



Cancer survivorship: Advancing the concept in the context of colorectal cancer



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ABSTRACT

Purpose: Previous conceptualizations of cancer survivorship have focused on heterogeneous cancer survivors, with little consideration of the validity of conclusions for homogeneous tumour groups. This paper aims to examine the concept of cancer survivorship in the context of colorectal cancer (CRC).

Method: Rodgers' (1989) Evolutionary Method of Concept Analysis guided this study. A systematic search of PUBMED, CINAHL, PsycINFO and The Cochrane Library was conducted in November 2016 to identify studies of CRC survivorship. The Braun and Clarke (2006) framework guided the analysis and interpretation of data extracted from eighty-five publications.

Results: Similar to general populations of cancer survivors, CRC survivors experience survivorship as an individual, life-changing process, punctuated by uncertainty and a duality of positive and negative outcomes affecting quality of life. However, CRC survivors experience specific concerns arising from the management of their disease. The concept of cancer survivorship has evolved over the past decade as the importance of navigating the healthcare system and its resources, and the constellation of met and unmet needs of cancer survivors are realised.

Conclusions: The results highlight core similarities between survivorship in the context of CRC and other tumour groups, but underlines issues specific to CRC survivorship. Communication and support are key issues in survivorship care which may detrimentally affect CRC survivors' well-being if they are inadequately addressed. Healthcare professionals (HCP's) therefore have a duty to ensure cancer survivors' health, information and supportive care needs are met in the aftermath of treatment.

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1. Background

Colorectal Cancer (CRC) is the third most commonly diagnosed malignancy worldwide, affecting approximately 3.5 million people annually (International Agency for Research on Cancer, 2014). Significant improvements in survival have been achieved as a result of evolving treatment modalities and screening initiatives which promote earlier diagnosis. However, substantial increases in the incidence of CRC have been forecast. In Ireland alone, colon and rectal cancer incidence is expected to increase by between 77% and 156% between 2010 and 2040 (National Cancer Registry of Ireland,

2014). Thus CRC survivors account for one of the most rapidly growing groups living with and after cancer.

2. Defining cancer survivorship

The term survivorship is used to denote recovery, or life with and beyond a plethora of conditions and circumstances, including cancer (Mullen, 1985), sexual abuse (Dallam, 2010), the atomic bomb (Preston et al., 2007) and the holocaust (Hursting and Forman, 2009). To add to this confusion, the definition of survivorship varies between and within contexts. In cancer survivorship, there is a glaring disparity in the definition of who constitutes a cancer survivor, with different regions and organisations advocating for definitions beginning 1) at diagnosis, 2) after the end of

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treatment, or 3) after a specified time has elapsed where the individual remains disease free (Khan et al., 2012; Leigh, 2007; Reuben, 2004; Rowland et al., 2013). Other considerations in the definition of cancer survivorship are the inclusion or exclusion of individuals who are terminally ill (Khan et al., 2012) and survivors' family members and friends (Feuerstein, 2007; Leigh, 2007). Furthermore, Hebdon et al. (2015) delineated a difference between cancer 'survivor' and 'survivorship'. The former describes the individual who has had a diagnosis of cancer, while the latter refers to the ongoing healthcare needs of the individual.

In his highly influential paper, *Seasons of Survival*, Fitzhugh Mullen (1985) divided cancer survivorship into three distinct 'seasons'; acute, extended and permanent. *Acute Survival* begins at diagnosis, characterized by diagnosis, treatment, fear, anxiety, and uncertainty about the future. *Extended Survival* begins at the end of treatment, or the point of remission. Extended survival is an individual experience, reliant on the individuals' adaptability and life situation. Watchful waiting, fear of recurrence, physical limitations and isolation from healthcare professionals (HCP's) are distinguishing elements of this phase. Finally, *permanent survival* is characterized by an evolving sense of being cured. However, the individual has been irrevocably affected by their experience of cancer physically, psychologically and socially.

Several concept analyses have examined survival in adulthood. However, these analyses focus on breast cancer survivorship among African-American women (Farmer and Smith, 2002), survivorship of chronic illness (Peck, 2008), cancer survivorship (Doyle, 2008) and cancer survivors (Hebdon et al., 2015) (Table 1). Little work has been undertaken to build upon the theories developed within these concept analyses, nor to examine the validity of these conceptual models among survivors with different types of cancer. Furthermore, much of the cancer survivorship literature has been influenced by North American perspectives, with publication in the field driven by the seminal works of Mullen (1985) and the Institute of Medicine (IOM) (2006). Cancer survivorship has only become a priority in Europe relatively recently, as survival rates have improved over the past twenty years (Organisation for Economic Co-operation and Development, 2015). The understanding of cancer survivorship will continue to evolve and mature as culturally diverse views of the concept emerge. Predicted increases in the rate of CRC survivorship will underpin continuing empirical attention to the experiences and outcomes of CRC survivors. It is therefore imperative that such pursuits are grounded in appropriate conceptual foundation. The core attributes of cancer survivorship proposed by Doyle (2008) remain salient, as cancer survivorship is indeed:

"A dynamic, emerging concept pertinent to all cancer care and may be defined as a process beginning at diagnosis and involving uncertainty. It is a life-changing experience, with a duality of positive and negative aspects unique to the individual experience but with universality." (Doyle, 2008, p. 502)

However, it is necessary to revisit the concept of cancer survivorship to ensure that the antecedents, attributes, consequences and definition of cancer survivorship reflect the experiences of homogenous tumour groups, as well as cultural, clinical and political maturation of the concept. Therefore, this concept analysis intends to extend the conceptual framework of Doyle (2008), examining its application to the concept of cancer survivorship in the context of CRC.

3. Concept analysis

Concepts are the building blocks of theory (Rodgers, 2000b).

However, problems arise when concepts are extensively used, as ambiguity arises in the definition and terminology describing the concept (Rodgers and Knaf, 2000). Without clear conceptual foundation, the quality of subsequent research and theory development is weakened (Weaver and Mitcham, 2008). Research on cancer survivorship issues has flourished over the past three decades. However, early interpretations of cancer survivorship may fail to fully encompass conceptual attributes as knowledge in the field develops (Walker and Avant, 1995). A PUBMED search of cancer survivorship terms (Fig. 1) yielded over one million results, with almost 300,000 papers published since Doyle (2008). Fig. 1 highlights the influential nature of seminal publications by Mullen (1985) and IOM (2006). Therefore Rodgers (1989) Evolutionary Method of Concept Analysis guides this paper, as it recognises the dynamic, interrelated nature of reality, and acknowledges that the use, application and significance of a concept may change over time.

4. Methods

The Rodgers (1989) method of concept analysis comprises of eight cyclical stages which facilitates inductive inquiry using a rigorous analytical approach to clarify the concept within the bounds of a particular context (Fig. 2). Identification of the concept attributes is a fundamental step in concept analysis, as they compose a definition of the concept which permits appropriate and effective use. Conceptual clarity is fostered as the antecedents, consequences, surrogate terms, references, and model case are described (Rodgers, 1989).

5. Data sources

PUBMED, CINAHL, PsycINFO and the Cochrane library were systematically searched in November 2016 (Table 2). Searches were limited to English language literature, and studies which included participants aged 18 years or older. To be eligible for review, publications must have referred to individuals with a diagnosis of CRC. Literature published prior to the publication of IOM (2006) were excluded, as it is a seminal publication which has shaped the direction of cancer survivorship care and research. Furthermore, the concept analysis by Doyle (2008) encompassed literature published prior to 2006. The volume of international grey literature on the subject of cancer survivorship has increased exponentially over the past decade in print and electronic form, thanks to the accessibility of social media platforms and other methods of self-publication. Combined with natural language barriers, it would not be possible to obtain an internationally representative sample of grey literature, and therefore lay perspectives have been excluded from this concept analysis. Nevertheless, this concept analysis makes an important contribution to the body of nursing knowledge. Sources were managed in EndNote 7.0. Duplicate and irrelevant studies were excluded following a review of the titles and abstracts. This resulted in 170 unique publications (Fig. 3). Eighty-five were randomly selected for review, accounting for 50% of eligible papers, exceeding the 20% recommended by Rodgers (2000a).

6. Data analysis

Thematic analysis of the data was guided by Braun and Clarke (2006). All included sources were read to gain familiarity with the literature. Included papers were imported to NVIVO 10, initial codes were generated and categorized into attributes, antecedents, consequences and referents. The codes within each category were analysed separately to identify potential themes. Codes were organized and reorganized into themes within each category until

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