



Contents lists available at ScienceDirect

## European Journal of Oncology Nursing

journal homepage: [www.elsevier.com/locate/ejon](http://www.elsevier.com/locate/ejon)

## Self-reported psychosocial needs and health-related quality of life of colorectal cancer survivors

Olinda Santin<sup>a,\*</sup>, Liam Murray<sup>b</sup>, Gillian Prue<sup>a</sup>, Anna Gavin<sup>c</sup>, Gerard Gormley<sup>d</sup>, Michael Donnelly<sup>b</sup><sup>a</sup> School of Nursing and Midwifery Queens University Belfast, Medical Biology Centre, 97 Lisburn Road, Belfast BT9 7BL, UK<sup>b</sup> Centre for Public Health, School of Medicine and Dentistry and Biomedical Science, Queen's University Belfast, Institute of Clinical Sciences, Block B, Royal Victoria Hospital, Belfast BT12 6BA, UK<sup>c</sup> N. Ireland Cancer Registry, Centre for Public Health, School of Medicine, Dentistry & Biomedical Sciences, Queen's University Belfast, Mulhouse Building, Grosvenor Road, Belfast, BT12 6DP, UK<sup>d</sup> Centre for Medical Education, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast, UK

## A B S T R A C T

## Keywords:

Unmet needs  
Colorectal cancer survivors  
Quality of life*Purpose of the research:* To investigate the prevalence and nature of unmet needs among colorectal cancer (CRC) survivors and the relationship between needs and quality of life (QoL).*Methods and sample:* Using the Northern Ireland Cancer Registry (NICR) as a sampling frame and working in collaboration with primary care physicians or GPs, the Cancer Survivors Unmet Needs (CaSUN) questionnaire and the Quality of Life in Adult Cancer Survivors Scale (QLACS) were posted to a randomly selected sample of 600 CRC survivors.*Key results:* Approximately 69% (413/600) met eligibility criteria for participating in the study; and 30% (124/413) responded to the survey. A comparative analysis of NICR data between respondents and non-respondents did not indicate any systematic bias except that respondents appeared to be younger (65 years vs. 67 years). Approximately 60% of respondents reported having no unmet needs, with 40% reporting one or more unmet health and social care needs such as fear of recurrence, information needs, difficulty obtaining travel insurance and car parking problems. QoL was significantly lower for CRC survivors who reported an unmet need. Highest scores (poorer QoL) were reported for fatigue, welfare benefits and distress recurrence.*Conclusions:* Overall, the majority of CRC survivors who had care needs appeared to have needs that were mainly psychosocial in nature and these unmet needs were related to poorer QoL.

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## Introduction

Currently, cancer survivors represent 3% of the United Kingdom (UK) population (Horner et al., 2008; Maddams et al., 2009); and colorectal cancer (CRC) is the fourth most common cancer in the UK with approximately 110 new cases diagnosed daily (CRUK, 2014). In 2008, approximately 334,000 people were diagnosed with CRC (CRUK, 2014). The number of people living with CRC as a chronic illness is increasing due to improved detection and survival (Maddams et al., 2009) and this change in the cancer population

highlights a need for long-term cancer care planning (Bray et al., 2013).

Service planners and providers need to consider the health and social care requirements for cancer survivorship as cancer patients and their caregivers experience poorer health than the general population several years after treatment has ended (Santin et al., 2012, 2013; Elliott et al., 2011; Hewitt et al., 2003; Schultz et al., 2003; Yabroff et al., 2004; Deimling et al., 2005; Keating et al., 2005; Nord et al., 2005; Eakin et al., 2007; Reeve et al., 2009). There is common agreement that there is a need to reconfigure current follow-up services for cancer patients in order to improve the match between care needs and service responses and to improve the efficiency and effectiveness of the cancer care system. The current configuration of the clinical follow-up system for CRC patients does not meet their post-treatment needs (Beaver et al.,

\* Corresponding author. Tel.: +44 (0) 28 9097 2292.

E-mail addresses: [o.santin@qub.ac.uk](mailto:o.santin@qub.ac.uk) (O. Santin), [l.murray@qub.ac.uk](mailto:l.murray@qub.ac.uk) (L. Murray), [g.prue@qub.ac.uk](mailto:g.prue@qub.ac.uk) (G. Prue), [a.gavin@qub.ac.uk](mailto:a.gavin@qub.ac.uk) (A. Gavin), [g.gormley@qub.ac.uk](mailto:g.gormley@qub.ac.uk) (G. Gormley), [michael.donnelly@qub.ac.uk](mailto:michael.donnelly@qub.ac.uk) (M. Donnelly).

2010). The transformation of the follow-up care system is at an early developmental stage in Northern Ireland and the rest of the UK; and it has been slow to develop in the rest of Europe (Rowland et al., 2013). In order to plan appropriate care for cancer survivors, the devolved governments of the UK in partnership with the voluntary sector have commissioned a number of projects to examine the health and wellbeing and service requirements of cancer patients post-treatment. Cancer population needs assessments are vital components in this knowledge generation (Richards et al., 2011), and it is imperative that this knowledge is disseminated to improve health care for cancer survivors across Europe (Rowland et al., 2013). Needs assessments assist in the prioritisation and allocation of services (Bonevski et al., 2000); and in ensuring that patients and their families experience high quality treatment and support (Thewes et al., 2004).

The few studies that have measured the needs of cancer survivors have used different methodologies and produced inconsistent findings (Thewes et al., 2004; Barg et al., 2007; Beesley et al., 2007; Hodgkinson et al., 2007a,b; Zebrack et al., 2007; Armes et al., 2009; Molassiotis et al., 2010; Harrison et al., 2011). For example, they have focused on female cancers (Thewes et al., 2004; Beesley et al., 2007; Hodgkinson et al., 2007b), younger cancer survivors (Zebrack et al., 2007) and early stage survivorship (Armes et al., 2009); and they have used non-psychometrically validated measures of need (Barg et al., 2007). Furthermore, the relationship between the impact that cancer has on QoL and needs for care is unclear (Gotay and Pagano, 2007). Although QoL instruments do not directly measure needs, often, needs are implied from these measures (Hodgkinson et al., 2007a). A conceptually clear and methodologically robust approach is required in order to address the lack of research in this area and to assess systematically the needs and QoL of cancer survivors and examine the relationship between care needs and QoL. There is an increasing role for the clinical nurse specialist to provide holistic care for patients in the context of newly reconfigured models of cancer follow-up care; and it is important that nurses are fully informed regarding the needs of cancer survivors. This paper aims to identify the needs of CRC survivors (via a survey-based quantitative assessment) and the relationship between need and QoL in order to inform practitioners and service providers about the issues faced by individuals living with and beyond CRC.

## Methods

### *Ethical considerations*

Ethical approval was given by the Office for Research Ethics Committees in Northern Ireland (ORECNI). Prior to data collection, steps were taken to ensure confidentiality and limit participant burden. Data were protected under the provisions of the UK Data Protection Act (1998).

### *Study sample*

A random sample of 600 CRC survivors, 2–15 years post-treatment, was generated from the Northern Ireland Cancer Registry (NICR) which is the most reliable source of cancer data in NI. The analysis adjusted for key variables including time of diagnosis. A questionnaire pack was mailed to the General Practitioner (GP) of each identified CRC survivor as stipulated by ORECNI in order to safeguard patients and to eliminate inappropriate mailing to, for example, an individual who was in the end stages of life. This method provided a reasonably quick and inexpensive way of reaching a large and representative sample of CRC survivors. GPs screened patients to ensure that they had a diagnosis of CRC at 18+

years, were not receiving active treatment or end of life care for cancer and they had no cognitive impairment. Questionnaires were forwarded by GPs onto their CRC survivor patients who met the inclusion criteria. Survivors who agreed to participate were requested to return a consent form with their completed questionnaire. Reminder letters and a second copy of the research pack were sent to the GPs of non-respondents. It was not possible to send questionnaires directly to cancer survivors due to ethical concerns. Following data collection, the anonymous study numbers on questionnaires were used to match questionnaires with patient information from NICR in order to identify and compare respondents and non-respondents in terms of date of diagnosis, age, gender, level of deprivation, marital status, cancer site, urban/rural residence and Dukes Staging. In order to establish area level of deprivation, patient's postcodes were matched to the Northern Ireland Multiple Deprivation Measure (NIMDM, 2005).

### *Outcome measures*

The Cancer Survivors Unmet Needs survey (CaSUN; Hodgkinson et al., 2007a,b) and Quality of Life in Adult Cancer Survivors Scale (QLACS; Avis et al., 2006) were mailed to the sample of CRC survivors. The CaSUN consists of 35 needs measured over five domains: Existential Survivorship (14-items); Comprehensive Cancer Care (6-items); Information (3-items); QoL (2-items); and Relationships (3-items). Respondents indicated on a five-point Likert scale whether they had no need (scored 0) through to a strong unmet need (scored 4) within the last month. Items and domains were scored and categorised in terms of 'Met need', 'Unmet need', 'Total need', and 'Strength/severity of need'. All need items were summed to provide a total score with higher scores indicating greater needs (range 0–35). The CaSUN has good acceptability, internal consistency and validity (Hodgkinson et al., 2007a). In addition and in order to ensure the applicability of the CaSUN in the NI context, feedback from key cancer HCPs on the CaSUN led to minor amendments such as changes to wording, the addition of 9 items and the removal of 1 item (fertility issues as survivors in this study were over 50 years old). The nine items added to the CaSUN included 'help with daily activities due to the changes in my body, access to GP, help to manage other illnesses, medication use, how to manage fatigue, coping with changes in appearance, follow-up review anxiety, worries and concerns following treatment and help to stay in contact after treatment'. The internal consistency of the modified version was 0.88.

The QLACS is a 47-item, self-administered multidimensional questionnaire which assesses QoL in the following domains: emotions, cognitive problems, pain, sexual functioning, social avoidance, fatigue, finance, recurrence concerns and family distress, benefits of cancer, positive feelings and appearance. Items were scored on a Likert scale ranging from 1 (never a problem) to 7 (always a problem). A review of QoL measures (Pearce et al., 2008) identified the QLACS as the best validated and most appropriate tool for the measurement of QoL of cancer survivors.

### *Analysis*

T-tests and chi-square analysis were used to compare survey respondents and non-respondents. Descriptive statistics were used to examine the prevalence of unmet need for individual items, needs domains and QoL. Linear regression was used to examine the relationship between total mean QoL and the reporting of unmet need. The model was adjusted for age, gender, marital status, locality, stage, site, time since diagnosis and level of deprivation. An identical approach was used to examine the relationship between unmet need and QoL in each CaSUN domain. Exploratory analysis

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