The Chemo Club: Insights on Facilitating Participation in an Exercise Club for Cancer Patients.

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ABSTRACT

The present article makes a contribution to this emerging literature by presenting findings from a study exploring patients' experience with the 'Chemo Club', an exercise program for cancer patients based in Perth, Western Australia. The findings presented explore a range of interfacing factors associated with the Chemo Club that attract and hold members to the program including: factors associated with history and ethos of the CC; factors associated with the structure and organisation of CC; and factors associated with the individual cancer patient.

Keywords: *Cancer, psychosocial; exercise; participation; qualitative research.*

INTRODUCTION

The whole thing about chemo gym is you've got access to the equipment, you've got a group around you, and a wonderful band of volunteers.

(Participant statement)

There is now evidence that physical activity improves quality of life and physical functioning among cancer patients and survivors,[1,2,3,4] with physical exercise training shown to be an effective component of comprehensive rehabilitation for cancer patients and survivors.[5,6] The evidence of the benefits of exercise for those treated for cancer has recently led to the development of a variety of exercise interventions for this population along a continuum including home, hospital and gym-based programs.[7,8,9,10,11] Comprehensive exercise programs for cancer patients are documented as safe, recommended for chemotherapy patients and feasible for many institutions using current resources.[7,12,13] Long-term adherence to such programs helps to maximise benefits.[14] There is now a call in the research literature for all healthcare

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professionals involved in the care of cancer patients to be aware of the evidence surrounding the benefits of exercise and to encourage patients to increase physical activity to improve their overall health and wellbeing.[15]

However, there are still major barriers to the incorporation of exercise in the therapeutic regime of cancer patients. As Alfano and associates[16] argue, as yet little is known about factors that enhance or limit cancer patients' ability to make positive changes in relation to their exercise patterns. There is limited direct research on the implementation of clinical exercise programs in the cancer setting, with scant work on the barriers to physical activity and exercise training in cancer patients[6] Although exercise programs have been shown to be acceptable to patients, there are problems of uptake that indicate a need for developing more effective recruitment strategies.[11]

As Peeters and associates[8] recently pointed out, with the increasing evidence of the benefits of exercise for cancer patients there is now a need for research on the factors that facilitate participation in exercise intervention programs for cancer patients from the consumers' perspective. If the benefits of exercise for cancer patients are to be translated into practice it is essential that the factors that encourage or limit participation in exercise programs are understood in order to maximise initial involvement and ongoing commitment. Research documenting insights from the patients' perspective on how best to promote activity and the desired components of exercise programs is required to inform effective practice development in this exciting new direction in oncology patient care.[8,11,17]

The present article makes a contribution to this emerging literature by presenting findings from a study exploring patients' experience with the 'Chemo Club', an exercise program for cancer patients based in Perth, Western Australia. The findings presented explore a range of interfacing factors associated with the Chemo Club that attract and hold members to the program.

THE CHEMO CLUB

The Chemo Club is a joint initiative of Dr David Joske, Head of Haematology at Sir Charles Gairdner Hospital and Mr Steve Smith, Manager/Owner of 'Aspire Fitness' Centre, both situated in Perth, Western Australia. The exercise sessions are attended by a physiotherapist, exercise physiologist and trained nurses who are all volunteers. The Chemo Club is free and operates totally on donated services. It is open to all cancer patients who are referred either through their treating physician or through Solaris Care. Solaris Care is a purpose built drop-in centre for cancer patients located at the Sir Charles Gairdner Hospital, Perth, which provides free support, information, advice and access to safe and supervised complementary therapies.

THE RESEARCH

The aim of the project was to explore the psycho-social experience of involvement in the Chemo Club from the perspective of its members. Ethical consent to conduct the research was obtained from the University Human Research Ethics Committee. Participants were informed of their rights in research and consent was obtained for participation in the study. The data was collected at CQUniversity and analysed and written up at Griffith University.

METHODOLOGY

An open-ended, qualitative descriptive design using in-depth interviewing was utilised for the study. Qualitative research is used to explore programs in health care to provide insights on quality and effectiveness and to assist in program improvement.[18,19] Such a qualitative approach is particularly appropriate where little is known about an issue[20,21] and so is well suited to a study of a unique program such as a chemotherapy exercise club where scant research literature is available. The qualitative methodology also ensures that the voice of the consumer informs and drives the outcomes of the research for in essence qualitative research is concerned with how people make sense of their world and their experiences.[22] The focus of qualitative research is on understanding the phenomenon of interest from the participants' perspectives, not the researcher's.[22]

Participants

The findings presented in this article are from interviews with nine chemotherapy patients who at the time of the interview were involved in the exercise program at the Chemo Club. The participants were consecutively enrolled by the Project Officer from the list of Chemo Club members provided by the gym co-ordinator. The participants were enrolled through the Project Officer for the study who was under contract with the University and thus independent of the Chemo Club. Data saturation is

used by qualitative researchers as a way of justifying the number of research participants and this is done during the data collection process.[23] By the fifth interview there was evidence of data saturation and so the decision was made to close consecutive enrolment after nine participants.

The participants were provided with a written Project Description of the research and an invitation for voluntary participation in the research. Enrolment was through a telephone call and interviews were conducted by speaker telephone at a time chosen by the participant. Apart from being over the age of 18 years and having the ability to give informed consent, there was no screening of participants. Prior to interviewing, participants were again informed of their ethical rights (e.g. informed consent, confidentiality, right to withdraw) and consent was obtained for the interview.

Demographics

The nine (n=9) participants ranged in ages from 57 to 74 years of age, with six (n=6) females and three (n=3) males. The participants were diagnosed with a range of cancers including Non-Hodgkins Lymphoma (n=3), Breast cancer (n=1), Colorectal cancer (n=3) and Ovarian cancer (n=2). All participants had had chemotherapy treatment at some stage of their illness trajectory, with the minority (n=2) still receiving chemotherapy at the time of interview and the majority (n=5) in remission. A majority (n=5) of participants had a history of exercise such as walking, dancing, swimming and cycling, outside of their involvement with the Chemo Club.

Interviews

Each interview began with the question: 'Could you talk about your experience as a member of the Chemo Club?' It was emphasised to the interviewee that there were no 'right' or 'wrong' answers; the interviewer was interested to hear of the participants own experience, in their own words and taking as long as they needed. The interviews proceeded at the pace of the interviewee with direction from the interviewer as required. As qualitative open-ended interviews, ample opportunity was provided for the participants to express the fullness of their experience, including any perception of lack of benefit or negative outcome. The line of questioning included the techniques of probing, paraphrasing and reflection to explore each participant's experience 24. The interviews lasted for approximately half to one hour and were digitally audio-recorded.

Analysis

The language texts were then entered into NVivo, a qualitative computer package produced by QSR International. All of the participants' comments were coded into 'free nodes' which are category files that have not been pre-organised but are 'freely' created from the data. The list of codes was then transported to a Word Computer Program and organized under thematic headings. The coding was established by an experienced qualitative researcher and completed by the Project Officer who has extensive experience coding qualitative data. There was complete agreement on the coding and emergent themes. There were 129 free nodes created from the transcriptions which were then collapsed down into themes. It is the findings associated with the theme 'factors impacting on club membership and participation' that are presented in this article. A paper from the study with the same methodology reporting benefits of participation is published elsewhere.[26]

FINDINGS

As can be seen by the following example, participants noted that there was a very low attrition rate in relation to membership and participation at the club:

- *Maybe in all that I've been going nearly a year now, and maybe two people haven't come back. I'm just roughly guessing, about 30 people would be there each session. Sometimes it may get up to 40 to 50 people.*

The length of time participants continue to participate in the CC is left up to them. The only reason noted for members leaving the CC is because of remission, for example:

- *Some people do go into absolute remission. The cancer has all gone, and then they don't come back. You know, they must go and do their own thing.*

The high level of continuity in membership and participation was independently confirmed by the consultant staff at CC. Thus, the CC stands as a good example of an exercise program for cancer patients that successfully attracts and maintains membership. Following

is a description of factors contributing to that success from the perspective of the club members interviewed.

As a background to the findings presented in this paper it is important to note that further findings from the study (McGrath et al., 2010) indicate that there is a high level of satisfaction with the CC experience. As detailed elsewhere (McGrath et al., 2010), the participants reported a wide range of psycho-social benefits from their involvement, including both the immediate and long-term experience of increased morale through the positivity of the group; a sense of personal empowerment; meaning-making; social support; the normalising comfort of a reference group of individuals who share the cancer experience; and a degree of physical rehabilitation. The benefits from the Chemo Club have as much to do with the positive social interaction and support as with the actual exercise. As the following discussion of findings indicates, many of the factors responsible for successfully attracting and retaining member to the program are directly related to these benefits.

Factors that facilitate membership and retention in CC

There are three sets of factors that contribute to the attraction and retaining of members that will be dealt with separately in the findings: factors associated with history and ethos of the CC; factors associated with the structure and organisation of CC; and factors associated with the individual cancer patient. However, as outlined in Diagram 1, these factors actually overlap in practice. In addition, the findings explore possible barriers to participation in the exercise club.

Factors associated with history and ethos

Participants spoke of the origins of the CC being based on an altruistic collaboration between the Director of Haematology at the local hospital and the manager/ owner of the Aspire Fitness Centre. As one participant explained:

- *[Name of Director of Haematology] spoke to him [Manager of Aspire Fitness Centre] about his idea for having exercise as part of the regime for people who are having chemotherapy. And [Manager of Aspire Fitness Centre] then volunteered the use of his gym. And so he, [Manager of Aspire Fitness Centre], is the driving force.*

The participants were enthusiastic in their praise of the Manager of Aspire Fitness Centre and noted that it is his positive energy, altruism and ability to empathise with, reach out to and motivate that is a key factor in the program's success. He is described as 'a very generous man' and 'just a saint'. The Manager of Aspire Fitness Centre is described as being a key factor in attracting to the program not only members but sporting stars and volunteers as well, as one participant summed up:

- *[Manager of Aspire Fitness Centre] ropes everybody in. He's organised a group of volunteers around him. And that ranges from young hunky guys who are in WA to play national sports, and he drags them down and they come round and help us with the gym equipment [laughs]. I think he's very popular, so a lot of the sports people go there as well. So they come and join our CC as well.*

The psycho-social benefits associated with CC membership are strongly linked to the Manager of Aspire Fitness Centre efforts to create a non-judgmental space where individuals can interact in a supportive way with each other, and physically participate in the exercise program at a comfort level appropriate to their individual capacity. Both the Manager of Aspire Fitness Centre and his volunteers are described as a strong presence at the CC.

Similarly, the haematologist responsible for establishing the CC is viewed by participants very favourably and his continuing evolvement in the club is highly valued, for example:

- *Today was good and we had a visit from [Director of Haematology], and he was the one who spoke to the manager about the exercise club. So every so often if he's got free time he comes down to a work out session and then talks to us all. And that makes you feel good, and anyone can go up and talk to him. And he always says to the manager "if anyone's got a problem, you've got my … mobile phone number. You just ring me and I can talk to them or whatever".*

The supportive, normalising and positive ethos of the CC is a key factor in attracting and retaining members. The altruistic ethos of the club is highly valued by members, as the following statement demonstrates:

- *It's a wonderful institution and to be done by volunteers, it's exceptional. It's humanity at its best.*

Factors associated with the CC club process

The CC is well advertised throughout the Hospital and the Solaris Care Centre so the invitation to participate reaches a wide range of patients. Participants indicated they found out about the CC through referrals from their haematologist, general practitioner, the Solaris Care Centre, the local cancer council and from informal acquaintances already involved who very positive about their experience.

The fact that partners and family members are welcome is an important positive factor as many are dependent on family support for transport and practical assistance, as can be seen by the following statement:

- *You're perfectly welcome to bring your partner, your husband, wife, or mum, dad if it's young people. And they can exercise, or just stand around. And quite a few of them have done that.*

The involvement of volunteers, often themselves cancer survivors or with a family member with cancer, who have exercise rehabilitation skills is a valued aspect of the CC club for members. The volunteers are seen as contributing a unique altruistic aspect:

- *And there are a lot of people who've kind of gotten over their cancer, and come back as volunteers who all seem to know what they're doing. Many of them are in sort of sports medicine, some physiotherapy, some massage. I don't know whether it's because it's voluntary that it's the best. Because people are doing because they want to do it, not because they are paid to do it.*

Key factors that encourages participation in the club are the respect and caring provided to the patients:

- *It's being treated with respect and great care by the people who run the gym and the volunteers. They're very caring about the whole process. And just the knowledge that somebody cares enough about people they've never met before to actually come along and volunteer their time too, to help us.*

The volunteers provide a non-judgmental supportive environment, as can be seen by the following statement:

- *Because they got an empathy, particularly with new people. And while they're doing exercises some of them will just talk to them. And even the volunteers have been though it [cancer] as well, so they, there isn't any fear of someone being upset about what you're talking about. All the people and all the volunteers are all been in your position, so they will understand.*

The emphasis is on creating an informal supportive environment that welcomes all adult individuals diagnosed with cancer:

- *It's a very informal set up, which is really very pleasant. And there's no discrimination of age, colour, creed. Some people are like 80 years old, and they're so patient. And so kind. And they go through these exercise routines with their people without question.*

An important factor contributing to membership in the CC and participation at the gym is the fact that it is free:

- *It's all free. [Manager of Aspire Fitness Centre] donates his gym for an hour on Tuesdays and an hour Thursdays. All the gym equipment is free to us to use within that hour. Obviously the cost factor, the fact that it's free and voluntary is a huge factor.*

The gym in which the CC meets is well resourced with equipment, a fact that is valued by members:

- *The good thing about the gym too is that there's a huge amount of equipment. There's more work stations than people, so there might be a bit of negotiation goes on about who uses it in what order, but there is so much equipment that you don't have to worry about standing around doing nothing waiting.*

The wide range of equipment at the gym is seen as providing many exercise options. The participants value the individual attention they are given and the fact that a program is designed for their individual needs, as one participant explained:

- *And it's the first time anybody has taken any interest to even try and do anything. The crew, they've set out exercises for us to do. Everyone's got different exercises and mine is just trying to build up my body muscle. Everybody's given a book, a personal training diary.*

Participants value the supervised and controlled exercise environment where there is a lack of pressure to perform, as one participant explained:

- *And what I like about it as well is that there isn't any assessment. I think it's just giving you an opportunity to exercise under controlled conditions. Because there's always somebody there watching. And you're under no pressure to, sort of keep up, or do anything in particular.*

A playful and fun approach is taken to encouraging members to exercise. Most importantly, the staff are aware of each member's physical limitation caused by the disease and the treatments:

- *It feels very safe. In contrast to other gyms where you get these people who've got a fitness training certificate but that's all. And they don't really understand that in our condition the last thing we need is to pull a muscle as well.*

Vignettes were provided of the adverse physical outcomes for other cancer patients who had been pressured to extend themselves at other gyms where the staff did not take into account the physical limits of cancer patients. The supervision and individual attention provides a safety net for members, as one participant explained:

- *But it's in a safe environment. They're watching you all the time, giving you hints, like sit up straight, which I found lacking in other gyms. You didn't always have anybody there that could tell you were doing something wrong. So I quite like that because I know that you're not doing any harm.*

There is a flexibility and individual focus in the exercise program that allows individuals to participate, or not participate, in parts of the program depending on their physical abilities and limitations. This is demonstrated by the following example:

- *You finish off a session with a cooling down walk around the oval. I don't participate in that, because previously to me having my breasts off, I was already booked in to have a knee replacement. So I find it difficult to walk.*

A major attraction to participate in the CC is the supportive and positive interaction with other member, as one participant ably expressed:

- *I've got to say that talking to all the people who go to CC, it makes me want to go and get some exercise.*

Factors associated with the individual cancer patient

It was noted by the participants that the CC would not suit everyone. The members expressed a strong non-judgmental acceptance of the fact that CC involvement is an individual preference. Individuals who are members spoke of their strong commitment to incorporating their involvement in their daily routine:

- *I mean you can sit in the chair at home just feeling so sick, um, but just making that effort. Chemo Club days are Tuesday and Thursday and nothing comes between those days if you know what I mean. In other words it's up to you as to how hard you pursue it.*

The characteristic motivation and determination of CC members can be seen in the following statement:

- *And the CC two years ago seemed like an insurmountable challenge to try and incorporate that with everything else. But this year I thought 'no, I've got to think about what's right for me', and this is really important for me. Because it's possible this year that by July or so I'll be in preparation for a stem cell transplant. And I thought 'I've really got to think about getting myself into the best possible shape before I have a transplant'.*

Barriers to participation in CC

Physical limitation is not a barrier to participation. There were numerous stories of individuals participating regularly in the face of quite significant physical hardship. However, there are points along the continuum of ill health where the severity of the illness or the invasiveness of the treatment translates into a barrier, as can be seen by the following statement:

- *There've been times when I've had to stop because of surgery or chemotherapy. I did visit about two years ago, but at that point I was just too sick to really, well, I think my morale was just so low.*

As the name of the program suggests, being on

chemotherapy is not a barrier. However, there are times when the side effects of the chemotherapy are so debilitating that it interrupts participation, for example:

- *If I go back onto chemo again, I'll just have to review that because it did knock me round a fair bit the last time. But, I've always gone back as soon as it was safe to go back. I am on chemotherapy now.*

For some participants, a barrier was the scarcity of time available to attend the CC after fitting in all the demands of work and survivorship. The scheduled hours for the CC can conflict with work commitments. Some members have personal time restrictions that limit their attendance. Travel time can also be problematic as demonstrated by the following statement:

- *But I mean I know that there are people that come and it takes them 45, 50 minutes. I'm sure many more would come if they lived closer.*

The problem of travel is compounded by the fact that some members have to rely on the good will of family members to drive them there and can have problems with availability and fatigue in relation to public transport.

DISCUSSION

There is now a wealth of literature available that affirms the importance of exercise for cancer patients. Recent research highlights the need for health promotion strategies for cancer patients to encourage positive changes in exercise habits.[16] The challenge, according to the literature, is to develop strategies that will engage cancer patients in regular exercise. The findings presented in this article are a direct response to the call in the literature for research that documents factors that act as both facilitators and barriers to participation in exercise programs for cancer patients.[1,11,19] In view of the major benefits to be gained from exercise programs for oncology patients, the hope and expectation is that the insights will go some way to assisting with the successful proliferation of such programs.

As Diagram 1 details, the findings indicate that there are a wide range of factors associated with the ethos and history, CC process and individual factors that impact on membership participation. At the core of the findings is the importance of a positive environment where patients are supported to participate in a flexible program with supervision and individual attention by those with an understanding of the impact of cancer and its treatment on the cancer patient's body and ability.

The findings make an important contribution to addressing Midtgaard and associates'[25] concern that the in-group processes associated with physical exercise interventions for cancer patients is, to date, a neglected topic in the literature. Midtgaard and associates'[25] research indicates that group cohesion for the exercise program they were documenting was characterised by a special 'esprit de corps' which enabled the team members to feel like part of a sport team and thus allowed their illness to fade into the background. The findings presented in this article on the CC also indicates the importance of a special 'esprit de corps' but, in contrast to Midtgaard and associates'[25] research, it is about accepting the physical limits of the body caused by the disease and its treatments and normalising the cancer experience. As discussed elsewhere in relation to the findings on the benefits of the CC for members,[26] it is the normalising comfort of a reference group of individuals who share the cancer experience that is at the core of the 'esprit de corps' of the CC. Indeed, the findings on the CC more closely resonate with research by Stevinson and Fox[11] that documents that positive features of an exercise program for cancer patients include the variety and scope of the exercises, the empathetic but positive approach of the instructors and the small group format, which was valued for the social support and inspiration members received from each other.

The work of Adkins[27] points to three factors facilitating participation in exercise programs for cancer patients: instilling a positive attitude toward exercise, confidence in conquering barriers and a supportive social environment. The present study affirms Adkins'[27] focus on the supportive social environment, yet suggests that the motivation and positive attitude to exercise are factors that individuals bring to the CC.

An important notion voiced by members of the CC is that such an exercise program is not suitable for everyone. Research by Stevinson and associates[28] affirms the idea of individual differences in relation to preference to participate in an exercise club with findings indicating that of the ovarian cancer survivors they surveyed just over half (53.8%) expressed interest in participating in a physical activity program. The most common preferences were for programs to be home-based, start post-treatment and involve walking. Their important conclusion is that the differences in preference were based on demographic,

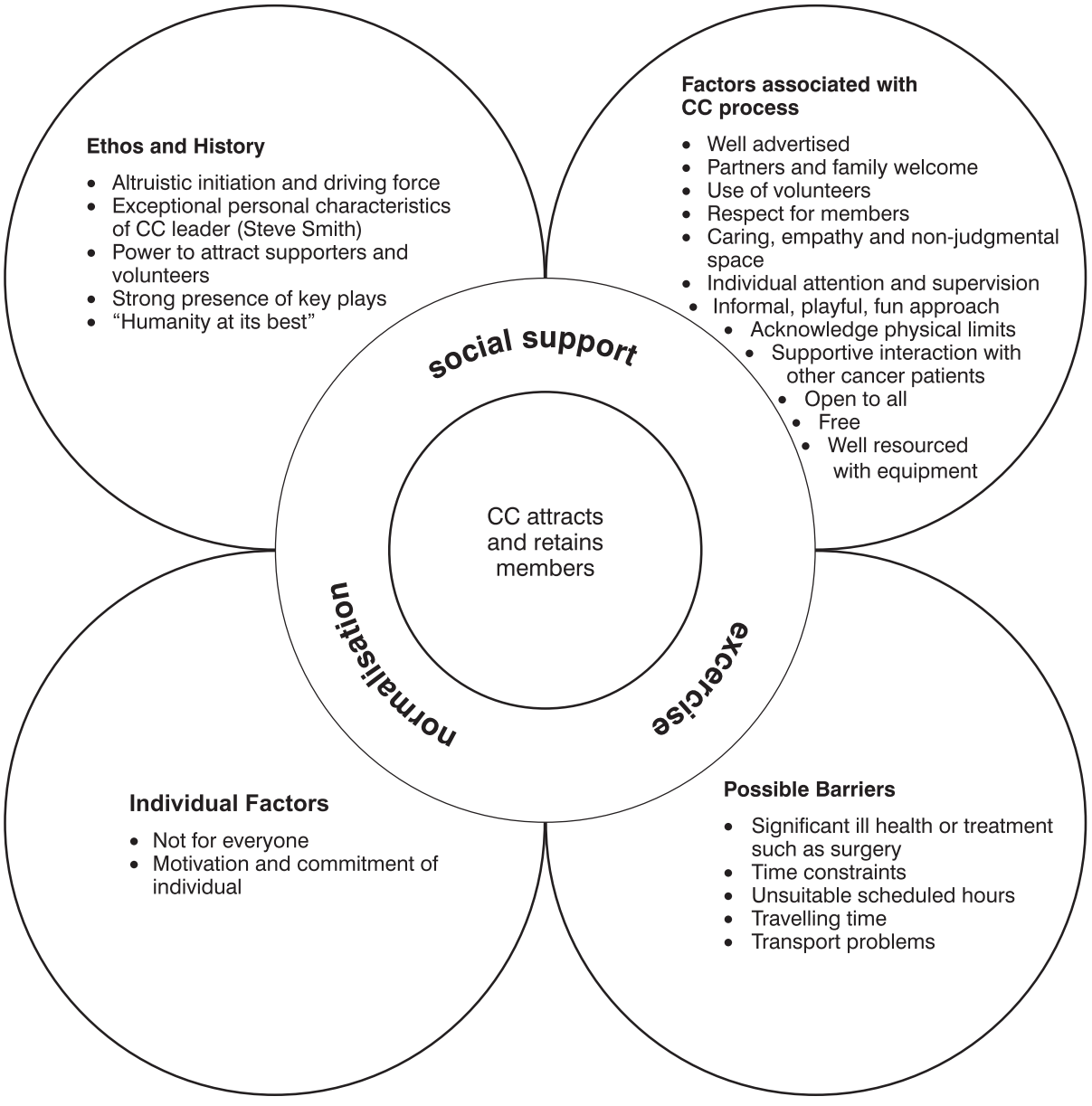

Diagram 1: Summary of findings on factors that contribute to attracting and retaining members to the Chemo Club exercise program.

not medical, factors. Rogers and associates' research[29] documented similar individual differences with the majority of participants preferring walking, moderate-intensity, home-based exercise with common exercise adherence barriers including lack of priority, issues with self-discipline, procrastination and fatigue underpinning individual reasons for non-participation among breast cancer patients during treatment. The effect of age in determining preference has been documented by Whitehead and Lavelle 4, with older breast cancer survivors preferring gentle, holistic exercise, tailored to their age and cancer-related abilities, involving other older breast cancer survivors and led by an instructor who is knowledgeable about both breast cancer and aging. The important point from all of this research is that there needs to be a variety of exercise programs to cater for individual needs and preferences.

The importance of individual attention and a flexible but supervised program is noted elsewhere in the literature. For example, research by Peeters and associates 8 indicates that a structured exercise program, providing an individualized fitness program tailored to the patient's illness, treatment and fitness level, is an effective

medium for addressing the extensive variability in disease and patient characteristics. Similarly, Milne and associates[14] found in relation to breast cancer patients that supervised exercise may help to develop a positive exercise motivational profile that could portend longer-term adherence.

Although there is scant literature on the barriers to participation, issues of time and parking are recorded as factors to take into consideration.[8]

RECOMMENDATIONS

Although each factor documented by the participants can be discussed in relation to the literature, it is important that the findings, as summarised in Diagram 1, are taken in totality. It is the unique interfacing of all of the factors that the members of CC see as the attraction that draws them to participate in, and gain benefit from, this exercise program. As a significant aim of publishing the findings is to contribute to the successful proliferation of exercise programs for cancer patients, it is important to emphasise that any of these factors may not have stand alone power of attraction. An exercise session at the local gym without, for example, the compassionate leadership, the in-group support, the individualised program, the respect, the volunteers and the lack of cost may not be effective in attracting and retaining membership of individuals coping with cancer. As with all issues associated with the psycho-social aspects of cancer care it is the holistic approach that is at the core of any successful program.

CONCLUSION

The insights in this article were generously provided by a group of people who are integrating a program of regular exercise into their lives at a time when they are dealing with all of the challenges associated with the diagnosis and treatment for cancer. The hope and expectation is that the collective wisdom expressed in this research can be used to help establish similar programs elsewhere so that other cancer patients can benefit not only at a physical but also a psycho-social level. At the core of this program is a supportive and compassionate individual response, as one participant stated:

- *I think they look after the individual people… their exercises are tailored towards their needs.*

ACKNOWLEDGEMENT

The authors would like to thank Dr David Joske and Mr Steven Smith for their contributions to the study.

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