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Living Life after Cancer Treatment: A Cancer Survivorship Support Group Evaluation

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Samantha is a PhD Student in the Department of Psychology at the University of Chester. Her PhD research explores the psychosocial impact of cancer on those with an intellectual disability, and those who support them. Samantha is involved in a wide-range of research, including attitudes towards Organ Donation, Mindfulness and Support Groups for cancer survivors. She has worked using a variety of research methodologies including systematic reviewing.

Nick Hulbert-Williams, University of Chester

Nick is a Chartered Psychologist, Associate Fellow of the British Psychological Society, and Fellow of the Higher Education Academy. He is currently a Reader in Psychology at the University of Chester. In addition to his teaching, and administrative responsibility as Departmental Research Strategy and Development Co-Ordinator, Nick leads a research programme exploring psychological aspects of cancer diagnosis and survivorship. He is Chair of the British Psychosocial Oncology Society, member of the NCRI Primary Care/ Psychosocial Oncology Clinical Studies Groups, and is co-editing a textbook on Cancer Care.

Michelle Tytherleigh, University of Chester

Michelle is a Chartered Psychologist and Senior Lecturer at the University of Chester, specialising in wellbeing, work wellness, positive psychology and learning analytics. Having worked in industry (UK and overseas) prior to academia, her doctorate research looked at the effects of stress hormones (cortisol) on memory, where she worked with both non-clinical and clinical populations. Michelle is interested in positive psychology, particularly, resilience, and emotional intelligence.

Sam Roberts, University of Chester

Sam is a Senior Lecturer in the Department of Psychology at the University of Chester. His research combines theories and methods from evolutionary psychology, social psychology and social network analysis to provide new insights into the dynamics of social relationships, and how these relationships may be affected by new technologies such as Facebook. He is also interested in how the quantity and quality of people's social relationships impact on their health and psychological well-being.

Heather Wilkinson, University of Chester

Heather is a Senior Lecturer in Psychology at the University of Chester. Heather studied for her PhD at the University of Liverpool and conducted research into the long-term forgetting of verbal and non-verbal information in patients with Temporal Lobe Epilepsy. Heather is working on research collaborations exploring the cognitive processes involved in emotion; the evaluation of a cancer survivorship support group; organ donation attitudes; and student attitudes of mental illness.

Elizabeth Taylor, Countess of Chester NHS Foundation Trust

Elizabeth is a Macmillan Support and Information Manager at the Countess of Chester Hospital. Prior to this, she worked in various nursing posts, and as a nurse advisor for NHS direct. As part of her current post she co-ordinates the Living Life after Treatment Programme for cancer survivors and their partners.

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Abstract

Purpose. Support group attendance has been found to be beneficial to cancer survivors' psychological wellbeing. This research explores the patient-reported efficacy of 'Living Life after Cancer Treatment' programme for cancer survivors who have completed treatment.

Method. Two focus groups were conducted including programme participants who were either two weeks or six months post-completion of a structured support group programme. One supporter (caregiver) who had recently completed the programme was also interviewed. Results were analysed using a Framework Analysis approach.

Results. Five themes were identified. In 'Meeting unmet social support needs', participants identified the importance of emotionally offloading without overburdening their families. Though not all participants benefitted from all information provided, in 'Meeting unmet informational needs' they reported that they could see how it benefitted others. In 'The benefit of belonging to a group' participants reported that smaller group discussions were particularly helpful in terms of developing peer-support. 'Looking to the future' was important and the programme was sufficient to meet some participant's needs; others, however, were keen to continue accessing similar support. In 'Programme evaluation' participants advocated the continuation of the programme, but many believed that it should be implemented sooner after diagnosis.

Conclusions. The programme is a valuable resource with survivors and supporters finding benefit in attending. Meeting previously unmet social support and informational needs is a chief outcome of this programme, echoing previous research. The findings are being used to inform development of this programme for both local and wider implementation.

Introduction

Support group attendance has been shown to improve the psychological wellbeing of cancer patients and survivors, reducing psychological conditions such as anxiety (Montazeri, Jarvandi, Haghghat, Vahdani, Sajadian, Ebrahimi et al., 2001; Roberts, Schofield, Freeman, Hill, Akkerman & Rodger, 2002; Stevens & Duttlinger, 1998), depression (Montazeri, Jarvandi, Haghghat, Vahdani, Sajadian, Ebrahimi et al., 2001; Stevens & Duttlinger, 1998; Winzelberg, Classen, Alpers, Roberts, Koopman, Adams et al., 2003) stress (Roberts, Schofield, Freeman, Hill, Akkerman & Rodger, 2002; Winzelberg, Classen, Alpers, Roberts, Koopman, Adams et al., 2003) and cancer related trauma (Winzelberg, Classen, Alpers, Roberts, Koopman, Adams et al., 2003) in comparison to those who do not attend support groups. This has been attributed to various factors, including the expansion of attendees' social networks and an increased informational awareness (Ussher, Kirsten, Butow & Sandoval, 2006). However, attendance of cancer support groups is not always high, and of those who choose to attend, the number who attend on an on-going and regular basis is relatively low (Classen, Butler, Koopman, Miller, DiMiceli, Giese-Davis et al., 2001; Krizek, Roberts, Ragan, Ferrara & Lord, 2001; Simpson, Carlson, Beck & Patten, 2002). Support group attendees are more likely to be those without a partner, to hold more favourable opinions about support group than non-attendees, to use more active and adaptive coping strategies, but also to feel more distress and anxiety (Grande, Myers & Sutton, 2006). Slevin, Nichols, Downer, Wilson, Lister, Arnott et al. (1996) also found that attendees were generally self-motivated. In contrast, those who do not attend support groups report receiving a higher level of emotional support from someone within their own social network (Grande, Myers & Sutton, 2006, Helgeson, Cohen, Schulz & Yasko, 2000).

It is important to note, however, that group membership may not be universally beneficial. Helgeson, Cohen, Schulz and Yasko (1999) for example, found that members' anxiety about both the illness itself and treatment increased following participation in a support group. This is, perhaps, not surprising and might even be expected where such discussions occur at an earlier time point after diagnosis, when patients are already vulnerable to higher levels of anxiety (Hulbert-Williams, Neal, Morrison, Hood & Wilkinson, 2012). Carmack Taylor, Kulik, Badr, Smith, Basen-Engquist, Penedo et al. (2007) note further that although distressed members can be positively influenced by having contact with non-distressed members, members who are less distressed may experience negative effects as their needs are not being adequately addressed by group discussion. Goodwin, Leszcz, Ennis, Koopmans, Vincent, Guthrie et al. (2001) also found that those who have a higher initial distress level benefit more from the support group than those with a lower distress level. There is a considerable literature which acknowledges that social support in the context of illness will only ever be beneficial where it accurately meets the needs and expectations of both provider and receiver. It is possible that in studies which report negative consequences, there was a mismatch between participant expectations and information provided.

Research exploring the support group attendance of partners of cancer patients suggests that the participation in support groups is beneficial to the psychological wellbeing of partners and allows for increased communication within their relationship (Sabo, Brown & Smith., 1986; Bultz, Specca, Brasher, Geggie & Page,

2000). Partner participation in support groups has been found to not only be a beneficial resource for the partner's themselves, but cancer patients can also benefit from having a well-supported partner (Bultz, Speca, Brasher, Geggie & Page, 2000; Cochran, Lewis & Griffith., 2011).

Social networks and the “*cancer family*”

Previous research has explored the notion that those who attend cancer support groups become part of a “*cancer family*” (Ussher, Kirsten, Butow & Sandoval, 2006), often in the absence of satisfactory support within their own existing social network. Stevens and Duttlinger (1998) found differences in the usefulness of support groups between established and new members; established members tended to find the sense of community the most helpful aspect of attendance, thus reinforcing the concept of the “*cancer family*” (Ussher, Kirsten, Butow & Sandoval, 2006, p. 2568).

Research into the emotional benefits of cancer support group attendance has found that support groups are beneficial by enabling members to share experiences and discuss mutual concerns, whilst also providing each other with emotional support in a non-judgemental and accepting environment (Docherty, 2004; Krizek, Roberts, Ragan, Ferrara & Lord, 2001; Stevens & Duttlinger, 1998; Ussher, Kirsten, Butow & Sandoval, 2006; van Uden-Kraan, Drossaert, Taal, Seydel & van De Laar, 2009). McCarthy, Thompson, Rivers and Jahanzeb (1999) found peer support to be the main psychosocial benefit from attending a cancer support group, and this has been reinforced elsewhere (e.g. Bloom, 2008).

Support group attendance has been found to improve acceptance and adjustment to illness. Stevens and Duttlinger (1998) found that breast cancer patients experience an increased adjustment to their illness when their participation in the support group was high. Similarly, van Uden-Kraan, Drossaert, Taal, Seydel and van De Laar (2009) found that participants felt more accepting of their illness and more confident about the treatment from participating in the online support group.

Information needs and survivor empowerment

It may be that the resultant benefits from support group attendance are more related to the provision of practical support, rather than simply the provision of emotional support. Slevin, Nichols, Downer, Wilson, Lister, Arnott et al. (1996) report that only 28% of patients in their study would definitely consider turning to fellow patient for emotional support.

The need for information is frequently highlighted as a key concern for cancer patients and survivors (Roberts, Schofield, Freeman, Hill, Akkerman & Rodger, 2002). Support groups provide a useful source of information and practical support (Cope, 1995), and improve attendees' knowledge about their illness and potential ways to overcome their symptoms (Montazeri, Jarvandi, Haghghat, Vahdani, Sajadian, Ebrahimi et al., 2001; Ussher, Kirsten, Butow & Sandoval, 2006). Stevens and Duttlinger (1998) suggest that there are differences between established and new members of support groups in relation to what information is most helpful: newer members find the provision of medical information the most helpful, whereas established members found the sense of community the most helpful aspect of

attendance. In a study of online support groups, van Uden-Kraan, Drossaert, Taal, Seydel and van De Laar (2009) report that the majority of information exchanged is found to be understandable and valuable, although not all of it is new. They theorise that the process of becoming more informed about their illness enabled participants to feel more empowered. This suggests that the effective mechanisms of support group information provision may be one of information consolidation.

Having an increased sense of empowerment over their illness and lives in general is a theme which is also found in other related research (Ussher, Kirsten, Butow & Sandoval, 2006): Strang and Mittelmark (2008) conclude, from their evaluation study, that this newly discovered sense of empowerment stems from learning about their illness from experienced peers, presumably in a more personalised and less formal format than information which may have been previously provided by health care professionals.

'Living Life after Cancer Treatment' Programme

Cancer survivors often report that the time of transition from active treatment to survivorship can be especially problematic (Leigh & Clarke, 1998), and at this time where healthcare professional support is withdrawn (Vivar & McQueen, 2005), other sources of support may be required. The 'Living Life after Cancer Treatment' programme is an end of treatment psychosocial intervention developed in our local NHS Trust Hospital which comprises five structured sessions facilitated by a Macmillan Support and Information Manager, an experienced cancer nurse and a range of guest speakers are also invited to each iteration of the programme, including: GPs, physiotherapists, former patients, complementary therapists and dieticians. An overview of topics covered within the programme sessions is provided in Table 1.

The programme was developed by the Macmillan Support and Information Manager in response to direct enquiries made to the service and current evidence around the subject at that time of development. A number of health care professionals and former patients set up a working group to plan the programme; this has developed over time in response to the feedback from programme attendees. The programme runs twice yearly and, in the lead up, clinical teams are asked to forward contact details of all patients who have recently finished treatment to the programme co-ordinator. This support group is rare in that it is not only available to patients, but also to their nominated supporters (usually a caregiver or family member). Approximately 20 patients and 10 supporters attend each iteration of the programme.

Table 1. Overview of the programme sessions and topics covered.

	Title of Session	Overview of Session
1	Question Time	Getting to know the other attendees, partners and professionals. An opportunity to ask questions of former attendees and professionals.
2	Building Stamina, Fighting Fatigue	Understanding why fatigue can still be a problem after treatment and finding ways to overcome it.
3	Developing coping strategies	Ways to relax and successfully manage stress. Discussing complementary and alternative medicines.
4	Living with uncertainty	Developing strategies to help adapt to life after a cancer diagnosis and deal with uncertainty.
5	An opportunity to think about the future	Discussing travel insurance and other services which are affected by a cancer diagnosis. How to maintain a healthy lifestyle. Exploring ways to improve services.

Study objectives

This research will explore the patient-reported efficacy of the 'Living Life after Cancer Treatment' Programme, an end of cancer treatment psychosocial support intervention provided within a UK-based secondary health care service. This is an independently developed intervention and so it is likely to vary from other similar interventions. It is important, therefore, to thoroughly evaluate it so that lessons can be learned for (a) improvement of the programme, and (b) wider role-out and implementation within other support group interventions. A particular focus will be placed on evaluating content and timing of the intervention giving the importance of supporting patients at the time of transition from active treatment. The research will explore both short and long term benefits of attendance from both cancer survivor and their supportive others' perspectives.

Methodology

Design

A qualitative approach was used for this research study in order to gain in-depth and personalised evaluative feedback from support group participants. Focus groups were used, where possible, to encourage participants to facilitate discussions with each other and provide clarification for other members of the group (Morgan & Krueger, 1993), thus enabling the collection of richer data. Focus groups also allowed for a comparison of similarities and differences in opinions between the group members (Morgan, 1996).

Participants

All participants from both a current iteration of the support group and from a group who completed the programme six months previously were invited to take part in the focus groups.

Current cohort. A total of 26 participants attended the course in the current iteration. This included 19 survivors and 7 supporters. Of these, five cancer survivors were recruited for the focus group, all of whom were in recovery from breast cancer treatment. Demographic and clinical information for these participants is summarised in Table 2. Just one supporter consented to participate in this study from the current iteration: he was a male of white ethnicity and 73 years of age. He was retired and lived with the survivor (his wife) whom he was supporting and commented that he was participating in the programme primarily to support his wife rather than based on meeting his own psychosocial support needs.

Retrospective cohort. A total of 27 participants attended the course in the retrospective iteration of the support group; six months had elapsed since completion of the programme and research invitation. This included 22 survivors and 5 supporters. Of these, four survivors were recruited for the focus group (three breast cancer and one non-Hodgkin's lymphoma survivor); no supporters from this iteration were willing to be interviewed (see Table 2 for further demographic and clinical description).

Table 2. Participant demographic information for the current and retrospective cohort of survivors.

	Current cohort (n=5)	Retrospective cohort (n=4)
Gender		
Male	0	0
Female	5	4
Age (mean)	53	63.25
Ethnicity		
White	5	4
Employment status		
Employed, full-time	1	0
Employed, part-time	1	0
Self employed	0	1
Retired	1	2
Not employed	1	0
Other	1	1
Have a significant other	5	1
Care for dependants		
Under 18	2	1
Between 18 and 65	2	0
Over 65	0	1
None	1	2
Cancer diagnosis		
Breast	5	3
Non-Hodgkin's Lymphoma	0	1

Procedure

The research protocol for this study was approved by a University Ethics Committee, an NHS Research Ethics Committee, and by the Research and Development Department at the Hospital through which the programme is delivered. Participants recruited from the current iteration of the programme were approached by a member of the research team during the penultimate session of the programme. A verbal overview of the research was provided for group participants. They were given an information pack to take away which contained an information sheet with the contact details of the researchers, and a response form they were required to complete if they wished to participate. Participants in the retrospective survivor cohort were sent information packs via the post. This also included an invitation letter, an information sheet with the contact details of the researchers, and a response form.

Focus groups and interviews were held in the same location as the support programme sessions so that all participants would be familiar with the location. This was outside of the clinical setting, in a less formal environment. Upon arrival, participants were given the opportunity to ask any questions they had about the study, and asked to provide written consent to participate. They then completed a short demographic questionnaire (see Table 2).

Both focus groups, and the interview, were facilitated by two members of the research team using a semi-structured interview schedule (see Table 3). This interview schedule was developed by the research team in order to encourage discussion along three broad themes: motivations for joining, and expectations from, the programme; evaluation of the programme content and how well this met participants' needs; and, suggested improvements for future iterations of the programme. Using this schedule in a semi-structured format enabled participants to discuss issues of particular importance to them, but also allowed for the flow of conversation to be maintained and guided to meet the study aims. All focus groups and the interview were audio recorded. Participants were assigned a participant number, which was used to anonymise their responses. Once the interviews were complete, participants were provided with a debrief sheet which summarised the purpose of the study, how their interview data would be used, and contained the names and numbers of relevant organisations should they wish to seek additional emotional and/or practical support.

Table 3. Summary of the main topic areas of the interview schedule

All participants	Additional questions for the retrospective focus group only
<ul style="list-style-type: none"> • Deciding factors when joining the programme • Expectations of gain from the programme • Did the programme meet expectations? • Were the sessions informative? • Benefits from meeting other survivors/supporters • Which bits worked best? • What didn't work so well? • Suggestions for the future iterations • Recommending the programme to peers 	<ul style="list-style-type: none"> • Maintenance of skills learned in the programme • Long lasting relationships from the programme

Analysis

Data were transcribed verbatim from the audio recordings and analysed using Framework Analysis (Ritchie & Spencer, 1993). Conducting a Framework Analysis involves five key phases of analysis. First is familiarisation with the transcripts, which involves reading and re-reading the transcripts, and identifying and noting key issues and repeated themes. Second, a thematic framework of potentially relevant themes and sub-themes is developed from (a) the aims of the study, and (b) important and recurring issues raised by the participants. Third, this thematic framework is then applied to each transcript in turn, with data being extracted and arranged according to the identified themes. Fourth, the framework is then tabulated with each theme and its subthemes being displayed on separate charts; each subtheme is allocated a column in the chart and each participant was allocated a row, which was in the same location on all charts for ease of comparison. Finally, the charts were examined and interpreted with associations and differences between them identified with a view to providing explanations of the participants' experiences and understanding. Framework analysis is a useful and effective means of qualitative data analysis and is used extensively in health sciences and evaluation research (Gerrish, Chau, Sobowale & Birks, 2004; Read, Ashman, Scott & Savage, 2004).

Results

The framework consisted of five themes including: meeting unmet social support needs; meeting unmet informational needs; the benefit of belonging to a group; looking to the future; and, programme evaluation. Numbers were used to identify participants and retain anonymity, and differentiation was made between participant groups through the use of prefixes: the current cohort of survivors (CS), the partner interview (P) and the retrospective cohort of survivors (RS).

Meeting unmet social support needs

All participant groups identified unmet support as a principle factor in deciding to join the programme; it was also identified as being one of the most significant outcome indicators of programme attendance. One participant in the retrospective cohort commented that she gained a lot simply from knowing that *“there’s someone out there still (...) wondering whether I’m coping.”* (RS1; 48-49).

Participants in the current cohort highlighted their need to emotionally offload during the support group as being extremely important; they also mentioned that they did not feel able to do this at home for fear of emotionally overloading their partners and families. Participants felt more comfortable sharing their emotions with other programme attendees who were able to fully understand the complex emotions that they were feeling. Although some participants felt that they were receiving adequate amounts of social support, their friends and family members could not understand the complex emotions which they were feeling.

“when you go through something like that, it’s, it’s so traumatic that nobody really around you, your friends and family, have ever been through it.” (RS3; 19-20)

The programme also offered reassurance to attendees who discovered that others were in a similar situation and experiencing similar emotions. One participant in the retrospective group expressed this sense of reassurance:

“I came here thinking I was the only one who felt like I did, that was crying (...) And it all came like a whirlwind and when I came here and found out that everybody was exactly the same as me” (RS1; 8-12)

This was echoed by other participants who valued the chance to meet others who had been through a similar experience, in some cases they looked to discover information that they had missed or ways in which they could do things differently. The one supporter we interviewed noted that both he and his wife gained reassurance from meeting others and hearing what they had to say about their experiences; he commented that his wife *“realises that there’s other people (...) fighting the problem”* (P1; 223-224).

This supporter joined the programme initially to support his wife, who had previously been through cancer and reported having no support during that first time. The supporter maintained attendance as he found it personally reassuring and beneficial too; his main hope was that his wife would gain from the programme. Within the current cohort, the survivors attempted to analyse their partner’s attendance (or non-attendance) in the programme, making comment that their partners felt comfortable sitting in the group and listening to what others had to say, especially once they knew that other partners were also attending.

Some participants were able to compare themselves to others in the programme, in some cases taking solace from the realisation that they were coping better than others in a similar situation. In other cases, the participants expressed concern about their fellow attendees:

“There was one person, don’t know which group she was in, I felt so, so sorry for her, I can still feel it now and she was so worried in case it was coming back” (RS4; 315-316)

One survivor from the current cohort had survived cancer many years previously and was determined that she would take all offered support, as the support systems were substantially better today than they were previously. Both she and her husband agreed that the main reason they were attending this programme was to ensure that they had taken advantage of all available opportunities. Her husband, who was the interviewed supporter, commented that whilst it was beneficial for them to attend the programme and take from it, it may have also been beneficial for the other survivors and their partners to meet them and to learn from their previous experiences.

Meeting unmet informational needs

Many of the participants revealed that when they were deciding whether or not to join the programme, they considered the possibility of gaining knowledge about their illness as being extremely important. One participant remarked that she was grateful of the chance to exchange information in an informal setting rather than talking to a doctor, as she would be too frightened to discuss some things with a doctor as they’re *“blunt, direct and it’s their job.”* (CS6; 250-251). Others commented that attending the programme has reassured them about symptoms which have been affecting them since their treatment. In addition to this, the programme offered some attendees a sense of validation, that what they have been doing to get better is what they should be doing; for instance, one participant commented that she was pleased to hear that exercise has been *“clinically proven that it does improve the outcome”* (CS7; 152).

A participant in the retrospective cohort expressed that she had gained more from the programme than she thought she would. Others in the retrospective cohort gained knowledge about practical aspects of life after cancer:

“I hadn’t thought about it (...), I mean I’m not going abroad but if I was, you’d just go “Ooh, I’ll book that insurance!” not realising that you can’t.” (RS4; 527-529)

During the programme, information leaflets were given to attendees for their reference after the programme had finished, participants stated that these were a useful addition to the programme.

The variety of the information offered was appreciated and participants felt that it kept the programme interesting. The participant in the supporter group commented that he only found around *“10 or 20 per cent”* (P1; 70) of the information was useful to him. Other participants commented that although they did not benefit from all of the information within the programme, they were able to see that other people in their position may have benefitted from it. However, one participant in the retrospective cohort was dissatisfied with the depth of the information given to them during the programme, stating that she believed that they were *“skimming the surface”* (RS1; 133).

Participants spoke of those who ran the programme sessions as sources of information, with the attendance of a GP within the current iteration of the programme being well received by the participants; they appreciated her being there to answer questions which other members of the programme team couldn't. The supporter commented that the programme co-ordinator made the information understandable and accessible.

The benefit of belonging to a group

The inclusion of both survivors and their supporters was viewed positively by all participants, though the ability to split up into separate break-out groups for discussion was appreciated. Smaller group discussions and break-out sessions were particularly helpful in terms of peer-support as this promoted further discussion and sharing of experiences. Participants suggested including more small groups in future, and alternating group membership to facilitate broader network building. Some participants commented that they would have liked to have had the opportunity to get know more people better than they did. One participant was pleased that there was a facilitated activity before the small group discussions as *"you've got to know each other then, you've settled down."* (CS8; 578-579).

Participants noted that they were pleased that the sessions were informal, and that they were made to feel comfortable from the outset. The supporter participant commented that he was dissatisfied with the organisation of the smaller partner discussion group as there was no guidance as to what they should be discussing and *"everybody's talking about anything else"* (P1; 155); he did, however, reflect that this idle discussion might in fact be beneficial to later discussions as it enables group members to become more familiar with each other.

Group dynamics were discussed by participants, with some noting that there were mainly women in attendance, and that a large proportion of programme attendees were breast cancer survivors, with one participant stating that *"I can't imagine that there weren't as many people suffering with other forms of cancer."* (CS4; 696-697). Participants also mused that discussing certain aspects of cancer in the company of women might make some men feel uncomfortable, and suggested being selective when forming sub-groups to avoid situations such as this.

Looking to the future

The issue of future uncertainty is one of the sessions covered in the programme, and was highlighted by participants as being particularly important. Participants summarised this as an ever-present concern, even when attending to other things; none of the participants expressed that they were comfortably able to cope with uncertainty or that they had overcome it. One participant who had previously experienced cancer, however, shared that her experience of uncertainty was different from her first cancer experience, as previously she was not offered any form of support:

"I had cancer 25 years ago and there was no support whatsoever so when I was diagnosed this time I decided I'd grab anything available, any support, or

you know, I've had a lot of support this time which I didn't have the first time." (CS7; 19-21)

Some participants were anxious about the programme ending and were keen to continue to be able to access support after the programme had ended. This could either be formally, through a regularly scheduled meeting supported by the programme coordinator or informally organised by attendees themselves. One participant reflected, however, that if the programme were to continue, it would be difficult to know when individual participants should stop attending: "*When do you stop though?*" (CS7; 742). Others commented that the support structure would be there for those who needed it and attendees could make the decision as to whether or not to continue receiving the support. One participant was particularly concerned about the length of the programme not being long enough:

"Cos it all happened in five weeks and then you're just forgotten" (RS1; 365)

For some participants, however, the five-weekly sessions were sufficient to meet their needs and they treated the sessions as a "*line in the sand*" (CS7; 73) in relation to their cancer experience and looked forward to being able to move past it.

"I left the programme and I never looked back. I was a new person." (RS4; 14)
"I might live 20 years, I might live 2 years. I don't want to spend 20 years thinking about that ca...breast cancer even if it's 2 years, I don't want to think about it anymore" (CS7; 98-99)

Whilst participants were divided as to whether the programme had fully prepared them to live beyond cancer, they agreed that the programme should continue and for similar programmes to be more widely implemented, with one participant stating that "*it'd be a shame if it didn't continue for other people.*" (RS4; 728).

Programme evaluation

Participants who had recently completed the programme were concerned about the nature of the referral to the programme and expressed concerns as to how thorough the invitation process was; some participants had not received an invitation to join the programme and knew of others who had completed treatment at the same time as them yet weren't invited to attend.

"I got an invite to it and I think out of nine, we'd all gone through it at the same time, but nobody else did." (CS6; 679-680)

One of the participants who did receive an invitation to attend the programme was particularly impressed with the invitation letter as "*every word on it was exactly how I was feeling*" (RS4; 5-6).

Most participants completing the current iteration of the programme felt that, whilst being helpful, the programme came too late. Some participants were concerned that the information they received, specifically relating to financial support and employment, would have been of more use whilst they were undergoing and immediately after treatment. One participant commented that, whilst the programme was of value to her, the support group she attended throughout her treatment was of

more use. In contrast, those interviewed six months after completing the programme felt that the timing was appropriate to their needs, as it allowed them time to come to terms with their cancer diagnosis, treatment and recovery first.

When considering the practicalities of the programme, for example, the location, length of sessions and the time the session was held, participants were generally satisfied. They were especially keen to comment that they were pleased that the programme was not held at the hospital, instead being held in a meeting room in the city centre making it easily accessible. The length of the sessions was deemed to be appropriate, with the time at the end of the session being particularly appreciated:

“There was always time (...) to actually have five minutes at the end to talk to somebody.” (CS4; 611-612)

“And not everybody wants to speak out in a group, it’s important to have a little bit of time when you can actually speak (...) without everyone listening” (CS7; 613-614)

Participants were in agreement that they would recommend this programme to other cancer survivors who were at a similar stage as they were.

Participants in the current cohort felt that there was some information not included in the programme which would have benefitted them; practical employment advice was a main concern as the session dedicated to this topic was considered to be geared towards those already in employment, not those who are seeking work. How to broach the subject of a previous cancer diagnosis with a future employer, and how to address a gap in employment due to cancer in a CV were of particular interest. Participants also expressed a wish for more research-based information regarding nutrition and more information relating to the financial implications of having cancer. There were no suggestions for topics which should be included in future from the retrospective cohort and, interestingly, the supporter was the only participant who considered the inclusion of information about reconstructive surgery and prostheses to be important.

Discussion

This study aimed to use qualitative methodology to evaluate the ‘Living Life after Cancer Treatment’ cancer survivorship support programme. The data endorsed the programme and provided positive feedback from the attending cancer survivors (both current and retrospective) and the supporter participant. Perceived levels of social support was considered to be an important contributory factor for joining the programme and also a major outcome of attending the programme; this clearly echoes findings of previous research (Docherty, 2004; Krizek, Roberts, Ragan, Ferrara & Lord, 2001; Stevens & Duttlinger, 1998; Ussher, Kirsten, Butow & Sandoval, 2006; van Uden-Kraan, Drossaert, Taal, Seydel & van De Laar, 2009).

A strength of this support programme was that it was open to, not only cancer survivors, but their supporters too, giving them a much needed opportunity to discuss issues which may be concerning but difficult to discuss in daily life. Previous research exploring support group experiences of partners of cancer patients has

found that attendance is beneficial and can improve communication within personal relationships (Sabo, Brown & Smith, 1986; Bultz, Speca, Brasher, Geggie & Page, 2000).

Participants frequently spoke of other members of the programme and how the group dynamic had been important. In particular, the supporter wondered whether it was perhaps more beneficial for other members to be in contact with himself and his wife, who had been through cancer once previously. Previous research has explored the beneficial effect of seeing other cancer survivors doing well and this would support his theory. Carmack Taylor, Kulik, Badr, Smith, Basen-Engquist, Penedo et al. (2007), for example, found that distressed members of support group can benefit from seeing non-distressed members and can model coping styles on them.

Previous research has demonstrated the importance to wellbeing of providing practical cancer-related information (Stevens & Duttlinger, 1998; Montazeri, Jarvandi, Haghghat, Vahdani, Sajadian, Ebrahimi et al., 2001; Roberts, Schofield, Freeman, Hill, Akkerman & Rodger, 2002; Ussher, Kirsten, Butow & Sandoval, 2006; van Uden-Kraan, Drossaert, Taal, Seydel & van De Laar, 2009), and participants in this study seemed to be in agreement with this. The information received was reported to be useful, reassuring and also validating. The participants felt comforted that what they were experiencing was normal, and that they didn't need to worry about common long-term side-effects of cancer treatment. The attendance of a GP to the current iteration of the programme as a co-facilitator was particularly well received by the participants who appreciated having the opportunity to speak to her after the sessions had finished.

Some participants reported that they had felt adequately supported during their diagnosis and treatment, but that it was at the end of treatment that they had felt abandoned until being invited to join the support programme (Vivar & McQueen, 2005). Whilst this was helpful to them, they were anxious about the short term nature of this support programme and that they were inevitably 'abandoned' again after week five, once the programme had finished. Whilst this was not a majority opinion, it could be problematic for those who are in need of additional support and who do not yet feel able and ready to cope alone. This could, perhaps, signal the need for a screening process at the end of the programme, whereby those who are still in need of additional support are identified and shown how to access further support.

Some of the participants treated the programme as a "line in the sand" and, afterwards, felt ready to move on with their lives, whereas others were keen to continue accessing support, and were looking for additional routes of support. This is clearly an area of contention between these participants, but it is an important consideration. The need for social support is subjectively determined and programmes must be built with this in mind, perhaps given some control and decision making responsibility to participants as to how long they choose to engage with the support programme for. Where it isn't possible for the support to be on-going, a clearly marked path to accessing additional support for those who require it seems essential; this is a practice which is undertaken throughout the course of the programme, with both written and verbal information being given to programme

attendees. Online support groups have been highlighted as an effective alternative to face-to-face support groups (van Uden-Kraan, Drossaert, Taal, Seydel & van De Laar, 2009) and could be a viable option for a long-term means of on-going support once a support programme, such as this one, has finished.

Most participants completing the current iteration of the programme felt that, whilst being helpful, the programme was offered too late and support should be offered from the very beginning, when the diagnosis is made. They also commented that a programme which aims to support cancer survivors in living life after cancer treatment should be implemented immediately after treatment completion, and many experienced a delay between completing treatment and receiving an invitation to the support programme. Conversely, participants in the retrospective cohort believed that the timing of the programme was appropriate for them, and that this delay allowed them time to fully adjust to their cancer diagnosis, treatment and recovery, before looking to the future. It is possible that this disparity arose because the current cohort were focusing more on evaluating how well the programme met their support needs, whilst the retrospective cohort were more focussed on evaluating how the programme met their informational needs as by the time the focus groups took place, support needs were no longer a priority. Despite this, all participants reported some benefit and saw the relevance specifically to the post-treatment experience.

It is important to note that only 25% of those approached agreed to participate in the study, and that this included just one supporter participant. Whilst this is not problematic *per se* for the evaluation research question, future research needs to now establish how generalizable these results are and, indeed, whether they are representative of those who didn't volunteer to take part. It is possible that their non-participation is useful feedback, in and of itself. Research exploring support group attendance of partners would be of particular interest, as little research has been conducted and findings from this study cannot be generalized.

The findings from this research are currently being used to develop and improve the 'Living Life after Cancer Treatment' programme locally. There has been a continued support for the local health service to develop cancer support services to better meet the needs of patients in follow-up after cancer treatment, and this is just one way in which empirical scientific data can be incorporated into beneficial and evidence-based cancer care.

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