

## **Older people's perspectives on shared decision-making, social support, and the role of independent advocates during cancer journeys.**

Patty Doran, Cathie Marsh Institute for Social Research, The University of Manchester

### **Abstract**

**Background:** Understanding the treatment decision is key to determining the explanations for under-treatment, therefore more clarity is needed about how and why decisions are reached. Social support is starting to be recognised as having an important role in the cancer patient experience. However, little research has been conducted to show the value of social support specifically to older cancer patients at the time of treatment decisions.

**Objective:** To gain personal perspectives from older cancer patients and their carers about whether they feel that they were involved in treatment decisions with their medical staff, and to explore if access to social support, provided by both family and independent advocates, impacts on the experiences of older cancer patients.

**Methods:** In-depth, semi-structured interviews were carried out with 11 participants referred to the study from the *Cancer, Older People and Advocacy* project organisations. Data from the interviews was analysed using narrative analysis techniques.

**Results:** The participants recruited to the study presented with a variety of complex situations and needs. Nine major themes were identified from the interviews. 1) Perceived lack of choice, 2) Deferring to clinical advice, 3) Shared decision-making, 4) Isolation, 5) Other problems made worse by cancer, 6) Support needs post-treatment, 7) Advocates enabling coping, 8) Blurring of practical and emotional support, 9) Lack of support during treatment.

**Conclusions:** From the participant's perspective the scope for treatment decisions was limited, and health professionals were trusted and relied upon to carry out the decision-making role. The practical and emotional support provided by independent advocates helped participants cope, in some cases with very complex situations. However, the lines between practical and emotional support are blurred and cannot be contemplated in isolation. Further research on the buffering affects of social support would contribute to our understanding of the role of social support in the experiences of older cancer patients.

**Acknowledgements:** Research for the *Advocacy and Cancer Study* was funded by a Research Impact PhD Scholarship from the University of Manchester Alumni Office, and completed with support and collaboration from Macmillan Cancer Support and the Older People's Advocacy Alliance.

## 1. Background

In the UK we have world-class cancer care, and some of the best cancer treatment facilities in the world, however, as yet unexplainably, older people with cancer are undertreated when compared to younger patients<sup>1,2</sup>. Research to date has shown the presence of pre-existing health conditions (more common in older people) explain some of the discrepancies in the treatment of older cancer patients, but the full extent of the under-treatment cannot be explained by health alone<sup>3</sup>. Cancer treatment is a complex topic. Each cancer patient presents as a unique case with a range of individual factors that need to be considered in order to best treat the person and their cancer.

In recent years, there has been an increased emphasis on shared decision-making and patient choice<sup>4</sup>. That is, each patient has the right to make their own decisions about their treatment, but their decision should be informed by the recommendations of their medical team. Recent studies have suggested that the perceived level of patient choice and involvement in treatment decisions varies greatly depending on whether the medical professional or patient perspective is measured<sup>5,6</sup>. One suggested explanation is that older patients are more likely to defer to the medical professionals opinion, and not view the decision-making process as one that they were involved in<sup>7</sup>. Understanding the treatment decision is key to determining the explanations for under-treatment, therefore more clarity is needed about how and why decisions are reached.

Social support is starting to be recognised as having an important role in the cancer patient experience. However, little research has been conducted to show the value of social support specifically to older cancer patients at the time of treatment decisions. On both sides of the shared decision-making process perceptions of social support are likely to have an impact. For example, cancer treatment can be very debilitating, and the administration of the treatment can involve frequent visits to hospital. Therefore, it is important that practical support is available to the patient to cope with the treatment<sup>8,9</sup>. However, it has been suggested that some older patients may overestimate the severity of the physical impact of the treatment<sup>10</sup>; therefore it is important that the correct information about side effects is provided by the clinical experts<sup>11,12</sup>. Additionally, throughout the whole cancer journey the need for emotional support has been repeatedly stressed<sup>13-15</sup>. In particular, patients report valuing support during consultations and having someone to talk to about their needs and concerns<sup>16</sup>. The current body of research suggests that the need for practical, informational, appraisal and emotional support should all be taken into account, by both patients and clinicians, when making treatment decisions. The support provided might be through pre-existing networks (such as partners, children and friends), or through new contacts made post the cancer diagnosis (such as specialist nurses and advocates).

Professional, independent advocacy services, often targeted at vulnerable groups such as older people, provide someone to support and 'speak up' for others<sup>17</sup>. In recent years, Macmillan Cancer Support has worked in partnership with the Older People's Advocacy Alliance (OPAAL) to deliver peer advocate services for older cancer patients. From this partnership there is emerging evidence that the provision of independent peer advocates helps meet social support needs, and improve the experience, of older people living with and beyond cancer<sup>18</sup>.

## 2. Objective

Given that cancer is such a complex area of study, the objective of the study is to gain personal perspectives from older cancer patients. The study aims to increase understanding of the needs of older cancer patients. The hypothesis is that social support (in the forms of information, practical, appraisal and emotional support<sup>19</sup>) increases the resources needed for older cancer patients to, as confidently as possible, approach their cancer journey. Specifically the study aims to firstly hear about older cancer patients' experiences of shared decision-making, and to secondly ascertain support needs during their cancer journey. The primary objective of the study is to allow the participants to be able to freely and

spontaneously discuss their experience. Additionally it is an objective of this study is to identify views on treatment choices and the prevalence of shared decision-making. There are two key research questions. 1. Do older cancer patients feel that they were involved in treatment decisions with their medical staff? 2. Does access to social support, provided by both family and independent advocates, impact the experiences of older cancer patients?

### 3. Methods

The *Advocacy and Cancer* study was planned in partnership with OPAAL and Macmillan Cancer Support. The results will feed in to a wider piece of evaluation work being conducted by this partnership to assess the value of cancer support advocates on the experience of older cancer patients. All participants were referred to the study by advocacy support organisations delivering services as part of the Cancer, Older People and Advocacy (COPA) project. The COPA project recruits and trains older people affected by cancer to provide independent peer advocacy and support to older cancer patients. Older cancer patients access advocacy services to gain extra support, often with specific issues during their cancer experience.

To be included in the study, a participant was either a patient who was 60 or over, had a cancer diagnosis, and had support from an advocacy service, or was a carer of someone meeting these criteria. Participants were excluded if their health was too poor, or the interview was likely to cause additional pain, discomfort or distress (assessed by their ability and willingness to consent to the process). Participants were all purposely selected from advocacy organisations supporting older people with cancer through the COPA project. Using the knowledge of their cancer support advocates, the COPA delivery partners identified potential participants for the study, made initial contact, and invited them to take part in the study. A participant information sheet was provided at this stage. Once initial consent to be contacted was obtained, a suitable time for the interview was arranged between the advocacy service, the participant, and the researcher (PD). At the interview, informed consent was gained and it was ensured that the participants understood the interview procedure.

To understand the experience and perceptions of older cancer patients, a phenomenological approach was taken in this study<sup>20</sup>. The interviews were all in-depth and semi-structured, lasting between 25 and 70 minutes. An interview discussion guide was developed and used during the interviews, however the interviews were conducted with the maximum amount of flexibility. The interviews were designed to take an inductive approach and be non-directive. Participants were asked what it meant to them to be involved in their cancer treatment decisions. Views were gathered about participants' engagement with the hospital system, the support that they received in making their treatment decision, and their perception of both barriers and positive elements in the shared decision-making process. The role of social support in shared decision-making, and more broadly, was examined. As well as the types of social support (informational, practical, appraisal and emotional), the source of support was also discussed, whether there was support from family, friends, or an advocate, and if having this support changed their perceptions, or experience. To aid in follow-up analysis, the interviews were audio-recorded and transcribed.

The data from the interviews was managed using NVivo 10. Principles of narrative analysis<sup>21 22</sup> were applied to identify common themes from the interviews. A framework was developed to allow comparison of themes and participant attributes (including age, cancer type, cancer stage, access to social support, living arrangements etc.). Principles of reflexivity were applied<sup>23</sup> to ensure that an awareness of the co-construction of the knowledge produced through the interviews was acknowledged. Additionally, as the study was designed in partnership with other organisations, the influence of their involvement was taken into account.

Ethical approval for the *Advocacy and Cancer* study was granted by the University of Manchester Research Ethics Committee (ref: ethics15151).

#### 4. Results

A total of 11 participants took part in interviews between June and October 2015 as part of the *Advocacy and Cancer* study. Participant characteristics are summarised in Table 1. Both patients (n=7) and carers (n=4) were interviewed, all the carers were female, and four of the seven patients were male. All but one of the patients were in their 60s, while one was in their late 70s. Two of the carers were partners of patients, while the other two carers were younger (in one case a daughter and the other a personal friend/carer). Four of the patients and one of the carers had significant co-morbidities. There was a wide range of cancer types and related treatment.

**Table 1: Participant Characteristics**

	Patient/ Carer	Gender	Age	Co- morbidities	Cancer Type (patient)	Treatment (patient)	Advocate engagement
P1	Patient	Male	60 – 64	Yes	Tongue	Surgery Clinical Trial	After
P2	Patient	Male	65 – 69	No	Bowel	Surgery Chemotherapy	During
P3	Patient	Male	65 – 69	No	Kidney	Surgery Biotherapy	After
P4	Patient	Female	75 – 79	No	Lung	Chemotherapy	During
P5	Patient	Male	60 – 64	Yes	Prostate	Hormone therapy	After
P6	Patient	Female	65 – 69	Yes	Breast	Surgery Radiotherapy	After
P7	Patient	Female	60 – 64	Yes	Skin	Radiotherapy	After
P8	Carer	Female	60 – 64	No	Tongue	Surgery Clinical Trial	After
P9	Carer	Female	<60	No	Prostate	Radiotherapy Chemotherapy	During
P10	Carer	Female	65 – 69	Yes	Prostate	Hormone therapy	After
P11	Carer	Female	<60	No	Skin	Radiotherapy	After

Three top-level themes were identified: 1) Patient choice and decision-making, 2) Practical and emotional support needs, and 3) Support from advocates. Relating to each of these themes a further three common themes were identified and explored. A summary of themes is outlined in Table 2. All nine themes are detailed further below.

**Table 2: Summary of themes**

Patient choice and decision-making	Perceived lack of choice
	Deferring to clinical advice
	Shared decision-making
Practical and emotional support needs	Isolation
	Other problems made worse by cancer
	Support needs post-treatment
Support from advocates	Advocates enabling coping
	Blurring of practical and emotional support
	Lack of support during treatment

#### 4.1 Patient choice and decision-making

The interviews revealed a complex interplay between patient choice, clinical advice, and shared decision-making. In many cases there was a perceived lack of choice expressed, however in some cases the same participants talked about choices that were available and made about different aspects of care. Not knowing enough about the disease and treatments, and deferring to clinical expertise was another common theme. The concept of shared decision-making was explored in relation to patient choice and clinical advice, while none of the participants were aware of the term “shared decision-making” there was some agreement that decisions were made in this way.

##### *Perceived lack of choice*

A striking finding from the interviews has been the lack of perceived treatment options, and therefore a lack of choice. Participant 6 (P6) had pre-existing health conditions that limited treatment options; these limitations were accepted without full understanding.

‘It wasn’t an option in my case. I don’t know why. They only just – well, said I just was too frail.’ (P6)

Limited understanding of the treatment options was also expressed by P7. In this case the limited understanding could be linked to lack of information, or the support to access and understand information about her cancer and treatment options.

‘No explanations of what it was for or anything – nothing. This is what I’m saying; I needed someone I could talk to to find out what the hell was going on. Even until today I still do not know if there were any other options.’ (P7)

In another example (P2), a participant had advanced cancer that was initially treated with surgery and then with chemotherapy. In this case the only other option the participant perceived was to have less invasive treatment, or no surgery, which was not a real option.

‘My other options were don’t do anything and it would have killed me.’ (P2)

Only in one case was a clear decision to stop treatment mentioned. P9, who had been a carer for her father, discussed how after just one session of chemotherapy her father decided he didn’t want any more.

‘It was his choice because he was offered radium and chemo, and he had radium and he went through the course of that but he had chemo...he had one session and he said, that’s it.’ (P9)

There were examples of choices that were made in relation to other aspects of care. In one example, P10 describes how her husband decided not to take up offered services from Allied Health Professionals.

‘Yeah, he was offered a dietician and he was offered help from a speech therapist. We was offered quite a few things, but [he] wouldn’t accept it.’ (P10)

#### *Deferring to clinical advice*

Linked to a lack of choice, was a common theme of deferring to clinical advice. Trust in the opinions of medical staff, and the belief that their knowledge and skills were much greater than the patients, resulted in an often unquestioned acceptance of clinical advice.

‘Well if that’s what [my consultant] suggests, he knows a heck of a lot more than I do, then if he says, that’s the best thing to do, I would accept it completely.’ (P4)

‘Doctors tell you, I suppose that’s what being old-fashioned is all about, you know. You take the doctor’s word and you trust them implicitly.’ (P6)

‘We just trust [our doctor].’ (P10)

‘So [my consultant] said, what they’ll do... I said, I don’t want to know what they’re going to do, just tell them to get it done.’ (P3)

#### *Shared decision-making*

Although none of the participants were aware of the concept of shared decision-making, there was evidence from discussions that efforts were being made on behalf of the consultants to explore the patients views and ensure that decisions were being made together.

‘[My consultant] said, if you need any more surgery, would you accept it? I said, if it starts spreading into different parts, I said, I wouldn’t want that, so that’s what I told him.’ (P1)

When exploring decision-making with P4, there was agreement that the decision in the end is the patient’s, however, at the some time she expressed not having enough knowledge to make the decision.

‘Oh, it has to be, yes, but I don’t know enough about it and I’ve kept away from the internet, because that is dangerous.’ (P4)

There was also evidence of awareness that the consultants are making an effort to elicit the patient’s views and feelings.

‘I think he’s waiting for me to say my bit.’ (P4)

‘When I go to see him, the way we discuss things, I think you could turn round and say, yes, that is in some way shared decision making. He doesn’t just go by the scans ... and say oh yes, he says, how do you feel, what do you think and whatever. So I can only assume from that that that’s shared decision making.’ (P3)

## **4.2 Practical and emotional support needs**

Social support came up in the interviews in a variety of contexts. This included support that was received during treatment, a perceived lack of support during treatment, and support needs after treatment. The

types of support that participants discussed most were practical and emotional support. However, information and appraisal support were also discussed, and there were crossovers between the different types of support. Support was not always needed just to deal with the consequences of cancer, but in many cases participants were experiencing other difficulties in their lives that were made worse or more complex by the cancer diagnosis.

### *Isolation*

Isolation and lack of access to support, or knowledge about what support is available, was a common theme. There was a common sense of lack of support discussed among both participants who lived alone and those who were married. It was highlighted that the carers of people with cancer need support as well.

‘People forget that when you’ve got somebody with cancer it’s the effects on the family and the very near and dear relatives. People don’t think about that. They only think about the person who’s got the cancer. I’ve noticed sometimes my wife just sitting there. I say, can you come back into our world love? Then I’ve found out, just through conversation, that she’s been sitting there thinking what’s it going to be like when... So it affects her as well. But there’s no support there for that.’ (P3)

Several participants brought up being alone with one’s thoughts, often associated with being physically alone, and linking back to the need for emotional and practical support.

‘But you do tend to live in a world of your own, and there’s no one there to sort of know how you really feel.’ (P6)

‘You’re living therefore with a death sentence, literally, and you can’t tell anyone this, you bottle it up.’ (P6)

‘As I say, your own mind becomes your own worst enemy. But there’s nobody anywhere...’ (P3)

‘There was nothing, she was on her own. In winter she’d be confined to that bedroom, that’s how bad her health gets, it will be confined to bed.’ (P11)

### *Other problems made worse by cancer*

Most of the participants were dealing with other issues in their lives at the time of their cancer diagnosis. These other issues became worse as a result of the cancer diagnosis, and were in many ways a greater concern than treating the cancer.

Housing was an issue that came up several times, in these cases participants were in social housing and were struggling to maintain suitable housing. In one case it was not initially accepted by the housing authority that the participant’s health was being affected by where they were living.

‘And because I’ve got bad asthma and I need to get fresh air very quickly, I’m stuck in this flat and I can’t breathe at all, it’s too claustrophobic because I’ve got COPD, and the kitchen and the bathroom have no windows. Yeah, it’s like living in a box.’ (P6)

In another case incorrect advice was followed and benefit payments were cut during the time of cancer treatment, so on top of the cancer diagnosis they were living in unsuitable accommodation, and it was a struggle to pay all the bills.

‘On top of all the problems we had as well, it didn’t help with them halving his money, because with him not coping with everything, I had to look for places for us to move to because we couldn’t afford to live where we was, so we had to keep moving, so that didn’t help.’ (P8)

Two of the participants had caring responsibilities prior to the cancer diagnosis. In one case, during his own cancer treatment one participant was still trying to ensure that his wife had the best possible care, as well as manage his own situation. In the end his wife moved into care and this created an emotional burden.

'I was getting so stressed out and emotional ... I couldn't talk about it'. (P2)

In the other caring case, the participant was a full time carer for her mother when her father became diagnosed with cancer. The participant's caring responsibilities meant that she could not support her father as fully as she would have liked.

'I would have loved to have gone and visited him [in the nursing home] but just unfortunately I couldn't'. (P9)

### *Support needs post-treatment*

The affects of the cancer diagnosis were evident post-treatment for participants. Depression after treatment was mentioned in several cases.

'Then he decides to go drinking all the time, he thought having a drink would solve it, but it didn't because it got him more depressed.' (P8)

'I've had to wait through it, I was quite depressed because of it for months and I had to fight my way out of it myself until somebody mentioned ... [the counselling service].' (P4)

'Obviously you can't do the things you used to be able to do. And that actually depresses you.' (P6)

Participants also discussed post-treatment side effects. Living with and managing bowel problems were a particular issue in two cases. The side effects add to frustration with the situation.

'And I have to have this bag on for life ... because of the radiotherapy I'd had previously. What it is, it's a load of mishmash down there because of the radiotherapy.' (P2)

'I don't want to live like that. I just don't want to live like that. There's nowhere at all that I can go to discuss that with people ... The way things are is that I feel if I went to [my CNS] she would just turn round and say something the likes of, oh, that's just part of the treatment.' (P3)

Fear of reoccurrence was another common theme. Participants mentioned the tailoring off of support once treatment was completed, and the need for emotional support to continue post-treatment.

'It's like you get a backache and you say is this the beginning of the end, and that's just the things that go through your mind. But there's no support there to help you to go through that.' (P3)

'I think what I'm afraid to ask is – I think we all are, you know – well, how much longer do you think I'll keep going. You want to know but you don't. And it'd be nice to be open about it.' (P6)

### **4.3 Support from advocates**

The participants spoke very highly of the advocacy services and the support that they had received from their individual advocates. Advocates often provided practical support including filling in forms, writing letters and attending meetings, and emotional support by listening and talking with the participants.



However, several of the participants didn't engage with the advocacy service until after their cancer treatment, highlighting a perceived lack of support when initially diagnosed.

### *Advocates enabling coping*

Engaging with the advocacy services was a turning point in many cases. The support received was highly valued, and in many cases held up as a reason for getting through the hard times.

'Without [my advocate's] support I don't think I would have got through it' (P2)

'It's been, you know, everybody has been trying to fight to keep me going and if it hadn't have been for [my advocate] to start with I wouldn't be here.' (P7)

The practical nature of the advocacy service, having someone to help with paperwork, phone calls and information gathering was repeated often. On their own, participants talked about being overwhelmed, however having the practical support helped them cope.

'Just the paperwork and that, and how you cope with the things, because we didn't get none of our... what we'd have to claim for, you couldn't work it out' (P8)

'Like I say, I'm useless with paperwork, I can't remember things, I have to write everything down, you know. I've done well to give [my advocate] all the paperwork I've given her over all these periods of illness. Because I'm useless with the paperwork, it just gives me a headache, I just get panicky with paperwork. I don't know why, I just do.' (P2)

'Truthfully, I don't know what I'd have done without my advocate. She's down to earth, she's straightforward, where I'm not very confident on the phone. She can make the phone calls, make herself assertive, and yet with common sense.' (P6)

### *Blurring of practical and emotional support*

Participants were asked what sort of support was of most valued, however this was a distinction that was hard for participants to make. 'Every bit of it has been useful' (P6). Having someone to accompany participants to appointments is an example where the practical support of help to get to the hospital is just as valuable as having the emotional support during the hospital visit.

'The [advocate] who was coming with me, she came with me regularly to chemo and it was brilliant ... she was so much company, you know, and she put me on the taxi then to bring me home and she's brilliant, helped an awful lot.' (P4)

'[My advocate is] going to help me to ask what questions I need to ask and this, that and the other, and she's going to write them down and she'll be there with me and be my memory, because my memory's terrible.' (P2)

The emotional support provided by the advocates was often referred to as a by-product of the practical support, but in many cases valued most highly by the participants.

'She doesn't realise she's helping me [emotionally] though' (P6)

### *Lack of support during treatment*

Only three of the 11 participants had support from advocates during their primary treatments. There was recognition from the participants that there would have been benefits if they had engaged with the service earlier.

‘I just wish that the advocacy was more than what it is, like when you are [first] going into the hospital that they are there ready to help you, because there was nothing.’ (P7)

‘It were just how to sort out the financial things, how to cope with...I didn’t think he would get depression, I didn’t think he would get the mood swings or anything, and I didn’t have nobody to talk to.’ (P8)

Often, it was information and advice about treatment and support that was perceived as missing by participants.

‘Only got my daughters, I didn’t have...people with solid advice that I needed. They kept saying, oh, you’ll be alright, just get on with it, and...yeah.’ (P8)

‘There is nowhere that anybody has pointed me or my wife to where we can get support with me having cancer, or even for my wife just to get her own support.’ (P3)

## 5. Discussion

The *Advocacy and Cancer* study collected perspectives from 11 participants on shared decision-making, social support, and the role of independent advocates after a cancer diagnosis. Participant recruitment was dependant on the support of advocacy organisations, and promotion of the study to potential participants by advocates and other staff. The benefits of these efforts have been high. Hearing the stories of people with limited social support, who have made the move to gain support from advocacy services, provides a contrast to the more common ‘expert patients’ used in many qualitative studies of this sort.

The findings from the interviews suggest that a crucial assumption of the study may be incorrect. The first research question asks if older cancer patients feel that they are involved in treatment decisions with their medical staff, however, this question is assuming that there were treatment decisions to be made. From most participants in this study there was a strong feeling that treatment was recommended by the medical team, and this was then carried out. Participants did describe some deliberation; however there was not a perception of realistic alternative options. Their stories do show evidence of some choices, in principle some treatments could have been refused, however this was not a voiced option for the participants. They were following what had been recommended. It should be noted that the participants spoke very highly of their medical staff, and valued and respected their treatment. There was also some evidence that consultants were taking a shared decision-making approach, even though the participants may not have been aware of this. This finding may explain some discrepancies from previous studies<sup>5</sup>.

The second research question focussed on the impact of social support on the treatment decisions of older cancer patients. The amount of support received by participants prior to engagement with the advocacy services varied. In most cases at the point of diagnosis and the start of treatment support was limited to partners, if they were in a relationship, and/or family and friends. Isolation was experienced by participants, included those who had some support from partners and the wider family. The great reliance on partners, in some cases, brought to the fore how almost equally affected partners are by a cancer diagnosis.

Support from independent advocacy services was overwhelmingly appreciated and valued. Participants had very trusted relationships with their advocates. The provision of practical and emotional support was seen as a vital mechanism to help participants cope with their cancer treatment, and on-going experiences of living with cancer and its consequences. In the cases where support was provided throughout cancer treatment, the emotional support provided by having someone attend hospital with the participant was highly valued. However, the practical support elements provided by attending hospital appointments, for

example helping with transport, were often talked about in tandem with emotional support. Therefore, the lines between practical and emotional support are blurred and cannot be contemplated in isolation.

Many of the participants had other serious issues and/or responsibilities in their lives at the time of their cancer diagnosis. Health conditions, caring responsibilities, housing and financial pressures were some of the other factors affecting the participants. In many cases, the support that advocates were able to provide to alleviate the pressure from these other issues allowed the participants to cope with the cancer diagnosis. As in most cases advocacy support was accessed after treatment had finished, the timing of the engagement may explain why much of the support was focussed on addressing other issues as opposed to facilitating support around cancer treatment.

### *Limitations*

The COPA advocacy services support a broad range of people affected by cancer, many of whom are experiencing a range of complex issues. The current study focussed on older cancer patients (60 or over) who were well enough to take part in the interview. The inclusion criteria limited the number of potential participants who were willing and able to take part in the study. Additionally, recruitment to the study was carried out by the advocacy organisations, and was not random.

Nearly all the participants in the study had experience of different cancer types. Measuring treatment decisions would possibly have been more successful if all participants had the same cancer type, and were offered the same treatment options, an approach that has been taken in previous studies<sup>24 25</sup>. However, the primary focus for this study was to engage participants who had accessed support from advocacy services, and this recruitment mechanism did not allow a large enough population to focus on just one cancer type when recruiting participants.

## **6. Conclusions**

Listening to the stories of older cancer patients and their carers provides important insight into personal experiences of having treatment and living beyond cancer. The results suggest that from the participant's perspective there are limited decisions to be made, and health professionals are trusted and relied upon to make treatment decisions. However, social support during the cancer journey is highly appreciated. The practical and emotional support provided by independent advocates helped participants cope, in some cases with very complex situations. In general provision of advocacy services has been increasing in recent years, however delivery of advocacy services is a diverse activity<sup>26</sup>, and there has been limited study of the impact of services. It is recommended that further research and evaluation of the benefits of independent advocates is carried out, specifically to examine the on-going benefits of social support provided by advocates to older cancer patients. Additionally, further research on the buffering affects of social support would contribute to our understanding of the role of social support in the experiences of older cancer patients.

## References

1. Coleman MP, Forman D, Bryant H, et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *Lancet* 2011;**377**(9760):127-38.
2. Giordano SH, Hortobagyi GN, Kau SWC, et al. Breast cancer treatment guidelines in older women. *Journal of Clinical Oncology* 2005;**23**(4):783-91.
3. Lavelle K, Downing A, Thomas J, et al. Are lower rates of surgery amongst older women with breast cancer in the UK explained by co-morbidity? *British Journal of Cancer* 2012;**107**(7):1175-80.
4. DH. Improving outcomes: a strategy for cancer: NHS, 2011.
5. Lavelle K, Sowerbutts AM, Bundred N, et al. Is lack of surgery for older breast cancer patients in the UK explained by patient choice or poor health? A prospective cohort study. *British Journal of Cancer* 2014;**110**(3):573-83.
6. Elkin EB, Kim SH, Casper ES, et al. Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *J Clin Oncol* 2007;**25**(33):5275-80.
7. Husain LS, Collins K, Reed M, et al. Choices in cancer treatment: a qualitative study of the older women's (> 70 years) perspective. *Psycho-Oncology* 2008;**17**(4):410-16.
8. Courtens AM, Stevens FCJ, Crebolder H, et al. Longitudinal study on quality of life and social support in cancer patients. *Cancer Nursing* 1996;**19**(3):162-69.
9. Ringdal G, Ringdal, K., Jordhoy, M., Kaasa, S. Does social support from family and friends work as a buffer against reactions to stressful life events such as terminal cancer? *Palliative and Supportive care* 2007;**5**(1):61-69.
10. DH, MCS, AgeUK. Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project: Department of Health, Age UK, Macmillan Cancer Support, 2012.
11. Arora NK, Finney Rutten LJ, Gustafson DH, et al. Perceived helpfulness and impact of social support provided by family, friends, and health care providers to women newly diagnosed with breast cancer. *Psycho - Oncology* 2007;**16**(5):474-86.
12. Eil K, Vourlekis B, Xie B, et al. Cancer treatment adherence among low - income women with breast or gynecologic cancer. *Cancer* 2009;**115**(19):4606-15.
13. Honda K, Kagawa-Singer M. Cognitive Mediators Linking Social Support Networks to Colorectal Cancer Screening Adherence. *Journal of Behavioral Medicine* 2014;**29**(5):449-60.
14. Hipkins J, Whitworth M, Tarrier N, et al. Social support, anxiety and depression after chemotherapy for ovarian cancer: A prospective study. *British Journal of Health Psychology* 2004;**9**(4):569-81.
15. Schroevers MJ, Helgeson VS, Sanderman R, et al. Type of social support matters for prediction of posttraumatic growth among cancer survivors. *Psycho - Oncology* 2010;**19**(1):46-53.
16. Korffage IJ, Audrey S, Hak T, et al. Recognising the importance of 'family time-out' in consultations: an exploratory qualitative study. *Bmj Open* 2013;**3**(1).
17. Atkinson D. *Advocacy: A review*: Brighton : Pavilion, 1999.
18. OPAAL. Every step of the way: 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer, 2014.
19. Berkman LF, Glass T, Brissette I, et al. From social integration to health: Durkheim in the new millennium. *Social Science & Medicine* 2000;**51**(6):843-57.
20. Carel H. Phenomenology and its application in medicine. *Theoretical Medicine and Bioethics* 2011;**32**(1):33-46.
21. Riessman C. *Narrative analysis*. Newbury Park, Calif.; London: Sage Publications., 1993.
22. Thomas C. Cancer narratives and methodological uncertainties. *Qualitative Research* 2008;**8**(3):423-33.
23. Swift JA, Tischler V. Qualitative research in nutrition and dietetics: getting started. *Journal of Human Nutrition and Dietetics* 2010;**23**(6):559-66.
24. Harder H, Ballinger R, Langridge C, et al. Adjuvant chemotherapy in elderly women with breast cancer: patients' perspectives on information giving and decision making. *Psycho-Oncology* 2013;**22**(12):2729-35.
25. Sowerbutts AM, Griffiths J, Todd C, et al. Why are older women not having surgery for breast cancer? A qualitative study. *Psycho-Oncology* 2015;**24**(9):1036-42.
26. Forbat L, Atkinson D. Advocacy in practice: The troubled position of advocates in adult services. *British Journal of Social Work* 2005;**35**(3):321-35.