The supportive care needs of carers of people affected by cancer stationed in British Forces Germany

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Carers are central to the effective support of people affected by cancer. Little is known however about the specific support needs of carers of military personnel. This study aimed to determine the supportive care needs of unpaid carers within British Forces (including military/civilian personnel, their families and dependent adults) currently stationed in Germany. Qualitative semi-structured interviews were conducted with seven carers (six men and one woman) in three British army garrisons across Germany, to identify core aspects of the experience of caregiving in this environment. Analysis of interviews with carers was based on qualitative thematic and content analysis. Three key themes were identified: (1) impact on carers of their partners being diagnosed with cancer; (2) provision of support; and (3) challenges to accessing and obtaining support. Central issues pivot around the context of working and living in the armed forces and a lack of supportive care infrastructure. While drawing on a small sample size, this study nonetheless identifies that carers of people with cancer within the armed forces, who are stationed in Germany require a specialised and contextually specific set of services to address their supportive care needs.

Keywords: carers, supportive care, armed forces.

INTRODUCTION

Carers are central to British health legislation; their role was highlighted powerfully in the Carers [Recognition and Services] Act 1995 (Department of Health 1995) and the importance of their role in relation to people with cancer has been well documented (Given et al. 2001; Thomas et al. 2002; National Institute for Clinical Excellence 2004). Since this time, further legislation has enhanced and underlined the importance of carers in upholding NHS statutory services, by supporting people to remain in their own homes and communities (Department of Health 1999).

The received definition of carer is represented in the Carers Act, which defined carers as people who provide 'a substantial amount of care on a regular basis' (Department of Health 1995, p. 2). A similar description of carers has been developed in the context of cancer as lay people who play 'a crucial role, undertaking vital care work and emotion management' (Thomas et al. 2001, p. 14). Carers perform a range of physical, emotional, practical and supportive tasks. Bowers (1987) developed a model to describe the range of activities of carers, which remains pertinent 20 years on. This model highlights different levels and forms of caregiving (anticipatory, preventative,
supervisory, instrumental and protective. Each of these may be seen within the context of caring for someone affected by cancer, for example anticipating nausea, supervising medication administration at home and providing support in managing the impact of cancer on relationships with others.

Recognition of the support that informal carers provide, and of their supportive care needs, can be found in national guidance (National Institute for Clinical Excellence 2004). It is known that the quality of the informal care that patients receive can have a profound effect on their well-being (Brown & Stetz 1999; Given et al. 2001; Thomas et al. 2002) and that many carers feel isolated (Scottish Executive 2005). Research in the 1980s and 1990s had focused on exploring the difficulties of caregiving, focusing on issues such as burden and stress (discussed by Nolan et al. 1996). Latterly the negative approach to understanding the role of carers has been refocused (following significant dialogue and debate stemming from the disability lobby) to identify the positive aspects of care and carer’s support needs.

Recent research has consequently sought to understand the more complex dynamics of care and caregiving relationships, recognising that care is complex and changing (Forbat 2005). Changes in caregiving may be as a consequence of the changing nature of the care-recipient’s illness, and result in carers having changing needs over time (Nolan et al. 1996). Caregiving in a cancer setting will be somewhat determined by the tumour type, treatment regimes and disease phase (Thomas et al. 2002). A longitudinal study examining the changing role of the carer during chemotherapy (Schumacher 1996) revealed that the demands of the carer and their patterns of involvement change in accordance with the patients’ needs as the patient progressed through their course of treatment.

Recent research identifies that although there is a policy precedent to ‘care for the carers’, they may still feel unsupported. In particular research commissioned by the Scottish Executive and published by Care 21 and OPM (Office for Public Management (OPM), Care21 and Scottish Executive 2006) outlines care for the 21st Century and points to the idea that the longer a person is a carer, the more pessimistic they are about unpaid care, and a sense that the English (Westminster) government and the Scottish (Holyrood) Executive (now Government) had failed to grasp the role of carers. Care 21 found that 54% of carers in Scotland reported negative impacts on their personal and social life (Office for Public Management (OPM), Care21 and Scottish Executive 2006). Furthermore, a survey published in April 2006 by Macmillan Cancer Support [n = 550 family or carers of people affected with cancer] found that more than one-third (36%) of carers felt that their relationship with the person who had cancer, and with family and friends, were put under enormous strain and almost a quarter (24%) felt abandoned at some stage (Macmillan Cancer Support 2006). These surveys have led to calls for improved service provision for carers (Office for Public Management (OPM), Care21 and Scottish Executive 2006).

There is increasingly a need therefore to better understand the role of carers and their need for support to sustain them, which sets the context for ensuring that the needs of carers are fully understood in order to respond to their supportive care needs. This paper explores the experiences of carers of people stationed in British Forces Germany (BFG) who are affected by cancer, and the support that they identify as being needed.

British Forces Germany

British Forces Germany is the name for British service personnel, civilians and their families who are based across five garrisons in Northern Germany. At the time of the study, there were five garrisons within BFG. Since completion of the study, one garrison has now closed (Osnabruck) leaving four remaining garrisons within BFG [Rhine (JHQ), Gutersloh, Bergen-Hohne and Paderborn]. BFG comprises approximately 54 000 people, of whom 26 000 are serving military or civilian personnel, 16 000 are dependent children and 12 000 are dependent adults, who are not employed directly by the armed forces. Military personnel are involved in troop deployments in over 80 countries across the World, making the BFG community a transient one. Primary and community healthcare is provided to all BFG personnel, by in-house services, at each of the five garrison sites. Secondary healthcare is subcontracted to the German hospital system via a contract with Guy’s and St Thomas’s Hospitals NHS Trust (GSTT).

Previous work has identified that although BFG personnel benefit from rapid access to diagnostic tests, surgical procedures and ensuing treatment for cancer as part of the German healthcare system, there are significant gaps in the provision of care and support for carers of people affected by cancer within BFG (Kearney et al. 2006). This work highlighted the relationship between service provision to British Military and adherence to National Institute of Health and Clinical Excellence guidelines (Maguire et al. in press). Little work, however, has specifically investigated the supportive needs of carers of people affected by cancer within the Armed Forces. The project proposal was developed by co-authors N.K. [Principal Investigator for this study and the Kearney et al. 2006 study] and M.K.M.K. assisted the project team with navi-
gating army structures/culture. He was the only member of the project team who has personal experience of army life, and is currently stationed in BFG.

PARTICIPANTS AND METHODS

This paper presents the qualitative findings on the supportive care needs and experiences of carers of patients with cancer in BFG. The findings form part of a larger, mixed methods study to investigate the supportive care and information needs of people affected by cancer, particularly carers, stationed in BFG and to understand their experiences of supportive care and information provision within BFG to identify gaps in practice and areas for improvement [Kidd et al. 2008]. This larger study had two strands. Strand one explored current service provision through analysis of number of people with cancer, alongside documentary analysis of policies. Strand two explored carers’ needs and experiences through interviews with key medical/military personnel and people affected by cancer. It is solely this second strand which is presented in this paper, where the findings are likely to be of interest to a wider population as they raise issues associated with service provision across countries and cultures around carer experiences. L.K. led the data collection; L.F. was project manager.

Ethical approval for the conduct of the study was received from the Ministry of Defence [MoD] Ethics Committee and from the ethics committee of the University of Goettingen Medical Faculty, Germany. BFG Health Services assisted in the recruitment of patients and carers to the study by providing an anonymised list of people affected by cancer across BFG from January 2003 to May 2007. The list was used to identify people within the sampling frame [Table 1] and letters were sent to relevant patients [n = 80] inviting them to participate in the study and to nominate the person they considered to be their primary informal carer. Both patients and carers were asked to return a signed consent form to the researchers if they were willing to participate. By returning their consent forms to the researchers, it ensured their anonymity to personnel within BFG.

In total, seven carers consented to participate in the semi-structured interviews. It is the findings from these interviews that we report in this paper. Six respondents were male [one was female] and all were aged between 35 and 55, and were currently caring for, or had previously cared for, a partner or spouse diagnosed with cancer while stationed in BFG. Breast and colorectal cancer were the two most commonly cancers diagnosed in partners/spouses of the carer sample.

Face-to-face interviews [n = 5, conducted in private meeting rooms] and telephone interviews [n = 2] were carried out with participants in two garrisons in Germany from November 2007 to January 2008 and lasted 30–90 min. The semi-structured interview guide was based on the National Institute for Health and Clinical Excellence [NICE] guidelines for supportive and palliative care [National Institute for Clinical Excellence 2004] but was flexibly applied to allow exploration of issues identified by participants. It has previously been used in work with people affected by cancer in BFG [Kearney et al. 2006]. Core topics on the interview guide included the impact on carers of their partner being diagnosed with cancer, the types of support and information they were offered at different stages following diagnosis, and which of these they had found to be particularly helpful or whether they perceived there to be any gaps in the provision of support. All interviews were audio-taped with permission and transcribed verbatim and were anonymised to ensure that they contained no identifiable information. Detailed field notes were made by the researchers following each interview, containing information on participants and initial impressions from the interviews. L.K. led the field work, and is an experienced cancer researcher.

Thematic content analysis was used to analyse the interview data [analysis was led by L.K. and L.F.]. Thematic analysis is a commonly used method for analysing qualitative data as it helps to identify patterns within the data and allow the researcher to describe the data in rich detail so that the reader gets a sense of the predominant or important themes [Braun & Clarke 2006]. This type of analysis is also particularly useful when investigating under-researched areas [Braun & Clarke 2006] as in the current study. Analysis of the qualitative data was performed in the following steps as outlined by Braun and Clarke [2006]: [1] the transcribed interviews were read through with the aim of obtaining an overall picture, familiarising ourselves with the data; [2] initial codes were generated; [3] these codes were collated into potential themes; [4] themes were then reviewed to check they still worked with our coded extracts; and [5] continual analysis

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<th>Table 1. Sampling framework for inclusion</th>
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<tr>
<td>• Military personnel, entitled civilians and dependents caring for someone with cancer diagnosed between Jan 2003 and July 2007</td>
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<tr>
<td>• Currently stationed in British Forces Germany</td>
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<tr>
<td>• Aged 18 years or over</td>
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<tr>
<td>• Written informed consent given</td>
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<td>• Able to read/write English [for completion of consent forms]</td>
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to refine the themes. Two researchers compared the themes for consistency and verification in a random sample of the transcripts (10%) and no disagreements were identified. The qualitative software package NVivo was used to help in the management of the data and to aid comparison of issues and experiences between participants.

FINDINGS

The provision of support for carers was a major issue for the people who participated in the study. The findings described here relate to carers’ supportive care needs and their experiences of the provision of supportive care within BFG. Key themes identified were: (1) impact on carers of their partners being diagnosed with cancer; (2) provision of support; and (3) challenges to accessing and obtaining support.

Identifiers have been used to preserve anonymity in quotations. C denotes carer. The number refers to the sequence in the study in which the person was interviewed. The data stem from a larger study with patients, hence numerals extend beyond 7.

Impact on carers

The impact on carers is reminiscent of other research with the general population, and is presented here to contextualise the later data focusing on support needs, and to begin to outline the different living and work context of this cohort.

Several carers described the impact of their partner being diagnosed with cancer as having both practical implications, for example, in changing the routines of their daily lives and emotional implications, in terms of their emotional reactions. In particular, while many may have been previously involved in caring for their young families or household chores, it was recognised among the carers that a greater responsibility for these duties now fell solely to them.

I have to do a lot more in the home you know . . . she was in a lot of pain so to begin with I was tooing and froing her to the doctors for tablets, this sort of thing. I suppose we had to change things we do at the weekend revolving around her illness. (C17)

I must admit I felt very isolated when [my husband] was ill . . . looking after my three children and doing all this on my own you know, was extremely difficult, it really was, I was absolutely exhausted with the running back and forward and you know different things you know it was really hard. (C32)

All of the carers interviewed acknowledged the difficulties that their carer role had created in relation to continuing to balance their employment and army life with their care giving tasks. In particular, carers spoke of having to rearrange their workload and responsibilities, for example, not being able to fulfil deployment duties overseas. Others spoke of the unpredictable nature of when various tests would be required which could often involve them having to make alternative working arrangements, in many cases at short notice and at an inconvenience to others. Their partners’ diagnosis and ongoing treatment arrangements also appeared to impact upon carers’ future employment plans.

Before all this happened, I was meant to be deployed in Afghanistan in January this year. So that’s all out the window and I’ve had to rearrange my working day around that [his wife having cancer]. (C11)

I have, with my job, got the possibility of a move to Paderborn Garrison, cause this one’s closing in 5 years’ time . . . so there’s a sort of career move that way but I’m thinking I don’t want to move until [my wife’s] treatment is finished. (C17)

In terms of emotional impact, several carers spoke quite frankly about their initial reactions to their partner’s diagnosis.

I was the broken one . . . not her, she’s actually very strong. (C20)

When we were first told, I was very angry . . . very angry indeed as to why it was [my wife] . . . very angry indeed. I just wanted to rip it out of her, just literally go in, rip it out of her and just . . . it’s gone, I don’t want it in my wife . . . it was a very emotional time. (C27)

Several carers also spoke of seeing the visible effects of undergoing treatment on their partners as being particularly difficult. Many expressed feelings of guilt during the ongoing treatment phase because they found themselves unable to identify when their partner was getting worse or unable to take away the disruption and distress that their partners were experiencing.

I feel I blame myself a little but not picking up earlier on how tired she was getting. (C17)

Some days I’ve had to literally lift [my wife] out of bed and walk her to the toilet you know . . . you don’t expect to have to do that. It’s very difficult knowing that the woman you married and as strong as she is, hasn’t got the energy to get out of bed and go to the...
toilet herself. She can’t get dressed, she wants to get dressed, but physically can’t. She’s still running around at 90 miles an hour, or as close as she can to it . . . but I mean she gets to the top of the stairs and has to stop, catch her breath and rest then walk the remaining three metres into the bedroom you know . . . that’s emotional to watch her be like that. (C27)

Provision of support

While carers spoke with the highest regard for the care and treatment that their partners had received from the German healthcare system, carers themselves appeared to be offered little specific support. Subsequently, carers relied on army personnel within BFG to offer them support; however, the standardised availability of this was seemingly lacking in several areas. In particular, there appeared to be a lack of practical support, in the form of home help, on offer to assist carers in managing to balance household and caring duties with their regular demands of army and working life.

Practical support in terms of giving runs to the hospital and back? No, I did all that. (C30)

That would have been the biggest help . . . on a practical level as well for myself I had three young kids and coming in at night and em, the house was a tip, it was just washing piling up . . . there was not enough hours in the day to get round everything . . . you need somebody just to come in and make a dinner or put a washing on or hoover the carpet. (C32)

The provision of emotional support mostly appeared to be offered by community psychiatric nurses and the Jigsaw Support Group, a support group for patients, carers and family members run in one of the garrisons. Awareness of these sources of support, however, was poor and many carers spoke of perceiving a lack of emotional support, particularly bereavement support.

We weren’t offered counselling . . . there was no emotional support whatsoever. [C31]

There was no one, there isn’t anybody. I asked the doctor, ‘is there bereavement counselling?’ . . . ‘no’ . . . ‘any kind of counselling at all?’ . . . ‘no’. I just have to get on with it . . . since [my wife] died, there’s been nothing, not a single thing. There’s been nothing from the army, nothing from any army civilian, no support from work . . . not any offer of help from anyone from there and nothing when my wife died . . . I have had to get on with it, they all seem to think ‘oh she’s gone now that’s it . . . get on with your life’. (C20)

The vast majority of support that the carers received came from their employers who were considered to have been ‘fantastically supportive’ (C27) in all cases. In particular, employers and colleagues had provided support and assistance by being flexible with regards to working hours, allowing time off for appointments at short notice, and changing duties or roles to fit in with caring demands and future plans.

The whole work [place] have been very supportive, always asking how [my wife] is . . . when I’ve needed time off, I’ve just been told to go you know. With her radiotherapy, she was doing this for 7 weeks every day on her own, and I suddenly found with two weeks to go, she was just exhausted and I had to turn around to work and say ‘look I’ve got to take some time off and just get her to the hospital and back’ . . . they just, you know, said ‘okay’. (C17)

Work was fantastic, work was literally unbelievable . . . I went and told my boss on the Monday about the cancer . . . he said ‘well I’ll see you later, you just keep me informed as things are going along . . . and if you need anything, please let us know.’ I was given the opportunity to [move jobs] . . . so it’s better for me because, if the regiment deploys anywhere or goes on exercise, then I won’t have to go, I will stay in this Garrison. I know I’ll be in that job for the next three years so I don’t have to go . . . but then if I need time to cut away then I’ve got the time to do that you know sometimes I need to take [my wife] to the hospital . . . ‘something’s not right, you know just a phone call . . . okay see you later’. (C27)

Challenges to accessing and obtaining support

In addition to the seemingly limited practical and emotional support available as perceived by carers, further challenges to accessing support more generally were identified. In particular, carers acknowledged that there was little information about available support services passed on to patients and carers. This was further hampered by the transient nature of the BFG community, which meant that awareness of support often relied on word-of-mouth and when people left the area through deployment activities, the knowledge held within the community changed and linkage of information was lost.

At the moment . . . you know, people don’t even know this stuff’s going on. So there might be people
Further difficulties arose due to the style of approach to accessing and obtaining support within BFG. For example, it was frequently commented upon by carers that the system for accessing support was reactive as opposed to proactive and as a result relied on carers to identify their support needs and find out where they could access help for themselves.

We’ve had to do a lot of digging ourselves, a lot of finding out ourselves. Everything’s there, it’s just a case of having to tune into it or get into it. (C11)

They treated me as if well... he’s a big boy who knows what’s going on and if he’s got a problem he’ll come and see me. There’s no proactive [approach]. (C30)

This approach was also made more challenging by the nature of community life within BFG. In essence, the BFG community was identified as being close knit which raised questions about anonymity and confidentiality. Many people lived close to people who worked in health and social care services in BFG and therefore, were uncomfortable at disclosing information about a cancer diagnosis and their needs for support to those who were already known to them. The first speaker mentioned SAFFA, which is the Soldiers, Sailors and Airmen’s Families Association:

They do have things like SSAFA . . . to be honest, we never really went down that road because it’s hard in BFG because the SSAFA people who employ them are practically your neighbours . . . are the people you actually live round about and it’s very difficult because I really wouldn’t like to talk to my neighbours. I feel it’s my home you know . . . it would have been better if it was people like strangers you were speaking to but it’s people you see every day. (C32)

It was also perceived that within BFG, there was a lack of resources and infrastructure to support people affected by cancer, perhaps because in the past, people diagnosed with cancer and their families returned to the United Kingdom [UK] to receive their treatment. Therefore, resources geared to care for people with cancer were not needed in BFG. As a result, there was little access to specialised cancer support, such as UK Macmillan Cancer Support Nurses. Carers commented that this kind of support would be particularly welcomed in order to provide reassurance and continuity of care between primary and secondary services and available forms of support services within BFG.

You know a Macmillan nurse can probably say ‘well that’s normal’ you know ‘that’s to be expected’. There should be, at least somewhere in British Forces Germany, that sort of support. If there was someone here on the establishment of this medical centre of hospital or organisation welfare support services that had that role, they would provide continuity as patients came in and went. (C11)

DISCUSSION

This paper has reported on the support needs of carers of people diagnosed and living with cancer while stationed in BFG and the challenges they face in accessing information and support to meet these needs. In particular, while support from employers was found to be exceptional, there were many areas such as the provision of practical home help and community nursing support and emotional support, and in particular, awareness of the provision of such support around the garrisons, was lacking.

All of the participants interviewed had been part of the armed forces for many years and were all partners or spouses, many with young children. Spouses/partners, in particular, are usually identified as a patient’s primary source of support during the treatment phase and beyond (Hodgkinson et al. 2007b). They experience fears and concerns caused by their partners’ diagnosis and the implications of this for them and their families. Indeed, ideas on causality have been identified as ‘deeply rooted’, and families develop curiosity about the causes of cancer (Wynne et al. 1992, p. 14) and are suggested to lead to new discussions within families about the presence of cancer and likely risks to relatives (Kenen et al. 2004). In particular, the carers in this study reported concerns relating to balancing household and caring duties with the regular demands of their employment, ensuring that their partners’ treatment went as smoothly and as unaltered as possible, managing their emotions, particularly feelings of guilt and fear, and how best to provide assistance to their partners. Similar findings have been reported in other studies of partners and family members affected by cancer (Triangali 1986, Bilinski 2007). It is necessary to understand these specific concerns in order to identify their needs for supportive care, particularly
given that partners often play a pivotal role in providing both physical and emotional care (Hodgkinson et al. 2007a) and experience elevated levels of distress (Lewis 2006; Kim et al. 2008).

Understanding the needs of carers of people with cancer stationed in BFG is essential since it appears that increasingly BFG personnel, dependents and their families are choosing to remain in Germany rather than return to the UK or take up the opportunity of deployment to another area. Similarly, the nature of employment for support staff within BFG has changed such that people are remaining in Germany for much longer than had previously been the case. One consequence of this is that people affected by cancer within BFG are being treated in Germany, rather than returning to the UK. It is becoming clear that the increasing numbers of people staying in Germany for longer periods will require a change to the health service infrastructure within BFG.

This study’s findings highlight that carers of people with cancer within the armed forces, who are stationed in Germany experience many of the same impacts of having a partner or spouse diagnosed with cancer as carers living in the UK. Of particular relevance to the context of this study, however, was carers’ needs for support in being able to balance their new caring roles with the continuing demands of their army life and employment, an area which has recently been studied to unpack the complex decision making and organisation when carers are in paid employment (Arksey & Glendinning 2008).

Carers within the armed forces are, perhaps more than other groups of carers, particularly reliant on being able to continue with their employment not just for financial reasons but because their whole way of life and residential status are dependent upon being able to fulfil their employment responsibilities. Many of the carers had been in the armed forces, and stationed in Germany, for a number of years and to leave the armed forces because they were no longer able to do their jobs would have had a significant impact on them and their families and their futures. Fortunately, carers spoke of receiving good support from their employers who made arrangements to help them balance their caring roles with the current demands of their jobs and made provisions for them to be able to stay in BFG rather than be deployed and have to be away from their families.

A better understanding of carers’ supportive needs and their experiences of supportive care provision within BFG is also important in light of the many challenges that were reported by carers and subsequently need addressing within the current infrastructure of health service provision in BFG. In particular, it was noted that provision of standardised supportive care for carers across BFG is hampered by a lack of awareness of existing supportive care services and organisations, both seemingly among patients and carers as well as among health and social care professionals since carers are rarely signposted towards, or given information on accessing, other forms of support. In addition, the system of referral to support organisations within BFG is one which puts the onus on the individual to identify and express their needs for support. The local, army culture, however, perhaps more so than in other UK populations, means that asking for help is not easy to do. Consequently, when people do come forward for information and support, it is often provided at a later stage than would be optimal. Thus while services are predicated on people being proactive, there will be a short fall in services being delivered.

Further challenges exist in relation to the lack of provision of practical home help and community nursing support as well as the lack of emotional and bereavement support that was perceived by carers. Given the increasing number of people remaining in BFG following a cancer diagnosis, there is a greater likelihood that the service infrastructure will need to change to become responsive to meeting both patients’ and carers’ practical and emotional needs in managing to balance their daily demands with the resultant demands placed upon them as a result of the diagnosis of, and treatment for, cancer. In particular, there is a need to establish a specialised cancer support network for patients and carers, either through employing specialised services within BFG or by enhancing collaboration with existing organisations in the UK, such as Macmillan Cancer Support and Cancer Backup. These networks, readily available to people living in the UK, could offer remote, context-specific advice, support and reassurance to people affected by cancer living in BFG as well as in armed forces stationed across the world.

The value of qualitative research lies in the depth of understanding gained from detailed descriptions of specific experiences (Clements et al. 2008). While the sample is small, it is appropriate for a qualitative study of this kind, seeking to obtain the depth of peoples’ experiences, and we believe that the experiences reported here are a valuable addition to the scarcity of literature on the needs of people affected by cancer in the armed forces. A limitation of the work, however, is that most of the respondents were male and all had partners who had been diagnosed with either breast or colorectal cancers. It is possible that information about the study did not reach some carers because of the approach to recruitment used whereby initial contact was made through patients themselves or that some carers were on deployment activities.
at the time of the study, making them unavailable to participate. Hence, it is plausible that the experiences of those who did not respond, those who were unable to participate because of deployment activities or those who had recently left BFG and those caring for people with different tumour types may have furthered our understanding of the key issues identified in this study.

Nonetheless, developing the current health services infrastructure within BFG to mature in line with the general trends seen within the armed forces, which enable people to remain employed despite long-term illness, is important in order that it provides a service that is responsive to the needs of its population. The findings reported in this paper make a valuable contribution to identifying key issues in supportive care and will facilitate the development of appropriate and responsive cancer services within BFG.

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