



Meeting the ongoing needs of survivors of rarer cancer

Jane Griffiths^{a,*}, Carole Willard^a, Andrea Burgess^b, Ziv Amir^c, Karen Luker^a

^aDepartment of Nursing Midwifery and Social Work, University of Manchester, Oxford Road, Manchester M13 9PL, UK

^bChristie Hospital NHS Foundation Trust, Wilmslow Road, Manchester, UK

^cMacmillan Research Unit, Department of Nursing Midwifery and Social Work, University of Manchester, Gateway House, Piccadilly South, Manchester, UK

KEYWORDS

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Summary

With more treatment options for people with cancer long-term survivorship is increasing. Physical and psycho-social needs have been identified in survivors of common cancers but very little has been written about the needs of patients with rarer cancers. Patients treated for rarer cancer are discharged to the primary health care team (PHCT), yet little is known about the assessment, management and support of these patients. Thirty-nine semi-structured interviews were conducted with (1) survivors of and (2) people living with rarer cancer (i.e. <5% of cancer burden). Participants were asked about physical and psycho-social needs and service provision. Data were analysed thematically using Atlas ti. Contrary to expectation, disease-free survivors of rarer cancer were indistinguishable from those living with disease in their ability to cope, and range of symptoms and needs. Participants with a clinical nurse specialist (CNS) reported that they were well supported on their return home and their needs were met. Participants without a CNS were referred to the PHCT who were unsure how to assess or support them. These participants felt abandoned. There is a need for the rehabilitation of patients with rarer cancer to strengthen individual coping mechanisms, and family and social support. Although there are resource and training implications, this is a potential role for the PHCT, district nursing in particular, and may lead to more focused and targeted provision of services.

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Zusammenfassung

Dank neuer Behandlungsmöglichkeiten nimmt die Lebenserwartung von Krebspatienten zu. Die körperlichen und psychosozialen Bedürfnisse von Patienten, die häufig vorkommende Krebserkrankungen überlebt haben, sind inzwischen bekannt. Über die Bedürfnisse von Patienten mit seltenen Krebsarten wurde dagegen bislang nur sehr wenig publiziert. Patienten mit seltenen Malignomen werden zwar in die Behandlung des *Primary Health Care Teams* (PHCT) entlassen, man weiß jedoch nur wenig über Evaluation, Management und Betreuung dieser Patienten. Insgesamt 32 semistrukturierte Interviews wurden durchgeführt (1) mit Patienten, die seltenere Krebsarten überlebt haben, sowie (2) mit Patienten, die mit selteneren Krebsarten leben (d. h. <5% aller Krebsneuerkrankungen).

*Corresponding author. Tel.: +44 161 275 7596.

E-mail address: jane.griffiths@manchester.ac.uk (J. Griffiths).

[„cancer burden“]). Die Interview-Teilnehmer wurden zu ihren körperlichen und psychosozialen Bedürfnissen und zu den angebotenen Dienstleistungen befragt. Es erfolgte eine thematische Analyse mittels Atlas.ti. Entgegen den Erwartungen fanden sich zwischen krankheitsfreien Überlebenden seltenerer Krebsarten und mit selteneren Krebsarten lebenden Patienten keine Unterschiede im Hinblick auf Coping, Symptome und Bedürfnisse. Teilnehmer, denen eine spezialisierte Krankenpflegekraft (*Clinical Nurse Specialist*, CNS) zur Verfügung stand, berichteten, dass sie bei ihrer Rückkehr nach Hause gut betreut und dass ihre Bedürfnisse erfüllt wurden. Patienten, denen keine CNS zur Verfügung stand, wurden an ein *Primary Health Care Team* überwiesen, dessen Mitarbeiter nicht wussten, wie sie die Patienten evaluieren und betreuen sollten; diese Patienten gewannen den Eindruck, im Stich gelassen zu werden. Patienten mit selteneren Krebsarten sollten rehabilitiert werden: Ihre Coping-Mechanismen sollten gestärkt und die familiäre und soziale Betreuung verbessert werden. Auch wenn dies Konsequenzen im Hinblick auf Ressourcen und Ausbildung hat, könnten hier *Primary Health Care Teams* und insbesondere Gemeindepfleger (*District Nurses*) eine wichtige Rolle spielen, um zu erreichen, dass Dienstleistungen in Zukunft gezielter erbracht werden.

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Introduction

There are now more treatment options for many people with cancer, and long-term survivorship is increasing ([Cancer Research UK \(CRUK\), 2006](#)). Many people will be disease free following treatment and ostensibly “cured”, although there is a reluctance to describe them as such. The term remission implies less certainty of long-term survival than cure. For those for whom there is no cure improvements in palliative treatments mean that they are surviving for extended periods before they die.

There is a burgeoning literature on cancer survivorship, although there is much debate about its definition. Definitions of survivorship vary from immediately after diagnosis, to a year after diagnosis, to the statistical starting point of 5 years after diagnosis and beyond ([Aziz, 2002](#); [Lyne et al., 2002](#); [Bowman et al., 2003](#)). Until relatively recently most survivorship literature emanated from the USA ([Mullan, 1985](#); [Hassey Dow, 1991](#)), but there is now an international literature on issues affecting people who have been treated for and survived cancer. The survivorship literature usually refers to people who have no clinical disease however ([Deimling et al., 2002](#); [Little et al., 2002](#)) with far less written about the experiences of the increasing number of people who are living long term with incurable disease ([Kullmer et al., 1999](#); [Bloom, 2002](#)).

The earlier literature on survivorship studied adults who had survived adolescent or childhood cancer. On the whole these people seemed to do well and were indistinguishable from the rest of the population. Survivors of childhood cancer appear to be fairly resilient to psychological distress for example ([Zebrack and Chesler, 2002](#)), with some reporting that they have grown from their experiences ([Parry, 2003](#)). They also have few long-term physical side effects from their treatment ([Zebrack and Chesler, 2002](#)). For people diagnosed as adults however there is increasing evidence on the late physical effects of treatment ([van de Poll-Franse et al., 2006](#)). For example, one study found reduced physical functioning in women treated for breast cancer who were 5 years disease free ([Helgeson and Tomich, 2004](#)). Most of this late effects research is in common

cancers however such as breast and prostate, with much less known about the late physical effects of treatment for rarer cancer, defined in this paper as less than 5% of the total cancer burden in men and women.

Not surprisingly, psychological needs have been identified in adult cancer survivors. High levels of anxiety have been found in people in remission who were long-term users of follow up ([Lampic et al., 1994](#); [Thomas et al., 1997](#)). Survivors often describe a change in identity, and challenges with getting on with their lives ([Breaden, 1997](#); [Little et al., 2002](#)). Again however, much of the research concentrates on survivors of common cancers ([Thewes et al., 2004](#)), with less known about the needs of people with rarer cancers ([Wettergren et al., 2003](#); [Wells, 2004](#)). For example [Deimling et al. \(2002\)](#) uncovered psychological needs in (disease free) survivors of breast, colo-rectal and prostate cancer; [Amir and Ramati \(2002\)](#) found full or partial Post Traumatic Stress Disorder in 39 breast cancer survivors; and [Thewes et al. \(2004\)](#) found unmet psychological needs among breast cancer patients in remission.

Research suggests that patients' and carers' needs at different points of the cancer journey are often unrecognised and therefore not met ([Rogers and Todd, 2002](#); [Harding and Higginson, 2003](#)). It would also appear that the provision of supportive care is at times inconsistent, unfocused and poorly coordinated ([Griffiths, 1997](#); [Willard, 2004](#)). It may be that this is particularly the case for rarer cancers ([National Institute for Clinical Excellence and Health \(NICE\), 2004a](#)), the subject of this paper.

In the UK The Cancer Plan ([Department of Health \(DH\), 2000](#)) and the Supportive and Palliative Care Guidance ([National Institute for Clinical Excellence and Health \(NICE\), 2004a](#)) recognise the tremendous impact of cancer on the lives of people and those close to them, and emphasise the importance of providing effective support from the point of diagnosis to the end of life. The majority of people who have been treated for cancer are discharged to the care of their general practitioner (GP) and the primary health care team (PHCT). District nurses (DNs) assess, support and give hands on care to patients who have a poor prognosis or who are dying ([Griffiths, 1997](#); [Goodman et al., 1998](#)) and have been

described as the backbone of palliative care in the community (Thomas et al., 1997; Wilson et al., 2002). DNs also visit people earlier on in the disease trajectory (Luker et al., 2000), yet little is known about the assessment and management of people by DNs and the PHCT who have survived cancer, or are living for extended periods before they die.

Method

There was no evidence in the literature on the needs and experiences of survivors of rarer cancers and whether these differed from survivors of more common cancers. This was the main impetus for the study. The need for research was further endorsed by service users working with Macmillan Cancer Support who were close collaborators in the design and conduct of the study. The ongoing needs of people with rarer cancers were identified as a priority for research by service users, in two workshops held by Macmillan Cancer Support in March and April 2003.

The aim of this research was to explore the ongoing physical and psycho-social needs of people with rarer types of cancer who:

1. Had been treated for cancer and now appeared to be disease free (group 1).
2. Were living with but not yet dying from cancer (group 2).
3. Ascertain gaps in service provision for people with rarer types of cancer.

Design

As the experiences of people with rarer types of cancer had received little research attention, a qualitative design was selected. We conducted individual interviews to enable us to explore their needs and views in depth (Fontana and Frey, 1994; Janesick, 1994).

Sample

The list of rarer cancer types is extensive and length of survival varies considerably among rarer cancer sites. For the purpose of this research, rare was defined as an incidence of <5% total cancer burden.

Following approval from a multicentre research ethics committee, participants were selected using convenience sampling techniques informed by principles of purposive sampling. A total of 39 people participated in the study. The majority of people (35) were 1–5 years post diagnosis of cancer. These cut off points were chosen because at 1 year, the initial treatment phase is usually complete and it is at this point that patients are perceived to be survivors (Bloom, 2002). Five years was chosen as the upper limit as this is the figure used by the National Statistics Office to define survival. A 5-year cut off point also helped us to recruit the sample as they were easier to trace than people who are, for example, 20 years post diagnosis. Two participants had been diagnosed before the 5-year cut off point but were included because treatment had started much more recently. Two more participants also exceeded

this cut off point but this did not become apparent until the start of the interview: their data have been included due to their relevance to the research question. Participants were drawn from a wide geographical area although due to the recruitment strategy, the majority (32) resided in the North West of England (see table for participants' characteristics).

Participants were recruited in two ways: through their Clinical Nurse Specialist (CNS) (myeloma lymphoma, carcinoid, neuroendocrine) or through support groups (kidney, vulval). People with oesophageal cancer were recruited via a support group facilitated by a CNS.

Type of cancer	Group 1	Group 2	Total
Kidney	4	2	6
Oesophagus	9	1	10
Non-Hodgkins lymphoma (NHL)	2	1	3
Hodgkins lymphoma	0	1	1
Multiple myeloma	0	9	9
Vulva	4	0	4
Carcinoid/neuroendocrine	1	5	6

Data collection

Data were collected by interviews with individual participants (often accompanied by partners) in their own homes and lasted between 1 and 2 h. Interviews used a semi-structured format and techniques informed by Maguire et al. (1996). To put participants at ease and gain insight into their individual experiences, participants were invited to tell their story from the point of initial diagnosis to the present time. By using this semi-structured format researchers were able to ask specific questions about participants' physical and psycho-social needs and service provision at different points in the cancer journey, and to explore additional issues raised by participants in depth. Interviews were audio taped and transcribed; researchers also made additional notes about the interview where appropriate.

Data analysis

In keeping with qualitative research, data analysis began during data collection by researchers reviewing audio-tapes prior to transcription. Following transcription, interview data were entered into a qualitative data analysis software package (Atlas.ti 5.0), to assist data analysis and management. Data were then analysed thematically. This involved each researcher initially reading through each line of data and summarising its meaning by assigning a code. Codes and corresponding data were then compared and contrasted by the researchers. Similar codes were merged and areas of difference noted to be pursued during interviews with subsequent people. As a result, themes, patterns and differences across the range of data from participants in groups one and two were identified. Identified themes were discussed at the research project steering group to facilitate interpretation of the findings. The steering group comprised

the two researchers, a nurse clinician, a palliative care nurse and two service users. Following this, researchers arrived at a consensus on the themes that represent their interpretation of the findings.

Findings

For the purposes of this research we described our entire sample as cancer “survivors” but made a conceptual distinction between survivors who were free from disease, might experience re-occurrence, but generally had a good prognosis (group 1) and survivors who were living with clinical disease and who at some stage would die from their cancer (group 2). The reason for this separation was that we had expected that the needs of the two groups would be different, i.e. greater in those with a poorer prognosis. On analysing the data however we found that prognosis was a poor predictor of symptoms and needs: the two groups were indistinguishable. So for example, some participants with a poor prognosis had a range of symptoms and needs, others had few or none; some participants with a good prognosis had many symptoms and needs, others again had none. This is evident in the quotations that follow where the prognosis of the participant is indicated by allocation to group 1 (disease-free survivor) or group 2 (living with cancer). The implications of this for practice are highlighted here, and developed further in the discussion.

Physical symptoms

The continued presence of physical symptoms following treatment for cancer is well known (CRUK, 2006). Our sample of people with rarer cancers was no exception to this and many had ongoing symptoms irrespective of prognosis or disease progression. For example participants with oesophageal cancer had a range of debilitating symptoms following oesophagectomy, such as dumping syndrome, acid reflux, fatigue and perhaps more unusually loss of balance as this participant described:

The acid at night ...acid reflux. Plus the fact I get so tired. Funnily enough one said at the support group ... he was losing his balance, and he's walking as if he's a drunk... and I've done that.
(Oesophageal patient group 1: diagnosed 2004).

The participants with multiple myeloma were particularly prone to suffering from long term and disabling effects caused by treatment. The following person described how he developed permanent peripheral neuropathy following participation in a drug trial:

I've got peripheral neuropathy in three areas, feet, fingers, midriff. The midriff has recovered but the feet and hands haven't and it's permanent. ...It's a burning sensation that just won't go away without pain killers. ... You hope the treatment will get you better but the side effects from the treatment that you're given can be as bad in some instances as the disease that you're trying to battle.
(Multiple myeloma patient, group 2: diagnosed 2000).

Another group with distressing physical symptoms were the women who had undergone radical vulvectomy for vulval cancer:

I can't even go and sit in the pictures because I can't sit. I'm very, very uncomfortable you know. Go out for a meal, I can't do that...I can't walk for that long. It's completely altered my life.
(Vulval Cancer patient 1, group 1: diagnosed 2003).
When I pee it goes to the left...How do I go to the toilet and stop flooding the wall? I trashed the house looking for something I could use and for the time being I've come up with an empty loo roll.
(Vulval Cancer patient, group 1: diagnosed 2001).

Psychological effects

It is well recognised that physical symptoms are inextricably linked to psychological symptoms. This was particularly evident in the women with vulval cancer. Their prognosis was good but the long-term psychological and psycho-sexual effects of being “butchered” were difficult to live with:

I couldn't imagine my husband touching me there because I'm right off it...I couldn't imagine anybody touching me there now, it makes me feel bad... He did all my dressings. But that was like a clinical touching, not a ... No I couldn't.
(Vulval cancer patient, group 1: diagnosed 2003).

For the women with vulval cancer it was the de-feminising nature of their surgery that caused them most distress. For other participants, an important psychological consequence of having cancer was uncertainty about the future:

Yes, yes, there is a big chunk of my conscious times when I worry about it because I'm always self-analysing. Is that pain anything to do with it, is the reason I am tired because of the carcinoid. ... Em, it's all that, it's all playing on your mind constantly. What's going to happen? Because I feel as if I can't plan for the future. You, know, I try and not say ... Oh, it's a difficult one because I sometimes think, well what is the future going to be. Am I going to be here in 12 months? Am I going to be here in two years? Am I going to be here in three years or ten years? I don't know, there's not any indication.
(Carcinoid patient, group 2: diagnosed 1999).

Another participant was concerned that the vague symptoms she was experiencing indicated that her original cancer had recurred or spread:

My arm is still swollen. My hands swell up quite a bit. So there is a lot of concern. I've had a mammogram. But I feel it's further back. ... I still don't feel right at all. You think well it could come back somewhere else. So it is really at the back of my mind all the time.
(Kidney cancer patient, group 1: diagnosed 2001).

In our sample, concerns and distress around possible recurrence or spread cannot be accounted for by prognosis. We interviewed people who were disease free, had a good prognosis, had no physical symptoms but were still not

coping well, for example this person who had been treated for NHL:

I feel pretty healthy most of the time ...I'm actually in no physical pain, but I have gone through quite a lot of mental torture because it's just twenty-four hours a day. It just never goes away. It's there when I'm dreaming and it's there when I'm awake, you know, it's a twenty-four hour thing ...I can't settle my mind into anything really...You stop living the day you get told you've got cancer, I think. Well, I did anyway. That was it. Life was over... I can only live day to day now. I can't see any future... I just can't be bothered.

(NHL patient, group 1: diagnosed 2003).

Many participants described surprisingly few psychological symptoms however whatever their prognosis. For example this person with oesophageal cancer and a poor prognosis was very well psychologically:

Up to now I've stared it in the faceI've dealt with it ...living alongside cancer...I don't feel as though my time is here yet, but I will know when it's ready...At the moment I'm just looking it in the face....I'm going to try and stay with that positive feeling inside. When I first get diagnosed I'm upset. I go down for about three days, maybe even a week, and then I come up again, and start facing it and fighting it...

(Oesophageal patient, group 2: diagnosed 2000).

Another person with Hodgkin's lymphoma and a poor prognosis also described himself as well psychologically:

I think with the way I am, it was just one of those things that I accepted had happened and there was no great mental turmoil.

(Hodgkin's patient, group 2: diagnosed 2004).

These data demonstrate that the psychological support needs of people are unpredictable, which has implications for the support they are offered when first discharged home, and in the long term.

Support after discharge

The participants with oesophageal cancer, lymphoma and multiple myeloma had access to a CNS and dedicated team who offered support from diagnosis, through treatment and after discharge:

I can't see a way you could improve the situation. I mean you ring (CNS) or you ring the doctor. The doctor said "anytime you want to ring me, ring me. I'll ring you back". (CNS) is the same. If she's not there, leave a message and she rings you back straightaway.

(Oesophageal patient 1, group 1: diagnosed 2004).

I had all this trouble with the hip and I just rang (CNS) and left a message. And she rang me back the same day and told me you know to go back on the pain killers because I wasn't taking any or anything since the transplant.

(Multiple myeloma patient, group 2: diagnosed 2003).

Some participants however were unable to benefit from having a close link with a CNS. Participants with kidney cancer, vulval cancer, and until very recently carcinoid, fell

into this category. For these people, referral to DNs for ongoing support after discharge was not always forthcoming, especially if they were perceived to have no physical needs.

Participant: I were in hospital about ten days. I just couldn't stop crying.

Interviewer: Do you know why?

Participant: I think I were frightened of dying. Even though they'd cut it out, I was still frightened of dying ... Still couldn't get over the fact that you know maybe I might be a few weeks and I might just die, you know I might just die you know. I couldn't get that out of my mind.

Interviewer: And when you went home, did you have the district nurses coming in?

Participant: No. I had nobody because they took all the staples out when I was in hospital ... But it were being at home on my own. D (husband) had to go back to work. ... And so you know I started crying again and that.

(Carcinoid patient, group 1: diagnosed 2001).

Even a poor prognosis did not always trigger referral to district nursing services. One participant recounted his experiences of being told his diagnosis and the lack of support afterwards:

The doctor said the best thing you can do is enjoy the rest of your life, get your house in order and we were absolutely devastated. We weren't given any advice. and we were just in pieces. There was no information. ... We came home completely devastated. There was nothing. We didn't know where to go. We didn't know which way to turn.

(Kidney cancer patient, group 2: diagnosed 2001).

When physical care was required, individuals could expect a visit from the district nurse. The purpose of the visit appeared to be to simply carry out the physical task, which was unproblematic if the patient had no psychological concerns. This was not always the case however as the following quote from a woman with a radical vulvectomy illustrates:

Interviewer: How long did you say the district nurses came for?

Participant: Four weeks.

Interviewer: And were you depressed at the time?

Participant: Mm.

Interviewer: Okay so they came in and they packed these wounds in the groin. Did they talk to you about your feelings at all?

Participant: Not at all because I always put a smile on my face.

The interviewer then asked whether the DN would have discovered that she was depressed if she had probed:

Interviewer: If a district nurse had actually scratched the surface and asked how you were feeling, do you think she would have found out?

Participant: Possibly, yeah.

(Vulval cancer patient, group 1: diagnosed 2004).

The DN obviously focussed on wound care and being presented with a "brave face" did not probe. Another case

was a participant with kidney cancer who received a visit from a DN for suture removal, and again there was a lack of focus on his psycho-social needs:

Interviewer: Did the district nurse ask you how you were coping? Or how you were feeling?

Participant: Not that I remember. She just came to take the stitches out after the operation.

Interviewer: Was that quite a difficult period of time?

Participant: It was. Yeah. Straight after the operation, it was really difficult. It was hard to get comfortable. And I didn't wanna go out shopping... I think it took a week or so before I could get out and go to the shops.

Interviewer: And what was your mood like at that time?

Participant: Well I was a bit down really. Just had the operation not knowing. Before the first check-up, you know, if things were progressing... I didn't have any support because you know, apart from my next door neighbour there was nobody. The family, they were miles away. They couldn't do anything.

(Kidney cancer patient, group 1: diagnosed 2001).

These individuals were visited by the district nurse because although they had a good prognosis they had physical needs. Although their psychological needs were overlooked, they were at least known to the district nursing team and were in the system. The situation for those with a good prognosis and no physical needs was potentially far worse with little or no support from the DNs and PHCT.

It can be seen from these findings therefore that the needs of this sample who had been treated for a rarer cancer were highly unpredictable and their access to support was patchy. The question is what if anything can be done about this, which the following discussion begins to address.

Limitations

This was a small-scale qualitative study so the findings are in depth, may be transferable to other settings but are not generalisable. Another limitation is that people with rare cancers are infrequent in the population so we had to use a sampling strategy that would help us to access them, i.e., CNSs and support groups. Arguably people accessed via these approaches are different from the rest of the population of rare cancer survivors, although the considerable variation in the responses of our participants would suggest that this might not be the case. Certainly people accessed via the CNS experienced a "gold standard service" which was a useful comparison to other people. People who access support groups may be different from the general population, although the extent to which those we accessed in this way were involved in the group varied enormously from being regular attendees to those who had attended a meeting once so were registered with the group but not using it. This however is another potential limitation.

Discussion and conclusions

The findings from this study contribute to current knowledge on survivorship and the late effects of treatment by adding the perspective of a group neglected by the literature:

people diagnosed with rare cancer. Our findings also have important implications for primary health care practice: people's reactions to diagnosis and treatment of rare cancer are highly individualised and prognosis is a poor predictor of ability to cope and need for support on return home. Some of our sample coped well irrespective of prognosis while others felt abandoned.

Cancer is becoming a chronic disease. Unlike some chronic diseases that develop slowly allowing the person time to develop strategies to cope with their symptoms, with a cancer diagnosis the period of time from feeling relatively well to, in some cases, extremely unwell may be very short. For our sample diagnosis triggered rapid referral for intensive treatment. It is perhaps not surprising therefore that the transition from hospital to the home environment was sometimes difficult. This was compounded by living with the uncertainty of a diagnosis of life threatening illness, and in many cases ongoing physical and psychological needs. In this respect our sample did not differ from patients with more common cancers (Lampic et al., 1994; Thomas et al., 1997; Amir and Ramati, 2002; Deimling et al., 2002; Helgeson and Tomich, 2004; Thewes et al., 2004; van de Poll-Franse et al., 2006).

The characteristics of those who do not cope well may in some cases transcend the rarity of the cancer: any cancer diagnosis might have a similar impact. Having a rare cancer does not help however. Generalist practitioners in primary care whom patients come into contact with on discharge such as GPs, practice nurses (PNs) and DNs, are unlikely to know much about rarer diseases they encounter infrequently if at all. While GPs and DNs are familiar with care at the end of life (Thomas et al., 1997; Wilson et al., 2002), the disease process, treatment, side effects and psycho-social consequences at earlier stages of the disease trajectory are very different according to cancer site.

There are now many CNSs based in secondary care who provide support for patients with the more common cancers such as lung, breast and colorectal. Despite this, there is some evidence to suggest that on completion of treatment, patients are expected to access ongoing support from primary care. Provision of this support is however patchy (Willard, 2004; Surbone and Peccatori, 2006). The individuals in our sample who had oesophageal cancer, multiple myeloma and lymphoma received a very high level of ongoing support from their hospital-based CNS: a number of participants deliberately chose to bypass primary care services, preferring to access an experienced, knowledgeable and skilled specialist in their particular cancer. Having a rarer cancer can possibly be an advantage when there is a dedicated CNS and numbers on the nurse's caseload are low (Lewis, 2006). However although perhaps desirable (Booth et al., 2005), it is not realistic to employ specialist nurses for all types of cancer, particularly if the cancer is rare and patients are few.

It is recognised that there are key points at which cancer patients require an assessment of their needs (National Institute for Clinical Excellence and Health (NICE), 2004a; Richardson et al., 2007). These include completion of treatment (the "survivors" in our sample) and the point of recognition of incurability (those in our sample who were "living with" cancer). Our data suggest that when patients with rarer cancer have no CNS and are in contact with

primary health care, professionals do not know how to assess or help them. DNs are ideally placed to assess patients on their transition home but that they have a tendency to focus on physical care and to avoid discussions about psycho-social concerns. This is perhaps because they are fearful of uncovering concerns that they cannot deal with, as other research suggests (Griffiths et al., 2007).

The expert patient initiative recognises the expertise of people with chronic conditions and empowers them to develop long-term coping strategies (Department of Health (DH), 2001; Wilson, 2001; Lorig, 2002). There are clear guidelines for cardiac and pulmonary rehabilitation (National Institute for Clinical Excellence and Health (NICE), 2001, 2004b), which are now mainstream services. Cancer rehabilitation is not however widely available in the UK (Rosenbaum et al., 2004; Grunfeld, 2005; Surbone and Peccatori, 2006). Cancer rehabilitation involves strengthening individual coping mechanisms (Kullmer et al., 1999; Wenzel et al., 2002; Persson and Hallberg, 2004), family and social support (Mellon and Northouse, 2001; Maughan et al., 2002) and improving physical functioning (Ronson and Body, 2002; Golant et al., 2003; Bulsara et al., 2004).

This approach to the rehabilitation of cancer patients resonates with the 'Stepped Care' approach to managing people with mental health problems in primary care (Bower and Gilbody, 2005). Demand for services has outstripped supply so care is only stepped up if the patient is not responding. The first step involves strengthening coping strategies and widening social support networks and may require minimal professional intervention. Connolly (2007) argues that a similar approach can be used by nurses working with cancer patients. He suggests that by utilising simple counseling skills nurses can elicit patients' concerns and help them to help themselves without becoming personally overwhelmed. Using the mnemonic "SAGE & THYME" he suggests two stages in which the nurses first establishes the Setting; Asks about emotions and concerns in order to Get a list; and Empathises. She then Talks to them about their support systems; Helps them to identify how they can help themselves and what has helped in the past; asks what do You think would help; asks whether there is anything the nurse can do (Me); and summarises (End). The onus on the nurse to sort everything out is therefore minimal.

As more people are surviving cancer or living with it as a chronic disease, increasing numbers of people will require help with adjusting to this. People living after cancer need coping strategies to get on with the rest of their lives (Curtiss et al., 2006). Time invested at the point of discharge in preparing them for the next stage of their recovery could be time very well spent. Although this has resource and training implications it is a potential role for the DN and PHCT and may lead to more targeted provision of their services. People with identified needs could be supported, and those who require it referred to appropriate colleagues before their problems escalate. This is particularly important in rarer cancers where provision of supportive care is inconsistent.

Conflict of interest statement

The authors of this paper have no conflicts of interest.

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