



When a policy decision meets practice realities: The case of cancer survivorship care and rehabilitation needs assessment

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ABSTRACT

Purpose: To analyze and describe health professionals' attitudes and perspectives on the complexities of cancer survivorship and rehabilitation needs assessment in a shared cancer care context.

Method: The design and methodology for this study was Interpretive Description and the analysis was informed by Symbolic Interactionism as the theoretical framework. Between April and December 2015 an ethnographic fieldwork was carried out by the first author in haematological wards at two Danish hospitals and in two primary care settings conducting cancer survivorship care programs. Participants were 41 health professionals working with needs assessment.

Results: The findings revealed an understanding of the health professionals' attitudes and perspectives and were distinguishable in relation to three structural conditions associated with the dimensions of survivorship care: *Patient Context*, *Workplace Priorities* and *Practice Culture*. Despite shared beliefs that needs assessment was essential to ensure survivorship care, the differential conditions surrounding the hospital and the primary care setting impeded the wider idea of formalized needs assessment, creating barriers to a seamless link between the sectors.

Conclusions: Meaningful resolution of these disjunctures will require broad solutions, recognizing that the organization of healthcare into disconnected systems, with their different conditions, history, habits and traditions, will certainly plague the “transition” problems in healthcare unless a wider perspective is taken. Thoughtful and informed clinicians working with decision makers and those who know the evidence and can interpret systems in context can certainly bring better options to light in order to develop high quality survivorship care that will support patients throughout their cancer trajectory.

1. Introduction

This study evolves around health professionals' challenges of conducting formal survivorship care needs assessments for all cancer patients whilst collaborating across hospitals and primary care sectors. Policy recommendations stressed the two sectors to collaborate around ensuring a new standardized needs assessment approach for all cancer survivors (Danish Health and Medicines Authority 2012). Conducting the needs assessment and collaborating whilst doing it revealed an unforeseen challenge for the health professionals often leading to a significant number of patients not receiving a formal assessment of needs (Handberg et al., 2017; Biddle et al., 2016).

2. Background

2.1. Cancer survivorship care and rehabilitation

Cancer is a leading cause of death but, fortunately, early detection and improved treatments have led to an increased number of cancer survivors (Are et al., 2013, Aziz 2007, World Health Organization (WHO, 2011). Cancer and its treatments result in side effects and reduced functioning for around half of the survivors and it is known that cancer survivors are at risk of adverse physical, psychological and social symptoms (Ganz, 2009; Alfano et al., 2012). Needs vary within different cancer types, but some groups of patients have very specific needs, such as patients with haematological cancers who have clinical needs at the end of treatment like the need for blood transfusions,

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infusions and treatment for infections and also practical and psychological needs especially evolving fear of recurrence (Swash et al., 2014; Sandgren et al., 2010). When considering all cancer patients' needs, there seem to be common characteristics of their needs associated with such psychological issues as anxiety and concern about those close to you, but also with physical needs like fatigue (Swash et al., 2014). Survivorship care (within which we include rehabilitation) seeks to address the physical, psychological and social needs of cancer survivors and their families and to help them to return to a meaningful life (Cancer.Net, 2015; Alfano et al., 2012; Boland et al., 2014).

Traditionally survivorship care has been initiated after treatment has ended (Johansen and Dalton, 2017; Feuerstein, 2007). However, steps are being taken to change the culture into one of initiating survivorship care at the time of diagnosis as this is believed to optimize relief of the symptom burden (Johansen and Dalton, 2017). The survivorship care programs in Danish primary care settings are offered for free and are available to all cancer patients as part of the National Health System (Danish Health and Medicines Authority 2012). These programs typically include an array of multidisciplinary evidence-based interventions, like physical training, stress relief and supportive care, aimed at restoring functioning and supporting participating patients to achieve independence and a meaningful life (The Danish Cancer Society, 2015; Danish Health and Medicines Authority, 2012).

Numerous studies have showed beneficial effect of physical elements of survivorship care, especially improvement in physical function, less fatigue, better physical fitness, less anxiety, sleep disturbance and depression (Dalton et al., 2010; Bourke et al., 2013; Brown et al., 2012; The Danish Cancer Society, 2015; Fong et al., 2012; Mishra et al., 2012; Puetz and Herring, 2012; Zhang, Li et al., 2017). Psychosocial interventions have been shown to be beneficial for symptom management, pain control, anxiety, depression, quality of life and mood (Galway et al., 2012; Parahoo et al., 2014; Sheinfeld Gorinet et al., 2012; Piet et al., 2012). Survivorship care should therefore be an assimilated element of cancer treatment; however it is known that a significant number of patients do not receive a formal assessment of needs even though this is described as prerequisite for ensuring referral to survivorship care (Veloso et al., 2013; Holm et al., 2012; Leblanc, 2015; Yu et al., 2017). It is problematic that many patients are not getting access to the survivorship care benefits and continue to be lost or abandoned in the “gap” between hospitals and primary care, often without any knowledge about the available evidence-based free-of-charge possibility for cancer survivorship care (Danish Health and Medicines Authority 2012; Grob et al., 2017; Faithfull et al., 2016; Jansen et al., 2015; Sterba et al., 2017).

2.2. A case in point on needs assessment in disconnected health systems

Existing guidelines and policy recommendations on cancer survivorship care are designed to ensure consistency and continuity in assessing the patients' needs, and planning for individualized survivorship care approaches (Danish Health and Medicines Authority 2012; Danish Health And Medicines Authority, 2016; Alfano et al., 2012).

The Danish healthcare system is divided into two sectors. The regional sector is responsible for hospital services and inpatient specialized survivorship care, whereas the primary care sector represents the local setting in the community responsible for general survivorship care usually after hospitalisation (Danish Health and Medicines Authority 2012). The intention is to have seamless care where all cancer survivors at hospitals have the opportunity to have a formal needs assessment around the time of diagnosis and a referral (if needed) to survivorship care programs in the primary care setting (Danish Health and Medicines Authority 2012).

Politically, the two sectors are run from two different administrations; however, every four years, health agreements are discussed and renewed between them to ensure that the sectors cooperate and the patients' trajectory can be as smooth as possible across sectors (Close

Health Offers, Strategy and Planning, Central Denmark Region, 2015). Health agreements were made to ensure that all cancer patients should receive a formal needs assessment: 1) at the hospital to identify the patients' possible needs and ensure referral to the primary care setting if in need, and 2) ideally again in the primary care setting to be able to make survivorship care plans with the patients and individualize the program (Close Health Offers, Strategy and Planning, Central Denmark Region, 2015).

In the Central Denmark Region, it was decided to implement a formal needs assessment (in hospitals and in primary care settings) that should consist of a conversation with the patient regarding the patient's possible needs preferably assisted by a two-page paper-based needs assessment form (Handberg et al., 2017). This intervention (the formal needs assessment) was described in the policy papers, but not directly developed for implementation in clinical practice. Thus, each region and the hospitals and primary care settings within it were left to decide how to implement the needs assessment (Danish Health and Medicines Authority 2012). The chosen needs assessment form in the Central Denmark Region comprises two pages where the first covers six domains: practical, work/school, family, physical, emotional and spiritual/religious, and 58 fixed areas to identify and state as possible needs (Handberg et al., 2017). During the conversation between patients and health professionals the form could be “ticked of” according to the patients' needs within the 58 fixed areas. On the second page, the patient and the health professionals could state and document the survivorship care plans to support the patient (Handberg et al., 2017).

It was expected that the needs assessment system for cancer survivorship care in the Central Denmark Region would be implemented in daily care by January 2015 (Close Health Offers, Strategy and Planning, Central Denmark Region, 2015). However, the actual mechanism of implementation in clinical practice was left up to the health professionals, a plan that appeared to carry with it several challenges comprising both the actual conduct of the needs assessment and also the cross sectorial cooperation on referral practice. This study was designed to explore the health professionals' challenges in implementing this policy initiative into their clinical practice with the aim to better understand possible barriers and facilitators to improve future practice with respect to applying system-wide policies into specific practice contexts.

3. Purpose

The purpose of this study was to analyze and describe health professionals' attitudes and perspectives on the complexities of cancer survivorship and rehabilitation needs assessment in a shared cancer care context.

4. Materials and methods

4.1. Setting

The data set for this study was obtained from health professionals (n = 41) through a five month period of ethnographic fieldwork conducted by the first author between April and December 2015.

The fieldwork was carried out in haematological wards at two hospitals (one rural and one urban) at the Aarhus University Hospital, and in healthcare centres conducting cancer survivorship care programmes in two different primary care settings in the Municipality of Aarhus (urban) and the municipality of Ringkøbing Skjern (rural), all situated in the Central Denmark Region. The two hospitals have a catchment population totalling 1.3 million individuals and the two primary care settings serve the needs of a population of 333,000 and 57,000 individuals, respectively.

The hospital setting in the haematological wards was chosen because this group of patients is known to experience extensive survivorship care needs due to the length and complexity of their illness

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