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ORIGINAL ARTICLE

A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care

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Abstract

Purpose The partners of cancer survivors may experience distress, anxiety, fear and uncertainty whilst also caring for and supporting a partner who is ill. As they concentrate on the cancer survivor's needs, their own needs may remain unaddressed. Primary care staff may be well placed to support partners as they are generally accessible and may have a better knowledge of the patient's background and family relationships. However, their current involvement in the cancer survivor's and partner's cancer-related care is unclear. This study aimed to describe the experience of the partners of cancer survivors in dealing with cancer-related issues in the first 3 years post-diagnosis, their use of primary care services in relation to these issues and the barriers in doing so and their views on the role that primary care could potentially play in supporting them as carers during this period.

Methods Semi-structured interviews with 22 partners of cancer survivors diagnosed within the last 3 years and recruited through six GP practices in the Thames Valley Region of the UK were analysed using the 'framework' approach to thematic analysis.

Results Three issues were identified as of particular concern to partners: providing practical support, providing emotional support and managing their own health and well-being. Few partners had sought or received support from primary care specifically for cancer-related issues, indicating confidentiality, lack of knowledge of family relationships and the greater need of the cancer survivor as barriers. Most partners would welcome a proactive approach from primary care and felt that this would provide an opportunity to discuss issues they were concerned about.

Conclusions Needs and concerns of the partners of cancer survivors in caring for patients are often not addressed. There is a scope for primary care to elicit these needs and provide greater support. Changes to clinical practice in primary care could lead to greater involvement of and to better outcomes for cancer survivors and their partners. A proactive approach to patients and their partners or other close family members at the time of diagnosis through an offer of support and the inclusion in a designated review appointment at the end of initial treatment would be useful.

Keywords Cancer survivors · Partners · Primary care · Framework analysis · Qualitative

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Introduction

Cancer affects not only the patient but also close family and friends [1–3]. Family members have to deal with the emotional impact of the diagnosis whilst also playing an integral part in the care and support of the patient [1]. Although the needs of the partners of patients at the end of life have been well documented [4], less attention has been paid to the survivorship phase. A recent systematic review concluded that the needs of partners and family members of cancer survivors often remain unmet in the areas of medical information and supportive care [5], and there is a need for health care practitioners to address these needs more directly. However, little is known about how this might occur, and what barriers to this exist. A number of family support interventions exist to address psychosocial and caregiving needs of family members. A recent systematic review and meta-analysis concluded that interventions can reduce caregiver burden and improve their ability to cope [6].

Since 2003, the Quality and Outcomes Framework (QOF) of the General Medical Services Contract for Primary Care has provided an incentive for practices in the UK to establish a cancer register and to conduct a review with new cancer patients within 6 months of diagnosis (a ‘cancer care review’) [7]. Whilst there is a growing evidence that cancer also affects the family members of cancer patients, support for partners of cancer patients is not currently offered as part of the cancer care review. Previous research has suggested that family doctors may be well placed to provide such support as they are generally accessible and may also have a better knowledge of the background and family relationships of cancer survivors and their partners [8–10].

We conducted an exploratory study with cancer survivors 6 months to 3 years post-diagnosis, their spouse or partner and healthcare professionals in primary care. The study aimed to describe the views of these three distinct groups on cancer care reviews and the role of primary care in cancer care in the first 3 years post-diagnosis. In a previous paper, we reported the experiences and views of cancer survivors and health care professionals [11]. In this paper, we report findings from the partners of cancer survivors on their experiences in dealing with cancer-related issues in the 6 months to 3 years post-diagnosis, their use of primary care services for cancer-related issues and the barriers to doing so and their views on the role that primary care, and a cancer care review in particular, could potentially play during this period. We define primary care in this paper as the care provided through the community-based practice of the patient’s general practitioner, family physician or family doctor, including nurses, receptionists and other members of the team. We chose this time period as initial treatment has usually been completed and the patient’s contact with the hospital is much reduced.

Methods

The study received ethical approval from the Oxford Research Ethics Committee B (08/H0605/112). Six GP practices in the Thames Valley Region of the UK (covering three counties) were recruited to the study via the Thames Valley Primary Care Research Network to include practices in rural and urban settings and with a mix of ethnic groups and levels of deprivation. Details of the practice characteristics and method of recruiting cancer survivors are provided in a previous paper [11].

Partners were recruited to the study via cancer survivors. Cancer survivors were eligible for recruitment to the study if they had been diagnosed with cancer 6 to 36 months before the start of the study, were 18 years or older and were not in the terminal phase of illness as measured by eligibility for the DS1500 (a short medical report denoting terminal illness with life expectancy of less than 6 months to claim benefits from the Department of Work and Pensions). Cancer survivors were excluded if their GP felt that they may be adversely affected by an invitation to take part in the study. Cancer survivors were identified from anonymised cancer registers at each practice. Practices were asked to provide a list of all eligible cancer survivors and their date of diagnosis, cancer type, ethnicity (if available), whether or not a QOF cancer care review was recorded as having taken place and the review date if available. The sample was stratified by time since diagnosis into three groups: 6–12, 13–24 and 25–36 months post-diagnosis. Survivors were then selected using maximum variation sampling strategies [12] to achieve maximum heterogeneity in the sample in relation to age, sex, ethnicity and cancer type. Survivors were recruited from each practice consecutively between March 2009 and January 2010. They were invited to participate in a semi-structured interview by a letter from their primary care physician. The letter was posted to the cancer survivor, and the cancer survivor was given the option to pass an invitation to their partner or close family member. All the partners who accepted the invitation to take part in the study were interviewed.

Written consent was obtained from each participant, and semi-structured interviews were conducted to explore their experiences of primary care involvement in cancer care, their views on potential improvements to care and their experience as a partner of a cancer survivor. Participants were advised that all data collected would be anonymised and treated in strict confidence. All interviews were conducted by EA (a psychology researcher with no specific links to primary care), and all but one participant were interviewed in their own home, with one choosing their local cancer centre. We told the participants that we would prefer to interview survivors and partners separately, but we would interview them together if preferred.

The interviews were audiotaped, transcribed verbatim and analysed by EA, MB and EW using the framework approach [13]. NVivo 8 computer software was used to organise data for analysis. The framework approach to analysis was developed in the UK specifically for applied and policy-relevant qualitative research where the objectives of the study are typically set in advance, often in relation to the needs of the funding body [14]. It is commonly used in applied health research [e.g. 15, 16]. The analytical process involves five stages: familiarisation (immersion in the raw data), identifying a thematic framework (drawing on a priori issues and questions as well as issues raised by participants themselves, in order to examine and reference the data), indexing (applying the thematic framework to all the data), charting (grouping the data according to the part of the thematic framework to which they relate using distilled summaries linked to transcripts via page numbers or hyperlinks) and mapping and interpretation (mapping the range of phenomena and, where appropriate, creating typologies and/or finding associations between themes with a view to providing explanations).

We first designed an initial analytical framework (Table 1, column 1) based on our interview guide and aims of the study. We then reread the interviews and noted down recurrent themes and any unusual topics that arose. As a policy-oriented study, we were particularly interested in identifying the difficulties experienced by the partners and the ways in which these could be addressed through policy and practice in primary care. We then used our analytical framework to index the interview transcripts, taking into account the manner as well as the substance of what was said. In the course of indexing the transcripts, the existing framework was

Table 1 Three key stages of framework analysis

Initial framework based on a priori issues	Revised framework used in indexing	Themes and sub-themes used to map the range of views and experience
Effect of patient's cancer on partner • Practical impact • Impact on social life/lifestyle • Psychological impact • Change to relationship with patient • Impact on the wider family (e.g. children) • Caring for patient • Support/information from family, others	Effect of patient's cancer on partner • Roles and tasks of partner • Involvement in practical care • Emotional impact • Effect on own health • Expectation of nursing care • Conflicts in care	Issues of concern to partners • Providing good practical care • Providing emotional support • Managing own health

Use of primary care services in relation to patient's cancer
• Involvement of primary care with patient
• Help/support partner looked for from primary care
• Information
  • Practical help
  • Psychological support
• Help/support partner received from primary care
  • Information
  • Practical help
  • Psychological support
• Facilitators to getting help
• Barriers to getting help
	Use of primary care services
	• GP support for cancer survivor
	• GP support for partner
	• Facilitators to support from GP
	• Barriers to support from GP
		Barriers to using primary care
		• Perceived confidentiality of doctor–patient relationship
		• Perceived limitations in primary care professionals' knowledge of family relationships
		• Prioritising the needs of the cancer survivor

Views on the potential role of primary care during this period
• Best ways of providing support to partner
• Views on cancer care review in the first 6 months after diagnosis
  • Involvement of partner
  • Subjects for discussion
  • Best person to conduct it
  • Best timing
  • Best frequency
	Views on primary care involvement
	• Views on cancer care review in the first 6 months after diagnosis
	  • Involvement of partner
	  • Subjects for discussion
	  • Best person to conduct it
	  • Best timing
		Views on cancer care review
		• Views on possibility of partner cancer care review
		• Views on how these would best be provided

modified as new elements were identified and others were combined or revised (Table 1, column 2). We then created a chart where we summarised, for each interview, what was said for each of the themes that had been identified. We then focused on the most dominant themes and sub-themes in mapping out the range of partners' views and experiences (Table 1, column 3) in relation to the aims of the study.

In designing the study and interpreting the interviews, we drew on experience from across the team, which included user representatives, health care professionals, a GP, social scientists and health services researchers. The framework and how it was applied to the data were discussed between the three analysts, EA (post-doctoral psychologist), MB (senior qualitative researcher in sociology of health and illness) and EW (senior health service researcher in supportive cancer care), to ensure the credibility and trustworthiness of the analysis. Because it was an exploratory study, the analysis concentrated largely on mapping out the range of views and experiences described by the participants rather than attempting to develop typologies or looking for associations between themes.

Results

Practices identified 319 eligible patients, 130 were invited and 38 patients agreed to participate. Twenty-two partners participated in the study. We do not know how many of the participants passed on an invitation to their partner or whether they had a partner. Eight participants took part in joint interviews with the patient, and 14 were interviewed separately. Interviews lasted between 17 and 67 min (mean =35 min). Participant characteristics are presented in Table 2.

Table 2 Partners' characteristics

Characteristics	No. partners (n=22)
Age at interview	
<50	4
50–70	14
>70	4
Sex	
Male	7
Female	15
Ethnicity	
White British	20
White other	1
Black African	1
Cancer types of patient	
Prostate	4
Colorectal	3
Head and neck	3
Lung	3
Melanoma	3
Breast	2
Hodgkin's disease	1
Testicular	1
Gynaecological	1
Bladder	1

Issues of concern to partners of cancer survivors

Providing good practical care

A fundamental concern that partners described particularly during the initial period following treatment was related to their need to provide practical care for the patient. For some, this involved close monitoring and quite specialised nursing care:

> "Every time she coughs and the phlegm comes up and goes straight on the voice box, so I'm forever going in there with the little brush to clean the hole out in the middle of the voice box" (P1228, husband, separate interview).

> "That first night you came home from hospital because he couldn't lie down, he sat in the chair that you're in now and I slept here, and every time he coughed he bled and I had to change his dressing and he's sound asleep, and I'm 'f…', patch him up again" (P119, wife, joint interview).

Often the requirement for practical care was short term but could constitute a significant, new responsibility. Most participants rose to the challenge and took on these new tasks without complaint. Some described feeling anxious when they found themselves needing to provide nursing care with minimum preparation:

> "I went down to the doctors and said 'look, I'm really getting quite worried, cos I'm I will do the best I can but… I'm by no means a nurse', he had had such intense care in the hospital I was feeling sort of quite… Not stressed, but it was a worry, it was nothing I'd had to face before, that I'd had this healthy husband who suddenly was quite an invalid when he came home" (P120, wife, separate interview).

Others expressed anxiety in relation to what they may need to do in the future:

> "I've got to know how to look after him, because obviously that would be the next phase, hopefully not for a long time but you know, if I don't know

> how I manage it, how can I look after him, that's my motive, to make life as comfortable for him as possible when and if it starts to go downhill" (P198, wife, separate interview).

For most, their anxiety declined if and when they were able to get the information they needed to provide the care appropriately, as the following example illustrates:

> "It's sort of little things like you say 'I can't go to the toilet' and of course having all this done there's no way you can strain yourself, and I'd been to the chemist and they'd given me like pessaries, and something very gentle, phoned up M [specialist nurse], 'it's Movicol you want, go and get that', I wish they'd told us that before, I'd have had some in ready, because, but it's something you don't think about" (P120, wife, separate interview).

For other participants, caring for a convalescing patient did not require specialised skills but was recognised as placing an additional demand on them, and they took some satisfaction in carrying it out successfully:

> "They discharged him after four days, they did ask if I could manage and I thought I could and I did, I mean he was weak, he had to be sort of helped, but not what I'd call nursing, no, take him to the bathroom, and see to him, well he could see to his own, but he was too wobbly" (P140, wife, separate interview).

Similarly, some found satisfaction in demonstrating their resourcefulness and adaptability in adjusting their normal routines, for example in preparing meals for the cancer survivor when their appetite had changed:

> "It's a culture shock because my husband has always been a very good trencherman, you put something in front of him, it goes, and then he's liable to say 'is that all there is?' and then all of a sudden he doesn't want to eat, so yes, that has been difficult, but okay, you fish out the recipe books" (P1217, wife, separate interview)

Providing emotional support

Partners described less confidence and more uncertainty in relation to providing emotional support for the cancer survivor and so found this aspect of their role more stressful. As the following example illustrates, some partners were uncertain about what approach to take in their efforts to meet their emotional needs:

> "I mean I was trying to be a pillar of strength whereas really I should have been someone to hug and cuddle which I didn't really do, did I" (FM1230, husband, joint interview).

Other partners recognised that they could not meet the cancer survivor's need for emotional and social support on their own and would have welcomed information on how to access other support, for example through support groups:

> "I would have liked to get some information of, you know, if there were some groups that he could have gone to, I mean because this is a big change socially" (P1227, female partner, separate interview).

Where the cancer survivor experienced high levels of psychological or emotional distress, the partner could feel overwhelmed by their need for support or could feel unable to provide it. As the following example illustrates, this could alter their relationship and become a source of stress and unhappiness to the partner:

> "As far as my relationship with [partner] goes, yeah, I mean that's changed beyond all recognition, that I'm, how to say this, I mean part of my role now is, I mean yes I'm her partner… but it feels as though at times I'm also called on to be sort of psychologist, psychiatrist, you know, it goes beyond just kind of listening or being there or being supportive, you know your relationship kind of takes on that kind of other dimension, so yeah, I mean making that transition is, yeah I mean it's difficult" (FM142, male partner, separate interview).

Providing emotional support could thus prove more difficult and demanding than providing practical support, where practical solutions were more readily available and success in mastering them could provide a sense of satisfaction and sustained self-esteem.

Managing their own health and well-being

Most partners focussed on the needs of the patient, and in the interview, it was often difficult to get them to talk about their own needs. However, some partners voiced concerns about the impact of the cancer survivor's illness on their own health and well-being. For most of those who did, this was initially related to the psychological impact of the diagnosis and subsequently to the demands of caring, as the following participants describe:

> "I'm over it now, but I was a bit low, wasn't feeling too good, and I got pretty tearful, and it was this business when [husband], wasn't so happy, it's a bad week this week, but… we can say that's what it is (a bad week), but, yes it is difficult" (P163, wife, separate interview).

> "I was really on edge and scratchy, and I get various sort of silly skin things that erupt, and they started, so I knew that I was bothered, so that three months, not

> good. …It probably affected me stressfully, and I did bite at him. …I was a bit insufferable I think. It's the not knowing, it's the uncertainty. Has it spread, is it in his bones? It's the 'what if's', and it's horrid." (P198, wife, separate interview).

For other partners, their concern was related to their previous reliance on the cancer survivor for support in dealing with their own problems, as this wife described:

> "Before last year when my husband was diagnosed he was actually giving me intravenous infusions on a two weekly basis, so I've been reliant on him, but I had to retrain to do infusions which I can do myself, and I don't have to bother him as long as he's sitting here, in case I have a reaction which is quite rare apparently, but if he's in hospital or having to go somewhere for treatment, um that is a difficult problem" (P1218, wife, separate interview).

Others worried about their own health deteriorating and the impact this could have on their partner:

> "If I hurt myself she's on her own, yeah, which is quite terrifying really because she thinks 'oh, you're not doing this and doing that', what I usually used to do, like gardening and cleaning windows, helping her with them, but, and I'm saying to myself 'I've only got to fall' or something like that 'then who's going to look after her', yes" (P1228, husband, separate interview).

Barriers to using primary care

Few participants had sought or received support in relation to caring for and supporting the patient or to their own needs in doing so. Three themes were identified in relation to the barriers to accessing support from primary care: perceived confidentiality of the doctor–patient relationship, primary care professionals' limited knowledge of family relationships and partners' felt lack of entitlement to support from primary care. These comments point to a number of implicit, unquestioned assumptions that partners of cancer survivors make about the appropriate use of primary care.

Perceived confidentiality of the doctor–patient relationship

Participants indicated that they believed doctors do not talk about patients to other patients, even if they are partners. As the following two examples illustrate, this assumption provided the rationale for both the limited information their family doctor gave them about the patient and their own reluctance to ask for more information:

> "She said he's responding really well, but that was about it really, and I didn't sort of want to talk about it but I did, you know, I didn't want to bring it up, because I'm not, you're not really supposed to discuss other people are you, when you're in with the GP (family doctor), but that's all she said—which was quite reassuring" (P198, wife, separate interview).

> "Well there's no point me mentioning it because I suppose they're not going to tell me anything because of patient confidentiality, so, that's why I haven't mentioned it, because it would put them on the spot really wouldn't it, because they'd have to tell me 'sorry, we can't discuss it', and then you'd feel perhaps a bit put out, no, they've never mentioned it" (P194, wife, separate interview).

Perceived limitations in primary care professionals' knowledge of family relationships

Several partners indicated that their GP did not seem to be aware that they were caring for a cancer survivor. One explanation offered for this was that the GP did not know they were living with a cancer survivor because the connection had not been made in their medical records:

> "No acknowledgement at all, I can only assume that because, I've always assumed that because patient records are separate that there's nothing on mine to say that in effect I'm living with a cancer sufferer, because it's not relevant and they haven't checked to know that we are" (P119, wife, joint interview).

This particular participant demonstrated a sense of frustration and disappointment throughout the interview, for example in repeating the refrain of 'no acknowledgement' when describing a range of interactions with the GP practice.

Prioritising the needs of the cancer survivor

A few participants also indicated that they had assumed that primary care support was intended for the patient and that it was not appropriate to ask for support for themselves:

> "I always thought it was the patient in terms of support so I wouldn't have thought about that, so maybe if that was brought up yeah I would be interested in that because I sort of associated that with the patient, I still do" (P155, wife, separate interview).

As the above example illustrates, partners themselves prioritise the support needs of the cancer survivor above their own, and while they may assume that this is shared with the primary health care professionals, it is the priority they give to the cancer survivor that inhibits them from seeking support for themselves.

Views on a cancer care review for partners

Most partners (17/22) said that they would welcome an approach by the primary care team through an invitation to attend a designated review appointment with a GP or nurse and felt that this would provide an opportunity to talk about the patient's cancer and their own needs in relation to this. An issue of particular concern was that of recurrence and, as the following example demonstrates, partners often wanted the opportunity to find out more about the likelihood of recurrence, how to detect it and how this relates to the purpose and process of follow-up care:

> "I'd like maybe to talk about the likelihood of it coming back, or him developing a different kind of cancer, touch wood, that would put my mind at rest and also know what sort of guidelines they have, because I think now he's going every six months to have his checkups, I'd like to know what they're checking for, and what would happen, what if anything happened in between, if it was different kind of cancer, how would we know" (P155, wife, separate interview).

Some partners regarded the opportunity to discuss cancer-related issues as so useful that they suggested formalising the cancer care review and repeating it at regular intervals:

> "I think if it was me personally I would want to make the review kind of more formal, that we see you every three months or every six months and you come in for a special appointment, just because presumably these people have got access to… information regarding sort of support services… and so on, and it would just be an opportunity to… discuss that, but it would just, it would make you feel like you weren't kind of left on your own!" (P142, male partner, separate interview).

Some also indicated that they would wish to attend even if the patient did not feel the need to see their GP themselves:

> "I would certainly have gone, I'm not sure R would, but I mean if it was available for me I certainly would, you know, it's, it's filling in those grey areas that I've got" (P198, wife, separate interview).

Several also mentioned that a review meeting on their own with a primary care doctor or nurse would give them the opportunity to stay informed and avoid potential gatekeeping by the patient:

> "Yes, that would be a good idea, yes, yes, it's best to know what's going on, I mean if you have it first hand you know the governor is not giving you a load of cobblers to keep you quiet, don't you, no, I think that would be a very good idea" (P1214, husband, separate interview).

This was the case even for partners who described their cancer experience as one shared with the cancer survivor. They commented that having a review appointment with their GP or nurse on their own might enable an openness which might otherwise be hampered by concerns over the patient's welfare:

> "I can imagine for some people they might want to raise issues which they didn't want to say in front of their spouse or, you know, if something were worrying me about the way he was behaving or something, you know a reaction" (P174, wife, separate interview).

For others, a review meeting on their own would provide the opportunity to raise issues related to their own needs and concerns as someone caring for a cancer survivor:

> "We're coping OK, but given all the things I've read about carers, getting stressed and all that kind of thing, it does surprise me that now this has been happening for 18 months, nobody has ever suggested that I should just have a check up, or talking to me to see if I'm caring [sic]. So as I say, it's absolutely fine, it doesn't worry me, but I can imagine if I was someone else in a different situation I could be getting ill and nobody would have picked it up." (P174, wife, separate interview).

Discussion

This study provides further evidence on the experience of the partners of cancer survivors 6 months to 3 years after diagnosis. During this period, partners were primarily concerned with providing good practical care and emotional support for the cancer survivor and with managing their own health and well-being. While the need to deal with aspects of personal or nursing care could initially create some anxiety, partners readily rose to the challenge and seemed to find satisfaction and self-esteem in doing so. The need to deal with the cancer survivor's psychological and emotional response to cancer could be more difficult to deal with, particularly when significant anxiety or depression altered the nature of their relationship. Partners indicated the need for appropriate and targeted information so that they could provide the best care to the cancer survivor and be prepared to meet the changing needs in the future. In our study, partners had rarely sought or received support for themselves from primary care, believing their own needs were not a priority. Nonetheless, they indicated that a proactive approach from primary health care professionals would be very welcome and would provide an opportunity to gain information and support for those who needed it. It was acknowledged that not everyone would wish to take up a review appointment.

A limitation of our study is the low number of partners from an ethnic minority background. We had attempted to recruit a more ethnically diverse sample by inviting every eligible cancer survivor from an ethnic minority background known to participating practices, but response rates among these cancer survivors were very low.

A further limitation is the dependence on cancer survivors to recruit partners. As the aim of the study was to gain the views of cancer survivors and their partners, this was the most efficient approach to recruitment. However, this additional level of gatekeeping may have biased the sample towards couples who communicated well or partners who were more engaged in coping with the patient's cancer. Studies which focus only on partners and family members could, in the future, avoid such bias by using methods to recruit partners directly, for example through support groups or posters in primary care practices.

Qualitative interviews are also shaped by the context in which they are carried out. By recruiting partners through the cancer survivors, we may have conveyed to the partners that our interest was primarily in the survivor and in the partner's experience only in so far as it related to caring for the survivor. This may have been reinforced by the topic guide which reflected our interest in identifying the difficulties experienced by partners and the ways in which these could be addressed in primary care. The limited discussion of partners' own self-care needs may reflect these contextual influences. Had we recruited partners directly, the researchers as well as the participants may have defined them and their self-care needs more clearly as the centre of interest and explored this aspect of their experience more fully. Whether the partner was alone or together with the cancer survivor may also have had an effect. When they are interviewed on their own, partners may feel less constrained to provide accounts they perceive to be acceptable to the cancer survivor [17] and more free to express negative views or feelings. By contrast, partners who are interviewed together may negotiate or jointly construct their account as a 'couple' [18]. In this study, there were examples of cancer survivors and their partner co-constructing their account in joint interviews, but these accounts were not dissimilar to those given by partners interviewed on their own. Both types of accounts are authentic in their own terms and, in future studies, exploring both may "result in a broader picture of the phenomenon and, as a result, reveal more aspects of 'truth'" [19].

The analysis of the interview data is also subject to contextual influences, and for this reason, it is essential that researchers continually reflect on the views and assumptions they bring to the research and how they are affecting the process of interpretation. Our work has been guided by a strong sense of advocacy and a wish to improve care. However, we found that our participants were generally less anxious and distressed in dealing with aspects of personal or nursing care and more positive in rising to the challenges they encountered than we had expected, which gives us some confidence that our interpretations are rooted in the data, not in our own prior views and assumptions.

Strengths of our study include the recruitment of primary care practices from rural and urban areas and areas with different levels of deprivation and of partners of cancer survivors with a wide range of cancers, ages and backgrounds. Whilst there is an extensive literature on the needs of carers at the end of life [4], there is much less known about the survivorship phase and about cancers other than breast and prostate [5]. Previous research has also recognised the tensions inherent in carers' dual position as both providers of support and potential recipients of care. Partners and family members feel it is their role to provide care and support, either without recognition and support for their own needs or with this very much taking second place [20, 21]. It has therefore been suggested that interventions are likely to be most acceptable to partners and other carers if they focus on improving their ability to provide care and do not appear to take attention away from cancer survivors [4]. It has also been suggested that a greater focus on proactive and preventive approaches which highlight positive aspects of caregiving and a focus on building skills and providing resources are required, rather than simply reacting when situations reach crisis point [20].

In our study, many participants indicated that they would appreciate a proactive approach from primary care and the offer of some time with a primary health care professional to discuss concerns. Although some partners would not need or would choose to attend a review appointment, it was felt that the offer would still be welcomed. In the UK, family doctors are currently incentivised to conduct a 'cancer care review' with all new cancer patients within 6 months of diagnosis, although there is no clear guidance on how this review should be conducted or what it should entail. Our earlier analysis of interviews with cancer survivors found that implementation is less than optimal [11]. Possible options to facilitate the involvement of partners include telephone contact from the primary health care team soon after diagnosis to acknowledge the diagnosis and to make them aware that support is available in primary care during the treatment phase. At the end of initial treatment, this first contact could be followed by offering the patient a specific review appointment [11] and extending this invitation to family members (either for a joint consultation or separately if preferred). An alternative would be to invite partners of cancer survivors to discuss their needs with their own family doctor, giving the family doctor the opportunity to provide, for example, verbal and written information on cancer and its treatment and to signpost them to other support services (such as Macmillan Cancer Support or other charities). This approach would require either the necessary links to be made between couples in primary care (e.g. by the GP asking the patient about their family situation and recording the details of the partner or close relative) or the patient passing an invitation on to their partner to contact their own doctor or the practice nurse if they wish. A further possible way to address the confidentiality dilemma would be to ask the patient if they agree to their medical history being discussed with their partner and/or other family members and then to record this in their notes for future reference. However, this might raise further complications and would need to be dealt with sensitively and potentially reviewed on an ongoing basis. Other possible options include the introduction of specialist cancer care nurses in the community, working across primary care practices or developing nurse-led telephone or web-based follow-up care services. There is a continuing debate over whether supportive care should be provided by secondary or primary care. For example, a nurse-led but hospital-based intervention to support family members of lung cancer patients has produced positive results [22]. Nonetheless, there are good reasons for basing at least some supportive care for families with primary care, which is family-oriented and community-based.

This study used a qualitative approach to gain insights into the ways the partners experience in supporting a cancer survivor in the post-treatment phase and their views on primary care involvement. Although qualitative research is not intended to provide statistically generalisable results, the insights provided are of relevance to health care professionals.

In conclusion, there is a room for considerable improvement in terms of supportive health care offered to partners and family members of cancer survivors both during and after treatment. This study underlines the importance of health care professionals, especially primary care teams, in being alert to the significance of the relationship when one member of a couple has been diagnosed with cancer and to recognise the partner's needs and concerns, which may differ from those of the cancer survivor. This is particularly important as many partners will be in an older age group and have health care needs of their own. Arguably, primary care teams are already in a position to see the lives of their patients more holistically, and in much more detail than specialists, and are therefore well placed to address these relational aspects. As the number of cancer survivors continues to increase, there is a definite need for the development of tools to assess and monitor the needs of partners and other carers and for user-informed interventions designed to meet these needs, which have been tested in well-designed studies.

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