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ARTICLE

Support systems for mixed-site recovering cancer patients to sustain physical activity: a qualitative study

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Abstract

Rationale, aims and objectives: Uptake and adherence to physical activity (PA) programmes for recovering cancer patients remain low with only 20% of patients meeting the UK guidelines of 150 minutes a week. The aim of our study was to examine the support systems that enabled a group of cancer patients to sustain PA for 6 months.

Method: Fourteen mixed site cancer patients aged 43-70 (11 women, 3 men) participated in a 2-phase PA intervention that took place at a University in the South West of England, UK. The intervention consisted of an 8-week structured exercise programme and a 4-month period of independent PA. Semi-structured interviews were employed to collect the data and a grounded theory approach was used for the analysis.

Results: We found that different types of support were required for each stage of the intervention. Internal support was necessary while undertaking a structured PA programme. External support was necessary to sustain PA to 4-month follow-up. The two aspects of internal support were identified that enabled the patients to adhere to the programme; support from exercise professionals and peer support from patients on the programme. External support that enabled the patients to sustain independent PA to 4-month follow-up was support from close partners or from a spouse.

Conclusions: Our study has provided valuable insight into internal support systems that enable recovering mixed-site cancer patients to adhere to a structured PA programme and external support from close relationships to sustain independent PA for an additional 4 months.

Keywords

Grounded theory, health, person-centered healthcare, physical activity, qualitative research, recovering cancer patients, support systems

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Introduction

Exercise has been shown to benefit cancer patients and improvements have been documented upon diagnosis [1], during treatment [2,3] and beyond [4]. Following advances in treatment, survival rates have improved [5] and more long term approaches for addressing patient needs are warranted [6]. Strategies to help patients self-manage have recently gained momentum, yet the availability of programmes to meet patients' needs remain sparse. Although the underlying mechanisms of exercise require further investigation, improving a cancer patient's physiological condition has been documented [6] and psychosocial benefits are not limited to quality of life [7-9]. Social support has been shown to be an important mediating factor for patients with chronic illness and can

help patients' ability to cope, leading to enhanced behaviour change [10-12].

Studies have shown the importance of counselling for patients with disease and illness, including diabetes [13], obesity [14] and chronic heart failure [15]. However, these interventions typically incur costs beyond the remit of medical intervention and need to be carefully employed in order to optimise patient benefit. Furthermore, some patients choose not to participate in formal counselling opportunities [16] and may be less able to self-manage the major psychological impact that typically follows a cancer diagnosis. Other studies have identified less formal approaches that can occur implicitly within the delivery experience of PA interventions [16-18]. This has been exemplified through PA interventions, as patient support systems emerge that can positively influence adherence to PA [18-20], even up to 5 years post-intervention [21].

The exercise professional delivering the intervention has been cited as providing social support [20,22-24], followed by fellow patients [25] and family and friends [12,26,27]. A recent qualitative study, investigating GP referral, identified a 'quartet' of social support including: (a) other patients, (b) family and friends, (c) exercise professionals and (d) other formal environments (including the researcher), demonstrating the wide array of options that can constitute social support, beyond formal counselling [23].

The added value of group *versus* individual PA is exemplified by social support and this should be emphasised [18]. Nevertheless, patients can be reticent prior to starting group-based programmes, as motives focus on personal desires to improve health, rather than on a desire to build reciprocal supporting relationships. The effect of group support mechanisms has not been studied through the integration of mixed site and mixed stage cancer patients as existing interventions focus on only one type of cancer or disease. Now that patients are living well with and beyond cancer [4], it could be argued that treatment options not performed in a clinical environment need to better reflect the experiences of daily life for improved community integration.

Our study used a qualitative research design that focussed on the social support mechanisms reported by mixed stage and site cancer patients during an 8-week structured PA programme and 4-month follow-up period.

Method

Design

We used a grounded theory approach to analyse the support systems that enabled a group of recovering cancer patients to adhere to a PA intervention. The intervention consisted of 2 phases. Phase 1 was an 8-week structured PA programme. Phase 2 was conducted by 4-months of independently sustained PA. The data were collected using audio-recorded semi-structured interviews between March and October 2014 at a University located in the South West of England, UK. The study comprised 3 data collection and analysis phases over 6 months and provided the opportunity to develop themes emerging from the first data collection phase into lines of enquiry at 2 further points in time (0, 2 and 6 months). This approach has provided some explanations of the support systems that enabled these recovering cancer patients to adhere to both phases of the 6-month PA intervention.

Study Setting

The PA intervention evaluated in this paper is the result of a partnership project between a University and a Macmillan Cancer Support Centre in the South West of England. Patients were referred to the programme by health professionals associated with the Macmillan cancer support centre. The Programme was delivered by university teaching staff and supported by students. The

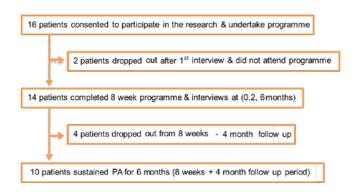
objective of the 8-week Programme was to introduce and promote independent PA through home-based strengthening exercise, posture awareness and walking activities. These were incorporated into activities of daily living to promote long-term sustainability.

Patients attended a 2-hour session each week for a period of 8 weeks. The weekly 2-hour session introduced a variety of physical activities and provided the opportunity for informal discussions to support patients. The practical elements of the programme included walking; Nordic walking; home-based resistance exercise; swimming; badminton; table tennis; dance; Pilates; flexibility, balance and posture exercises and gym-based resistance and cardiovascular equipment. Tasks were agreed on a weekly basis and patients were encouraged to wear a pedometer to independently monitor daily PA.

Participants

Having agreed to take part in the Programme, 16 patients volunteered to participate in the research. The patients were selected on the basis of a convenience sample, as is congruent with grounded theory research [28-30]. Sixteen patients were provided with an information letter and consented to be interviewed at 3 designated points over the 6-month data collection period. The first data collection period was prior to the take-up of the Programme; the second period followed completion of the 8-week Programme and the third period was 4 months after programme completion. Two patients were waiting to join the Programme but were unable to do so due to on-going health problems. Therefore, 14 patients were interviewed on all 3 occasions over the 6-month period (42 interviews in total). Fourteen patients attended the 8-week Programme. Four of the 14 patients (negative cases) were unable to sustain independent PA due to on-going health problems (Figure 1). However, these 4 participants attended the final interview at the 6-month point and were included in the analysis to provide an alternative perspective [29]. The University of St Mark and St John Research Ethics Committee approved the study.

Figure 1 Showing patients progression through the intervention



Data collection methods

Data were collected by the 3 authors and another member of the research team. Semi-structured interviews were recorded on Olympus Digital Voice Recorders, transcribed *verbatim* and anonymised. The interviews took place on the university campus on all 3 occasions. To describe the study all patients were asked questions relating to their socio-demographic and morbidity characteristics at the start of the first interview (see Table 2).

Table 1 Patients' socio-demographic, morbidity and pre-intervention diagnosis characteristics

Patients Men n (%)	Patients Women n (%)
3 (22)	11 (78)
68 (2.1)	52 (9.7)
3 (100)	11 (100)
0 (100)	10 (90)
3 (100)	0 (100)
0 (100)	2 (20)
0 (100)	1 (10)
0 (100)	1 (10)
7 (67) 8 (33)	2 (75) 3 (25)
	n (%) 3 (22) 68 (2.1) 3 (100) 0 (100) 3 (100) 0 (100) 0 (100) 0 (100) 0 (100)

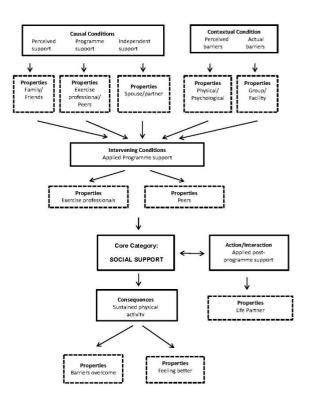
Data analysis

The memoranda that emerged from the coding processes were used as the method for generating grounded theory. We used the memoranda as a means of describing and explaining the patients' experiences of the support that they received to adhere to the Programme and sustain their PA for 4 months. We manually analysed the data in order to understand fully the richness of data through human interpretation [31]. To ensure a robust approach to the application of grounded theory a number of critical characteristics were implemented throughout the data analysis. These included consecutive data collection and analysis over a 6-month time period. This enabled the analysis to cyclically inform the data collection process as is recommended in grounded theory studies [32]. Sequential analysis facilitated the development of concepts and categories from the data while at the same time allowing new possibilities to emerge from the data via subsequent data collection episodes. Detailed guidance for the initial data analysis (open and axial coding) was provided by the first author to the 3 members of the research team to enable a consistent approach. The first author checked the analysis for consistency and reviewed the concepts and categories from the data in order to assure the continuation of theoretical development.

Memoranda were used to formulate questions for subsequent sets of interviews. The first author advanced theoretical development through selective coding and the application of the axial coding paradigm as shown in Table 2. The second author assisted by reviewing this process

[29]. Memoranda were used by the authors to explore the different dimensions of the emergent themes from the axial coded data, the first author reviewed this process. The final analytical characteristic used to ensure a robust approach to grounded theory analysis was the construction of the end product of the research [32]. This involved the first author selectively coding the data [29] and developing a 'core story' from the axial coded memos. This, in turn, led to the development of a conceptual model (Figure 2). This was followed by a descriptive account of the findings, supported by evidence from the lived experiences of the patients in the study.

Figure 2 Conceptual model demonstrating support systems to enable sustained PA for recovering patients



To enhance the power of the present study the following principles of what constitutes excellence in qualitative research were adapted from Tracey [33] and applied throughout: (i) worthiness of the topic and significant contribution of the work via contribution to debates on support systems necessary to promote PA behaviour for patients with chronic diseases; (ii) rich rigour through the application of grounded theory techniques; (iii) resonance through the transferability of the findings to similar exercise programmes in similar situations and (iv) sincerity through the use of the participant voice. To enhance transparency, the study included an audit trail of the data collection and analysis process including: audio recordings; transcripts; coding; the development of a theoretical framework (Table 2) and a conceptual model (Figure 2).

Table 2 Theoretical framework showing support systems to enable sustained PA for recovering cancer patients

Types of themes /categories	Explanation	Theme in this research	Properties
Core Category	Represents what is central to the research	Social support	
1) Causal Conditions	Sets of events / happenings that influence the phenomena	Perceived support prior to the Programme	Family and Friends
		Programme support during the Programme	Exercise Professionals and Peers
		Independent support to follow up	Spouse or Partner
2) Contextual Conditions	Sets of conditions that intersect at a time and place which create a set of problems which people respond to	Perceived barriers	Physical Psychological
	through actions/interactions	Actual barriers	Lack of group support Lack of facilities
3) Intervening Conditions	Conditions that alter the impact of the causal conditions on the phenomena	Applied Programme support	Exercise professionals Peers
Actions/Interactions	Purposeful acts that are undertaken to solve a problem and in doing so shape the phenomena	Applied Post-Programme support	Life Partner
Consequences	Range of outcomes	Sustained physical activity	Barriers overcome Feeling better

Results

In Figure 2 we have presented a conceptual model which is configured around the core category of 'social support'. The concept of 'support systems for the development of a physically active lifestyle' was the phenomenon investigated and 'social support' emerged as the core category. This category was selected as it represented the views of the patients who relied on social support to adhere to the 6-month PA intervention. The patients identified a range of support systems that had helped them to adhere to the 6-month PA intervention. The support systems are classified as 'internal' and 'external'. Internal related to social support during the 8-week PA programme. External related to social support from completion of the Programme to the 4-month follow-up point.

Causal Conditions

Causal conditions relate to sets of events or happenings that influenced the phenomena [29]. Three causal conditions emerged from the data, these were 'perceived support' prior to the Programme, 'programme support' during the 8 weeks and 'independent support' to 4-month follow-up.

Perceived Support

Prior to the take up of the Programme, most of the patients 'perceived' that the support necessary to adhere to the 8-week Programme would come from their family and friends. Patient 2 explained how she thought that she would be supported by her partner, family and friends:

"My partner will be very supportive, she goes to the gym and goes skiing. I will also be swimming with her and a friend of ours. So, I have huge support from friends and children too, who are all fit."

Patient 5 was of a similar opinion and explained how family, friends and neighbours were all behind her taking up the PA programme and presumed that this was where her support for the programme would come from:

"I've got lots of support, the amount of people who are gunning for me is tremendous. Not only family but friends and friends in my street, it is tremendous really."

Programme Support

Having completed the 8-week Programme the patients identified that the 'support during' the Programme had come from exercise professionals and peers on the programme and not from their family or friends as they had predicted. Patient 2 explained that the exercise professionals were very supportive:

"The three instructors were utterly devoted to us. There was somebody familiar for us to turn to if we needed. We had complete support from all the team involved and it made us all feel as if we were the only people they were looking after."

Patient 1 had a similar view about how supportive the team of exercise professionals were:

"It was the team, yes in all honestly I couldn't turn and say one did any more than the other, they were all brilliant."

There was a strong supportive group dynamic between the instructors and the patients. This enabled patients to help support each other as the group was empathetic, sociable and friendly.

The second form of 'support during' the Programme related to the peer support that the patients had received from each other during the 8 weeks. Patient 8 explained that she encouraged other patients to push themselves a little further when they were exercising on the treadmill:

"We would be trying to walk a certain distance, say half a kilometre and when we had done half a kilometre I would say shall we do a bit more. For the people that were finding it difficult I think I was helping them, motivating them a little bit."

Patient 3, who was one of the quieter group members, explained that the equipment layout in the gym, with the treadmills being side by side, made it easy to talk to other patients while exercising:

"I didn't make friends with many people on the course but I am quite a loner anyway. Chatting to a lady who was a runner enabled me to learn a bit more about using the equipment, although the staff did too. The walking machines were quite good for that because you were in a row and you could talk and get to know people."

Patient 9 found the competitive element that emerged between some of the older and younger patients in relation to their weekly pedometer scores to be supportive as it encouraged her to do more:

"It becomes competitive, you want to do more than you did last week because that girl over there did 8000 steps and I only did 4000. There were a couple there who were a bit younger than me and I wanted to prove you didn't have to be young to be fit."

A contrasting perspective in relation to peer support was given by one patient. Patient 4 explained how she found it helpful just being in a group with other recovering cancer patients. Patient 4 tended not to want to discuss her cancer with other patients, she found that listening to other patients discuss their cancer made her realise that other people were in a similar position to her:

"It was nice being in a group with the other people, you see for yourself that others are in similar situations. I'm the type of person that does not tend to talk very much about my cancer and a lot of them did, so I would sit and listen."

Independent Support

The patients discussed the 'independent support' that enabled them to sustain their PA to 4-month follow-up. A variety of examples of support were provided that included friends, family, support group, self-support, peers, partners and spouses. However, the most common response related to the support that came from the person closest to the patient, which was either their spouse or partner. This again was in contrast to the patient's initial views of who would be supporting them throughout the programme. The patients originally predicted that support would come from friends, family and neighbours.

Interestingly, the 2 patients who had not managed to sustain their PA up to the 4-month follow-up point did not have any support from either a partner or spouse. Patient 14 described how she found it hard to continue being physically active, as her husband was working away and unable to support her in maintaining her activity:

"It's difficult with my husband working, I have got friends but they have their own lives to live and during the evenings they are out doing their own thing. So it is hard not having my husband here and I don't know if there is any other support people could give me."

Patient 9 explained how she had always been an active person until she developed cancer and the Programme had initially motivated her to become active, but that further health problems and a lack of support had prevented her from sustaining her PA:

"I was always motivated, I did not need any drive, I have never needed a push until I got this cancer. It did knock me backwards but when I went on that program I thought crikey I can do more than I think. I really felt upbeat and then of course things happen in life and I've had a few knock backs."

Prior to participation in the PA intervention the patients thought the support that would enable them to adhere to both of the PA phases would come from family and friends. Having completed Phase 1 (8-week programme), the majority of the patients identified the exercise professionals and the peer support group they formed as motivating them to adhere to the Programme. The patients also identified the main person who supported them to sustain PA during Phase 2 (4-month follow-up), as a spouse or partner, rather than from friends and family more broadly as they had initially predicted.

Contextual Conditions

Contextual conditions are sets of conditions that intersect at a time and place creating a series of problems to which people respond through actions and interactions [29]. 'Perceived' and 'actual' barriers were the themes that emerged from the data. The properties of the 'perceived barriers' theme related to the 'physical' and 'psychological' barriers that the patients thought may prevent them completing the Programme. The properties of the 'actual' barriers theme related to the 'lack of facilities' and 'support group' that some considered necessary to continue being physically active after completing the 8-week Programme.

Prior to commencing the Programme most of the patients perceived there to be barriers that could prevent

completion. These were categorised as psychological and physical barriers. Patient 10 explained how she was anxious about not being able to cope with the demands of the Programme:

"There is a bit of nervousness of about what I will be able to cope with. I'm hoping that there will be people there telling me when I'm doing it right or wrong. Hopefully, with the guidance I'm going to get I should be okay."

For most patients physical barriers related to the chronic fatigue they had experienced as a side-effect of their treatment. Patient 7 was concerned about the physical effects of the treatment she was undergoing and the impact that this may have on her energy levels:

"The only barrier I can see is how well I actually feel on the day. If it is the week after a chemotherapy session, I might not have the energy to do it."

Having completed both phases of the 6-month intervention the actual barriers identified by the patients that made it difficult for them to sustain their PA were in contrast to what they had expected. Barriers to adherence identified by the few patients unable to sustain PA to follow-up included lack of group work and limited access to the facilities as the main barriers. Patient 13 identified how much she had liked being part of the group and this was difficult to sustain once Phase 1 of the Programme finished, she also did not have a partner or spouse for support:

"As a single woman on your own you cannot do much, I miss the social network. I used to join in with the group but now I walk on my own or just with my daughter."

Patient 14 explained that it would be difficult to sustain her PA as the Programme had finished the lack of structure and support made her feel like she could not engage independently:

"It's not available here or in any in other places. I just can't think of anything else at the moment that I could do, because I can't ride a bike."

Intervening Conditions

Intervening conditions are conditions that alter the impact of the causal conditions on the phenomena [29]. The emergent theme was 'applied programme support' during the 8-week Programme. The properties of the intervening condition were 'exercise professionals' and 'peers'. Having identified that the main forms of support that enabled the patients to complete the Programme came from the exercise professionals and the patient's peergroup, the patients then explained how these forms of support were established. All of the patients identified how supportive the exercise professionals were. Patient 4 explained that the exercise professionals had always

listened to any questions the patients had and gave them supportive advice:

"The team that ran the programme were very good. If you had any questions, they'd answer you and they showed a lot of interest in what we had to say."

Patient 1 described how one of the exercise professionals had built his confidence over the 8-week Programme through supportive feedback on his fitness test results:

"You do the step-up test which we did the first week and the last week to compare our scores. It was the way that one of the instructors sort of built my confidence. He said 'I could see this has done you good, you've got more colour, you're looking better and you're even smiling'. It's all about putting the confidence back in you isn't it."

The second aspect of applied programme support came from the patients' peers who were also participating in the programme. Patient 12 was able to give an example of how supportive the group had been to one patient, who had gone through breast reconstruction surgery half-way through the Programme:

"One week we all had a moment's thought for one lady, because she was having her breast reconstruction. So I said 'how about it folks and shouted give it hell girl', all of us were like yippee and that sort of thing. She was in the next week and didn't have the scars or anything. I said 'I thought you had your operation last week'. She replied 'yeah, you all had a yippee for me didn't you'."

A common theme evident from all of the patients was how the group-based intervention enabled them to discuss their cancers informally and at their own pace with the other patients on the programme. Patient 9 identified how beneficial it was to be able to discuss her cancer with others who were in the same position as her:

"The group of people were all friendly and we were able to talk about our experiences, which you can't do at home. There's not quite the understanding from people who have not walked down the same path."

Actions/Interactions

Actions and Interactions are purposeful acts undertaken to solve a problem and in doing so shape the phenomena [29]. The theme identified in the data was 'applied post-programme support'. The property of theme related to how the patient's 'life partner' (partner or spouse) supported them from Programme completion to 4-month follow-up. For example, Patient 1 stated that his wife encouraged him to walk more often:

"The wife was very supportive, she encouraged me to walk more, you know leave the car and walk."

For Patient 8, her husband was her main support, he would go out walking with her which had the added benefit of improving his fitness:

"Hubby has been supporting me because we've been going out for walks in the evening after work. So I'm getting him back into exercise as well."

Patient 2 gave details of how her partner had provided support over the 4-month follow-up period by walking the dog together:

"My partner has always been very keen to support me because she is very active. So when we can, we get out and take the dog for a walk together, which is terrific."

Most of the patients explained that the way that their spouse or partner had supported them over the 4-month follow up period, generally related to encouraging them to walk or going out walking with them.

Consequences

We report here the consequences of the resulting outcomes from the Actions and Interactions identified in the section above [29]. The consequence themes identified in the data related to 2 different outcomes. The properties of the theme related to how the patients 'barriers were overcome' and how they 'felt better' as a consequence of engaging with PA for 6 months. The majority of the patients (10/14) completed the 6-month PA intervention as shown in Figure 1.

Having completed the Programme the patients were able to explain how they had overcome their initial barriers to PA. Patient 4 explained how his initial anxiety dissipated as soon as he got to know the other patients on the Programme:

"I was initially a bit nervous and apprehensive, but that was soon sorted out when I got to know the other people."

Patient 10 also explained that her initial concern about starting the programme related to her initial nervousness about joining the group:

"The only real barrier was being a bit nervous about starting, it was just the initial coming in but we were all soon put at ease. The trainers were all easy going and friendly."

Patient 2 explained how the Programme had made her feel better and had given her back her fitness which the cancer had taken away. She believed that the support that she received during the Programme was the reason for this:

"I feel better because I am more active now. The cancer took a lot away initially, but so much has been given back to me. It is the encouragement we received, nothing was too much trouble. We really appreciated all the support from all of those involved with the Programme."

Patient 7 felt better because of the support she had received from other patients on the programme. This had reassured her that it was possible to get over cancer:

"You can chat to people and realise they have been through the same thing as you. I'm still in treatment but most of the people seemed to be coming out the other side, so it's quite reassuring to hear that. A nice thing that came out of the whole thing was the number of people who cared about me."

The key to these patients sustaining PA to 4-month follow-up was the time they had spent together during Phase 1 of the Programme. This had shown them that PA was possible for them, that increased fitness enabled them to take control of their recovery and that it was possible to get over cancer.

Discussion

In healthy populations and those with chronic illness social support has been shown to be an important feature in enhancing positive behaviour change [10-12]. Social support has been shown to be a mediating factor when measuring levels of coping, quality of life and mental health for those with chronic and/or traumatic illness [34]. The findings from our study support those of others who have also found group-based exercise programmes to be beneficial for cancer patients [11,16,35]. Our patients also placed a great deal of importance on the support they received from group members that enabled them to adhere to the structured phase of the intervention. However, the patients in our study supported each other informally as they got to know each other during the 8 weeks, without the pressure that can arise during a structured discussion group. Informal support during group exercise programmes has been shown to be a preferable option to more focussed group therapy sessions that patients would not have chosen to be part of [16]. As with our study, the participants noted feelings of empathy and acceptance and found the groups were useful in terms of exchanging information and forming new friendships [16]. In a similar intervention, despite participants initial motivations being personal desire to improve their own health, the incentive to attend included a sense of group membership [35]. The patients in our study noted how they were able to make comparisons to others that led to increased understanding of different coping methods. This helped them to gain a perspective of their own cancer and in turn reduce their anxiety levels, as has been shown elsewhere [11].

We also found that the cancer survivors placed a high level of importance on the support received from the activity facilitators on the intervention [36]. Our findings have shown that exercise professionals increased the patients confidence through listening to their concerns, providing supportive advice and setting regular achievable goals.

Research has shown that in order for PA interventions to make the most effective use of any beneficial effects of group formation they should include the process of group integration into the intervention process [18]. However, our study contrasts with this perspective [18], as no formal group integration took place. This allowed the patients naturally to support each other through informal conversations during the PA sessions. It was the opportunity that the group-based sessions provided the patients to discuss their cancers, informally and at their own pace, that the patients valued the most. The size of the group (14 patients) facilitated supportive relationships to develop embryonically.

In contrast to the internal aspects of support already identified [11,16,35], the participants in our study identified a range of external support factors that helped them to independently sustain their PA up to the 4-month follow-up. These factors were external to those directly associated with the implementation of the Programme and included support from friends and family and self-support. However, we found that the most effective means of support for independent PA specifically came from a life partner, not from wider family or friends, which is where the patients originally expected support to come from.

Conclusion

In conclusion, our study has provided valuable insight into the support systems that enabled a group of recovering cancer patients with mixed-stage and mixed site cancers, to adhere to a 6-month PA intervention. The patients highlighted how being on a programme with other recovering cancer patients enabled them to gain perspective on their own cancer. The support that the patients received from each other gave them confidence to engage with and adhere to the structured phase (8 weeks) of the intervention. This in turn gave the recovering cancer patients the confidence to continue with PA up to the end of the second phase of the intervention to sustain PA levels independently. PA was sustained with the support from their 'life partners' who provided the support to continue being physically active beyond the initial 8-week intervention. As reported [17,37,38] physical activity was significant in the recovery process of the patients in this study.

Acknowledgements and Conflicts of Interest

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