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Preparing breast cancer patients for survivorship (PREP) – A pilot study of a patient-centred supportive group visit intervention

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ABSTRACT

Purpose: The process of breast cancer follow-up has psychosocial benefits for patients, notably reassurance, although attending hospital appointments can increase anxiety. Discharge from hospital follow-up can also invoke anxiety as many patients seek reassurance from continued specialist follow-up. Inevitably, due to increased survival and associated resource issues, opportunities for follow-up and support will be reduced. We delivered and evaluated an intervention which supported the transition from cancer patient to cancer survivor, for breast cancer patients being discharged to primary care.

Methods: We delivered and evaluated a pilot of a patient-centred group intervention 'Preparing Patients for Discharge', aimed at reducing distress. Between January and September 2008, 172 participants were recruited and 74 (43%) expressed an interest in participating in the intervention; 32 of 74 took part, and participated in its evaluation using a semi-structured evaluation questionnaire, standardized measures [Hospital Anxiety and Depression Scale (HADS) and Clinical Outcomes for Routine Evaluation (CORE)] and independent qualitative interviews.

Results: The qualitative analysis of questionnaire data indicated key factors were 1) shared experience, 2) support and reassurance, and 3) positive views about cancer and being discharged. The interview data revealed that the intervention enabled participants to: share experiences, focus on emotional needs, and have open discussions about recurrence, while increasing confidence in being discharged and using alternative support services. However, no significant differences were found in pre–post-interventions scores of HADS and CORE.

Conclusions: Providing a structured group intervention approach for breast cancer patients offers an early opportunity to support cancer survivors and facilitate and encourage self-management.

Introduction

In the UK, cancer survivorship has become a priority area in cancer care due to improving survival rates. An estimated 2 million people are living with cancer (Maddams et al., 2009), and this is predicted to increase to 4 million by 2030 (Maher and McConnell, 2011). The UK has an estimated 550,000 breast cancer survivors (Breast Cancer Care, 2013), reflecting the successes of early detection and advances in treatment. Conversely, this has placed significant strain on hospital-based breast cancer follow-up which has led to questions about the sustainability of this approach (Davies Nicola and Batehup, 2011). Alternative models have been proven to have similar outcomes to hospital-based follow-up including primary care led follow-up (Grunfeld et al., 2006; Grunfeld et al., 1995, 1996), nurse led follow-up (Beaver et al., 2009) and patient initiated follow-up (Brown and Payne, 2002) often with high patient satisfaction (Adewuyi-Dalton et al., 1998). However, it seems a sea change in the process of follow-up has not yet occurred despite policy guidelines recommending reduced duration of specialist follow-up (NICE, 2002) and/or the opportunity for patient choice in determining a follow-up regime (NICE, 2009).

Moreover, there exists a widespread understanding of the psychosocial impact of cancer and the importance patients attach to reassurance from clinical specialists (Absolom et al., 2009; Jiwa

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et al., 2011; Greenfield et al., 2009). It is also extensively appreciated amongst clinical staff that fear of recurrence is common in survivors and that this causes significant distress (Gray et al., 1998). A recent study highlighted that the most significant unmet needs of cancer survivors are psychological distress and fear of recurrence; providing evidence of the need for continued support after treatment (Armes et al., 2009). Furthermore, the transition from cancer patient to survivor presents both physical and emotional challenges in recovery (Allen et al., 2009) and at a time when patients face losing the specialist reassurance, they are increasingly expected to self-manage. How patients achieve this transition towards the end of follow-up is currently under researched.

The National Cancer Survivorship Initiative (www.ncsi.org.uk) focuses primarily on promoting recovery, health and well-being following a cancer diagnosis and treatment for those who have had curative treatment, and also those who are living with active disease through an increased awareness of the long-term impact of cancer and its treatment (Macmillan, 2008). The NCSI Vision (2010) outlines five key shifts in the approach to cancer care that are supported by DH policy (2007). These shifts include: promoting recovery, health and well-being; assessment of individual holistic needs; promotion of self-management; tailored support; and measuring experience using patient reported outcome measures in aftercare.

The transition from cancer patient to survivor encompasses many tasks for an individual and to complicate this process further, there is the issue about who should provide follow-up cancer surveillance. A new structure for hospital follow-up “Better for less” is being implemented locally and is a patient-led, self-managed follow-up programme where scheduled follow-up visits were reduced from anywhere between 5 and 12 appointments to just 3 which coincide with mammographic screening and with the 3 and 5 year endocrine treatment decision-making appointments. It is important to consider this process of discharge from follow-up as this can be a challenge for a substantial minority (Harrison et al., 2012; Thompson et al., 2012). The prospect of losing the safety and support of the hospital system, can be characterized by feelings of apprehension, vulnerability and abandonment (Cardy, 2006; Jefford et al., 2008; Lewis et al., 2009b). It is likely that primary care teams will be key players in the long-term support of cancer survivors (Jiwa et al., 2012; Grunfeld et al., 2006; Pascoe et al., 2004; Campbell et al., 2002).

The level of psychosocial support that should be offered after discharge from routine hospital follow-up remains unclear. While on the one hand hospital follow-up has been shown to increase anxiety (Stark et al., 2004), patients continue to report psychosocial benefits from this type of follow-up, predominantly the reassurance that it offers (Beaver and Luker, 2005), however, this reassurance does not seem to allay anxiety in the most anxious (Stark et al., 2004). Often the catalyst for the anxiety is the pervasive, persistent fear of cancer recurrence (Armes et al., 2009; Harrison et al., 2012). Further, some patients experience differing levels of anxiety and preferences regarding discharge from secondary care (Kahn et al., 2011). In a review of follow-up Sheppard (2007) suggested further research into the qualitative experiences of patients post-discharge and whether ongoing psychosocial support is warranted.

Patient preference is central in follow-up (NICE, 2009). Some patients favour continued hospital follow-up (De Bock, 2004) whereas other patients reported greater satisfaction with GP follow-up (Adewuyi-Dalton et al., 1998). It is questionable whether patients are adequately informed about the longer term effects of treatment for breast cancer (Luker et al., 1996), and brief consultations offer limited opportunities to discuss informational or psychosocial needs (Beaver and Luker, 2005). Cancer survivors may not be aware of the signs and symptoms of recurrence (Donnelly et al., 2001; Absolom et al., 2009) or the often delayed long-term consequences of cancer and its treatment. Providing information and education to survivors is one way to increase their awareness of the centrality of their role in self-managing a life-threatening illness such as breast cancer.

A body of evidence supports the use of psychosocial interventions for both cancer patients (Rehse and Pukrop, 2003; Stanton et al., 2005) and those with other chronic diseases (Coulter and Ellins, 2006). Internationally there are breast cancer specific interventions *Taking Charge* (Cimprich et al., 2005), Centering Cancer Survivorship (Trotter et al., 2011), a self-management model (Loh et al., 2013) and *Moving forward* (Breast Cancer Care, 2013) which offer a similar group approach with encouraging outcomes, further highlighting the utility of such group interventions with breast cancer survivors.

This study aimed to deliver and evaluate a supportive patient-focused group visit approach to facilitate the transition from cancer patient to cancer survivor.

Methods

Ethical approval for this research was granted by the North Sheffield Research Ethics Committee (07/Q2308/57). This was a pilot study of a patient centred supportive group visit intervention (Preparing Patients for Discharge – PREP). The PREP intervention was refined, delivered and evaluated in collaboration with patients and key stakeholders (Patient, Oncologist, Surgeon, Clinical Nurse Specialist, Cancer Support Centre staff). The process of development was informed by the MRC guidance for complex interventions (MRC, 2000; Craig et al., 2008). The intervention content was based on themes derived from a review of the literature and our previous research with patients that considered their concerns about being discharged from hospital follow-up (Thompson, 2009; Jiwa et al., 2006). The theoretical framework of the intervention was informed by a component of Bandura’s Social Cognitive Theory, self-efficacy (1977), which refers to a patient’s ability to cope with a given situation such as life limiting illness. Cancer patients with high self-efficacy demonstrate improved self-care behaviours and decreased physical and psychological symptoms (Egbert and Parrott, 2001). Within our theoretical framework (Thompson, 2009) we considered patients’ perceptions about: hospital follow-up being a ‘safety net’ and understanding patients ‘attachment’ to medical care, the long-term impact of cancer on individuals and their families, the psychological threat of life-threatening illness and patients access to the breast clinic for re-referral and support after discharge.

The content of the intervention was refined further, following discussion with consultants, nurses and service users from the North Trent Cancer Network Consumer Research Panel.

The intervention (see Table 1)

The group intervention was delivered over a four week period; each weekly meeting lasted two hours. The intervention was structured so that each meeting had a specific theme: Week 1: Experience of follow-up; Week 2: Living with having cancer; Week 3: The threat of recurrence, signs and symptoms; Week 4: Moving on from follow-up. There were between six to nine participants who were all breast cancer survivors. Within the sessions participants sat in a circle, they initially worked in pairs and then discussed issues within the wider group.

This patient centred group intervention was delivered using counselling skills and a structure that enabled some flexibility to respond to individual participants concerns. The course was piloted