



Research paper

The conceptualisation of health-related quality of life in decision-making by intensive care physicians: A qualitative inquiry



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ABSTRACT

Objectives: To explore how intensive care physicians conceptualise and prioritise patient health-related quality of life in their decision-making.

Research methodology/design: General qualitative inquiry using elements of Grounded Theory. Six ICU physicians participated.

Setting: A large, closed, mixed ICU at a university-affiliated hospital, Australia.

Results: Three themes emerged: (1) Multi-dimensionality of HRQoL—HRQoL was described as difficult to understand; the patient was viewed as the best informant. Proxy information on HRQoL and health preferences was used to direct clinical care, despite not always being trusted. (2) Prioritisation of HRQoL within decision-making—this varied across the patient's health care trajectory. Premorbid HRQoL was prioritised when making admission decisions and used to predict future HRQoL. (3) Role of physician in decision-making—the physicians described their role as representing society with peers influencing their decision-making. All participants considered their practice to be similar to their peers, referring to their practice as the “middle of the road”. This is a novel finding, emphasising other important influences in high-stakes decision-making.

Conclusion: Critical care physicians conceptualised HRQoL as a multi-dimensional subjective construct. Patient (or proxy) voice was integral in establishing patient HRQoL and future health preferences. HRQoL was important in high stakes decision-making including initiating invasive and burdensome therapies or in redirecting therapeutic goals.

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1. Introduction

Clinical decision-making in the intensive care unit (ICU) is an important yet complex process and is the art of practicing intensive care medicine, extending beyond the application of medical technology.¹ When ICU physicians make clinical decisions, they consider the nature of the patient's problems, chance of survival, interactions between chronic and acute problems, pre-

dicted outcome and treatment options in accordance with patient wishes.² Discourse in the spectrum of clinical decision-making has prompted a shift from paternalistic models to those based upon patient autonomy.³ More recently, shared decision-making is emerging as an ideal approach in critical care that involves “meeting in the middle”.^{4–6} Advanced directives were initially believed to be a way of protecting patients' autonomous choices particularly with regard to end of life decision-making despite their known limitations.⁷

As many critically-ill patients are unable to provide a first-hand account, clinical decision-making process within ICU are challenging. Communicating patient preferences for treatment and establishing premorbid health-related quality of life (HRQoL) can

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be difficult.^{8,9} Future HRQoL is clinically considered to be an important goal of intensive care therapy and indicator of treatment success. Little is known about how ICU physicians conceptualise HRQoL and prioritise it within their clinical decision-making.¹⁰ Anticipated future quality of life and functional outcomes are highly valued by patients and their families. These are a central focus in discussions regarding the extent of treatment.¹¹ Other research indicates that as predicted functional outcomes decline, so does the likelihood of patients accepting high-burden interventions.¹²

There is limited and conflicting research investigating the prediction of HRQoL following ICU by physicians. One study of 1932 judgements in 521 patients, found ICU physicians were unable to predict future HRQoL for patients at 6 months post ICU discharge.² In contrast, our previous publication of a small sample of 34 patients, found that physicians were relatively accurate in predicting one-year HRQoL.¹³ Additionally, the subjective nature of HRQoL makes it a difficult construct to understand, evaluate and communicate.¹⁴ As HRQoL outcomes are important to patients and their families¹⁵ it is essential we gain further understanding of how ICU physicians conceptualise and prioritise HRQoL. In particular, ICU physicians are ultimately responsible for decisions regarding the initiation, provision and redirection of therapeutic goals with potential variation in clinical practice styles.^{10,16} Whilst HRQoL is a defined construct able to be objectively measured using validated tools,¹⁷ the academic meaning of HRQoL was not explored with participants. Instead, HRQoL was used in an esoteric way in this study where participants responded to and interpreted HRQoL based on their individual understanding of the term. The aim of this study was to explore how intensive care physicians conceptualise and prioritise patient HRQoL in their clinical decision-making in ICU.

2. Methods

2.1. Researcher reflexivity and relationship with participants

The primary researcher (KH) was a female senior intensive care physiotherapist who worked in the ICU. KH acknowledged the influence of prior clinical experience on her perspectives and belief. Through her clinical experience the researcher had often encountered and felt empathy towards the suffering ICU patient and valued patient preferences for their future HRQoL highly. She was conscious of the risk of judging the quality of decision-making and the influence this may have on her analysis of the data. This risk was managed through regularly debriefing with her supervisor and keeping a diary of responses to the data throughout the analysis process.

KH undertook recruitment (due to limited resources where it was not possible for another researcher to recruit) and conducted the interviews. As KH was a familiar and trusted colleague of the participants; this may have enhanced recruitment and data collection. Alternatively, the pre-existing professional relationship between researcher and participant may have resulted in the participant responding in a limited manner if they were concerned that their clinical decision-making and practice may have been judged. Furthermore, a power imbalance may have existed in the relationship between ICU physician and physiotherapist, in favour of the physician. This too may have impacted the nature of the information shared where the participants may have been more willing to share their information.

2.2. Study design

This study used a generic, qualitative descriptive approach, influenced by Grounded Theory rather than driven by this 'pure' method.^{18,19} Such an approach was well suited to the time-

pressured, ICU environment where repeated access to a limited pool of participants to inform data collection and theory generation, was not feasible. Social constructivism was the underlying theoretical perspective, which supports the existence of multiple realities and places emphasis on the interaction between the participant and researcher. We also drew upon elements of Grounded Theory that included: data being emergent, using data from earlier participants' responses to evolve questioning and Charmaz's systematic approach to data analysis by paying attention to meaning.^{20,21}

2.3. Setting and ethical approval

The study ICU was a secular Australian tertiary, public sector, mixed medical-surgical 20 bed, university-affiliated department operating under the 'closed unit' practice. Within a closed model, the intensivist is directly responsible for patient care whereas in an open model, any physician can make care decisions.²² The institutional ethics committee approved this study and informed consent was obtained from participants.

2.4. Participants, sampling and recruitment

There were eight intensivists practicing in the ICU at the time of this study. Due to a small number of available consultants to select from in a single centre it was not possible to use a purposive sampling approach and instead the sample was chosen based on convenience rather than data saturation. Six participants out of eight were available and approached and consented to the study enabling all interviews to be completed.

2.5. Data collection and generation

In this exploratory work, semi-structured interviews were chosen to obtain detailed and in-depth data from the participants regarding their clinical experience.²³ The interviews lasted approximately one hour per participant. The interview questions were informed through our previous quantitative study results examining prediction of ICU outcomes¹³ and ICU clinical expertise. An experienced qualitative researcher (LR) critically reviewed these questions. Two experienced ICU clinicians (>20 years experience) (LD and SB) reviewed the questions for their relevancy and applicability to the setting and topic. Open-ended questions were chosen to gain insight into the participants' experience and use and understanding of HRQoL information in their practice (see [Appendix A](#)). These questions formed the basis for the semi-structured interviews providing comprehensive data and further prompting questions were utilised where required to explore the issues further.

2.6. Data analysis

After interview transcription, Charmaz's technique of comparing 'data with data, data with codes, codes with categories, category with category, category with concept' was undertaken.²⁰ This process was assisted through the use mind mapping computer software (iMind Map™ Version 7, Think Buzzan, United Kingdom), which acted as a visual aid to schematically display the data to facilitate linking and selecting of categories. The final stages of data analysis moved towards a 'selective phase' where categories are integrated and further defined²⁴ to understand the decision-making process.²⁵ After in-depth and repeated data analysis, no additional data was found to develop new properties or categories. Within this relatively small sample, repetition of the major themes occurred across participant data. An example of this repetition within a sub-theme is provided in [Table 1](#). Despite the small sam-

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