a daily basis in the context of individual patients while reflecting on notions of life and death may be a source of stress for this population.

Decision-making has been shown to be a highly subjective process involving an array of beliefs and emotions across a wide range of clinical areas. The results from this study suggest that this is also the case for those decisions

made by intensivists within an end-of-life setting as they draw upon their considerations of their professional role, the effectiveness of current treatments beliefs and the need to reflect upon and respect the needs of the patient. Furthermore, they also have to struggle with some of the most critical tensions there can be in a medical setting; they have been trained to cure patients, but should they prolong a patient's life while sacrificing some of their dignity? How can they be responsible for such important decisions without being absolutely certain? And, finally, how can they bear the burden of this decision if it is wrong? General practitioners are often seen as the gatekeepers to specialist health. Intensivists are likewise gatekeepers – but not to life – to death. On one hand, they are given the responsibility to decide whether death should be avoided regardless of the cost or, on the other, when no quality of life can be offered instead.

> Cause a good death is also as important as a good life. (Jerry)

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