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‘Being’ a ventricular assist device recipient: A liminal existence

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ABSTRACT

Ventricular assist devices (VADs) are playing an increasing role in the management of heart failure. VADs are mechanical circulatory devices that support or replace the function of a failing heart. Currently, VADs are only offered in theUnited Kingdom (UK) to patients waiting for a heart transplant; however, the use of these devices is likely to increase in the near future. Presently, there is a dearth of literature exploring the day-to-day realities of living with a VAD, which will become increasingly important as the role of VADs is increased.

This paper adopts an interpretive phenomenological approach to uncover the experience of ‘Being’ a VAD recipient. Semi-structured interviews were conducted with 20 VAD recipients. The overarching theme is that life with a VAD is a liminal existence. This comprised four subthemes: the first examines how the VAD imposes limitations on recipients' lives that can precipitate a loss of identity; the second focuses on temporal disruptions, recipients' sense of time changes from authentic to inauthentic; the third explores how the VAD itself is liminal, it is positioned as temporary rather than as the ‘answer’ to the condition; and finally, we discuss VAD recipients' projections to the future and the possibility of an end to the experience of liminality.

1. Introduction

> Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial (Turner, 1969: 95).

This paper draws on the concept of liminality to discuss the experience of living with a Ventricular Assist Device (VAD). The concept of liminal states originates from cultural anthropologist Arnold Van Gennep (1960), who conceived it in relation to passage rites. It was further developed by Turner (1969), who coined the term ‘liminality’ to describe an ambiguous state which occurs following the loss of one social state without the development of another: a time of flux. Whilst its origins lie in anthropology, liminality is being increasingly used to aid our understanding of the experience of illness, in particular in relation to cancer where studies have highlighted a desire for normality and an awareness of the impossibility of returning to the pre-cancer normality (Balmer et al., 2015 Rees, 2017; Trusson and Roy, 2016). It is suggested that through a constant cycle of healthcare appointments illness can plunge us into a sense of temporal boundedness and liminality (Coventry et al., 2014). Relatedly, that liminality can be an enduring state that persists for the remainder of a person with cancer's life (Little et al., 1998). The concept of liminality is also suggested to provide insights into the way cancer survivors find themselves at the margins of everyday life (Blows et al., 2012). The concept has been applied to kidney transplant recipients, for whom liminality becomes particularly apparent when they attempt to re-enter ‘normal life’ and discover that the life offered by the transplant is not as expected (Crowley-Matoka, 2005).

1.1. Phenomenology and time

This paper focuses on the experience of time and identity following the implantation of a VAD. There is often a tendency for the temporal elements of chronic illness to be dismissed (Gergel, 2013), and a need has been highlighted for health care

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professionals to develop a more nuanced understanding of patients' temporal experience (Shubin et al., 2015; Ellingsen et al., 2014). A review of experiences of time in chronic illness identified four structures, of which calendar or clock time is the most frequently used, which may lead us to believe that this has the greatest impact on the individual (Jowsey, 2016). However, Shubin et al. (2015) have problematized the tendency to focus on time as a linear form when attempting to understand the experiences of health and illness, they argue that time is often presented as something which is both consciously intelligible and easily manipulated by both the patient and the health care professional. Schutz (1962: 215-16) highlighted a need to distinguish the 'objective' time of clocks and calendar from 'inner time with which our actual experience (s) are connected with the past … and with the future'.

Our study adopted a phenomenological perspective to explore time as experienced by VAD recipients. Phenomenology can offer a potential means of bridging the gap between medical and existential meanings of illness (Carel, 2011). Phenomenology aims to break through the taken-for-grantedness of daily experiences to expose the more fundamental lived meanings of the experience, to bring forward and make manifest what is normally hidden in human experience. Heidegger's major work, 'Being and Time', focuses entirely on the question of Being, of which time is a core component (Heidegger, 1962). Heidegger sees human experience, identity and time as interwoven; we are temporally situated and our past, present and future are all experienced in unity. Our 'Being' is always relational, time cannot be understood as an external framework, it is central to our experience of the world. Further, our 'being-in-the-world' is always futural; we are always projecting towards the future and it is through our futural projections that we develop an understanding of ourselves (Shubin et al., 2015).

1.2. *Ventricular assist devices*

VADs are a form of mechanical circulatory support which are used increasingly to support patients with advanced heart failure on the waiting list for a heart transplant (NHS Blood and Transplant, 2015), they take over some or all of the pumping function of a patient's heart. There has been rapid development in VAD technologies over the past decade, which has led to a great expansion in the use of the devices (Emin et al., 2013). The VAD comprises of internal and external components. Internally there is the pump itself which is usually attached to the left ventricle, and externally there is a controller and batteries. Implantation requires major, open-heart surgery followed by a lengthy rehabilitation period. The VAD carries the risk of serious complications including bleeding and thrombosis, stroke, infection and device malfunction (Rogers, 2016). The VAD recipient, or their caregiver, are primarily responsible for day-to-day care of the device including: maintaining a constant power supply, cleaning and dressing the exit wound, and managing medications. This can result in significant changes to the lives' of the patients and caregivers (Kato et al., 2014). Previous research has highlighted the receipt of the VAD as a disruption to patients' sense of normality (Hallas et al., 2009; Ottenberg et al., 2014; Marcuccilli et al., 2013), which imparts significant changes to all aspects of life (Sandau et al., 2014).

This paper explores the experiences VAD recipients in the UK under the indication of bridge to transplantation (BTT). Presently, in the UK, VADs are only commissioned as a BTT or bridge to myocardial recovery (NHS Commissioning Board, 2013). Under BTT the device is used to sustain individuals eligible for transplantation until a donor heart becomes available. Bridging to myocardial recovery is where the device is used to relieve strain on the heart affording the possibility that it may recover sufficiently for the device to be explanted, however, this is a rare outcome achieved by less than 4% of a UK sample (Özalp et al., 2014). In the US, and much of Europe, VADs are also used for long-term support, known as destination therapy (DT). This is particularly prevalent in the US where it accounts for over 40% of all VADs implanted (Kirklin et al., 2014).

Our understanding of the ways in which medical technologies intervene into our lives is limited (Haddow et al., 2015; Lauritzen and Hydén, 2007). Medical technologies, like the VAD, originate from the world of medicine as such their aims and rationality are developed in this domain and do not necessarily correspond with the life-world of the patient (Lauritzen and Hydén, 2007). A role for phenomenology has been indicated in understanding and evaluating new technologies (Svenaeus, 2007, 2013). This paper uses the lens of Heidegger's phenomenology to explore the meaning of 'Being' a VAD recipient, to uncover the implications of the device for recipients' life-worlds.

2. Methods and methodology

2.1. *Design*

The data presented in this paper formed part of a PhD study conducted in the UK between 2012 and 2015. This study adopted an interpretive phenomenological approach based on Heidegger (1962) to explore the experience of 'Being' a VAD recipient. Phenomenology is an appropriate methodology for the investigation of phenomena that are central to the lived experience of human beings but not well understood (Carpenter, 1995). Further, it focuses on human experience as a topic in its own right (Langdridge, 2007). In order to understand an aspect of human experience, phenomenological researchers borrow the descriptions of others allowing them to become more vicariously experienced in the phenomenon (Van Manen, 1984; Giorgi, 1997).

2.2. *Procedure*

Ethical approval for the study was granted by Newcastle and North Tyneside 1 NHS Ethics Committee (Reference: 12/NE/0218).

Participants were recruited via a VAD implanting centre in the UK. Clinicians involved in the care and management of VAD patients were used as gatekeepers. They identified potential participants and sought consent for the researcher to make contact. Interviews were scheduled at a time and location of the participants choosing. Participants were given the opportunity to withdraw from the study at several time points during the recruitment process. Each interview was initiated with the question 'please tell me a bit about the process by which you came to receive a VAD?' The intention of this approach was to elicit a brief synopsis of the individual's medical history that had culminated in the implantation of the VAD. This narrative approach afforded respondents the opportunity to give the history of their illness in their own words, focusing on particular events that were key to them. Such an approach is in line with the phenomenological basis of the study, which focuses on the lived experience of the individual (Finlay, 2008). Participants' stories often highlighted interesting issues that had not been anticipated, these were often explored with later questions. Responses to the initial question were varied; whilst some respondents were relatively brief, others spoke uninterrupted without the need for prompts for up to 10 min. In total interviews lasted between 39 and 105 min.

A purposive sample of 20 VAD recipients, and 11 partners, were included in the study. Participants were eligible for participation in the study if they were living with, or had previously lived with a VAD. The majority of patients were implanted with the HeartWare®