



Research article

Haemato-oncology patients' perceptions of health-related quality of life after critical illness: A qualitative phenomenological study



Geraldine O'Gara^{a,*}, Simon Tuddenham^b, Natalie Pattison^a

^a The Royal Marsden NHS Foundation Trust, Fulham Road, London, United Kingdom

^b Sunnybrook Health Centre, Toronto, Canada

ARTICLE INFO

Article history:

Received 13 June 2017

Received in revised form

19 September 2017

Accepted 26 September 2017

Keywords:

Health-related quality of life

Haemato-oncology

Critical care

Post-traumatic growth

Phenomenology

ABSTRACT

Introduction: Haemato-oncology patients often require critical care support due to side-effects of treatment. Discharge can mark the start of an uncertain journey due to the impact of critical illness on health-related quality of life. Qualitatively establishing needs is a priority as current evidence is limited.

Aims: To qualitatively explore perceptions of haemato-oncology patients' health-related quality of life after critical illness and explore how healthcare professionals can provide long-term support.

Methods: Nine in-depth interviews were conducted three to eighteen months post-discharge from critical care. Phenomenology was used to gain deeper understanding of the patients' lived experience.

Setting: A 19-bedded Intensive Care Unit in a specialist cancer centre.

Findings: Five major themes emerged: *Intensive care as a means to an end*; *Rollercoaster of illness*; *Reliance on hospital*; *Having a realistic/sanguine approach*; *Living in the moment*. Haemato-oncology patients who experience critical illness may view it as a small part of a larger treatment pathway, thus health-related quality of life is impacted by this rather than the acute episode.

Conclusions: Discharge from the intensive care unit can be seen as a positive end-point, allowing personal growth in areas such as relationships and living life to the full. The contribution of health-care professionals and support of significant others is regarded as critical to the recovery experience.

© 2017 Elsevier Ltd. All rights reserved.

Implications for clinical practice

- Critical illness may be only a small part of overall haematological cancer treatment pathway.
- Health-related quality of life impacted by overall cancer treatment rather than acute episode.
- Cancer treatment and acute illness may allow for post-traumatic growth.
- Support of health-care professionals and family critical to long-term recovery experience.

Introduction

It is estimated that there were approximately 918,000 new cases of haematological cancers globally in 2012 (Ferlay et al., 2015). Symptoms and side-effects of disease and treatments such as chemotherapy, radiotherapy, bone marrow transplant, stem cell

transplant and biological therapies can be severe; up to 7% of such patients becoming critically ill during their hospital admission, requiring the support of critical care services, rising to 15% for patients with de novo acute leukaemia (Gordon et al., 2005; Schellongowski et al., 2016). Mortality rates of up to 43% have been reported (Hampshire et al., 2009; Bird et al., 2012) compared to 21% for the general intensive care unit (ICU) population (Intensive Care National Audit & Research Centre (ICNARC) 2013).

Patients with a haematological malignancy have higher mortality, low longer-term survival and are often severely unwell

* Corresponding author.

E-mail addresses: Geraldine.O'Gara@rmh.nhs.uk (G. O'Gara), Natalie.Pattison@rmh.nhs.uk (N. Pattison).

at presentation to critical care due to infection from treatment-related bone marrow suppression (Blightman and Wigmore, 2011; Schellongowski et al., 2016). This has led to reluctance by clinicians to admit such patients to the ICU (Benoit et al., 2003; Azoulay et al., 2015). Intensive care (ICU) and hospital mortality in this cohort is 50% and 58% (Azoulay et al., 2015; Schellongowski et al., 2016); despite this, the most recent United Kingdom (UK) guidance is that critically ill patients with a haematological malignancy, who are appropriate for life-extending treatment or with a good performance status, should be considered for an unrestricted ICU trial (Wise et al., 2015; Schellongowski et al., 2016).

Recent advances in oncological and critical care have led to extension of survival time (Azoulay et al., 2011; Schellongowski et al., 2016) and improved prognosis (Hampshire et al., 2009; Bird et al., 2012; Azoulay et al., 2013, 2015). Some of the factors responsible for this improvement include earlier referral to ICU, earlier antibiotic therapy, better management of sepsis, haemodynamics and ventilation and the use of non-invasive ventilation (Schellongowski et al., 2016). However, multi-organ failure is still a strong predictor of poor outcome for patients with haematological malignancies who are admitted to ICU with hospital mortality of 45.7% for two or more organ failure (Bird et al., 2012). Furthermore, local audit data suggests that haemato-oncology patients with a diagnosis of leukaemia or lymphoma have a length of stay (LOS) greater than 16 days in critical care (Achilleos et al., 2012). Therefore, discharge from critical care can mark the start of an uncertain and difficult journey (McGovern et al., 2011; O'Gara and Pattison, 2013) associated with a broad spectrum of physical and psychosocial sequelae (NICE, 2009) and often refractory effects upon health-related quality of life (HRQoL) (Dowdy et al., 2005; Oeyen et al., 2013; Allart et al., 2013).

A wide range of physical and non-physical morbidity has been reported in critical illness survivors, including: weakness, muscle loss, sensory and pain issues, respiratory problems, swallowing and communication issues, loss of energy, anxiety, depression and post-traumatic stress disorder (NICE, 2009). In addition to these issues, cancer survivors may also experience, among others, health sequelae such as heart disease, gastro-intestinal problems, incontinence, lymphoedema, sexual dysfunction and chronic alopecia (Macmillan Cancer Support, 2013). It is thus even more important that haemato-oncology cancer survivors are provided with healthcare that is patient-centered and relates to their unique concerns (Hall et al., 2013; Schellongowski et al., 2016) such as consequences of high-intensity treatment, increased risk of infection, late effects, and survivorship issues.

Qualitative interpretations of quality of life (QoL)

Health-related quality of life is a multi-dimensional concept that is related to physical, mental, social and emotional functioning (ODPHP, 2014). It is regarded as an important patient-reported outcome measure following critical illness (Hofhuis et al., 2009; Department of Health (DoH), 2012a) and is high on the research agenda for critically ill cancer patients who survived critical care (Azoulay et al., 2011) as well as cancer patients in general (DoH, 2012b; National Cancer Survivorship Initiative, 2013). When using the concept in healthcare, HRQoL denotes a focus on the effects of illness and treatment on quality of life (Guyatt et al., 2007). However, current measures have limitations and can be perceived as blunt; qualitative studies after ICU recovery interpreting HRQoL have shown that they are rarely developed or validated in collaboration with patients, despite this being critical in order to reflect the patient perspective (Ramsay, 2011; Lim et al., 2016).

Haematological cancers are a unique and diverse group which, for some, requires extensive and debilitating treatment involving

Box 1: Inclusion Criteria.

Adults (patients >18 years of age)
 Patients with haematological malignancy who spent more than three days in ICU (in order to gain rich data)
 Speak, understand and read English
 Patients who the clinical nurse specialist (CNS – patients' key worker), as an independent member of the clinical team to facilitate approach, considers well enough to participate

long periods of in-patient care (such as bone marrow transplant and chemotherapy), whilst other forms are chronic in nature with frequent relapsing requiring active treatment and management over a number of years (NICE, 2016). Exploring recovery and perception of HRQoL for haemato-oncology patients is thus particularly relevant due to these complex conditions and associated aggressive and intensive treatment regimens (Grundy and Ghazi, 2009; Oeyen et al., 2013).

Interviews related to individual interpretations of HRQoL allow people to specify the unique and important factors affecting their quality of life and to describe the relative importance of these factors. This study aims to qualitatively explore haemato-oncology patients' perceptions of HRQoL following critical illness, describe how their needs change over time and explore how healthcare professionals can support such patients.

Aims

- *Primary*
 To explore qualitative perceptions of haemato-oncology patients' health-related quality of life after critical care.
- *Secondary*
 To describe long term needs in relation to haematological illness post ICU and explore how healthcare professionals can support patients. To understand how patients' experiences change, over the course of a year, during their recovery after critical care.

Study design

A phenomenological interview study seeking to explore interpretations of HRQoL of patients with a haematological malignancy who were admitted to ICU. The premise of phenomenology is to increase the understanding of the human experience of illness (Madjar and Walton, 1999), gain a deeper and shared understanding of the meaning of a person's lived experience and it allows descriptions of phenomena as experienced in life (Van Manen, 2014).

Ethical considerations

The study protocol was given a favourable opinion by a regional Research Ethics Committee (approval no. 14/LO/0384), the local Research and Development Department and a Patient and Carer Research Review Panel. Written informed consent was taken prior to interview, with further consent taken at a year for the second interview.

Setting

A single-centre study based at a specialist cancer tertiary referral centre. Inclusion Criteria are outlined in Box 1:

Methodology

In order to explore the participant experience, a qualitative method of phenomenology was chosen (Van der Zalm and Bergum,

Download English Version:

<https://daneshyari.com/en/article/8570693>

Download Persian Version:

<https://daneshyari.com/article/8570693>

[Daneshyari.com](https://daneshyari.com)