



Needs of Carers of People Affected by Cancer and Information Needs of People Affected by Cancer

Final Report

May 2008



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

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May 2008

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STIRLING**

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NURSING AND MIDWIFERY

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EXECUTIVE SUMMARY

- I Following an assessment of the needs for, and provision of, carer support and information for people affected by cancer in British Forces Germany (BFG), it was considered that although support and information is available, there is a lack of a comprehensive and integrated system for ensuring that people's support and information needs were being consistently met
- II Many service personnel, civilians and their families have a desire to remain in Germany for cancer care and cancer treatment rather than return to the UK
- III Many spoke of receiving excellent support from employers and information about cancer and cancer treatment from the German designated health providers. There were, however, a number of challenges identified around access to formal support services for carers and information provision for patients and carers within BFG
- IV There is a lack of awareness amongst patients, carers and health and social care professionals of the types of support and information available to people affected by cancer within BFG
- V There is a lack of systematic referral systems in place with which to refer individuals and their families onto relevant organisations and agencies from where they can gain support and information to help manage their needs
- VI Many people experience difficulties in accessing support and information because the onus for identifying and expressing needs are left to the individual rather than health and social care professionals coming forward to offer support and information
- VII The costs and time lag associated with translation of German information can mean that people are often left with little information at the point at which they perceive they need it most
- VIII There is a lack of support and information for people in the follow up and terminal stages of their illness and for carers following bereavement

- IX There is a lack of access to community nursing and practical home help support as well as specialised cancer support and cancer networks

- X An information strategy should be developed within BFG. A number of issues are important to consider in the development of this including: clarification of the health and social care professionals that are expected to be involved in the delivery of information to people affected by cancer and the types of information that they provide; the creation of links with specialist cancer information organisations; tailored information on different types of cancer and cancer treatment should be made available to people; people should be signposted towards information available in the English language and towards reputable and trustworthy websites that they can obtain further information from; there should be more information made available which specifically addresses the role and needs of carers of people with cancer, more information about the daily impact of living with cancer, more information on the stages beyond treatment

- XI A specialist information booklet on the types of support available within BFG to people affected by cancer should be developed containing information on the role/remit of different organisations and agencies and methods of referral and communication with these agencies. Existing processes of communication and level of awareness between these organisations should be examined

- XII A systematic and coordinated system of referral should be introduced to ensure that patients, carers and health and social care professionals are aware of available support within BFG and that people have easy access to these.

- XIII Networks with community nursing and home help services within the German health care system should be made to determine the feasibility of extending these services to people living within BFG.

- XIV Identify the agencies and services involved in palliative care within BFG and consider the feasibility of introducing alternative palliative care services to hospice in patient based services that currently exist and create challenges for people living in BFG

SECTION 1: INTRODUCTION

In 2006, the Cancer Care Research Centre was commissioned by the Defence Medical Welfare Service (DMWS) to conduct an independent piece of research into the supportive care needs of military personnel and UKBC civilians diagnosed with cancer and their families (dependants) stationed in British Forces Germany (BFG). The findings from this assessment revealed that people affected by cancer¹ stationed in BFG benefit from rapid access to high quality hospital and clinical services for the investigation, diagnosis and treatment of cancer (Kearney et al. 2006). The assessment also identified, however, that there were several gaps in the provision of structured support for carers of people diagnosed with cancer in BFG and a lack of a comprehensive information strategy which aimed to meet the information needs of patients, carers and family members affected by cancer within BFG (Kearney et al. 2006).

As a result of these findings, the Cancer Care Research Centre was more recently commissioned by BFG Health Services and DMWS to carry out a secondary study. This study had two principal strands:

- To identify the supportive care needs of carers of people with cancer in BFG and to describe their experiences of supportive care provision in BFG
- To identify the cancer information needs of people affected by cancer and to describe their experiences of information provision in BFG

1.1 Supportive Care for Carers of People with Cancer

1.1.1 Why carers are important

The importance of the role of informal carers is central to British health legislation and was first documented in the Carers (Recognition and Services) Act 1995 (HMSO 1995). 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). More recently, research has identified the continuing importance of carers, for example,

¹ We use the term 'people affected by cancer' in the following report to represent patients, carers and their family members.

Care 21's report on informal care giving in Scotland which called for improved service provision (Care 21 et al. 2006).

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" (HMSO 1995 p2). 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 p14).

Carers perform a range of physical, emotional, practical and supportive tasks. Bowers (1987) developed a model to describe the range of activities of carers, highlighting the following: anticipatory, preventative, supervisory, instrumental and protective caregiving as differing levels and forms of caregiving. 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, such as colleagues.

Recognition of the support informal carers of those affected by cancer can provide, and of their different needs, can be found in service and practice guidance (NICE 2004). It is known that many carers feel isolated (Scottish Executive 2005) and that the quality of the informal care that patients receive can have a profound effect on their well-being (Brown et al. 1999; Given et al. 2001; Thomas et al. 2002).

Research has also underlined the importance of seeing care as dynamic, complex and changing, resulting in carers having changing needs over time (Nolan et al. 1996). Caregiving in a cancer setting will differ as a consequence of the different tumour types, treatment regimes and disease phase (Thomas et al. 2002). A longitudinal study by Schumacher (Schumacher 1996) examined the changing role of the carer during chemotherapy. The findings revealed that the demands of the carer and their patterns of involvement changed in accordance with the patients' needs as the patient progressed through their course of treatment.

This evidence sets the context for ensuring that the needs of carers are fully understood in order to respond to their supportive care needs.

1.1.2 Carer support needs

Much research has to this point been focused on notions such as burden and stress in care as discussed by Nolan et al. (1996). Latterly a negative approach to understanding the role of carers has been re-focused to identify carer's support needs.

The Carers Act (HMSO 1995) gave carers the right to their own needs assessment focusing on their ability to provide informal care. More recently, the National Institute of Clinical Excellence (NICE 2004) reinforced this message by recommending that family members and carers are offered the opportunity for their needs for support and information to be assessed separately from those of the patient, particularly at stages of illness acknowledged as particularly demanding and when extra help might be needed.

Families and carers provide crucial support for patients (Thomas et al. 2002), yet their importance can go unrecognised by professionals. Watching a relative live with cancer symptoms and treatment side-effects (as well as the sometimes physical demands of caring) can result in emotional strain, uncertainty, fear, altered roles and lifestyles and matters of personal and sexual intimacy. For example, Kissane et al (1994) found that one-third of spouses of people with cancer were considered clinically depressed, compared with only 6% prevalence among the general population. Indeed, Kurtz et al (1995) estimate levels of carer's clinical depression to be as high as 58%.

Carers' emotional distress can be greater than that experienced by the patient yet family members have fewer opportunities to express their feelings. In addition, it can be difficult to encourage families and carers to express their own needs as they often put the needs of the patient first. Some studies have even suggested that the health outcomes for longer term carers of someone with cancer are thought to be poorer (Nijboer et al. 1998).

Evidence (Macmillan Cancer Support 2006; Vincent 1998) suggests that carers are most likely to have needs around:

- Information and advice
- Practical support and services
- Emotional support
- Skills and training

- Their own health
- Opportunities for a break from caring
- Dealing with health professionals

Specific support services should therefore be developed to meet carer needs. Practical needs revolve around help with transport, maintaining the home and caring for any other dependents, financial matters, coping with distressing symptoms and dealing with the tiredness that accompanies caring. Help may also be needed in dealing with their own and others' feelings.

One additional important challenge in providing support to carers is resistance to the identity and label 'carer'. Research and practice alike often identify that people will choose to identify themselves not as a carer but as a husband/wife/daughter (Henderson et al. 2002). This presents significant difficulties in providing support services which require people to take on board the identity of carer. Forbat (2005) describes a need for services and research to reach out to individuals using language that enables people to see services as relevant to them and their needs.

Previous work of the Cancer Care Research Centre (CCRC) (Kearney et al. 2006) identified significant gaps in the provision of formal support for informal carers of individuals with cancer who were stationed in Germany. The services that are available were not offered to all informal carers, nor did they comply with NICE (2004) recommendations for carer support and informal support. Kearney identified the need to develop a carer support system that would address three key areas: (i) the provision of a transparent process of support for carers, (ii) recognition of the needs of carers at different stages of the experience, and how carer needs will differ to patient needs, (iii) provide contact numbers and information for carer support.

1.1.3 Summary of carer needs

The important role of carers has continued to be reinforced in legislation since the 1995 Act, and a substantial evidence base has been built up through research about the role and needs of carers. In particular, carer support needs have begun to be identified, though much work remains to be done in identifying what carers themselves would want. One key area is in the provision of information to carers and for carers, which is outlined in the next section.

1.2 Information Provision for People Affected by Cancer

As far back as 1980, researchers had already documented the importance of information provision for people with cancer (Cassileth et al. 1980). Since then there has been a growing awareness of its importance of information for patients at each stage of the cancer journey (Adams 1991; Meredith et al. 1996; Jenkins et al. 2001; Balmer 2005;Cox et al. 2006). There is a growing wealth of evidence to support the beneficial effects of providing accurate and relevant information to people affected by cancer (NHS Centre for Reviews and Dissemination 2000;NICE 2004). In particular, the provision of cancer information is a necessary pre-requisite to informed decision making (Bilodeau et al. 1996;Hagopian 1996) and helpful in promoting participation in self care (Ream et al. 1996). It is also believed to help relieve anxiety and offer people affected by cancer a sense of control over what is happening to them (Ream and Richardson, 1996), improve knowledge and understanding about cancer and its impact and enable people to cope better in managing its impact (Bottomley et al. 1997;Mesters et al. 2001), and increase satisfaction with cancer treatment (Davison et al. 1997).

It is not only the person with cancer whom the disease affects, however, and there is now a growing recognition of the impact that a diagnosis of cancer has on carers and family members (Lewis 1990;Thomas et al. 2002). This, in addition to the vital role that carers and family members play in the management of cancer and its impact (Thomas et al. 2002), has led a growing body of literature to advocate the provision of accurate and relevant information for not just patients but their carers and family members too (Harris 1998; Rees et al. 2000; Morris et al. 2002; Beaver et al. 2007).

There is evidence within the literature to suggest that information needs vary by factors such as age (Bilodeau et al. 1996;Galloway et al. 1997;Graydon et al. 1997); education level (Bilodeau et al. 1996), and disease/treatment related factors such as, time since diagnosis (Luker et al. 1996), stage of disease (Brandt 1991) and type of treatment (Bliss et al. 1995), and that patients and carers may experience different needs for information (Rees et al. 2000). Information needs by patients and their carers and families have also been found to vary over the course of the cancer journey (Harris 1998;Leydon et al. 2000). In particular, the challenges that patients and carers face and the roles that carers especially find themselves adopting across the cancer journey may change over time (Morris et al. 2002) as they deal with the varied phases of the experience and the pervasiveness of the illness (Chapman et al. 2003).

Subsequently, many recommendations have been made for the provision of information to individuals with cancer and their families within existing literature and policy. In particular, it has been recommended that individuals with cancer and their families should be given clear information at all stages of their treatment from diagnosis onwards (Calman et al. 1995). It has also been acknowledged that preferences for the type of, and format in which, information is offered to people are likely to vary in accordance with their preferences for information or demographic factors, such as age, gender and education level (Bilodeau et al. 1996; Mills et al. 1999). Hence, it has been recommended that a comprehensive range of high quality information materials should be available locally to patients in a variety of formats (NICE 2004) and individualised assessment carried out to allow information to be tailored to match the individual's cultural and educational level (NHS Centre for Reviews and Dissemination 2000). It is known, however, that patients do not always find the same information sources of use or relevance to them (Balmer 2005) and that patients' use of particular sources of information during the cancer care continuum (Luker et al. 1996). Therefore, information that is relevant to particular stages or preferences should be offered and in a timely manner (Department of Health 2000). There is a vast quantity of cancer information available to individuals with cancer and their families, hence, assistance and signposting should be offered to help people navigate, to understand and to cope with any difficult implications of the various sources of information available (Kearney et al. 2006). Provider organisations should also ensure that, where translations are not currently available, arrangements are made to translate culturally sensitive information into the person's preferred language (Kearney et al. 2006).

SECTION 2: BACKGROUND AND CONTEXT FOR THE STUDY

2.1 British Forces Germany

British Forces Germany (BFG) is the name for British service personnel, civilians and their families who are based in Germany. It is the successor of the British Army of the Rhine (BAOR) and Royal Air Force Germany (RAFG), which were disbanded in 1994 after the end of the cold war. 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. The nature of this population is transient owing to troop deployments in over 80 countries across the World. British Forces have been stationed across Northern Germany since 1945, until recently have been concentrated in five main Garrison areas: Gutersloh, Osnabruck, Bergen-Hohne, Paderborn and Rhine (JHQ). The Osnabruck Garrison closed in 2008 leaving four remaining operational Garrisons within BFG. British Forces are stationed in Germany for reasons of national and NATO security with the agreement and support of the German government. The United Kingdom Support Command (Germany), known as UKSC(G), is based near Monchengladbach and provides the peace-time infrastructure. In addition the UKSC(G) is responsible for matters of housing, construction, schooling, planning, social and welfare services and health care for its population. In many ways the UKSC(G) can be likened to a local authority within the UK.

2.2 Healthcare Provision within BFG

Healthcare is provided for military personnel based in Germany, civilians, dependents and other entitled personnel. Since 1996, healthcare within BFG has been provided based on a combination of in-house resources and contractors to deliver required care. The Soldiers, Sailors and Airmen's Families Association (known as SSAFA Forces Help) is responsible for providing primary and community based healthcare services. Secondary healthcare in Germany is privatised and provided to German citizens based on their health insurance. Following the closure of the British Military Hospitals in 1996, Guy's and St Thomas's Hospitals NHS Trust (GSTT) contracted all hospital/secondary care to a number of designated German hospitals (known as DGPs). Hence, the British Army in effect pay for secondary healthcare in Germany.

Primary and community based healthcare services are provided in all Garrisons and Stations and are similar to the care received by general practitioners in the UK. All medical centres are staffed by military and civilian GPs, practice nurses, health

visitors, midwives, speech therapists, physiotherapists and community psychiatric nurses. Dental services are similarly provided through military and civilian dental officers and support staff. Pharmacists are attached to the medical centres.

GSTT subcontracts secondary care to five German hospitals (one is attached to each Garrison to ensure good access to hospital services). These are located at Hannover, Osnabruck (this situation may change given the closure of Osnabruck), Bielefeld, Paderborn and Viersen (near Rheindahlen) and provide elective and emergency inpatient and outpatient care. The DGPs are all large hospitals, broadly equivalent in terms of services to a District General Hospital in the UK. A high standard of medical care is provided in the DGPs and many of the medical and nursing staff speak English. Bilingual Hospital Liaison Officers (HLOs) are employed within the DGPs to support British patients and to facilitate with communication, explanation and translation of medical information, and liaison with other healthcare staff and agencies within BFG, such as the welfare agencies. Hospital Liaison Officers are available on a seven day, twenty four hour basis.

A recent strategy for community based service provision within BFG was produced (The Community Services Strategy for British Forces Germany 2006-2010). This strategy aims to bring together all the major providers related to safety, health, education and training, social welfare, spiritual needs, employment and accommodation. In it the vision of community based service provision within BFG was outlined as follows:

We want British Forces Germany to be a community of choice, now and into the future. We want all elements of the community to enjoy a high quality of life with easy access to services and support that, where practicable, are at least equal to those provided in the UK.

2.3 Supportive Care Provision within BFG

A number of agencies and organisations exist within BFG as part of primary and community based healthcare services to deliver high quality supportive care to people affected by cancer. Formal support, although not specific to people affected by cancer, appears to be mainly available through the Medical Centres and organisations such as the Defence Medical Welfare Service, Army Welfare Service, British Forces Social Work, Home Start, G1 Chaplaincy and the Army Families Federation. Voluntary groups, such as Jigsaw, a support group for patients with cancer and their carers and families run by people affected by cancer, are beginning

to be seen as valuable adjunct to formal support services delivered by health and social care professionals within BFG.

SECTION 3: CURRENT STUDY

3.1 Aims

Two parallel studies were conducted; each had their own aims:

3.1.1 Needs of informal carers

The aim of this element of the project was to evaluate the perspectives of informal carers of people affected by cancer in Germany to assess their needs and preferences for supportive care. This aim was to:

- Assess the supportive needs of informal carers in British Forces Germany
- Identify any gaps in supportive care for informal carers and barriers to levels of awareness and use of services
- Review and assess the nature and volume of supportive care available and provided to informal carers of services personnel and entitled civilians in Germany affected by cancer
- Determine ways in which supportive care can be delivered more effectively to informal carers now and in the future

3.1.2 Information needs of people affected by cancer

The aim of this part of the project was to gather information to inform the development of an information strategy based on the perspectives of people affected by cancer and those involved in their health and welfare. The aim was to:

- Assess the information needs of people affected by cancer
- Review the provision of information and consider future requirements
- Provide information to inform the development of a comprehensive information strategy for BFG.

3.2 Methods

Each of the two parallel studies had two interrelated strands of work within them.

For the needs of informal carers study these strands were

Strand 1: review of current service provision

- Review of cancer statistics across BFG to determine number of individuals with cancer
- Analysis of policies, service plans and contracts for services for carers
- Interviews and focus groups with personnel involved in the provision of supportive care for Services personnel and entitled civilians.

Strand 2: carers' needs and experiences

- Postal survey of carers of individuals diagnosed with cancer since 2003 across BFG
- Interviews and focus groups with carers
- Interviews and focus groups with personnel involved in the provision of supportive care for Services personnel and entitled civilians.

For the information needs study the two strands were

Strand 1: review of the factors that will have a direct impact on the provision and need for information

- Review of the profile of people affected by cancer in BFG
- Review of the current information sources available to Services personnel and entitled civilians within Germany
- Review of the current international literature in relation to the information needs of people with cancer

Strand 2: a comparison of the assessed need with current information provision

- Focus groups with people affected by cancer across the five Garrisons
- Focus groups and questionnaire with Key Stakeholders involved in the provision of information for Services personnel and entitled civilians across the five Garrisons.

3.3 Sample

3.3.1 Inclusion criteria

Across the two studies the inclusion criteria for carers, patients and health and social care professionals was as follows:

- Military personnel, entitled civilians and dependants who have experience of cancer
- Health and social care professionals involved in the delivery of cancer/supportive care to military personnel, entitled civilians and dependants affected by cancer in Germany
- Aged 18 years or over
- Written informed consent given
- Able to read and write English (for completion of the consent forms)
- Deemed by their GP as being physically and psychologically fit to participate in the study

Military personnel, entitled civilians and dependants who were no longer stationed in Germany were excluded from the study. All of the consenting nominated carers were sent a questionnaire by post.

3.3.2 Recruitment of patients & carers

BFG Health Services provided the researchers with anonymised information about people affected by cancer since 2003 in BFG. From an original estimate of 300, the final figure from BFG was reduced to 80 people. In addition to there being less people affected than originally estimated, some cancers were deemed inappropriate for the study so invitations to participate in the study were issued to the 80 people identified above.

Letters of invitation, study information and consent sheets were distributed to the selected sample of people affected by cancer by BFG Health Services to inform them of the project. Participants were asked to return a consent form with contact details to the research team if they wished to participate in the study. This ensured anonymity was preserved until consent was given. For the carers needs study the participants were asked to obtain the consent of the person they regarded as their primary informal carer.

The recruitment of people affected by cancer was enhanced by advertising the project in the BFG newspaper Sixth Sense. This proved to be of some use as around 20% of respondents were recruited via this process.

3.3.3 Recruitment of Health and Social Care Professionals to the study

To ensure relevant health and social care professionals were included in the project, the service user groups identified below were invited to nominate personnel for involvement:

- British Forces Germany Social Work Services
- Army Welfare Service – community support team
- Council of Voluntary Welfare Work
- DMWS
- HIVE Information Centre
- SSAFA
- WRVS Services welfare
- G1 Chaplains
- G1 Compassionate
- Hospital Liaison officers
- Homestart
- Unit Welfare
- Local charity or support groups

Letters of nomination were sent to the Leads of these organisations to ask them to discuss participation in the study with health and social care professionals in their organisations, and if willing to nominate their details to us (with permission) so that they could be formally invited to participate in the study by research staff. All nominated staff were issued information sheets and consent forms. On these consent forms the health professional was asked to indicate the level of involvement they were consenting to, be that questionnaire only or to also attend focus groups/be interviewed.

3.3.4 Sample size and representation

Consent forms were returned by 33 patients/carers (20 patients and 13 carers) and 29 health and social care professionals. This was a 40.7% response rate for the patient/carer sample and a 63% response rate for the health professional sample. Representation from all Garrisons was achieved in the patient/carer sample but some

Garrisons were better represented than others: JHQ (n= 13), Gutersloh (n=8), Paderborn (n=4), Hohne (n=2), and one person was unknown (presumably as they had not completed this section of the consent form). Four patients/carers had returned to the UK prior to or during the time of the study. A similar pattern was seen in the health professional sample, with some Garrisons being better represented than others: JHQ (n=13), Gutersloh (n=10), Hohne (n=3), Paderborn (n=2) and Osnabruick (n=1). A number of health and social care agencies within BFG were represented in the health professional sample: BFG HS (n=15), Army Welfare Service (AWS) (n=5), Jigsaw Support Group (n=3), BFG Social Work (n=2), Defence Medical Welfare Services (DMWS) (n=2), Army Families Federation (AFF) (n=1) and Homestart (n=1).

Of the patient/carer sample, nine carers returned questionnaires (69.2% response rate) and seven consented to be individually interviewed by the researcher (53.8% response rate). Five of these interviews were conducted face to face and the remaining two were conducted via telephone. In total, 18 patients and 4 carers consented to take part in the focus groups (n=22) (56.6% response rate). In total, 15 patients/carers were available to attend the focus groups and the remaining seven were interviewed via the telephone. Of the health professional sample, 19 people returned a questionnaire (67.8% response rate). In total, 18 professionals consented to take part in the focus groups (64.3% response rate). In total, six professionals were available to take part in the focus groups and 12 were interviewed via telephone. Table 1 summarises the sample sizes for each aspect of the study.

	Patients/Carers	Health/social care professionals
Nominated/made contact	n=81	n=46
Consented to participate	n=33	n=29
Returned questionnaire	n=13 (carers only)	n=19
Interviewed/focus group	n=7 (carers – individual interview) n=22 (patients/carers – focus group)	n=18

Table 1. Summary of study sample

3.3.5 Non response

Table 2 summarises the reasons for non response (following consent) within both the patient/carer and health professional samples.

	Reason	Number
Patients/Carers	Not able to attend focus group	n=5
	Couldn't make contact with person	n=2
	Deployment	n=1
Health/social care professionals	Deployment	n=2
	In hospital	n=1
	Regards job too administrative to contribute	n=1

Table 2. Summary of reasons for non response

3.4 Data Collection

As already outlined, data was collected through the use of questionnaires, interviews and focus groups both with service users and service providers. The content of the questionnaires and the interview schedules for each participant group were based on the Supportive and Palliative Care Guidelines (NICE 2004). The interview and focus group schedules are in Appendices 2 to 4 the questionnaires in Appendices 5 and 6.

3.4.1 Questionnaires

Both the carer (n=13) and the health professional (n=28) questionnaires were issued when the relevant consent forms were received.

3.4.2 Interviews and focus groups

Focus groups and interviews were held in Germany throughout November 2007 and January 2008 at JHQ and Gutersloh. In addition telephone interviews were carried out with patients, carers and health and social care professionals during January and February 2008.

3.4.3 Re-analysis of transcripts from previous study

As part of the review of the current service provision for the carers needs study, relevant transcripts from the previous study were re-analysed. Transcripts of interviews with German health professionals, military personnel and representatives of services such as HLOs were re-read in the light of this research. Specifically,

previous transcripts were read alongside transcripts from this study, to identify evidence that supports and contradicts the new data.

3.5 Ethical Issues

Talking about and reporting experiences of supportive care can potentially be distressing for people affected by cancer. Considerable care has been taken to conduct interviews and focus groups in a sensitive manner, responding to participants' emotional responses and not probing distressing areas unnecessarily. Participants were clearly informed that they had the right to halt an interview or participation in the study at any time, without this affecting their role in service or access to treatment.

The recruitment process employed meant that participants had adequate time in which to consider their involvement and to discuss it with others. Written consent was obtained from all participants and they were all assured that their details will be kept confidential at all times. All tapes and transcripts were anonymised and stored securely within the University of Stirling.

This study has gained approval from both DREC and the standard MoD ethical processes.

3.6 Data Analysis

Both the carer and health professional questionnaires were analysed using the questionnaire design and analysis package SNAP. Descriptive statistics were used to present related findings, using frequency counts for responses to closed questions.

Interviews and focus groups were recorded and transcribed verbatim. The software analysis package NVivo was used to aid the qualitative data analysis of these transcripts. Analysis of the data was thematic. Thematic content analysis is a useful approach for answering questions about the salient issues for a particular group of respondents or for identifying typical responses. It offers an accessible and flexible approach to the analysis of qualitative data. Analysis of the qualitative data was performed by the following steps, as outlined by Braun and Clark (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) such themes were then reviewed to check

they still work with our coded extracts; 5) continual analysis to refine these themes ready for discussion in the final report.

For reliability and validity purposes, two researchers have each coded some interviews and focus groups and the results compared. Subsequent transcripts were then coded separately by the researchers.

3.7 Challenges and limitations

A number of challenges were encountered in this project, which should contextualise the data which is presented in subsequent Sections.

Initially, the process for applying for MOD ethical approval took considerably longer than expected. This caused a delay in the start to the project, and shifted the timeframe for interviewing and conducting focus groups into the winter holiday period.

Due to the tight timeframe of the project, it was not possible to include all participants who had expressed interest in being involved. Some were scheduled to participate but did not attend, while others were unavailable during the dates/times of the meetings.

There were a smaller number of people affected by cancer on BFG lists than anticipated. Since 20% of respondents identified themselves to the researchers through advertisements placed in Sixth Sense and through word-of-mouth, it would appear that BFG lists have not identified all affected personnel.

The timing of research interviews over the Christmas break led to lower attendance at the Jan 11th focus group. Some personnel did not return from leave until after the focus group, thereby limiting the contributions of all staff.

Postal delays may have negatively impacted upon response rates. Postmarks on some envelopes indicated that letters had not come directly to Stirling, thereby reducing the individuals known to the research team.

Fewer health/social care professionals took part than had been anticipated. Despite communication to remind the referrers of the study, the number of professionals was reduced. Further discussion about key contacts would have been valuable at the outset of the study. Additionally, further discussion around the consent and

nomination process would have been important to ensure that professionals were aware that simply by being nominated they had not consented to the study.

The number of focus group discussions with health and social care professionals was limited, due to travel difficulties resulting from cancelled flights. Due to the tight timeframe of the research fieldwork these could not be rearranged, which has meant that interviews were conducted via the phone. The information and discussion gained during phone interviews and focus groups is anticipated to be substantially different, with phone interviews gaining less detailed information, due to the lack of interaction with other participants to spark ideas and debate.

Lower response rates were identified at two Garrisons. In particular – Osnabruck (which was beginning to close down at time of study) and Hohne (which has a younger population, so may not have as high a prevalence of cancer as other Garrisons, and hence less interest in participating in this project).

SECTION 4: FINDINGS

The following chapter describes the findings from the questionnaires, interviews and focus groups that were conducted over a four month period with patients and carers or family members, and health and social care professionals across BFG. The following chapter is subdivided to describe the (i) experiences of carers, in particular, their perceptions of their supportive care needs and the provision of supportive care within BFG, (ii) the experiences of both patients and carers in relation to their information needs and information provision within BFG, and (iii) the experiences of health and social care professionals working across BFG, in particular in relation to the provision of supportive care for carers and information for people affected by cancer. Table 3 summarises the key themes and sub-themes emerging from the analysis that are discussed in the following chapter (the section of the chapter in which each theme is described in detail is shown in brackets). The quantitative findings can be seen in more detail in Appendices 7 and 8, however, where relevant, the quantitative and qualitative findings have been combined in the following sections to demonstrate confirmation or convergence of the study findings between both sets of data.

Themes	Sub-themes
Carers' perceptions of supportive care (4.1)	Impact on carer (4.1.1) Personal coping strategies (4.1.2) Provision of support for carers (4.1.3) Challenges to accessing support (4.1.4)
Perceptions of information needs and provision (4.2)	Degree of information provided (4.2.1) Types of information provided (4.2.2) Sources of information provision (4.2.3) Challenges to information provision (4.2.4) Information provision strategies within BFG (4.2.5)
Health and social care professionals perceptions (4.3)	Provision of formal support (4.3.1) Provision of voluntary support (4.3.2) Information provision (4.3.3) Challenges to provision of support and information (4.3.4)

Table 3. Summary of key themes and sub themes

4.1 Carers' Perceptions of Supportive Care

The provision of support for carers was a major issue for the people who participated in the study. Four key themes were identified from the focus groups and individual interviews conducted with carers of people who had been diagnosed with cancer: (i) the impact on the carer, (ii) their use of personal coping strategies, (iii) the provision of support for carers, and (iv) challenges to accessing support.

4.1.1 Impact on Carer

Several carers described the impact on them of their partner being diagnosed with cancer. This impact was described by carers as having both a practical element, for example, in changing the routines of their daily lives, and an emotional element, for example, in terms of their initial reactions to receiving news of their partner's diagnosis. In terms of practical day to day life, several carers spoke of the change in their lifestyle and the new responsibilities that their carer role entailed. In particular, whilst many may have been previously involved in caring for their young families or for taking responsibility of household chores, it was recognised amongst the carers that a greater responsibility for these duties now fell solely to them. These additional tasks had to be balanced with their regular demands, for example, continuing to work.

"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 tooting 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

"the last two nights [child's] asthma kicked in really really badly...to the extent that we've hardly had any sleep at all...and I was up again about half 6 'cause obviously the girls are getting up at 7 and I have to get up before them to have a wash and a shave and get myself ready." C27

"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 really hard." C32

Many of the carers interviewed acknowledged some of the difficulties that their carer role had created in relation to continuing to balance their employment with their caregiving 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 leave work early, in many cases at short notice and inconvenience to others, as well as the concerns they experienced when they found their minds weren't really on the job. 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

"That was a problem with work...because they would literally say 'right come along for this test and come back tomorrow for another test' and I couldn't get any forward planning." C17

"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

For the carers interviewed, their partner having cancer did not appear to have major financial implications for them. However, it was acknowledged that this could be an issue for more junior ranking soldiers.

"A junior NCL may be not as well paid as I am you know and if their wife or partner or whatever was diagnosed with cancer which meant they couldn't work, that would be a really big problem." C11

"I was quite prepared to take unpaid leave if it came to it...and fortunately we were in a financial position that that hasn't really been an issue...whereas it might be a worry to a younger soldier." C17

In terms of emotional impact, several carers spoke quite frankly about their initial reactions to their partner's diagnosis and how this had left them feeling as evidenced in the examples below.

"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 spoke about the emotional impact of seeing the visible effects of undergoing treatment on their partners as being particularly difficult. Some also expressed their 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 [his 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

"There's nothing you can do to take it away [the metallic taste following chemotherapy]...I go and get her pineapple...but as soon as she's finished eating the pineapple, 30 seconds to a minute later it's back but it's back with a vengeance...doesn't matter what you do, you don't feel as if you're doing enough...all the side effects, there's nothing you can do, you can't take it all away." C27

Having their partners diagnosed with cancer, also made carers more aware of their partners' own mortality and changed their outlooks on their lives and their plans for the future.

"Rather than us thinking...'oh well we're going to be in our 90s', we no longer think like that you know. As a couple, we not think, well I'm 52 and [my wife's] 50...we've got a good 10 years together." C17

"We were emigrating to [another country] in January you know but that's now 'stop, marking time'...that'll be on the back boiler for as long as it [needs to be] and we will emigrate at the end of all of this." C27

4.1.2 Personal Coping Strategies

The carers interviewed described several personal coping strategies that they used in order to live with, and manage, the impact on them and their family of their partner having cancer. These personal coping strategies were principally designed to manage their emotional reactions to the impact of their partners' diagnosis and their

new carer roles. Several carers spoke of the value and importance of being open and honest with their partners and their young families as demonstrated in the following examples.

"[My wife] would come home and we'd have dinner and talk through every consultation." C17

"We've been brutally honest with [the children] all the way through but we haven't filled their heads with medical jargon. We sort of like spoke to [the children] as every stage has come along, we talked to [the children]...I think that's paying dividends now 'cause if [the children] are feeling sad or emotional, they will come and talk to us straight away, yeah we're a very open family." C27

In particular, through this, carers also spoke of being able to gain emotional strength and support from their partners who had been diagnosed with cancer and other family members as shown in one of the examples below.

"I had a lot of support from my friends...and from [my wife] believe it or not. [My wife] is a very strong person...very strong indeed. One thing I've learnt over the last eight months is that they [my children] are very intelligent for their age. Their whole concept of cancer and life is phenomenal...and for [children] at such a young age, they're just so compassionate and so caring." C27

Several carers commented that an important part of their role was to try and conceal their emotional reaction, to simply try and get on with things and to stay strong for the family:

"[I] try not to show any emotion in front of them [children] because I don't think it's right for them to see your parents cry. At the end of the day, I'm the father aren't I...I'm the father figure, I'm the man of the family, I'm not supposed to be the weak one...I'm there for everybody...everybody's supposed to lean on me." C27

"We just...we just battle on, I mean I don't even see the point of throwing my hands up in the air and saying 'I can't cope with this'." C30

Many also spoke of dealing with their emotional reactions by using humour as a personal coping strategy as demonstrated below.

“Years ago, my friend had his arm almost blown off...initially you treat it then laugh about it after...because that’s the coping mechanism...because a soldier can’t be seen to be...weak. I’ve got all my friends to lean on and okay, they’re not professionals by any means...but I think a soldier’s way of dealing with things is in the first instance to laugh...because that’s the soldier’s way.” C27

“My way to deal with...em...crisis it to try and joke about it or laugh about it.” C30

As demonstrated in the quotes above, many of these personal coping strategies appear to be bound culturally by their sense of identities as a man, as a father figure and as a soldier.

4.1.3 Provision of support for Carers

4.1.3.1 German healthcare system

Carers commented on the efficiency of the German healthcare system and praised it for its high quality care of their partners and their desire to remain in Germany in order to receive the best possible treatment and care.

“We live over here permanently. I mean I’m not planning on moving back to the UK. At the end of the day, I think we long term would like to stay out here.” C17

“We weren’t prepared as a family to move back to the UK [from Germany] and the treatment in the UK, I’m not saying the treatment isn’t as good as it is in Germany, but my understanding is...that it’s a hit or miss...especially with the drug Herceptin, you know it is a postcode lottery because here [in Germany] it is the best there is, it’s automatic.” C27

“We’re in our own environment here...we got married here, the [children] have grown up here you know, we know the systems, we know the military system...you know you’re safe...to go back to the UK, into a civilian way of life...I don’t really want to know to be honest.” C27

However, they did not speak of being offered much in the way of carer support for themselves from the German health providers. One carer, for example, stated:

“My husband had a particularly good doctor who was a German doctor who helped him a lot as well but for myself it’s...it’s like they don’t speak...really speak to the dependants you know...it’s very much on the outside.” C32

Principally, available support was offered to patients at this time from the Hospital Liaison Officers (HLOs) who took to dealing with issues such as, translation of medical information and consultations, and although this resource was highly valued by patients and their families, there seemed to be no support specifically directed at carers from them at this time. Similarly, although several carers spoke of the involvement of agencies such as, the Red Cross Welfare Staff, it is unclear whether they provided specific support to carers.

Furthermore, despite the evidence cited above demonstrating the impacts that carers experience in many areas of their lives once their partners have received a diagnosis of cancer and been discharged from hospital, the provision of formal support for carers within BFG also appeared to be limited. Indeed carers commented:

“When you are in hospital...the German provider hospitals...the support and the attention to medical advice and practice is second to none. It’s when you are not there that the problems come. You know, support is not as good when you are not in hospitals or the medical centre.” C11

“You’re dumped on the German system and you are dealing with them really.” C17

4.1.3.2 Practical support

In particular, although carers found themselves taking responsibility for a greater degree of household and family duties and visits to the hospital, there was little support in the way of practical home help and help with transport offered. The quantitative data revealed that, 63% of carers who responded to the postal questionnaire, reported they had not received all the practical support that they needed. Indeed, this lack of practical support provision seemed to be reflected in the qualitative data. Only one carer spoke of receiving assistance with household duties:

“I’ll clean and tidy and I’ll iron and I’ll do all the rest of it but with everything else going on, there’s just not enough hours in the day and Jigsaw provided us with some funds to pay for a cleaner.” C27

Others who were asked about practical assistance replied:

Interviewer: *“Have you been offered any assistance around the home?”*

C17: *“No, no...”*

Interviewer: *“...no home help or anything?”*

C17: *“No.”*

“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 Welfare Office was believed by carers to be a valuable resource in offering practical assistance when making arrangements to have their partners flown back to the UK. They were also helpful in transporting family to and from the airport when they were due to visit and for providing assistance in getting partners and their families to the hospital for appointments.

“The Welfare Officer involved was actually very good at organising everything...he organised [my wife’s] passport and organised the RAF to fly us back.” C20

“All I would need to do is phone up the Welfare Office...’right such and such a family’s coming out these dates, these times, landing at such and such airport’...’don’t worry there’ll be somebody there to pick them up’.” C27

“The Army Welfare Officer and a Civilian Welfare Officer...they helped us...they provided a driver ‘cause, I don’t drive so my husband wasn’t in any fit state to drive anywhere. By then I couldn’t visit him ‘cause it’s sort of like a hundred miles round trip to the hospital every day so I needed to somebody to take me up there.” C32

4.1.3.3 Emotional support

Although several carers acknowledged the informal support that they had received from friends and family, the provision of formal support services within BFG designed to provide emotional support were seemingly limited. The quantitative data from the carers who responded to the postal questionnaire revealed that 57% perceived that their emotional support needs had not been met. Similar perceptions were identified in the qualitative data as demonstrated in some of the quotations below.

"We weren't offered counselling...there was no emotional support what so ever." C31

"I think that the German system do have things like em counselling and that but because we were British, it just wasn't open to us...we were very much on our own." C32

The principal forms of emotional support directly providing support for carers identified were the community psychiatric nurses (CPN) and the Jigsaw Support Group.

"I've now found out there's a thing called Jigsaw and they are trying to set up a support group out there [Gutersloh Garrison]...that's another thing you get support from is actually other patients. I went off to the support group meetings on camp and all of a sudden you had loads of people that were all affected by it and then you're...you sort of get into a little community you know." C11

"We had a CPN here...I've still got a local referral to him. If I feel as if it's getting too much for me and I need to just go and...I don't know...talk about things and get it off my chest then I can basically unload. It's just a case of phoning him up and he can have a chat with you...he'll either come to the office at work or pop up here [medical centre] or he'll come round to the house you know and it's there for me if I need it." C27

"We discovered Jigsaw...[my wife said] 'you know everybody here is the same as me, I feel normal'...and that is the phrase 'I feel normal' 'cause everybody that was say about whether they were a carer, a helper, or a patient, we were all in the same boat and we all understood that...you've got a connection. They'll say to me 'I know how you're feeling' you know and then...the carers would go at one end, talk about things and all intermingle and things like that." C27

4.1.3.4 Bereavement support

Each of the carers interviewed during the study were at different stages in the cancer journey, for example, their partners had been newly diagnosed or were currently undergoing treatment. Only one carer interviewed had recently been bereaved and spoke of his experiences of support provision around this time. Sadly, he perceived that although he had good experiences of the support offered to him and his wife by the German health providers, the hospital liaison officers and his employers during

her active treatment, there had been little offered in the way of support following his bereavement.

"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

"There was no one, there isn't anybody. I asked the doctor, 'is there any bereavement counselling?'... 'no'... 'any kind of counselling at all?'... 'no'." C20

4.1.3.5 Support from employers

The majority of practical support for carers was offered by their employers who were seen to have been *"fantastically supportive"* (C27) in all cases. The quantitative data confirmed that virtually all of the carers who responded to the postal questionnaire reported that their Unit had been supportive in allowing time off work to go to appointments and transport to the hospital if necessary. The qualitative data also revealed that support and assistance provided by employers included, being flexible with regards to working hours, changing duties or roles to fit in with carers' current situations and future plans, and offering carers' extensions to their service. All of these provisions were seen as valuable by all carers.

"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, just 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

"We're a very small unit and there was manpower to help me in that...to take me back and forward to the hospital and to take [my husband] to his appointments...they were fantastic." C32

4.1.4 Challenges to Accessing Support

During the interviews a number of challenges to accessing formalised support services became evident. In particular, these related to awareness of available forms of support for carers within BFG, the style of approach in accessing and obtaining support, issues related to rank or position within the army, and the need for specialised and dedicated support for people affected by cancer. These issues are described in further detail below.

4.1.4.1 Awareness of available support

The accounts of carers' experiences of support provision above, highlight that few of them were aware of the various forms of support on offer within BFG. Carers' comments relating to the Jigsaw Support Group, as shown above, revealed how little information about such services is passed on to people affected by cancer. Some further examples highlight this finding.

"At the moment...you know, people don't even know this stuff's going on. So there might be people out there who're suffering with you know, affected by this and they don't realise that there is actually...there is support out there because they just don't know about it. Pushing the information out is quite key because you could set up all the support you like but unless you've let people know about it, you're not going to benefit are you?." C11

"On this form [referring to the postal questionnaire], there was about 15 different organisations...and I'd never heard of any of them really." C17

Interviewer: *"Are you aware of Jigsaw?"*

C32: *"No."*

Interviewer: *"It's been set up by soldiers that have had cancer themselves"*

C32: *"Oh no, I've never heard of that before."*

Furthermore, although much support was provided to carers by employers as demonstrated in the earlier quotations, information about what kinds of support they could provide carers with was again not readily forthcoming.

Interviewer: *“Did you know about the availability of compassionate continuance before your wife had been diagnosed?”*

C27: *“I didn’t know about it...nobody knew about that.”*

4.1.4.2 Approach to accessing support

The above findings may be related to another important issue which emerged during the interviews relating to the style of approach for accessing and obtaining support. It was frequently commented upon amongst all of the carers interviewed that the system for accessing support was reactive as opposed to proactive. In particular, many commented that the onus was on the individuals themselves to speak up when they needed support and to find out what they needed and where they could access this 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.” C27

“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

“The way I interpret it...the support is there but we’ve got to go and look for it. The Padre, the Army Welfare Service, SSAFA Forces help, WRVS, you know...it is there but you’ve got to go and look for it. It should be very much people knocking on the door.” C31

Hence, many more challenges around this particular approach to accessing and obtaining support exist as a result. For example, one carer recounted a conversation which revealed that people don’t necessarily know the forms of support that they need or can access at a particular time if it is not offered to them in advance.

Support Group Leader: *“right there’s funds in the pot, do you need any support, any assistance?”*

C27: *“no don’t need any assistance’...”*

Support Group Leader: *“well what (about) a cleaner?”*

C27: *“also commented that “you know it wasn’t until she suggested it [that we realised it would help].”*

4.1.4.3 Community life within BFG

Two issues related to community life in the armed forces were identified as contributing to the challenges around accessing and obtaining support. In particular, it was identified that the close knit nature of the community within BFG created difficulties for some people in accessing supportive care services. This was because many of the people employed to offer these services, also lived nearby in the local community. Therefore, there were concerns over confidentiality and some people reported feeling uncomfortable at disclosing information about a cancer diagnosis or their needs for support to people who was already known to them.

“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

A re-analysis of the DMWS transcripts identified data that reiterates the close-knit nature of the BFG community from the perspective of a health professional.

“(another participant) and I were working together when our next door neighbour died so F1 had all that to deal with as well. ‘Cos it was unfortunate at the time but it was a bit too close to home as well really.” DMWS/FG1/M1/HP

Another issue raised in the current study was related to the transient and changing nature of army personnel within an army community as a result of deployment. This creates a challenge for accessing and obtaining support because often the awareness of available support within an area relies on word of mouth. Therefore, when army personnel are deployed or leave the area, then this linkage is lost and carers who could make use of supportive care services may not learn about their existence. One carer referred to the Jigsaw Support Group as an example of this.

“I see a group of people trying to get together, trying to sort something out and then you know give it six months or you know when a person’s moved on, whatever, it will just drop down.” C11

4.1.4.4 Rank and role within BFG

It was acknowledged by several carers that the ability to be flexible with your employer and to manage your workload patterns around your current situation and events that arose was dependent upon your role/rank within the army. It was also acknowledged that the likelihood that one would be able to remain in Germany for the duration of their full care provision and treatment if they held a more senior position within the army or had been stationed in Germany for several years.

“Whatever rank structure in the Forces and...the situation would be the response you got. If you were talking about a soldier, then that would be almost like a career ending thing. I’m quite lucky that I’m working in headquarters you know quite a senior person that I can actually manage to work around all this sort of treatment and stuff like that.” C11

4.1.4.5 Lack of resources and infrastructure

Lack of resources and infrastructure to support people affected by cancer was also commented on by several carers. In particular, it was identified that until recently, the response to someone being diagnosed with cancer was to send them back to the UK. As acknowledged earlier, however, there is now a greater desire amongst people with cancer to remain in Germany since they perceive this as their home and not the UK.

“I bet that happens with a lot of services people who are affected by cancer...they instantly say ‘right post them back to England.’ C11

“Up until recently...‘you’ve got cancer, right back to the UK’ you know’.” C27

“I don’t think the resources are here to do it. The size of the detachment...you know we don’t have the full infrastructure to support it.” C30

4.1.4.6 Access to specialised cancer support

Carers frequently commented on the need for specialised support for people affected by cancer. Although they acknowledged the work of existing agencies who came into contact with people affected by cancer, it was believed that people affected by cancer within BFG were suffering because they did not have access to specialised cancer support, such as Macmillan nurses. In particular, carers frequently commented that this kind of support would be welcomed in order to provide support and reassurance that the feelings they experienced were ‘normal’, that what their

partners' were experiencing in terms of side effects were 'normal' and also saw this as a means to providing continuity of care between primary and secondary care. In addition, this was also seen as an effective means to link up the various forms of support that were available within BFG. A Macmillan nurse could provide ongoing information on that support and assistance so that it could be accessed more appropriately and in a timely fashion, rather than simply at times of crisis.

"There isn't a Macmillan nurse [in Germany] and that level of support is missing because it's just getting on the phone to someone who sort of knows about it who can advise on types of food, what [my wife] is feeling or not feeling well at certain stages. 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

"You just don't have anybody to [talk to]...I think it would be good if [my husband] could go to somebody...to tell your fears or how scared you are. I think that would be better because it goes on and on into this big cycle...on and on and on and on and all of a sudden this tap opens. Myself, I was in the medical centre and it just flooded, it just came out you...inconsolable afterwards but you feel alright. Somebody to say that actually how you're feeling is normal, I think that would be the biggest help." C32

4.2 Perceptions of Information Needs and Provision

The issue of information provision within BFG was a major source of concern for many of the participants in the study, particularly for patients diagnosed with cancer. Four key themes around experiences were identified from the focus groups and individual interviews conducted with patients with cancer and their carers including, (i) degree of information provided, (ii) types of information provided, (iii) sources of information provision, and (iv) challenges to information provision. A fifth theme was also identified where participants offered suggestions as to ways in which information could be provided to people affected by cancer in a timely and consistent manner. The findings relating to this theme are described in the final section of this chapter.

4.2.1 Degree of Information Provided

Although many of the patients and carers commented that they had been given some information following diagnosis, this was considered to be limited in its scope and

many expressed the view that there was little awareness of the specific types of information that both patients and carers needed. The following examples highlight that information provision in general has been ad hoc and inconsistent. Some participants spoke of being offered excellent information about specific issues at the time of diagnosis, principally around type of cancer and type of surgery and treatment.

Interviewer: *“Can you remember much about the sort of information you were given at the time?”*

P4: *“Yeah, the doctor came in and explained everything...he explained that they were going to go in and look at it and if it was a tumour then they would have taken it away and then put a drain and that in and em then they would go to the lab and it would be checked for cells and that sort of stuff so he explained it really well. The urologist that done the scan was actually quite good, he spoke really good English and when he'd done it [the scan] he was looking up websites in German and English and writing it all down and explaining it.”*

“I've always had access in the first instance to either a Professor or the senior doctor and they have in my view been able to provide all the information. They've gone at pains to say, you know do you have any questions or concerns.” M1/P/FG2

Others, however, reported that they were given very little information around the time of diagnosis.

Interviewer: *“Can you remember much about the sort of information you were given at the time?”*

P1: *“Er...yeah, I wasn't given an awful lot to be perfectly honest with you. Nobody sat down and said well actually this is what you've got. It was pretty sketchy to be honest with you and I think it was one of the weaknesses of the system here.”*

“Absolutely nothing...” M2/P/FG1

“No information at all, the only information I got was when I actually saw the doctor and I got to ask questions.” P3

“Cancer Backup...I got all my information from, but there was nothing...nothing from the hospital.” F3/P/FG2

The quantitative data revealed that 78% of carers who responded to the postal questionnaire stated that they had received information about their partner's

diagnosis, the type of treatment they would undergo and what this involved for them. This contrasted with the findings of the qualitative data, however, which identified that often, carers were given very little information.

Interviewer: *“Was there any information offered to you as a family member?”*

M2/C/FG2: *“Nothing to be honest, we dealt with it together...there was no information given to me. We almost did everything together to find out the information, there was no additional information given or available to be honest.”*

4.2.2 Types of Information Provided

4.2.2.1 Information on cancer and its treatment

Many of the patients' accounts revealed that they believed they had been given excellent information on their type of cancer and treatment plan from medical staff within the German health provider hospitals. However, despite this, it emerged that there was no one from either the German health provider hospitals or within BFG who offered information about what patients and carers could expect from the treatment in terms of its physical, psychological and social impacts, both in the short and longer term.

“The only information I got em [was] in terms of the actual cancer itself. When I started...it was very much a case of ‘right you’re starting your chemotherapy tomorrow and this is what’s going to happen’. The doctors were excellent, they really did give me good information about my treatment...but it wasn’t really support in terms of ‘this is how you’re going to feel, this is how you can get through it’...it’s very much a case of ‘this is your treatment and this is what we expect the results to be’. There was no other information about little things. I got some information from [back home in UK] but there was nothing I felt here. With each treatment I had, I progressively felt worse and nobody told be about that.” F1/P/FG1

“I’d never heard of lymphoedema, I didn’t know it was a side effect of having my lymph nodes removed. I didn’t know that a 10 week course of treatment was not going to cure it, it was just to help with the fluid I’d built up at the time. I didn’t realise I was going to be living with another life long issue which I can prevent from getting worse.” F2/P/FG1

“Nobody told me that my gums would recede during chemotherapy. Nobody told me that my hair would grow back different. Just the little things. Nobody told me that I was only going to lose the hair from the top of my head or people are different. I

"I must admit, I think they were a bit...when I was asking about the side effects of the chemotherapy...I think they were playing it down slightly. I had to sort of really ask her about all the long term side effects...they weren't too up and coming with the long term side effects." P3

"They never really explained that [the side effects]...they just spoke of the operation and...that a high percentage of people survived this type of cancer...but they never really went on to say like years down the line it would do this or that." P4

The importance of ensuring that these types of information are provided in order to ensure that patients and their families are managing their side effects in the most appropriate and effective ways possible was clearly highlighted in the following example.

"He [Macmillan nurse back in the UK] talked me through the lymphoedema...he told me I was actually making it worse. I didn't know I was making it worse. I didn't know you're not supposed to carry on with certain things because I didn't have that information." F2/P/FG1

4.2.2.2 Information on practical and financial support

Both the quantitative and qualitative data confirmed that there seemed to be little information offered to patients and their families on the different kinds of support available to them within BFG on issues related to finances, help with children and schooling, employment, housing, practical day to day help within the home, and the roles of the various support agencies and services available within BFG. In particular, within the quantitative data 63% of carers stated that they perceived they had not been offered enough information on the practical support that they needed in order to care for someone with cancer. Perceptions of information on practical support from the qualitative data support these findings.

"My main concern was 'am I still going to get paid' and you know it's a stupid thing to worry about but I didn't know what the army's line was. I didn't know if I was going to get kicked out of the army or what...nobody told me." F1/P/FG2

"I've got to suffer financially because there's nothing in place to sort of back me up. But there's nobody even...it took me months and months and months to actually find out the definitive answers on it between myself and the director." F2/P/FG1

"I didn't know about them [CAMS]...cause M [daughter]...has got behavioural problems now due to lack of oxygen when she was a baby...I never knew about them either cause you don't hear about them...they can't help [me] if I don't hear about it." F5/P/FG1

Interviewer: *"Does the army volunteer information about finances?"*

F3/P/FG1: *"Not as far as I know."*

F2/P/FG1: *"Not at all actually."*

4.2.2.3 Information on follow up and recurrence

Furthermore, there also seemed to be a lack of recognition of peoples' continuing needs for information in the stages beyond diagnosis, for example, after treatment or in the period known as follow up or survivorship and no information provided about the risk of recurrence.

Interviewer: *"Were you given any sort information...told where to go if you've got any further problems?"*

C32: *:"Em...well not really no...we just, if there were any problems we'd go back to the doctor...there was never anything specific given."*

"I'm still a little bit in the dark about what I expect my follow up treatment to be, check ups and stuff like that. I've asked each time I go [to the hospital]...but there's no one there tells you what's laid down and they don't seem to make appointments like in the UK." F3/P/FG2

In another example, one patient was not given information on various tests that she would be likely to undergo during the follow up stages. Subsequently, when she was called to undergo these tests, she was unsure as to whether it was part of her routine follow up or whether something was wrong as no one had explained the purpose of the tests.

"[They] just whipped me in for a test and did a scan on me and I didn't know that was even going to happen...I had no idea they were going to do an ultrasound and of course when somebody does something on you like that and you're not sure and you weren't told, you think 'oh is there something wrong'...you start to think the worst." P3

Information provision in the stages of follow up and survivorship was identified in the interviews as being extremely important as many survivors of cancer feel that they are at risk of isolation and likely to be anxious and fearful of coming forward with information needs at this time. The following examples highlight these perceptions.

“Although they’ve told me I’m clear, I could still do with somebody being here to support me through this quite difficult bit because it’s just going to be a continuous race going over hurdles the whole time. I’ve got 2 years now living with the fact that it might come back which is really quite hard to think about. So it’s not just the during treatment and during the fact you’ve got cancer, it’s actually the you know post that as well.” F1/P/FG1

“What’s going to happen to me in 6 months? Because then I’m going to be more and more isolated you know from the information purpose and maybe a little bit more anxious and less able to come forward and say this is what you need you know. I think there needs to be a strategy or something in place so we won’t have to take the responsibility.” F2/P/FG1

“they just do their job they do, they help you and they say ‘oh you have to wait 6/7 years now until you can see if you’re clear you know...because we don’t know if it’s coming back or spread or not so.” F5/P/FG1

4.2.2.4 Information about emotional support

Subsequently, the examples cited above also highlight the importance of being offered information about emotional support and counselling. This was a key gap identified in the quantitative data. In particular, 57% of carers who responded to the postal questionnaire reported that they had not been provided with enough information on emotional support. The qualitative data revealed that there was a lack of forthcoming information on counselling and emotional support and that this would have been welcomed by many.

“I’ve never had any counselling or ever been approached for counselling...neither has my wife. Not only do [we] need physical help with regards to medication and treatment but [we] also need some sort of emotional help...possible counselling.” P4

“I had to wait three months until I had another scan to see if the lesions had grown on my lungs...I just completely went to pieces...I was just given beta blockers to cope, there wasn’t a support group at that time, there wasn’t any information they could

give me...so they just gave me beta blockers to cope with the anxiety that I was feeling, I felt very very lonely and let down.” F2/P/FG2

4.2.3 Sources of Information Provision

Despite the challenges identified in accessing and obtaining information, the qualitative data was useful for identifying where people affected by cancer sourced information. The following section describes these in more detail.

4.2.3.1 Hospital Liaison Officers

Patients commented that the Hospital Liaison Officers (HLOs) could prove extremely helpful if they had the time to come to each appointment. In one example, a patient describes how the Hospital Liaison Officer was able to help reassure her and explain things to her.

“If I didn’t understand, I would go through the Liaison Officer...every time I’ve needed to do to an important appointment, she’s arranged to come along with me. I was a whole day at the hospital where they did some tests on me and she was there for the morning then she had to go away and come back again with me afterwards so I was there the whole day and she was there to explain things.” P3

4.2.3.2 Fellow patients and carers

Opportunities to share experiences between patients and their families were seen as a particularly valuable approach to receiving information.

“Now we’ve set up the Jigsaw thing...you don’t realise what other people are going through and what they’ve gone through and things they’ve done to help with their treatment. It was very...I was going through blind.” F1/P/FG1

“I’m interested in the fact that it has brought me together with people like [F] who we’ve helped each other because we’ve both got cancer...it’s just someone we can connect with. I know my husband finds it very very good to talk to [M]...it may not even be about cancer or caring for us but just there’s someone else who knows that pressure he’s under as a carer.” F2/P/FG1

Many of the participants referred to the information they had received through informal support networks such as close friends who had also been diagnosed with cancer and were living back in the UK. For the patients diagnosed with cancer, these

networks provided a wealth of information on what they could expect from their treatment and offered a degree of reassurance:

"It wasn't till I phoned by friend in the UK that they said, you know, 'yes you've got to expect with each and every treatment that you're going to get worse. They're just topping up, poisoning your body and your body is not going to be able to fight it each time as well as the first'...so I thought 'right fine, I can get my head around that now.' I thought, somebody's told me." F1/P/FG1

4.2.3.3 Internet and telephone help lines

Many patients also used the Internet and specialised telephone help lines to obtain further information. Many found these sites useful to avoid issues related to translation of information and used them to obtain more detailed information than they had been initially offered and for a degree of reassurance. Frequently cited sources included, Cancerbackup and Cancer Research UK.

"I phoned them [Cancerbackup] and asked for just booklets on things I felt I would need. Not like a whole range of books but just like you know how it's going to affect my sexuality, my diet, all the things that I felt relevant to me." F2/P/FG1

"[My wife] just went straight onto the internet and you know got every bit of information you could get on DCIS." C31

"I did a lot of the information scouring myself. I did look up as soon as they told us what type of cancer it was, I went on the computer to find out what type it was. We put in it was a seratoma...I just typed that in and it threw up a load of stuff. It explained things easier with the internet.." C32

4.2.3.4 Accessing UK resources

Many of the participants spoke of accessing information resources and specialised health professionals when back visiting the UK. This was seen to offer them information and support that they did not consider was available to them back in Germany.

"In fact, I've got some family back home that they...like a Macmillan nurse...she goes round to cancer patients so I got some information from there." F1/P/FG1

“We went back to the UK recently...and one of my main purposes was to go and speak to a Macmillan nurse. I went there and I asked the questions and they gave me contact numbers, they gave me information leaflets, he talked me through the lymphoedema.” F2/P/FG1

4.2.4 Challenges to Information Provision

During the interviews a number of challenges to information provision for people affected by cancer in BFG became evident. In particular, these related to the style of approach used in identifying information needs and providing information to people affected by cancer, the army culture and one’s role within the armed forces, translation of information, issues related to relying on the Internet for information, and the need for professionals with specialised knowledge about cancer and cancer information, and issues around information exchange between primary and secondary care. These issues are described in further detail below.

4.2.4.1 Style of approach to accessing information

Participants perceived that the responsibility for identifying information needs, accessing information about cancer and its management, and finding out what available support services there were on offer within BFG often fell to themselves.

“As time when on, I started to look a little bit more myself and some family from the UK did...but nobody actually really explained anything here or came to me and said ‘right you know well with this type of cancer, it’s this or it’s that’ you know....there was no information really. It was very much a case of ‘well if you want to there’s a website, you can go and investigate’.” F1/P/FG1

“I put in place a CPN for myself, CAMS for the children as support but that’s because I know how to access these agencies. If I didn’t, there was no one who actually brought forward that information to me and it’s very hard to sit here...and realise that ‘well yeah actually that wasn’t there for me and that wasn’t there for me’.” F2/P/FG1

The challenging nature of this particular approach, however, was identified by some participants who commented that they didn’t know what information they needed or didn’t like to ask for information as demonstrated in the following examples.

“I think if I had wanted to, I could have got someone, you know I could have phoned up the WRVS or one of the Welfare Services and I’m sure they would have been

delighted to assist me but I would have preferred if they had actually just turned up and said 'let's go and have a cup of coffee and a chat'." P1

"It was just from the point of view 'well we're here if you need us' but I didn't know what I needed...and they couldn't tell me what I needed." F2/P/FG1

"I'm not the person like I'd go out and ask...if you have to go out of your way and talk to different people and ask, I'm not the person to do that, I don't like to pester people you know." F5/P/FG1

In other cases, participants also commented that they didn't like to research information too much themselves and were fearful of what they might find out from scouring the Internet or reading books about cancer, for example.

"Me and my husband are very much...we don't research a lot of things...we've got to take that leap of faith. I'm too fearful to go on the internet because my mind would play tricks on me." F2/P/FG1

"When it comes to websites you know we take this one with a bit of a pinch of salt and that. There's loads of stuff out there that you can read yourself to death by getting onto some of these sites." C11

"We haven't gone on the internet and researched it every waking moment that we've got, every spare second 'cause my personal feeling is that em 95% of what you get on the internet is negative information." C27

Several of the participants commented that they would have found it valuable to speak to someone with cancer, about what they had experienced and how they had managed the impact of cancer and its treatments. However, there had been little previous opportunity to do this and many were unaware of the existence of groups such as the Jigsaw Support Group.

"I didn't know what I was going into...to speak to other people at that stage [would have been useful]." F1/P/FG1

"Before I had found out about the Jigsaw group...I was just this, what I thought, was one person in BFG with cancer. I knew there must be people but there was no one to talk to." F2/P/FG1

"I only heard about this Jigsaw earlier when I was at the CPNs [community psychiatric nurse]...she said 'aw you know there's actually a group called Jigsaw' and I said 'I've never heard anything' you know you don't hear nothing." F5/P/FG1

4.2.4.2 Army culture

The culture of the army and one's role within that was also sometimes seen as a barrier to effective information giving and seeking. This appears to strengthen the need for moves towards a more proactive approach to information and support provision. For example, there was a definite sense of a "just go and get on with it" attitude or that soldiers would prefer not to ask for help or would surely ask if they needed it, and therefore, little recognition of the importance of this proactive approach to information giving and provision of support as shown in the following examples.

"At no point was I given a CT scan, at no point was I given blood tumour marker tests...no leaflets...no information. It was just 'you're a squaddie, get on with it.'" M2/P/FG1

"At the end of the day, we're talking about soldiers...soldiers will not ask for help because it's a sign of weakness." F2/P/FG1

"My husband wouldn't go out and just ask for help...you need somebody to like you know given them a smack on the back and say 'look you need some help' sort of thing. He's struggling now, he's scared and I can see him struggle." F5/P/FG1

"You know I've got to go and speak to [somebody]...I'm traumatised...you do have this thing that it's a sign of weakness and you don't want to show that sort of weakness..." P1

4.2.4.3 Translation of information

The language barrier was also identified as being a major contributory problem to the challenges surrounding information provision by all of the participants. In many cases, although information was given, it was written in the German language only.

"The only thing is...I mean they've given me loads of these little blue books that they give out to all patients...it explains all about your therapy, radiotherapy and chemotherapy and your surgery but they're all in German." P3

“The appointment card was a green card with the chemotherapy stuff written on it...it wasn't even in English.” F1/P/FG2

Little material in the English language seemed to be available to patients and carers and, despite the availability of English information on the internet, patients were often not signposted towards this (as further described later in this section.) Subsequently, the translation of information offered proved to be a challenge. In particular, many commented that the time taken to get information translated could be many weeks, far longer than they had anticipated. This means that people frequently became more anxious during this time if they were waiting for information on, for example, test results. The frustration that people experienced when they were then faced with further challenges such as the costs of translating various pieces of information and who it was that was responsible for this, was evident in many of the participants' comments.

“The translation of that information [about lymphoedema] took 7 to 8 weeks. People were arguing about the cost of translation and who was going to translate it. The liaison staff are only allowed to translate non-medical things. I'm happy with my treatment but you know I actually said to them 'I've got bloody cancer and I'm living now with what you're telling me is a life long thing'. I've had to drag the information and now I'm waiting weeks and weeks.” F2/P/FG1

“The information that was written was written in German and it was sent to the Medical Centre...I mean it used to take them a week to translate it. They did have a translator there but you were waiting a long time especially if you were worried about something like cancer, I would really like to know now, you know. Their processes in the Medical Centre was slow...really really slow.” C32

4.2.4.4 Reliance on the Internet

Despite the fact that the Internet was largely perceived as a valuable medium for sourcing information related to cancer, it was acknowledged within the interviews that there were limits to the value that such sources of information could provide in the absence of the knowledge and support provided by a specialised health professional. In particular, people expressed fears of being overwhelmed with information and not being confident on which sources they felt they could trust. In another example, one patient describes the challenge of obtaining information from UK websites which described the processes of treatment in a UK context and which proved to be slightly different from the process of treatment that she underwent in Germany.

Subsequently, specialised support for assisting patients and carers and for helping them to identify reputable and trustworthy information when using the Internet was believed to be valued by the participants in the study.

"I got into a British website 'cause I wanted to know a bit more about the radiotherapy and that was quite helpful and said what you should expect...although it wasn't quite the same as what happened. The British seemed to allow you to wash the area with very mild soap and use creams on the breast...I'd looked in the little blue book they'd given me and they said don't do that...you can't wash it at all." P3

A further difficulty in accessing information using UK based websites and telephone lines is the reluctance of people to discuss aspects of one's care if they've had treatment in a different country or send on information.

"I looked on the internet, but quite a lot of people will have this caveat that they actually can't discuss your treatment with you 'cause you've had treatment abroad. I was sort of checking up and seeing what the research was saying but I didn't find they were prepared to commit. I wonder if it's because we have our treatment abroad and they feel that they're not so familiar with our treatment." F1/P/FG2

"There's another lady...she's had problems with Cancerbackup because she didn't have a UK address and they wouldn't send her anything." F2/P/FG2

4.2.4.5 Need for specialised knowledge on cancer

Many perceived that although they had been offered some information from agencies, such as the Welfare Office, this was challenging because these professionals lacked a specialised knowledge of the nature of cancer, its treatments and its subsequent impacts on their daily lives. Several participants commented that having cancer could be very isolating and there was a risk that they could often feel alienated. They commented that what they needed was a specialised health professional with a knowledge and understanding of the nature of different types of cancers and its treatments in order to be able to understand their situations and to offer relevant and timely information and reassurance to them.

"I can go and speak to my doctor, he's fantastic...but he'll never...he's not a cancer specialist. The difference I think it makes when you speak to somebody that can just give you a few tips is just so comforting...it's incredible, it's just so reassuring." F2/P/FG1

"I do get the sense that sometimes in the medical centres, some of the staff are afraid to make the connection (signposting to websites) because they don't have the experience and knowledge and I think sometimes they withdraw from that. You know if you're in the UK, there are a range of professionals that are around to support you and your work, but over here there isn't that, we don't have the Macmillan nurse or breast care nurse...professionals can be quite isolated in their practice." F1/P/FG2

"Between the diagnosis and various stages of treatment, there was a great chasm where lack of experience in primary care...could have finished me off." M3/P/FG2

The participants revealed that there seemed to be a lack of signposting towards sources of further information for people, for example, reliable websites or support groups providing the opportunity to share information and experiences.

"People knew there was this group somewhere in BFG but nobody had access to the information. There was no awareness of any support for us." F2/P/FG1

Interviewer: *"Did anyone actually give you any good websites to look at?"*

C32: *"No, nobody did."* C32

"a list...they're already in place [informational websites]...all they need to do it put that information forward [to people]." M2/P/FG1

Subsequently, people spoke of relying on people not directly involved in their care to provide them with information or signposting to further forms of information. As a result, information was often received on an ad hoc basis.

"I actually used the girls' paediatrician...she said 'try Cancerbackup UK'." F2/P/FG1

4.2.4.6 Information exchange between professionals

There also seemed to be little sharing of information between primary and secondary care, meaning that if patients experienced problems with their treatment and its side effects when back at home, they were reliant on some one at their local medical centre to help treat them quickly and appropriately. In one example, a patient described how there was a no sharing of information between the hospital and medical centre about his care and treatment and as a result, they did not know how to treat him appropriately when he experienced a very severe reaction to the radiotherapy.

“My doctor knew the treatments that I was getting but at the same time the med. centre had nothing in place or nothing that they could sort of go to to find out how to treat what the side effects were. That’s where the problems started...they had to give me three injections to stop me being sick...like ‘we’ll try this first, right that’s not working, right we’ll try this one, right that’s not working...having to keep trying different ones to get it to work. So they weren’t prepared for that side of life. ‘Oh how do we deal with this...we don’t know, let’s just stab him anyway’...which wasn’t their fault, they were doing the best that they could at the time but em it could have been better. There was no sort of liaison between the med. centre and the hospital.”

P4

4.2.5 Information Provision Strategies within BFG

There was the recognition that in order for information to be provided to patients with cancer and their families, in a timely and consistent manner, several strategies were needed. In particular, to ensure that information provision strategies were successful and implemented they had to have the support from the top of the chain of command. As example quotation showed how such support can be useful for raising awareness and encourage relevant and timely information to be provided in a strategic manner.

“When I was in Aldershot [patient who runs an informational website about testicular cancer], I got to know the Regional Clinical Director very well because she came to one of my awareness talks and she ordered every doctor in the South West Region in the army to come down and listen to one of my talks.” M2/P/FG1

“You need to start from the General...and work your way down and everyone alongside him (sic)...you need to hit the high racket.” F2/P/FG1

“I think we’ve found that [it’s important to get support from the top]...certainly just the higher up you get, the more likely it is to have a little bit of clout.” F3/P/FG2

Several strategies were perceived as being potentially useful in helping to ensure that patients and their families were given relevant and timely information and to take away the challenge of feeling fearful or guilty for asking for information about particular entitlements. A number of health and social care professionals within BFG from different agencies could have a role in information provision so that it didn’t just fall to the responsibility of one person, for example, GPs. It was acknowledged that better communication between the different agencies involved would help to facilitate this.

“The Med. Centre, hospital liaison office, St Johns Ambulance...the welfare offices should also have an information pack to be given.” F2/P/FG1

“If there was something in place that said actually ‘you are entitled to this or there is a certain amount that you are supposed to support the soldier with whether he’s the patient or the carer’...then that responsibility is taken away, that emotion is taken away, it’s just black and white, it’s just policy.” F2/P/FG1

“I think on the thing is that everyone else has assumed that everyone else has done something and then the breakdown in communication between the agencies. But I think you see the GP on a regular basis, the HLO you see at the hospital...and the Unit Welfare Officer’s possibly so it’s coming from all angles.” F3/P/FG

Two patients also suggested the importance of having a centralised location where information could be held and accessed by both patients and their families as well as health professionals.

“That would have been lovely for me to know that my doctor could go to his drawer and pull out that policy and procedure and say ‘do you know what [F], I’m not familiar with it all but I’ve got all the information there we need’. I think there should be recommendations and everybody that’s admitted...should get the information about support groups. I think there should be something somewhere that says there’s always a drawer full of information packs for when ever someone’s diagnosed.” F2/P/FG1

“I don’t know how they would do it but a...centralised centre somewhere in Germany where information is kept...if for talking’s sake a Garrison has someone in the same sort of predicament as me, you can phone them up this centre and say right what can they expect and how do they deal with it...and they could turn around and say right ‘well it could be this...you need to get these drugs’...rather than at the last minute. A centralised point or some website where they can go and get information through within a 24 hour period....they could get information on radiation for cancer, what foods they can provide, what good supplements they can provide.” P4

“Even if [information] could be put on an Army Medical website, rather than just a general website where the doctors are going looking for it themselves off their own back...then we can pull this off the Military website and then give that to patients.” P4

As acknowledged in the earlier sections, it was believed to be particularly important that a greater amount of information was made available on the nature of the side effects of different kinds of treatments, both in the short and longer term, and how these could be effectively managed.

Despite, the provision of support groups such as Jigsaw and the creation of informational websites such as 'Check em lads' being considered a valuable resource by patients, carers and family members, one of the main challenges faced relates to spreading awareness of the existence of such resources and the role that they can play in offering information and support to people affected by cancer. In particular, participants' comments seemed to reflect that there was a degree of resistance and a lack of support for such resources from medical professionals within BFG.

"The Med, Centre's...some of them have refused to put up the posters [publicising the support group] and I find that absolutely shocking because it was the Med. Centre's who couldn't give us when we asked for information on were there any cancer support groups for BFG and dependents." F2/P/FG1

"People come into the Med. Centre...I've given them posters, I've given them postcards...'put them up on the wall'...nothing, not even when they had cancer awareness week, nothing." M2/P/FG1

4.3 Health Professional Perceptions

A number of health and social care professionals employed across BFG were interviewed for their perceptions on the nature of support and information offered to people affected by cancer within BFG. A number of themes emerged from the data including: (i) the types of formal support available to carers of people with cancer, (ii) the information available to both patients and carers at different stages of the cancer journey, and (iii) challenges around the provision and access of support and information for people affected by cancer as perceived by health and social care professionals. A fourth theme, relating to strategies that could be used to help facilitate the seamless and reliable provision of support and information for people affected by cancer, was also identified within the interviews with health and social care professionals. These themes are described in further detail in the following sections.

4.3.1 Provision of Formal Support

4.3.1.1 Practical support

A number of professionals indicated that numerous different forms of practical support, such as help with transport to and from the hospital and child care, is available to carers and family members of people diagnosed with cancer. Mostly, this type of support was offered by the welfare services within BFG.

“All of the Welfare Officers have transport provision or are able to access transport through the transport office at the Garrison headquarters.” HP14

“... and that may not only be for the actual service user who's got the cancer, but the “partner of” or “family member of” who you can support through that...that could be even down to organising practical support...if it's child care, trying to find funding for child care or whatever so people can go and visit their partner you know, things like that, its, its on a practical sense...we would endeavour to try and get money from somewhere to do that, so it may not be to actually support the cancer patient service user but it's the family as well, what ... its really whatever we can do.” FG1/M1/HP

Practical support around the home was believed to be out with the remit of the welfare services. However, there was a distinct impression from the professionals that there were no forms of practical home help available for carers of people with cancer.

Interviewer: *“For the patient that’s still at home...what provision for support is there?”*

HP38: *“As in home help?...no help, that’s the bottom line really...there isn’t any provision for home help, not that I’ve ever come across. If we have someone who at home is relatively mobile and is able to get around, they just stay at home, their partner or spouse will be back and forth from work normally and hopefully they have friends who will pitch in. In the UK, I suppose there would be some home help, somebody that could help with the tasks of daily living...it’s not quite as instant here. There is something like that in the German community, but not for us no.”*

4.3.1.2 Medical/Nursing Support

It also became clear, from the professionals, that there was no provision for community nursing support. It was acknowledged that although systems of such care may be in place within the German health and social care system, people within BFG did not have access to this. The lack of community nursing care could be attributable to the fact that the nurses working the Medical Centres within BFG are not insured to work outside the Centres. As a result, the professionals acknowledged that this was often frustrating for them and that they realised a greater amount of responsibility for such issues fell to carers, families and friends.

“I mean I remember her [a patient] saying ‘all I want is a bath’ but she was so weak she would have needed some assistance with that...I mean I’m not an expert on these things and I’m not really sure what’s available and what’s not but there was no special equipment in her house, there was no qualified help so all we could really do was sit with her, I mean maybe go and rub her feet you know rub her hands or whatever and just really sit and chat...that was about as far as we could provide and officially we shouldn’t have done that because it’s not within our remit.” HP06

“There isn’t 24 hour nursing care in the community to support the family.” HP35

“There’s no one that could help with bathing or personal care...it always falls on the family to help out. I know that when there’s been somebody who’s been terminally ill and has died at home while I’ve been in Germany, the nursing staff got involved and volunteered but it was voluntary because they can’t be covered by insurance...they’re not covered to work outside the Medical Centre. For someone who’s terminally ill, it’s just infuriating, you feel like you want to go round there and bath the patient because the support person’s going to fall over...their partner’s knackered...sometimes there’s juts no-one to find who can help. You feel totally useless cause you can’t provide practical support that probably would be available if

someone was paid to do it. It wouldn't have to cost a hell of a lot of money but it would mean an awful lot to some of these families that are just left trying to do everything.” HP38

“I think I've had three or four patients who died in the community that I have looked after and it has been really really hard to keep them at home. We have got no nurses in the community who are going round looking after bedsores and things like that.” FG2/M1/HP

Furthermore, it was commented on by several health professionals that GPs don't routinely do home visits unless it's a particular circumstance, such as a terminally ill patient.

“As a rule the doctors don't do home visits, however, if there is a patient that requests a home visit it is up to the discretion of the duty doctor...if someone was terminal...they would probably class that as an exceptional circumstance.” HP31

Several of the professionals commented that there was an organisation known as 'Caritas' within the German healthcare system which provides nursing care to people in their own homes but at present does not visit people living in BFG. One professional commented that part of her role was to start building links with this organisation and to offer funding so that this service could also be made available to people living in BFG.

“we've got Caritas which is a German agency where we're building up you know relationships and getting support...medical and nursing support for people, children and adults in their own home and that would be paid for by the army.” HP04

4.3.1.3 Financial support

Professionals' comments revealed that there were some forms of financial support available for carers and families, for example, for fuel or child care. The extent to which wider professionals knew about these or indeed the extent to which carers were informed of these options is unknown.

“I understand that families can even get extra fuel coupons when they've got a child or relative, adult or, or child in, in hospital.” HP38

"I have before managed to acquire funding for a child care for say a month, a month at a time, so a one off payment, so it means that if someone is financially can't afford it ... then we can, we can look at funding for them." FG1/M1/HP

4.3.1.4 Emotional support

Many of the professionals interviewed commented that there were various forms of emotional support available to patients and their carers and family members. In particular, professionals from the Medical Centre and Army Welfare Service, commented that they provided emotional support to people in the form of counselling. Other forms of emotional support, such as bereavement counselling, are offered by community psychiatric nurses (CPNs).

"We offer...a confidential support in the form of counselling to individuals who are serving and their families and UK British Civilians that also work out here, such as teachers, doctors and that sort of thing. What we can do is refer on to...Jigsaw. Army Welfare Service can do bereavement counselling or we can put them in touch with Cruse or any other sort of cancer organisation." HP19

"The families...well anybody can access CPNs out here [in Germany] and the CPNs offer a grief counselling service and that referral is through your GP." HP40

4.3.1.5 Support from Unit and employers

Many of the professionals interviewed acknowledged that a greater degree of responsibility for the care of the person with cancer falls to carers and family members and relies on the need for employers to be aware of, and supportive towards, this. In many cases, the professionals indicated that Units and employers were hugely supportive of their staff.

"I think like anything else, with the military units, when they're looking after either their soldiers or those soldiers' dependents, it's often down to individual Units how effective they are and how supportive they are. I think in the majority of cases, that the Units will be as supportive as they possibly can be given the resources they've got." HP06

"it's the local support that really helps them and also work being very sympathetic and allowing the spouse to take as much time off as is necessary...almost kind of writing them off for 6 months so they're not going to be, you know, sent anywhere or anything like that." HP38

4.3.1.6 Returning to the UK

It was acknowledged that the Army Welfare Service plays a large role in assisting people to make the necessary arrangements to return to the UK if they wish to. In particular, this seemed to be when people wished to return to the UK to be close to friends and family or in the case where a partner was terminally ill.

“that’s where the units would refer them direct to us because in the Queens Regulations, it states that if anybody’s going to have a compassionate posting that...there needs to be accompanied by a report. Basically what we do is the report with background information, we’d give a number of options of outcomes and then we would give a recommendation.” HP19

“The Welfare Office we have here are very good...they will get people back to as near as they can to where their family are and they’ll be back very quickly and they’ll be looked after in that they’ll have family support and can do their treatment locally.” HP38

“If we needed to find information, it could be if a family was moving back to the UK...we may go to the Citizen’s Advice Bureau or whatever of the Job Centre Plus to find out about what benefits that that person may be entitled to or what they could do as far as housing [concerns].” FG1/M1/HP

For families caring for children with cancer, it was acknowledged that when a child is diagnosed with cancer, and particularly in the terminal stages, families often return to the UK.

“I’ve not had an end of life [of a child] in 6 years...the child in need and the family are always repatriated in every case.” HP35

Following the diagnosis of a child with cancer, community children’s nurses and social workers working in BFG are found to be on hand to support families emotionally during this time and to ensure that their preferences were heard. They were also there to help plan and support the arrangements made for their return to the UK if this was what the family chose to do. In particular, this involves ensuring that the family are relocated to a suitable area of the UK, with support finding housing, schooling and appropriate social work agencies.

“my work has been supporting the family here emotionally and planning and supporting their move back to the United Kingdom ensuring that they’ve got...you know the school links are all set up...I might refer them to social services in the local area and look at what services are available for the family to try, you know children’s hospices and things.” HP04

4.3.2 Provision of Voluntary Support

As well as formal support provided by the Medical Centres and agencies within BFG, there were two key forms of voluntary support identified; Home Start and the Jigsaw Support Group. These groups mainly focussed on providing emotional support, however, they were also there to help with practical issues, such as shopping, where necessary.

4.3.2.1 Home Start

The role of Home Start, an organisation designed to help families with young children, was also mentioned but like the support offered by the Army Welfare Service, this service wasn’t specific to people affected by cancer. Furthermore, there seemed to be a widely held view that most people who had young children with cancer would request to return to the UK and hence, support for children with cancer and their families was very limited indeed as it was often not warranted.

“Home Start is pretty much the only thing...they would do things like shopping for people and they offer a sort of ‘friendly face’ sort of support type of thing usually for people settling in the area, mums with young children and things.” HP31

4.3.2.2 Jigsaw

A wide range of professionals also spoke about another source of support within BFG, specifically the Jigsaw Support Group. All professionals identified this as being a valuable resource for their patients and their carers and families as well as for themselves.

“I think the start of Jigsaw might be a good good move...certainly for new patients I have it would be a good source of information, it’s got all the websites for all the different types of cancer...and it certainly gives people another group, another forum rather than the doctor. They’re speaking to a different forum that they may be more happy to talk about certain things.” HP38

“The support groups [are a] valuable meeting point...not just for individuals but also for all the others are affected in more or less the same way and to realise they’re not on their own.” FG1/F1/HP

4.3.3 Information Provision

Health and social care professionals’ accounts of the types of information needed by patients and carers related largely to where information could be accessed, rather than the type of information provided. Few specifics relating to patients’ information needs at different stages during their cancer journey were reported. The professionals indicated that patients would obtain the information they wanted from hospitals, from agencies such as DMWS or AWS, support groups such as Jigsaw or from the internet. In general patients were required to be proactive and ask or find out for themselves.

4.3.3.1 Types of information provided

In the few cases where specific types of information were mentioned, these related to: i) advice for siblings and grandparents of a child with cancer on emotions and contacts; ii) a prosthesis for a breast cancer patient; iii) counselling and grief support; and, iv) benefits provision for carers.

For example, one health professional reported that when asked for information by the parent of a child with cancer, she searched a website and obtained what was required:

“I would look on the website of CLIC for ... advice for me as well ...one that the parent recently asked me about for the siblings and the grandparents and there were some super books that I ordered that came ... who you could talk to and how you would feel as a brother or sister, as I say the grandparent one was absolutely lovely, 'cause that’s somebody that we don’t particularly spend a lot of time with but em ... some grandparents feel loss of control etc., it was a lovely guidance document.”
HP35

Another tells of emailing Cancerbackup for specific information for a patient:

“I e-mailed them about, em, finding out about, em, you know the prosthesis that breast cancer patients can have put in their bras and stuff.” HP06

One health professional also sought information on welfare benefits for carers:

“..in one case I was looking for, on the government health, the government website for carer’s allowance, trying to work out whether someone was eligible or not.” HP38

Health professionals also mentioned the ‘Blue Book’ given out by German health staff at cancer diagnosis, but it was likely to be in German for some cancers:

“I have here is something which is produced ... by the Germans ... but it is only on breast cancer... That was their reference book for, you know handing out ...[to] the patients what to do if you had been diagnosed with breast cancer.” FG1/F1/HP

Health professionals’ understanding of the types of information needed by patients and carers may be limited by lack of directives as to what information should be provided and when; it was noted that:

“...there isn't a sort of em, protocol or a guideline as to – if, today I'm diagnosed with cancer eh, what are the routes, who, who ... you know what information should I be provided with at that time, who should be, who should I be sent to speak to, to get counselling.” FG2/M1/HP

4.3.3.2 Information at diagnosis and treatment

Knowledge of the information available relating to the different stages of the cancer experience was lacking. It was implied that information per se would probably not be provided until a firm diagnosis of cancer had been made and that health professionals would not want to provide it until that time:

“I'm not sure that a lot of information’s going to go in until final diagnosis is made anyway... I wouldn’t give information out eh, without a firm diagnosis.” FG2/M1/HP

However, once diagnosis is made:

“I'm giving out information by, giving people a piece of paper, its useful to a degree...” FG2/M1/HP

A major source of information for patients at this time is seen to be the HLO at the hospital:

“...if they're diagnosed, the eh, the HLOs have the, like Cancerbackup and what have you and that is the, the main thing that they're given that... plus any information

that their said doctor at the hospital then passes onto them, but mainly they just use the Cancerbackup...they still give out the packs for free to people out here..."
FG1/F2/HP

It is understood by health professionals that German hospitals are responsible for giving out health-related information at the diagnosis and treatment stages:

"The general hospital(s) are quite good ... they are quite good, they'll explain anything they need explaining..." HP31

"... em, when it comes to sort of a treatment regimes and chemo, things like that then obviously the hospital ... the hospital is usually very good and explained it to them all and they understand..." HP38

This, however, may present problems:

"Sometimes they ... the, the difficult bit that I've found has been things like their pain control... and what they're taking and why they're taking certain drugs, which sometimes I think they've lost a little bit in translation or there may be a different system eh, within the sort of German sys, you know German hospitals and how they deal with these symptoms compared to what I'm used to in the UK..." HP38

There is a general conception that the information provided in the German medical system is 'matter of fact' (FG1/F1/HP), limited to essentials, less open to cross-examination and dependent on the degree of information-seeking by the patient or carer:

"...the DGPs answer questions, you know, as much as they know, you know, but it depends whether the right questions are asked doesn't it?" HP06

4.3.3.3 Information sourcing

Health professionals agree that people are 'signposted' (HP06) to where they can find information, be it hospitals, welfare agencies or support groups, but it is down to the patient/carer to find out the information required. This is in spite of the belief in over 45% of health professionals responding to the postal questionnaire that their place of work had booklets or leaflets available for people affected by cancer. There is an assumption that patients are knowledgeable about their own condition, as HLOs in hospital act as translators and sources of information during the hospitalisation

process. The internet, particularly cancer-specific websites, is cited as a common source of information provision and is a regular theme, as exemplified by the following:

"...we would look to, to say to them ... you know, look to access Macmillan or Cancerbackup or, you know whoever it, it might be but then you're kind of assuming people have, have access to the Internet and not, you know not everybody does..."

HP03

Internet access is reported to be available at more than 40% of workplaces. Alternatively, the welfare or other officer can access the internet for the patient, print off the information for them and discuss it. This tends to be on an 'ad hoc' basis (HP04) and is exemplified by one comment:

"...if people want to come in and talk about it or go through it, it's like almost helping someone look through ... help them see the wood from the trees if you like, you know and, and decipher it, then we would sit down with people and do that... but I'm sure there's lots of other people that would do that as well if it was needed." FG1/M1/HP

The widespread use of the internet as a source of information is substantiated by responses to a questionnaire survey which indicated that over 60% of respondents downloaded information for patients.

The DMWS is not, however, seen as a resource that provides medical information as such although they do hold and distribute leaflets dealing with different types of cancers:

"[Leaflets]... from Cancerbackup, but other than that we would ... we very much avoid, certainly giving information... we would rely on em, the primary care providers..." HP03

It is apparent that patients have to know what information they want and then find someone who can either give it to them or find it for them or tell them where they can find it. A health professional reflected on the emphasis on patients to take the initiative on finding information:

"...isn't it funny that the patients are the ones that are ultimately making that effort ..."

HP03

This was reiterated in a focus group setting, where a patient is described as having to find out specific details for herself, but health professionals perceive difficulties around this:

“I know certainly from [Patient], when she rang up Backup and said, this is my diagnosis, this is what my treatment is, they just sent her everything they had on, not just her condition and the various parts of treatment and it was up to her then to go through what she ... and as she said, she read what was appropriate to her at which stage but I think a lot of people find it quite daunting that they just get this huge pack of information and its like, there you go and ... you know, make what you want of it... but I think people need something else out here where they can go to people at various stages and go ... right, now I'm starting this, I want more information on this... how it's going to affect me...” FG1/F2/HP

The indication here is that health professionals perceive that information tailored to the individual at each stage from diagnosis through treatment and afterwards is lacking, and if the patient/carer does not know what is appropriate at each stage they will have problems. Information is available, but not necessarily accessible.

“...you're saying we provide this information ... that, that, that needs to be available, but who's actually giving it to the patient...?” FG1/F1/HP

This statement is corroborated by quantitative data from postal surveys which indicated that only 26% of health professionals responding were aware that their workplace had a person responsible for ensuring that information was available for people affected by cancer.

4.3.4 Challenges to Provision of Support and Information

During the interviews, a number of challenges to the provision of support for carers and information for people affected by cancer were identified by health and social care professionals in addition to some of the gaps previously highlighted. In particular, these related to the changing population within BFG, awareness of support, referral systems, specialist services, palliative care interaction with the German and UK healthcare systems, army culture and role within the army and skills and training required. These issues are described in further detail below.

4.3.4.1 The changing health needs within BFG

It was acknowledged by many of the health and social care professionals interviewed that the population within BFG was beginning to change. It was considered to be no longer a population who suffered from acute illnesses and injuries which could be treated fairly quickly and with little recuperation time required to one in which many more of the population were living with cancer and other long term and chronic illnesses. Furthermore, a greater number of service personnel and their families are choosing to remain in Germany when ill. The comments from patients and carers, reported earlier, demonstrated their strong desire to remain because many had been stationed in Germany for many years and had built their lives there. The more long term health conditions, combined with a commitment to live in Germany suggests that there needs to be a greater range of supportive health and social care services in BFG.

“Within BFG, historically, oncology patients would be, if you like, sent back to the UK...however, over the years things have changed in Germany. What we’re finding is that more families are settling in Germany and they’ve got no family or friends or home base back in the UK so they actually choose to stay in BFG. I think in recent years this is what’s highlighted the gap in the provision because we’re not geared up to provide it because historically we haven’t had to.” HP06

4.3.4.2 Awareness of available support

Many of the health and social care professionals interviewed perceived that there was a lack of available support for carers of people with cancer and in particular, a lack of awareness on the various forms of practical support on offer. There also seemed to be a lack of awareness about the role of other supportive care agencies within BFG and how they could help to support carers and families of people with cancer. A few of the interviewees mentioned the role of the Medical Centres, Army Welfare Service and Home Start, for families with young children, yet outwith these bodies there did not seem to be an awareness amongst the professionals of other forms of support available.

“As far as carers are concerned, I think there’s certainly less, practically speaking, there’s less [that they can] access directly other than over the internet and over the telephone to charities and support groups.” HP14

“[Lack of awareness of other agencies]...it’s not to with anything other than literal ignorance in each other’s presence or existence...the left hand doesn’t know what

the right hand's doing kind of thing. You know as an organisation [DMWS], we've been around since the second world war and so many people still don't know who we are, they don't know what we do. I don't doubt that there may be a couple of service providers of organisations that we're aware of but what we're not aware of is that actually they can help in the community...for example, Home Start...it wouldn't surprise me if they could provide something or other...I don't know if SAAFA have certain provisions. There might be pockets of resource available but they've not linked up because nobody's kind of gripped the whole situation and said 'right exactly what have we got here and how can we consolidate this service'." HP06

"We have Army Welfare Service...I don't think there's much in the way of actual physical help. Home Start is pretty much the only thing...there is no-one as far as I'm aware there's pretty much nothing else." HP31

"For the people I've had, it's mostly been through...mainly GPs, I'm not sure that they get much support apart from you know in-patient support when they're in hospital. Outwith that, really for carers and [patients] it's just the Medical Centre...I don't think anywhere else [offers support]...maybe through the Welfare Office depending on what their problems are." HP38

In particular, the availability of formal practical and emotional support was also raised as a key area for concern and it was acknowledged that the majority of existing support offered to carers within BFG comes from voluntary groups.

"I think the biggest concern that we have is what happens to patient, what type of practical and emotional support have they got when they leave hospital." HP06

"There is a lot of support available within the army community...I suppose there's an emphasis on emotional support as opposed to practical support." HP40

Furthermore, the transient nature of the BFG community results in varying levels of knowledge and awareness of different forms of support available to carers, as people move between Garrisons and countries.

"the partners or spouses become absolutely wrecked having to look after somebody...they have no help, particularly if they've not been here that long, they don't know people...that is the nature of our community here, the turnover is pretty quick." HP38

4.3.4.3 Army culture

Comments about the culture of army life revealed that many people do not wish to ask for or seek support. There was the perception that the culture was very much one of self sufficiency and people tended to “just crack on with things”. As a result, many people may fail to be proactive in their response to seeking support or indeed, believed that they were not entitled to any support following illness, such as a diagnosis of cancer. This suggests the need for health and social care services and agencies within BFG to be more proactive, to ensure those who might feel pressured not to ask for help are clearly informed of the support available.

“I have offered to talk to partners but... in the patients that I have offered that to most of them have turned round and said ‘no, thank you very much’...the one [patient] that I can think of specifically, she said ‘my husband doesn’t do things like that’... but they’re military you see, it’s a military, well sorry ... that tends to be ... a bit of military ethos isn’t it.” FG2/M1/HP

4.3.4.4 Systematic referral process

The lack of awareness of available forms of support for carers may be attributable to the fact that there are few systems of referral in place for when a practitioner comes into contact with a patient with cancer or their carer or families. From the comments received, there also appeared to be no satisfactory system of referral from secondary to primary care once patients had left hospital.

“Basically my feeling is that things are just not geared up at all to deal with home care, home support and that sort of thing. It is quite lacking, it’s not for lack of good intentions on behalf of people, but there’s just no sort of official structure or resource that’s in place. I think a lot is done with good will and on a voluntary basis.” HP06

“There isn’t a ‘point person’ if you like...it’s very much ad hoc, there isn’t a sort of protocol or a guideline as to ‘if I’m diagnosed with cancer, what are the routes, what information should I be provided with at that time, who should I be sent to speak to get counselling’? There should be a protocol that lays out exactly, if somebody is diagnosed, this person should be notified and it almost becomes a tick box thing so we know we’ve don’t that and there aren’t gaps there.” FG2/M1/HP

“You do have to work harder in Germany to track patients and what’s happening and to get information and to make sure and to make sure it’s shared with the right professionals as well.” FG2/F3/HP

4.3.4.5 Specialist services

Comments received from professionals supported the view that the Medical Centres and other agencies within BFG provide good care. However, in offering the most comprehensive service possible they had become generalists in their work rather than specialists in each individual area. There was a distinct concern, about the lack of specialist services for people affected by cancer in BFG which could create a number of challenges. In particular, patients, carers and their families are often directed to information sources that are not relevant to their situation and hence, do not provide them with any assistance or support. Furthermore, health and social care professionals perceive that where specialist services are lacking, the onus is on them to create or find relevant sources of support which can prove difficult.

“It’s quite difficult because locally services have...are fairly simplistic and there aren’t many very specialist services. So what I would be doing is directing people to national information which aren’t always relevant here.” HP04

“I think they’re good central places and they deliver a good service [the Medical Centres] but they are generic, basic Medical Centres. Specific services don’t exist so everything I find that I feel people need, I have to create or find you know. I don’t assess every single carer in their own right, it’s only those families that I’m involved with...in the UK, carers would have access to general caring support that has no statutory basis whatsoever and that’s healthy you know people shouldn’t be dragged into social services because they need more support as a carer.” HP04

Due to a lack of specialist contacts, health and social care professionals often commented that there were few people to turn to for advice on cancer and cancer care. It was acknowledged that there needed to be systems in place set up to allow professionals to source further information, particularly information relevant to a UK context when making arrangements for peoples’ return to the UK. Several professionals acknowledged the difficulties in employing Macmillan nurses within BFG but commented that Macmillan nurses were experts in palliative care and to have contact with that kind of service would be valuable for both them as well as patients and their families. It was acknowledged in the previous section that simply linking into UK-based forms of support, such as Macmillan nurses wasn’t sufficient, however, since this could create difficulties with obtaining advice because of the differences between the care and treatment offered through the UK and German healthcare systems.

“You know the hospital would help us to a degree but they have different views to what I remember being told [in the UK] so you’d be muddling through a little bit really ‘cause we don’t have a Macmillan person we can ring in the UK.” HP38

“One of the things I think we do lack is the back up nurse or the Macmillan nurse...those sort of support is lacking...the trained professional who has experience of counselling and support. We do try to fill in and do what we can and I think that we try very hard to provide as comprehensive a service as possible...to our patients.” FG2/M1/HP

4.3.4.6 Palliative care

For many patients who are terminally ill, they and their carers are almost always advised to return to the UK for palliative care. Much of this is because in Germany, GPs are responsible for their patient’s hospice care, rather than specialised hospice medical staff, like in the UK. It was acknowledged that this wasn’t always practical or possible for BFG-based GPs to do this. There also seemed to be little in the way of welfare provision within BFG for people and their families in the terminal stages of their illness. It was, therefore, commented that many people would be advised to return to the UK if they required palliative care. The fear was voiced that in this situation, people may fail to reach adequate services to support them at the end of life. Language and cultural barriers were also identified as challenges to palliative care provision.

“I would have thought that by that time, they might have moved back to the UK because we’re talking long term care and it’s not just that, it’s specialist care you need it to come from lots of different avenues and co-ordinating those cancer specialist services over here [in Germany] is quite different and I’d be worried that someone might kind of fall through the net really.” HP04

“medically [there would be provision]...welfare wise...we would really be looking at moving the patient back to the UK where they’ve got wider support networks rather than trying to cope here.” HP16

“[in a German hospice] when you get there you can’t really talk to the staff who work there because your German’s not good enough...the one locally, it’s about half an hour away and it’s very good but I couldn’t go in every day from where I am, I just couldn’t take that much time out to go and look after my patients. I’d like to but...we don’t really fit into that system because the way they run the hospice is obviously

slightly a bit different [than in the UK]. Whereas in the UK, they're looked after by their own doctors there mostly whereas here it seems to be very different...so it wasn't going to be a viable option for several reasons.” HP38

“It's very very difficult for us to access terminal care here [in Germany]...you have to wait for beds... and it's of course very disturbing if you are a patient who is dying in an area where people don't speak your language.” FG2/M1/HP

Furthermore, there seemed to be no provision of Hospice at Home services for people affected by cancer in BFG. One professional commented that a service like this, that is available back in the UK, would be extremely valuable for many people.

“They're [patients and carers] nervous about the language barrier so I'm fairly sure that if I was losing somebody to cancer, I wouldn't necessarily want them in a hospice in Germany but a Hospice at Home, I know from experience [in the UK] that was just wonderful and I wonder if that's something that could be built into a cancer care strategy here.” HP40

4.3.4.7 Interaction with German healthcare system

The German healthcare system was praised by the professionals for many aspects including the speed and efficiency of care and treatment delivered to patients. However, it was acknowledged that the language barrier could be a problem when interacting with the German healthcare system and in addition to this, it was also acknowledged that the advice and treatment offered by the German healthcare professionals may on occasions differ from what would be offered by GPs in the Medical Centres within BFG. Balancing peoples' expectations about how they would be cared for in a German healthcare system compared with a UK healthcare system was also raised as an area for consideration. Hence, this could lead to confusion for both professionals and for patients and carers.

“It gets very fragmented once you go beyond the medical centres...then you get private practitioners and they all have different opinions and different diagnoses and it can be very confusing for families.” HP04

“You can't just lift the British out of Britain and put them in Germany and say “get on with the German system”, you need to bring some of what they've come to expect from Britain in as much as the emotional side of treatment, just because culturally the way health is dealt with in both places is completely different and you kind of need to

marry up the two, but medically wise, they're going to get a far better treatment out here than they'll get in the UK, in which case we need to sort something emotionally out for them but they can get all that information they require." FG1/F2/HP

It was also acknowledged that the cultural differences between the UK and German healthcare systems became more apparent to people by the ways in which they were told of their diagnosis. Many professionals commented that the German professionals could be direct and blunt, but on the other hand, this was also seen as welcomed by some professionals as well as their patients and carers. Furthermore, it was recognised that this facilitated communication between primary and secondary care as the medical notes were written in a straightforward and unambiguous way. It was also acknowledged that the German medical staff frequently delivered news about a cancer diagnosis when the person was alone and did not have anyone accompanying them to the hospital.

"When they're delivering diagnosis or news of treatments or anything like that they can come across as extremely abrupt so it can be quite shocking for the patient." HP06

"some patients quite like to be told bluntly "this is what you've got", no pussy-footing around, they're being straight to the point, this is what you've got, this is what we're going to do...I don't think I've had any of the cancer patients complain about people being too blunt with them. The notes are very straightforward and I would expect them to be...the paperwork spells it out...I know exactly [what's happening]." HP38

The re-analysis of DMWS transcripts has revealed a comment about the challenges faced by AWS staff wishing to communicate with German medical staff. Some feel that any direct contact is discouraged, which is not the case in a similar UK situation:

"I think we're actually discouraged from liaising too much with the medical staff because that is the role of liaison officers and they want to keep it separate really". DMWS/FG1/F1/HP

Another challenge in interacting with the German healthcare system, identified in the current study, was recognised as being related to the provision of medications. For many patients they will be prescribed medication commonly used in Germany, however, within BFG, only British-approved medications should be used. Hence, medical practitioners and pharmacists working within BFG are often left to find an

alternative medication to the one that their patient had been prescribed by German medical staff or to follow this prescription but to take on a greater responsibility for the clinical risk involved since it's not licensed for use within a UK market. Furthermore, the preparation process involved in some drugs is simply not feasible for staff working within BFG.

“They are likely to come on highly complex cancer care regimes that would not be the normal, staple sort of prescribing of primary care ... into an environment where we don't have pharmacists who regularly receive those prescriptions, eh, they will need interpretation and some of those medicines will be licensed medicines in German but not in the UK so our primary care environment is essentially a British, primary care environment and this is a very big area of clinical risk as far as I'm concerned. Sometimes cancer care regimes involve the complex intravenous injections and we've absolutely no capacity to prepare those.” HP47

This can create confusion and anxiety for patients and their families since they cautiously question why the drug is not approved for the UK market. Such systems reduce their confidence in the use of an alternative drug because they believe it to be less effective than the original prescription. It can also create confusion for GPs because if they proceed with the German-approved drug, then they are often not familiar with the drug itself, its side effects and interactions with other drugs.

“There is a big issue about the confidence ... of the patient in both the British system because maybe they think we're fiddling around with their therapy.” HP47

“If we can come up with a British alternative then that's fine then, then there is still a risk eh, because we're dealing with medicines that we don't often handle, so that's one risk, but we, we should be able to get to grips with what that product is, what the side-effects are to look out for and counsel the patient appropriately, if it's a product which is only licensed in Germany then as far as the British GP is concerned he or she is prescribing an un-licensed product that means that the GP accepts a larger amount of responsibility for any outcome, positive or negative and I think that's a ... again a very important point to underline.” HP47

4.3.4.8 Interaction with UK healthcare system

It was acknowledged that it could also be hard for transferring care to UK based practitioners to ensure that would receive appropriate and timely advice, care and treatment, and support. It was acknowledged that this was often attributable to the

fact that patients and carers were interacting with two very different healthcare systems, i.e. Germany and UK, and that health and social care professionals found it hard to stay up to date and aware of available forms of support and services in the UK. Furthermore, it was often recognised that often there were very few people that they could contact in the UK who would be able to advise them. One practitioner, in speaking of helping someone to return to the UK, described the challenging nature of this.

“You’re trying to catch up with something you’ve not done for several years but you’ve got no-one to pick up a phone to cause actually you’re not in the system in the UK...they do try to help but it’s a very difficult position to be in trying to get someone into a hospice in the UK when you’re out here. The other thing I got caught out with was things like carers benefits and things like that. I hadn’t really thought about it and it worked out that these people could have claimed something but I had no idea because I don’t do it enough and I’m not in the system in the UK and I haven’t been for a few years...you just completely don’t know because you’re not in it, you’re not doing it every day.” HP38

“whilst the Department of Health has set out very clearly that our patients are all entitled to NHS treatment and I can send them anywhere, it really doesn’t come down to that, I’ve had an awful struggle trying to get some patients back and seen and treated [back in the UK] ... ultimately they then turned round and said oh but its our decision whether we pay for this because its an expensive treatment.” FG2/M1/HP

4.3.4.9 Role within BFG

It was acknowledged that the provision of support varied depending on one’s role within BFG. For example, military personnel were believed to be offered a greater degree of support, and should they wish to return to the UK, it was believed that they’d be likely to return to an area in which they had family members. On the other hand, civilian personnel were believed to be offered less support, were more likely to be forced to return to the UK and were less likely to be relocated to an area close by their family when they arrived in the UK.

“I mean, I think the military machine and being part of the military galvanises itself up on our processes and protocols and things happen, I think its slightly different for civilians over here, they’re on their own and they probably are supposed to be more

reliant on the Occupational Health side of their employers organisation, and that's probably where it doesn't always work." FG2/F3/HP

"Military's not a problem, they'd get a posting back to where the family are normally. If it's a civilian and they want to go back, I'm not quite sure...if it's as easy as that 'cause they come out [to Germany] for a set contract job and there might not be a post they can go back to in the UK so they're a bit stuck really." HP38

"For the civilian side of things, there's less of a support and there's more...a feeling, well you've got to get them out because they're going to end up as our problem." FG2/M1/HP

4.3.4.10 Skills and Training

Many of the health professionals interviewed, in particular, noted that they were generalist staff and as such, often perceived that they lacked skills and training in areas that they may have to encounter on occasions with patients, for example, the administration of intravenous drugs.

"I don't know all the answers with being a general community nurse you know I'm not a specialist. If...the patient was needing intravenous medication, I think that would be a limitation and as there is no-one with guidance in the community...I think that would be a limitation 'cause I wouldn't I don't have the qualification or the expertise to be able to help administer them." HP35

Several professionals also commented that there was a need to understand families' needs and the types of support that they may find valuable. As noted above, professionals identified a need to have a better understanding of what was currently happening with the UK healthcare system in order to stay up to date and offer appropriate advice and reassurance to their patients.

"I think there's a need for...a wider education package of what the support is that families need." FG2/F3/HP

"I think it would be very useful to have somebody come over [from the UK] from time to time just to talk to us about very simple things really, just what's going on in the UK, what sort of services we might be offering but also raising our awareness again of how you look after your patient from diagnosis to end of treatment however that

may be. You know, how do you look after the family, how do you look after carers of the patient and things like that.” FG2/M1/HP

4.3.5 Suggestions by health professionals

Several of the health professionals that were interviewed contributed ideas that may help improve the existing situation for people affected by cancer, and assist health professionals in their roles. These suggestions range from fairly minor, small improvements to wider reaching changes and processes within BFG. An example of the latter is the way all of the relevant agencies are alerted to new cancer diagnoses. A health professional suggested that a protocol be set up to do this:

“Its very much as (another participant) said really, well she might find out through a variety of agencies, maybe there should be a protocol that lays out exactly, if somebody is diagnosed, this person should be notified and, and it almost becomes a “tick box”, you know we’ve done that, we’ve done that...” HP43.

“Oh yes I would agree, because I think that ... looking at the family I supported and I felt very stressed about, I think if there had been that process maybe there might have been an opportunity for some of those issues to either be flagged up earlier and dealt with”. HP36

Such a protocol would allow for an improvement in the provision of support and information within BFG. Related to this suggestion is the idea that the newly created cancer support group JIGSAW becomes embedded in the existing medical system. Again this would improve the provision of information and support within BFG:

“so I think Jigsaw should be around everywhere...and it should be advertised, it should be basically steered through the medical system which, which is already here, you know primary care...” HP10

Another idea, also echoed by some patients and carers, is that there exists a nominated person that the patient can contact throughout their treatment

FG1/F2/HP: *“One person that the patient, each patient got one person that they could go to... that stayed with them throughout their treatment, not sort ... not necessarily saw them every time they had treatment but was a contact number for them that they could check in with them once a month that they held all that information”.*

Interviewer: *“Somebody with a medical background?”*

FG1/F2/HP: *“Yes.I don't think they necessarily need to be a nurse em, but equally you need that medical background. And that they know when was the appropriate time for what information”.*

An alternative source of support for patients could be provided by visiting experts:

“There was some centre back in the UK who realised and understood our particular situation and was able to provide some sort of support and if possible, some sort of visiting support on a, on a ... maybe even on a monthly basis, I mean if it was a big enough operation then perhaps somebody could come once a month to, to see our patients and talk to [them].” HP43

Several health professionals acknowledge that the provision of a full-time cancer nurse would not be cost effective but for them to have access to someone such as a Macmillan nurse would be very beneficial.

“I mean I certainly would have valued having access to a Macmillan nurse only just to be able to ring up and chat through, and of course when you go on the web and you look at the information they always have the little caveat that they can't give you much feedback because you've been treated abroad and the care is delivered differently so you would feel that it's negated at that point, so I think some sort of support em, but not a permanent support over here, I don't think that would work em ... sort of, you know, somebody perhaps who did work in the UK but maybe could come out at times might be helpful.” FG1/F2/HP

Visiting experts could also play a role as part of health professionals' career development plans:

“personal development plans identifying ones needs, but cancer care doesn't feature very highly because it's not something that happens an awful lot.all regions, they have weekly training sessions, so there would be an opportunity ... to have somebody come and talk to us ... BFGHS-wide.” HP43

One GP thought that health professionals within the German hospitals should be made more aware of the patient circumstances outside of the hospital, in terms of support they are receiving from BFG and their home/work situation. The perceived view appears to be that the German Provider Hospitals see BFG patients as short-term patients who will be moving on away from their area and this has an impact on the way such patients are treated:

“I mean I would wish that the German system, the German contract hospitals are involved to a certain extent to be able to be informed....you know, so that actually when the patients are in the hospital and, and receiving their treatment, that the doctors there or the nurses there know what else is happening or what, what access this patient has outside the hospital.....and how that can possibly impact on the treatment [at the hospital]” HP10

Communication among the various health professions was highlighted by a pharmacist who suggests a more formalised case conference style process for ensuring all key personnel are aware of what is happening for patients:

“I mean it may well be that in pockets informally meetings are going on and, and people are, you know, are doing the business, but I think the problem is that that’s not formal and as a result I would have concern with growing numbers and with us not having, as far as I’m concerned, a, sort of an organizational approach which includes looking at medicine issues.” HP47

Learning from experiences with previous patients was highlighted by one health practitioner:

“to come along to one of our education programmes and talk to us about your experience, ... just to tell us why we didn’t get it right, 'cause we clearly didn’t get it right and that’s actually significant event analysis isn’t it ...” HP43

These suggestions are presented with an awareness that some may already be in place. However, it is significant that participants still named them as areas which required attention, which highlights the need for clearer communication and the need for better awareness among staff of existing protocols.

All of the ideas presented above could potentially lead to improvements in the provision of support and information within BFG. Health professionals have clearly spent a good deal of their time thinking about their role within BFG and are keen to make improvements to the service they provide.

SECTION 5: DISCUSSION

Many of the patients and carers interviewed for this study remarked on the high quality and speed of services they received and the dedication of health professionals they have come into contact with. Many also understood the many challenges faced by people employed within BFG to provide supportive care and information for people affected by cancer. Much of this report has focused on areas for improvement within British Forces Germany, therefore reporting shortfalls and areas for improvement. The provision of support for carers and the information needs of patients and carers are just a part of the whole cancer care process for people affected by cancer within BFG. This research identified a number of outstanding issues for BFG which are identified in this report. These should be understood in the context of systems which are also reported as supportive to people affected by cancer.

It appears that increasingly BFG personnel, dependents and their families are choosing to remain in Germany rather than to be deployed elsewhere when their service has finished. 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 opting to have their treatment in Germany, rather than return to the UK. Many health professionals recognise that increasing numbers of people staying in Germany for longer periods will require a change to the health service infrastructure within BFG. In terms of cancer care, most health professionals accept that processes are not in place that would allow them to provide the level of service they feel they should be providing.

One of the more striking observations, particularly noticeable during focus groups with health professionals but applicable across many patient and carer interviews too, is the apparent lack of awareness of the wide range of organisations and services available within BFG. Examples became apparent during the course of this research of health professionals who were unaware of the existence of other support organisations. Equally, there were examples of health professionals knowing about the existence of groups, but being unsure of their remit, function and systems of referral. If the various organisations within BFG are unaware of each other or the roles they play, then the provision of support for carers and the information needs of patients and carers in BFG is likely to continue to fall short.

Support from employers within BFG was identified as being exemplary, however, other areas of formal and practical support for carers appear to be very difficult to obtain. Transport to and from hospitals is readily available but the provision of services such as home help and community nursing care is not. For many of the carers we have interviewed this kind of support could have an important impact on their well-being. Several carers talked of the isolation and exhaustion that resulted from the increased caring role they had to play since their partner's cancer diagnosis. The sense of isolation was particularly noticeable among carers whose partners had finished their treatment in German hospitals. According to many carers spoken to during this research, the provision of formal support for carers within BFG appears to be very limited. Although formal support, from organisations such as AWS and BFG SW Services is available, many carers appear either unaware of its availability, prefer not to use it, or feel that it does not meet their needs.

The system of referral to these organisations is one which puts the onus on the individual to identify and express their needs for support, however, as identified in the examples in this analysis, this approach was often seen as a barrier to the use and awareness of these services. Indeed, there appears to be an acknowledgement and acceptance of this by most health professionals that the service they provide is reactive rather than pro-active. Many of the health professionals, carers and patients suggest that the army culture makes it difficult to operate within this reactive model. The local culture means that asking for help is not easy to do, so when people do come forward for information and support this is often provided at a later stage than would be optimal. Thus, while services are predicated on patients and carers being proactive, there will be a shortfall in support being delivered. A method of addressing this, as suggested by several health professionals in section 4.3.5 above, is the setting up of what some termed a "tick list" of people who should be notified of any newly diagnosed cancer patients.

The emotional impact on carers of having a partner or spouse diagnosed with cancer was identified in great detail. There appeared to be, however, little formal provision for emotional support offered to carers despite many of the health professionals describing this as being part of their role within BFG. Many carers spoke of being able to access emotional support where they had existing contacts with these types of services, however, others found these services difficult to access or seemingly unavailable. Again, these findings reinforce the idea that the message of the availability and awareness of supportive care services simply isn't reaching the target population of their services and that approaches to accessing such services are

currently falling short. A particularly valuable source of emotional support was identified as being the Jigsaw Support Group, a support group for people affected by cancer run by volunteers with experience of cancer themselves. This group has been well received by those wishing greater emotional support than what they perceived they were able to access formally and by the examples given the group seems to provide an opportunity for the sharing of experiences, knowledge and information. Its importance within a system of support for people affected by cancer in BFG is evident given that volunteers are currently in the process of setting up satellite groups to coordinate with the group that currently exists in JHQ.

There also appears a lack of awareness of the kinds of information that people affected by cancer within BFG need; in particular information about the daily impact of living with and managing the effects of cancer and its treatments and information beyond the stages of diagnosis. This lack of awareness extends also to when such information is needed and *how* and *where* it can be accessed. People often find out about support services through word-of-mouth connections, which by the nature of army service are often broken when people are redeployed. Difficulties in providing and receiving information are exacerbated by many carers and patients not knowing what support they need or not knowing whether information is reputable and trustworthy. Further issues, such as language and cultural barriers, present difficulties given the nature of interacting with a different healthcare system from the UK. More use could be made, however, of existing reputable material found through specialist cancer organisations, such as Cancer Research UK or Cancerbackup and greater signposting towards such resources is called for. This suggests the need for an information provision strategy that takes into consideration these various factors.

A common thread identified by patients, carers and health professionals was the need for specialist advice, such as a Macmillan nurse, in relation to the management of cancer. The challenges around having such a service in BFG were acknowledged by all groups, however, it was believed that there could be some form of specialist support set up in order to provide reassurance and advice to patients and carers and where health professionals could also access advice, training and support. Means of providing such specialist support are worthy of further consideration. Such a service or contact with a similar type of professional may also help to maintain continuity between primary and secondary care services in BFG and also facilitate communication and awareness of the various forms of support available for people affected by cancer within BFG as well as helping to meet the educational and training needs of health and social care professionals within BFG.

There are some issues surrounding the provision of medications that have come to the fore as more people with cancer get their treatment within Germany. There has been an increase in the prescribing of medications that BFG pharmacy staff are unfamiliar with and in some instances, patients with cancer are being prescribed drugs that are licensed for use in Germany but not in the UK.

The increasing numbers of people choosing to remain in Germany for their care and treatment has implications for palliative care and support around bereavement. It was recognised, in the examples given, that the end of life was a particularly challenging time for both carers and professionals and that many families made the choice to return home to the UK. For some, however, this is not always a feasible or desired choice; therefore it is becoming increasingly necessary to have processes and arrangements in place for such individuals and their families. It is likely that because of difficulties interacting with the German hospice system, a greater degree of responsibility for palliative and end of life care will fall to health and social care professionals working within BFG. Provisions such as Hospice at Home services and increasing awareness of the availability of bereavement counselling services could help to make this time easier for all groups.

SECTION 6: RECOMMENDATIONS

The findings from this study have generated a number of issues for further consideration in the future development of supportive services for carers of people with cancer and in a future information provision strategy for people affected by cancer across BFG. A number of recommendations are made based on the evidence in this report.

6.1 Information provision

It is apparent that there is an inconsistent approach to information provision for people affected by cancer in BFG. Several gaps were identified in relation to the types of information required, the timing of information provision, and how people can access information. Furthermore, the extent to which carers were offered information varied and language issues were often cited as a barrier to obtaining appropriate and relevant information. There is a need to provide:

- clarification on which health and social care professionals can be involved in the delivery of information and the types of information they are able to provide
- more tailored information on different types of cancer and cancer treatment,
- signposting to information that is readily or already translated into the English language
- signposting to reputable and trustworthy websites
- more information specifically directed at carers of people with cancer
- more information about the daily impact of living with and managing the effects of cancer and cancer treatments
- more information in the stages beyond diagnosis
- more information on the available sources of support within BFG

Recommendation 1: Develop an information strategy which takes into account the above issues, particularly relating to who is responsible for information provision, types of information that should be provided, timing of information provision and access to information provision

Recommendation 2: Create links with specialist cancer organisations to promote the use of existing information resources related to cancer, cancer treatment and cancer care, e.g. Cancerbackup

Recommendation 3: Introduce greater signposting to reputable and trustworthy sources of informational websites for people affected by cancer

6.2 Interagency communication

It is apparent that many health professionals are unaware of the existence of other support agencies within BFG and in particular their roles and remits in managing and supporting people affected by cancer.

Recommendation 4: Clarify the roles and remits of different organisations and agencies within BFG and how they can support people affected by cancer and examine the existing processes of communication between agencies within BFG.

Recommendation 5: Develop a specialist information booklet on the types of support services available within BFG, their roles and remits in relation to the management and support of people affected by cancer, and methods of referral/communication with these agencies

6.3 Systems of referral

It is apparent that referral to support agencies within BFG is ad hoc and inconsistent. There are no systematic systems of referral set up between agencies to ensure that patients and their carers have easy access to the support services that they might wish to. In particular, a proactive system needs to be developed where the onus of referral is on the service providers rather than the service personnel themselves.

Recommendation 6: Develop and coordinate a referral process to ensure that people are aware of available support services and have easy access to these.

6.4 Practical support and community nursing care

It was clear that there is no practical home help support available to people affected by cancer within BFG and there are no provisions made for community nursing in the home.

Recommendation 7: Develop networks within the German healthcare system to determine the feasibility of extending their home help services to people living across BFG

Recommendation 8: Consider the insurance and indemnity policies and procedures related to community nursing to determine the feasibility of introducing a community nursing service within BFG

6.5 Palliative and end of life care

It is apparent that the provision of care and support for people with cancer at the end of life is challenging yet is likely to become a greater issue with people choosing to remain in Germany for their cancer treatment and subsequent care.

Recommendation 9: Identify the agencies and services involved in palliative and end of life care of people affected by cancer within BFG and clarify their roles and responsibilities

Recommendation 10: Consider the feasibility of services such as Hospice at Home and develop networks with the German healthcare system to determine the feasibility of extending their current systems of palliative care to encompass people living across BFG; AND/OR Consider virtual link with UK Hospice to provide specialist advice

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APPENDIX 1: MEMBERS OF THE STEERING GROUP

Lt Col K Solly	SO1 Med UKSC(G)
Lt Col CA Millwater	SO1 Med (Des)
Prof N Kearney	CCRC
Dr L Kidd	CCRC
Mr M Wilson	CCRC
Prof M Kochen	Con Ger Health Svces
Rev Smith	Carer Representative
Mrs J Littler	BFGHS
WO2 E Crawforth	Patient Representative
Maj AJ Day	SO2 Med UKSC(G)
Col JS Grinstead	DCOS UKSC(G)
Col C Dieppe	BFGHS
Col C Batty	BFGHS
Capt C McWilliam	BFGHS
Maj N Probert	SO2 G1 PS

APPENDIX 2: FOCUS GROUP SCHEDULE FOR PATIENTS & CARERS (INFORMATION NEEDS)

- For **patients**, what information did you want at these times, what information were you offered at these times?
 - o On diagnosis?
 - o During treatment?
 - o After treatment?
 - o When at home: night time/ out of hours?
 - o End of life?

- For **carers and family**, what information did you want at these times, what information were you offered at these times?
 - o On diagnosis?
 - o During treatment?
 - o After treatment?
 - o When at home: night time/ out of hours?
 - o End of life?

- Were you asked what information you wanted at any stage and in what format?

- Did you have to request information or was it given to you as standard?

- Who offered you information? health professionals, other professionals, friends, etc

- How good was this information? Did it meet your needs? Was it relevant?

- Was it appropriate, too little, too much, just right? Were you able to take it all in?

- Did you try to access other information that was not offered to you by health professionals? How did you do this? (e.g. fellow patients, written information, computers, internet, etc). What was the quality of this information? How did it help?

- Was there anything you wish you'd had information about but weren't offered?

- How can health services provide information more effectively? What can be done to help people who can't seek information themselves? What about people who do not want to seek information themselves?

- Are there any other issues you would like to discuss with us in relation to your information needs and the information that was provided to you

APPENDIX 3: INTERVIEW SCHEDULE FOR CARERS

After introducing themselves to the participant and answering any questions, the interview will go ahead if the participant is willing and able and has signed the informed consent form. The interviewer will ask a series of open questions and use the participants' cues to move the interview forward. The following outline is designed to be used by the interviewer in a flexible and responsive manner.

Setting the scene

- Can you tell me about what happened to you after your partner/child/other came to be diagnosed with cancer?
- In what ways did it impact on your life and the things you did?

The interviewer will ask the interviewee to expand upon the responses made in the postal questionnaire. Focus will be on gathering more in-depth information on the experiences of:

- A) *the actual type of support received from formal sources (as per table in postal questionnaire)*
- B) *informal sources of supportive care*
- C) *How people are made aware of the services available – referral practices, information sources etc*
- D) *gaps in provision*

Diagnosis

- What services were you offered or told about and by whom?
- Did you use any of these services?
- What services/support would have helped you at this time?
- What information (written/verbal) did you receive?

During treatment (if applicable)

- What services were you offered or told about and by whom?
- Did you use any of these services?
- What services/support would have helped you at this time?
- What information (written/verbal) did you receive?

End of treatment (if applicable)

- What services were you offered or told about and by whom?
- Did you use any of these services?
- What services/support would have helped you at this time?
- What information (written/verbal) did you receive?

Overall

- What kind of support did you find particularly helpful?
- Is there anything that you can think of that could be done better to support carers like you?
- Do you have anything else to add?

APPENDIX 4: INTERVIEW SCHEDULE FOR HEALTH AND SOCIAL CARE PROFESSIONALS

- What information and support services are provided to carers and families of people affected by cancer at these times?
 - o On diagnosis?
 - o During treatment?
 - o After treatment?
 - o When at home: night time/ out of hours?
 - o End of life?
- How is it ensured that families are made aware of the support available? (E.g. protocols, referral practices)
- Who is responsible for making sure this support is offered and provided where needed?
- What links/relationships do you have with other organisations/agencies that provide this type of support to carers/families?
- Would you say there were any gaps in provision of information and support to carers are at the moment?
- Can you tell us about any examples of good practice in this area?
- Do you have any suggestions on how the provision of information and support to military personnel and their families can be improved?
- Are there any barriers to the successful development supportive care services for carers?
- Is there anything else you would like to discuss in relation to the support provided to people affected by cancer who are stationed in Germany?

Focus groups

The participants would also be presented with the key findings from an analysis of the survey and qualitative interviews with unpaid carers for discussion.

They would also be presented with proposed recommendations for service development – and asked to discuss their potential in relation to barriers to successful implementation etc.

APPENDIX 5: INFORMATION NEEDS QUESTIONNAIRE



The needs of informal carers of military personnel, entitled civilians and dependents affected by cancer in Germany

Postal Questionnaire

Introduction

The questions below ask you about your experiences of caring for someone affected by cancer. They ask about the demands made on you and the support you were provided with during the time of finding out what was wrong, what happened to you during any treatments the patient received and how you were supported, what services you used and the information you were given.

All your answers will be treated confidentially and nobody, apart from the University of Stirling research team, will know that you have taken part in this study.

Thank you.

About you and the person you care for

- Q1** **The person diagnosed with cancer that you care for, is he/she:**
- Wife.....
 - Husband.....
 - Son.....
 - Daughter.....
 - Other relation.....
 - Close friend.....
 - Other.....
 -
- Q2** **What year were they diagnosed with cancer?**
- 2003.....
 - 2004.....
 - 2005.....
 - 2006.....
 - 2007.....
 - not sure/unknown.....
 -
- Q3** **What position or rank did they and/or you hold at the time? (if applicable)**
- Q4** **What base/garrison/station were they/you in at the time of diagnosis?**
- Q5** **At the time of diagnosis did you have any other caring responsibilities, e.g. children, elderly relatives?**
- Yes.....
 - No.....
- Q5a** **If yes, please write in the number of people who you were rsponsible for, and the ages of any children at the time of diagnosis**

About how you were supported at this time

Q6 Were you, as the person close to the patient, provided with all the information you needed about what was wrong and what would happen to the patient in terms of treatments etc?

Yes.....
No.....

Please write down the two people or services you think were the best sources of information for you.

Q7a best source of information 1)

Q7b best source of information 2)

Q8 Do you think that you were provided with all the practical support you needed to care for someone affected by cancer?

Yes.....
No.....

Please write down the two people or services you think were the best sources of practical support.

Q9a best source of practical support 1)

Q9b best source of practical support 2)

Q10 Do you think you were provided with all the emotional support you needed?

Yes.....
No.....

Please write down the two people or services you think were the main sources of emotional support.

Q11a best source of emotional support 1)

Q11b best source of emotional support 2)

Q12 Were you, or the person diagnosed with cancer, provided with information or support on:

	Yes	No	Not applicable
future employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
future housing needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
future child schooling needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q13 Was the relevant service unit co-operative:

	Yes	No	Not applicable
In allowing time off for hospital/GP appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In providing transport for attending hospital or visiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In arranging Aeromed flights for return to the UK	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In providing accommodation for visiting family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

About the services you may have used

Q14

	Yes	No	Not applicable
Were you provided any information on financial support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were you offered any information about services that were available if you felt anxious or depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were you offered community nursing care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you receive any assistance in caring for children or other dependents during the time the patient had treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q15 If you answered YES to the caring for children question above, please tell us who provided this assistance

Q16 Were you offered any information or services to help you:

	Yes	No	Not applicable
maintain your own health during this time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
communicate with the health professionals who were treating the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q17 Did you encounter any difficulties when receiving care from German health services

- Yes.....
- No.....
- Not applicable.....

Q17a If YES, please describe what these difficulties were

What could have been done better to support you during the time you cared for a person affected by cancer:

Q18a **around diagnosis?**

Q18b **during treatment?**

Q18c **after treatment?**

Q19 **In the boxes below, please tell us what services you know about, how you know about them, and whether you used them at any point during the patient's cancer journey - for example when the patient was diagnosed with cancer, during their treatment or when treatment ended.**

	<i>Tick box if you are aware of this service</i>	<i>Tick this box if you were told about it or referred to it at any time since the patient's cancer diagnosis</i>	<i>Tick this box if you received support or services at any time since the patient's cancer diagnosis</i>
Army Welfare Service - community support team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
British Forces Germany Social Work Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Council of Voluntary Welfare Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Defence Medical Welfare Service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIVE Support Team Officer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIVE Information Centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
SSAFA (Soldiers, Sailors, Airmen & Families Association)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
WRVS Services welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G1 Chaplains	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G1 Compassionate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital Liaison officer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homestart	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unit Welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Local charity or support groups (please write name in box below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please write name in box below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Name of local charity or 'other'</i>			

Thank you so much for filling out this questionnaire.

Please return the questionnaire in the pre-paid envelope provided by Monday 5th November to: Cancer Care Research Centre, University of Stirling, Stirling, FK9 4LA

APPENDIX 6: HEALTH PROFESSIONAL QUESTIONNAIRE



Assessment of the information needs of people affected by cancer in British Forces Germany (BFG)

Please answer the following questions so that we can find out what information is provided for people affected by cancer where you work. Most answers are either YES, NO or DON'T KNOW so it should not take you more than 10 minutes to complete.

SECTION 1 is about you

SECTION 2 is about booklets and leaflets

SECTION 3 is about general cancer information

Please read carefully the following definitions that we are using before you answer the questionnaire

Screening 'is the term used to describe the investigation of asymptomatic individuals in order to detect disease at an early stage when it is more amenable to treatment' (SIGN 67, 2003).

Diagnosis is 'the process of identifying the disease by the signs and symptoms' (National Cancer Institute). This may involve people at any stage of disease including recurrence.

Treatment includes patients receiving surgery, chemotherapy, radiotherapy, hormone therapy, biological therapies and complementary therapies.

Supportive care 'helps the patient and their family to cope with cancer and their treatment of it - from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment' (NICE). It can include symptom management and psychosocial care.

Rehabilitation 'involves activities to help a person adjust, heal, and return to a full, productive life after injury or illness. This may involve physical restoration such as the use of prostheses, exercises, and physical therapy, counselling, and emotional support' (American Cancer Society).

Follow up is when cancer patients 'complete their primary treatment and return to the community. They will be looked after by their GP and other members of the primary health care team but, historically, many have also attended for hospital-based follow-up.'

Palliative care 'involves the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments' (NICE).

Section 1: About you and your place of work

Q1 What is your professional job title?

Q2 Where do you work?

Q3 Is there anyone where you work responsible for making sure that information is available for people affected by cancer?

Yes.....

No.....

Don't know.....

If YES, please give their name

and job title

Section 2: Booklets/Leaflets

Q4 How many different booklets/leaflets are there available at your place of work for people affected by cancer?

none.....

between 1 and 4.....

between 5 and 9.....

ten or more.....

If you ticked 'NONE' in question 4 please go directly to section 3, otherwise please answer the following questions

Q5 How do people affected by cancer obtain these booklets/leaflets (please tick all relevant boxes)

Booklets/leaflets are displayed on a table.....

Booklets/leaflets are displayed on shelves.....

Booklets/leaflets are handed out by staff.....

Other.....

Please specify

Q6	Are any of these booklets.....	Yes	No	Don't know
	written and produced by BFG Health Services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	specifically for patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	specifically for carers, for example relatives and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q7	Do any of these booklets/leaflets provide information.....	Yes	No	Don't know
	about screening?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	about diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	about treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	about transport during treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	about finance/benefits?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	about supportive care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	on follow-up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	About palliative care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	for patients with sensory impairment (blind/deaf)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section 3: Other information

Q8	Are there any other types of information that your place of work has for people affected by cancer to use?	Yes	No	Don't know
	Video to give to patient/carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Audio to give to patient/carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Access to internet by patient/carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>Please specify</i>			

Q9 **Do you as a health professional download information from the internet to give to patients?**

Yes.....

No.....

If YES, please specify three 3 most popular sites that you use

1st most popular

2nd most popular

third most popular

Q10 Do you recommend any websites to patients/carers?

Yes.....

No.....

*If YES, please specify 3 sites
that you recommend:
1st recommended site*

2nd recommended site

3rd recommended site

Thank you so much for filling out this questionnaire.

**Please return the questionnaire in the pre-paid envelope provided by [insert date here] to: Cancer Care
Research Centre, University of Stirling, Stirling, FK9 4LA**

APPENDIX 7: RESULTS OF HEALTH PROFESSIONAL QUESTIONNAIRE

A total of nineteen questionnaires were returned by health professionals. Given that 24 were issued this represents a return of 79%. Seven of these responses were from staff at JHQ, five from Gutersloh, plus one each from Osnabruck, Paderborn and Bergen-Hohne. Three respondents had BFG-wide responsibilities but it was unclear where the one remaining respondent was from.

Six respondents described themselves as welfare officers or workers. Three returns were from GPs and a similar number were from nurses/nurse officers. Two respondents are involved with Homestart. The remaining respondents were from hospital operations, the Army Families Federation, patient support, and learning & development. Two are volunteers with JIGSAW, the recently set up cancer patients' support group within BFG.

Is there anyone where you work responsible for making sure that information is available for people affected by cancer?

Yes	26.3%
No.....	63.2%
Don't know.....	10.5%

Only five respondents (26%) were aware that their workplace had someone responsible for ensuring that information is available for people affected by cancer. One of these thought that all members of the DMWS team should be making sure such information is available while another thought it the responsibility of ALL practitioners who interface with cancer sufferers.

How many different booklets/leaflets are there available at your place of work for people affected by cancer?

none.....	42.1%
between 1 and 4	42.1%
between 5 and 9	10.5%
ten or more	5.3%

More than two-fifths thought their place of work did not have any booklets or leaflets to provide to people.

How do people affected by cancer obtain these booklets/leaflets (please tick all relevant boxes)

Booklets/leaflets are displayed on a table	18.2%
Booklets/leaflets are displayed on shelves	9.1%
Booklets/leaflets are handed out by staff	72.7%
Other	18.2%

Of those that did have such booklets and leaflets, over 70% thought that these were issued by hand by staff members, compared to 18% who displayed them on tables and only 9% on shelves. The category 'Other' includes both JIGSAW volunteers who issue leaflets through HLOs and medical centres or when posting out JIGSAW information packs.

Are any of these booklets.....

	Yes	No	Don't know
written and produced by BFG Health Services?	27.3%	45.5%	27.3%

specifically for patients?	81.8%	0.0%	9.1%
specifically for carers, for example relatives and friends?	45.5%	18.2%	27.3%

Just over a quarter of booklets/leaflets are thought to be produced by BFG HS. The vast majority (82%) are aimed at patients and just under a half have been written specifically for carers.

Do any of these booklets/leaflets provide information.....

	Yes	No	Don't know
about screening?	72.7%	18.2%	9.1%
about diagnosis?	63.6%	27.3%	9.1%
about treatment?	72.7%	18.2%	9.1%
about transport during treatment?	9.1%	72.7%	9.1%
about finance/benefits?	9.1%	63.6%	18.2%
about supportive care?	45.5%	36.4%	9.1%
on follow-up?	27.3%	54.5%	9.1%
About palliative care?	18.2%	54.5%	18.2%
for patients with sensory impairment (blind/deaf)?	0.0%	63.6%	27.3%

Very few leaflets and booklets would appear to offer information on areas such as transport, finance & benefits, or palliative care.

Are there any other types of information that your place of work has for people affected by cancer to use?

	Yes	No	Don't know
Video to give to patient/carer	5.3%	78.9%	15.8%
Audio to give to patient/carer	0.0%	84.2%	15.8%
Access to internet by patient/carer	36.9%	57.9%	5.3%
Other	15.8%	72.7%	5.3%

Only one respondent thought that their place of work had video information to provide to patients and carers. Internet access for patients and carers is available in more than 40% of work places (one respondent from the 'other' category describes patients being advised individually on suitable sites).

Do you as a health professional download information from the internet to give to patients?

Yes	63.2%
No.....	36.8%

Nearly two-thirds of respondents download information from the internet to give to patients. Of these, around a third regularly used each of the following organisation's websites: Cancerbackup, CRUK, and Macmillan. A couple of respondents used clinical knowledge websites such as prodigy or gnotebook and a quarter regularly used search engines such as google and ask.com as their starting point for finding information on specific cancers. Only one person mentioned regularly using the JIGSAW website from which to download information.

Do you recommend any websites to patients/carers?

Yes	68.4%
No.....	26.3%

Just over two-thirds of respondents (68%) recommend websites to patients and carers. Over a half of these recommend cancerbackup while smaller numbers also suggest

patients and carers use the CRUK and Macmillan sites. The JIGSAW website was recommended by a quarter of those who said yes to this question. One respondent recommended the checkmads site. The NHS website was recommended by one respondent as a good starting point with balanced content and useful links. Another respondent suggested the health information website patient.co.uk.

APPENDIX 8: RESULTS OF CARERS QUESTIONNAIRE

Only twelve carers consented to their involvement in this study and of these, nine made questionnaire returns, a response rate of 75%. In all cases it was the spouse who was diagnosed with cancer. In other words, no respondent was caring for a child, other close relative or friend who had been diagnosed with cancer. However, at the time of diagnosis two-thirds of respondents had other caring responsibilities, in all cases children.

Q6 Were you, as the person close to the patient, provided with all the information you needed about what was wrong and what would happen to the patient in terms of treatments etc?

Yes 7
 No..... 2

The majority of carers (78%) felt they had been given all of the information they needed about their partner's condition and treatment [note: this high figure is contradicted in later questions]. Of these, most thought the German hospitals were their best source of such information. Just over a half thought of their HLOs as good sources, while fewer numbers cited UK hospitals, their Garrison medical centre, Welfare Services, Cancerbackup and a friend.

Q8 Do you think that you were provided with all the practical support you needed to care for someone affected by cancer?

Yes 3
 No..... 5
 none asked for/not needed..... 1

In terms of practical support, most carers (63%, excluding those who had not asked for or not needed any support) thought that they had **not** been given all the support that they needed. All respondents were invited to name their two best sources of practical support; over a half named friends as their best source, while fewer numbers suggested medical staff (UK, BFG and German hospital), HLOs, their Unit Welfare or other sufferers/support groups.

Q10 Do you think you were provided with all the emotional support you needed?

Yes 3
 No..... 4
 none asked for/not needed..... 2

Similar numbers thought their emotional support needs had **not** been met (57%). Low numbers suggested any best source of emotional support. Two carers suggested Welfare Services. Similar numbers suggested family and friends and UK based medical staff. One carer mentioned their HLO and another had an open referral to a CPN if needed.

Q12 Were you or the person diagnosed with cancer provided with information or support on:

	Yes	No	Not applicable
future employment	0	6	3
future housing needs	0	4	5
future child schooling needs	0	4	5

None of the carers were given information or support on the three issues listed in question 12, future employment, housing needs or child schooling needs.

Q13 Was the relevant service unit co-operative:

	Yes	No	Not applicable
In allowing time off for hospital/GP appointments	7	0	2
In providing transport for attending hospital or visiting	6	1	2
In arranging Aeromed flights for return to the UK	1	1	7
In providing accommodation for visiting family members	1	2	6

All carers were given time off their work for any hospital or GP appointments and most were readily provided transport for visiting their spouse in hospital. The need for flights home to the UK appears low with only two carers thinking this applicable. One of these thought their unit helpful in arranging such flights. Similarly, low numbers required accommodation for visiting relatives and of these only a third had their needs met.

Q14 About the services you may have used

	Yes	No	Not applicable
Were you provided any information on financial support?	0	6	3
Were you offered any information about services that were available if you felt anxious or depressed?	1	7	1
Were you offered community nursing care?	0	6	2
Did you receive any assistance in caring for children or other dependents during the time the patient had treatment?	1	5	3

The provision of information appears to be severely lacking in the areas of financial support, and anxiety & depression with only one carer offered information on the latter. None of the carers were offered community nursing care and the only assistance one carer had with childcare came from family members who happened to be visiting at the time of need.

Q16 Were you offered any information or services to help you:

	Yes	No	Not applicable
maintain your own health during this time?	1	7	1
communicate with the health professionals who were treating the patient?	6	3	0

Only one carer had been offered information or services to help maintain their own health. A high proportion of carers (two-thirds) were given assistance in communicating with German health professionals and this perhaps reflects the role of the HLOs.

Q17 Did you encounter any difficulties when receiving care from German health services

Yes	5
No.....	3
Not applicable	1

The language barrier, when communicating with the health professionals, has proved a difficulty for four of the five carers who had problems with the German Health Service. The HLOs were commended for their role by two carers although one acknowledged that their HLO was sometimes too busy to attend every appointment. The remaining problem

related to an alleged error by a doctor that led to the couple wanting the follow-up care to be completed in the UK.

Question 18 asked carers what could have been done better to support them during the time they cared for someone affected by cancer: around diagnosis, during treatment and after treatment. Below are the full lists of responses

Around diagnosis

“I needed more time off work to accompany wife to appointments for emotional support. Sometimes not possible as this was often at very short notice”

“Counselling, support groups, information on how to care for patient”

“More emotional support and someone to talk to who had more experience of the situation I was in”

“None”

“Nothing - it was very good”

“More information available and easier to access”

“Nothing really. I was given time off as and when I required it”

“Diagnosis was very slow. Indeed cancer was not diagnosed until after surgery and numerous theories were presented causing confusion”

“Offer from medical centre at X for sharing of information”

During treatment

“I needed more time off work to accompany wife to appointments for emotional support. Sometimes not possible as this was often at very short notice”

“Counselling, support groups, information on how to care for patient”

“Husband suffered severe side-effects and more help in getting medication to combat this would have been better. Support with practical things could be better, e.g childcare, ironing etc while caring for husband”

“None as my wife went back to UK”

“Nothing - it was very good”

“More information available and easier to access”

“Nothing really. I was given time off as and when I required it”

“Excellent”

After treatment

“I needed more time off work to accompany wife to appointments for emotional support. Sometimes not possible as this was often at very short notice”

“Counselling, support groups, information on how to care for patient”

“Building husband up to get back to normal could have been better with access to e.g. dieticians. Our situation happened very quickly and we hardly had time to take things in. In shock long time & no idea what to expect, fear of unknown, real worries”

“Army gave wife free flights in 1st yr but then they stopped. As she is still recovering in UK 7 yrs on I feel she should be entitled to free flights twice a year to UK”

“More support is needed after treatment or when not in hospital”

“Treatment still ongoing”

“Nothing really. I was given time off as and when I required it”

“Excellent”

Q19 In the boxes below, please tell us what services you know about, how you know about them, and whether you used them at any point during the patient's cancer journey - for example when the patient was diagnosed with cancer, during their treatment or when treatment ended.

	<i>Tick box if you are aware of this service</i>	<i>Tick this box if you were told about it or referred to it at any time since the patient's cancer diagnosis</i>	<i>Tick this box if you received support or services at any time since the patient's cancer diagnosis</i>
Army Welfare Service - community support team	4	1	1
British Forces Germany Social Work Services	4	1	1
Council of Voluntary Welfare Work	1	0	0
Defence Medical Welfare Service	3	2	2
HIVE Support Team Officer	4	1	0
HIVE Information Centre	5	0	0
SSAFA (Soldiers, Sailors, Airmen & Families Association)	7	0	0
WRVS Services welfare	4	0	1
G1 Chaplains	6	1	1
G1 Compassionate	1	0	0
Hospital Liaison officer	6	5	5
Homestart	6	1	0
Unit Welfare	7	3	3
Local charity or support groups (please write name in box below)	2	1	1
Other (please write name in box below)	1	0	0

The first numeric column in the above table illustrates how poorly known some of the organisations are among the carers. In particular, the Council for Voluntary Welfare Work and G1 Compassion have very poor awareness. Conversely, most carers appear well aware of SSAFA, HLOs, Homestart and G1 Chaplains. Very few carers had actually been told of most of these organisations since the patient's diagnosis. Similarly, very few carers actually received support from any of them. The recent emergence of JIGSAW, the cancer support group, is highlighted by the three carers who put this organisation in the 'other' boxes.