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Employing patient-reported outcome (PRO) measures to support newly diagnosed patients with melanoma: Feasibility and acceptability of a holistic needs assessment intervention

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ABSTRACT

Purpose: Living with a melanoma diagnosis can be challenging. We aimed to assess the feasibility, acceptability, and perceived value of a nurse-led intervention that utilised patient-reported outcome (PRO) measures to identify and address the supportive care needs of newly diagnosed patients with Stage I/II melanoma over the first 4 months post-diagnosis.

Methods: We conducted an exploratory, repeated-measures, single-arm, feasibility trial. One baseline (4 weeks post-diagnosis; T1) and one follow-up intervention session (4 weeks after wide local excision; T3) took place, two months apart. Patient survey data were collected monthly, at four assessment points (T1-T4), followed by exit interviews.

Results: A recruitment rate of 55% (10/18) was achieved. The skin cancer nurse specialist (CNS) performed 19 in-clinic patient assessments within 6 months. One patient missed their follow-up intervention session (90% retention rate). Three participants (30%) were lost to follow-up at T4. Patients endorsed the standardised use of easy-to-use PRO measures as a means to help them shortlist, report and prioritise their needs. The CNS viewed the intervention as a highly structured activity that allowed tailoring support priority needs. A sizeable reduction in information needs was found from T1 to T4 (Standardised Response Mean [SRM] change = −0.99; $p < 0.05$). From T1 to T2, significant reductions in psychological (SRM change = −1.18; $p < 0.001$), practical (SRM change = −0.67; $p < 0.05$) and sexuality needs (SRM change = −0.78; $p < 0.05$) were observed.

Conclusions: The intervention appears to be feasible in clinical practice and acceptable to both patients with newly diagnosed melanoma and clinicians. Future research is warranted to test its effectiveness against standard care.

1. Introduction

The past decades have seen a steady increase in annual rates of melanoma within the UK (Arnold et al., 2014). In 2012, 14,445 people in the UK (4.4% of all cancer cases) were diagnosed with melanoma (International Agency for Research on Cancer, 2012), which is now ranked fifth behind the leading cancers of breast, lung, colon/rectum and prostate (International Agency for Research on Cancer, 2012). Living with and living beyond melanoma can be challenging (Hajdarevic et al., 2014); yet, little is known about the specific healthcare needs of this patient population. Recent evidence suggests that up to 25% of patients may have unmet needs in the mid-to long-term after primary treatment (Molassiotis et al., 2014). Negative psychosocial effects of a melanoma diagnosis may include emotional hardship due to altered body image, adverse effects on relationships, fear of the sun, uncertainty about the future, and on-going symptoms such as pain and lymphedema (Stamataki et al., 2015). Effectively supporting people with melanoma means offering nursing care that

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takes their healthcare needs into consideration (Hansen, 2014).

Comprehensive needs assessments are now considered an important component of cancer care practice (National Cancer Action Team, 2013; Young et al., 2012). Key government initiatives and policy guidelines advocate for the needs of people with cancer (Department of Health, 2007; National Cancer Action Team, 2013; National Institute for Clinical Excellence, 2004; NHS Scotland, 2008; Scottish Government, 2016) and skin cancer (Hansen, 2014) being addressed to minimise distress, improve the experience of care, and reduce healthcare costs through effective self-management. Such needs assessments are often facilitated through use of self-report questionnaires –known as patient-reported outcome (PRO) measures (Valderas and Alonso, 2008)– that collect information from care recipients about their perceived healthcare needs or concerns (Richardson et al., 2007). Clinicians can use this information to offer care that is tailored to a person's unique needs (Kotronoulas et al., 2017a, b, 2014).

There is evidence, however, suggesting that clinicians in busy clinical settings often fail to assess patients' needs and make appropriate and timely referrals (Kasparian, 2013). One reason may be the fiscal and human resource challenges that healthcare systems currently face, which could deter clinical teams from implementing novel care interventions. Another reason may be that clinicians do not systematically use tools into their current workflows that can help them identify one's unmet needs. Enhancing care in busy clinical settings means meeting end users' (be it care recipients or clinicians) requirements, priorities and expectations for care interventions that are low-cost/maintenance and easy to learn/deliver (Evans-Lacko et al., 2010; Francke et al., 2008; Mair et al., 2012; Scottish Intercollegiate Guidelines Network, 2015).

Given the afore-mentioned gaps, we aimed to test a nurse-led, PRO measures-driven intervention to enhance identification and management of the supportive care needs of people with newly diagnosed melanoma. Nurses are considered to be the most appropriate health professionals to assess PRO measures as they are more receptive to and give greater weight to such information (Greenhalgh et al., 2005). Therefore, the aim of this study was to assess the feasibility, acceptability and perceived value of a needs assessment intervention for newly diagnosed patients with Stage I or II melanoma over the first four months post-diagnosis. Secondary objectives included exploration of (a) the prevalence and intensity of reported supportive care needs and (b) patterns of change in patients' supportive care needs over time.

In accordance to the objectives above, the primary research questions were as follows:

1. What is the feasibility of a PRO measure-driven, nurse-led needs assessment/management intervention for newly diagnosed patients with melanoma in terms of patient availability/recruitment, time and resource requirements, missing data, and patient retention?
2. What is the acceptability of the intervention for newly diagnosed patients with melanoma in terms of adherence, perceived burden, and timing?
3. What is the perceived value of the intervention in supporting patients with melanoma and enhancing health care services offered?

Secondary research questions included the following:

4. What is the prevalence of supportive care needs of newly diagnosed patients with melanoma within the first 4 months after initial diagnosis?
5. How do supportive care needs of patients with melanoma change within the first 4 months after initial diagnosis when participating in the intervention? What is the extent of any change?

2. Methods

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement was employed to guide reporting of this study (von Elm et al., 2007). The study received a favourable ethical opinion from the West of Scotland REC 3 (15/WS/0226).

2.1. Study design and setting

An exploratory, repeated-measures, single-arm, feasibility trial was conducted at out-patient clinics within one NHS board in Scotland. The adopted study design is particularly suitable for early-phase exploration of an intervention's feasibility and acceptability.

2.2. Sample

Patients: A convenience sample of newly diagnosed patients with melanoma was identified by members of the melanoma multidisciplinary team and recruited during weekly meetings. Patients were invited to take part if they were: (a) Diagnosed with melanoma Stage I or II regardless of tumour thickness. (b) Within 1 month post-initial diagnosis following a multidisciplinary team meeting. (c) Aged 18 years or over. (d) Deemed by a member of the multidisciplinary team to be physically and psychologically fit to participate. (e) Able to read and write English. (f) Able to provide written informed consent. Patients not meeting the afore-mentioned criteria were excluded.

Health Professionals: The skin cancer nurse specialist employed within the participating NHS board was invited to the study and asked to provide written informed consent.

2.3. The intervention

The intervention consisted of (a) a pack of "intervention PRO measures" that aimed to identify the supportive care needs of study participants, and (b) face-to-face patient consultations with the skin cancer nurse specialist that were driven by information gleaned from the intervention PRO measures. The intervention PRO measures pack comprised the National Comprehensive Cancer Network's (NCCN) Distress Thermometer and Problem Checklist (DT & PC) (National Comprehensive Cancer Network, 2012), and the Supportive Care Needs Survey-Melanoma module (SCNS-Melanoma) (McElduff et al., 2004). Combining these validated and brief tools into an 'intervention PRO measure' ensured that both generic and melanoma-specific needs can be identified quickly during consultations.

At the time of each intervention session, participants were asked to complete the intervention PRO measures in a quiet room in the hospital immediately prior to their consultation with the nurse specialist. Completed intervention PRO measures were then passed on the nurse specialist for review. The subsequent consultation was based on information collected on priority supportive care needs that was used to direct nursing actions, provide tailored support and intervene accordingly. At the end of the consultation, the nurse specialist documented all interventions initiated and actions taken in a case report form. The nurse specialist was given no specific advice about how to respond to patient needs.

Implementation of this person-centred model was further enhanced by working with people with melanoma throughout the study in an attempt to ensure that the intervention met their preferences and priorities (Carr et al., 2003; Kotronoulas et al., 2017a, b; Ruland, 1998; Ruland et al., 1997).

2.4. Procedures

All eligible patients were thoroughly informed about the purposes and procedures of the study, and provided written informed consent. Patients participated in the study over four, equally spaced (monthly) time-points. This timeline was chosen to allow sufficient time for feasibility testing, whilst minimising the attrition rate. Each patient received the intervention twice. Each intervention session was followed