Original Article

Rethinking the Meaning of "Wellness" for a Person with Cancer: A Qualitative Study to Explore What Elements Constitute "Wellness"

Jodie Nixon^{1,4}, Raymond Chan^{2,3}, Emma McKinnell², Elizabeth Ward^{4,5}, Elizabeth Pinkham⁶, Laurelie Wishart^{4,5}, Elizabeth Miller², Bena Brown^{4,5,7}

¹Department of Occupational Therapy, ²Division of Cancer Services, ⁶Department of Physiotherapy, ⁷Department of Speech Pathology, Princess Alexandra Hospital, Brisbane, Australia, ³School of Nursing, Queensland University of Technology, Brisbane, Australia, ⁴School of Health and Rehabilitation Sciences, University of Queensland, Brisbane, Australia, ⁵Centre for Functioning and Health Research, Metro South Health, Australia

Corresponding author: Jodie Nixon, PhD. Department of Occupational Therapy, Princess Alexandra Hospital, Brisbane, Australia. E-mail: jodie.nixon@health.qld.gov.au

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ABSTRACT

Objective: This study explored what people with cancer and their family members define as wellness, and what they perceive to be the needs to support wellness during the cancer experience. Methods: This study utilized qualitative focus groups underpinned by an interpretative descriptive design. Participants included people with a cancer diagnosis having completed/currently undergoing cancer treatment, and/or family/friends. Participants were invited to share their experience and perceptions of cancer wellness, which was then mapped in relation to Hettler's six dimensions of wellness. Results: Twenty-six participants (16 people with cancer, ten family/friends) were involved in the process. All six dimensions of wellness were reported by the groups with 19 descriptive content categories that related to these domains.

The data revealed that people with cancer and family/friends have individual and diverse meanings of wellness. Participants offered suggestions for strategies to promote wellness relating to the environment and supportive care interventions. Conclusions: People with cancer and their families experience wellness individually. Cancer wellness models should consider the personal nature of wellness in relation to the six domains of wellness when developing wellness programs, including health professional access, an environment that supports wellness, the provision and access to reliable information, and support the key needs of being physically active and financial security.

Key words: Barriers, cancer, facilitators, survivorship, wellness

Introduction

The concept of "wellness" in the population of people with a cancer diagnosis has evolved alongside the recognized importance of psychosocial care.^[1,2] In 1948,

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the World Health Organization started discussing the merit of wellness in relation to health care, and "wellness" is

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currently defined as: "...the optimal state of health of individuals and groups." For wellness to be achieved, people must be able to fulfill physical, psychological, social, spiritual, and economic needs; additionally, people need to be able to obtain role expectations of family, community, and other places of connection. Over the past two decades, more people are living following a cancer diagnosis, many with long-term side effects, as such, cancer is now considered a chronic disease. To manage the long-term impact of a cancer diagnosis and its treatment, many facilities have recognized a shift in service delivery is required to provide ongoing surveillance and management of cancer but also to support the overall wellness of people living with cancer.

A number of national bodies have recommended components of care that should be included in a wellness model or program.^[2,5] Wellness models of care have been constructed worldwide to provide an array of resources to help support people with emotional, physical, spiritual, and social needs.[1,6,7] The Clinical Oncology Society of Australia (COSA) Model of survivorship care recommends using six dimensions of the Wellness Model proposed by Hettler, [8] as a guide to inclusion in support programs. [1,5] The six dimensions of wellness include physical, social, occupational, intellectual, emotional, and spiritual [Table 1 for definitions].[8] Wellness models of care can vary from dedicated cancer/wellness centers to programs embedded into current practice. However, regardless of type, limited uptake of wellness interventions by patients/families has been reported by multiple studies. [6,7,9] A needs and expectations study of attendance at a wellness center in Canada (n = 33) reported that nonattendance was focused on communication and administrative issues, distance from the center, and challenges with parking availability and cost. [6] A study of 188 people with cancer in Australia reported that main barriers to attending a wellness program were parking (72%) and feeling unwell (36%). [10] Due to the low attendance and uptake of wellness programs, studies have shown that there are emerging concerns from health providers that wellness models have insufficient evidence to warrant further establishment or continuation.[11]

For the purpose of this paper, the definition of survivorship used by COSA, based on the National Coalition for Cancer Survivorship will be used, and states "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life." Despite survivors reporting a high interest in receiving ongoing survivorship support, patterns of participation in wellness programs are low, [12,13] highlighting the potential mismatch between consumer needs and the services being provided. As medical treatment advances and social expectations evolve, it is helpful to revisit these concepts by understanding the

contemporary views of patients and their support people.^[14] In order to gain a balanced understanding of the health need to inform health service planning, a review of the changing patterns of health needs and subsequent alignment of service delivery is required.

Therefore, the purpose of this study was to gain insights regarding what constitutes wellness for people living with cancer and their families/friends. This information was sought as the first step, to begin to inform the planning for a wellness model of care in the treating cancer care facility.

Methods

This study utilized an interpretative descriptive design.^[15] The research was approved by the local human research ethics committee (HREC/17/QPAH/50-AM/2018). Informed consent was obtained from all participants. The Standards for Reporting Qualitative Research was used to ensure methodological rigor.^[16] Data collection occurred between November 2018 and February 2019.

Participants

Patients and their family/friends attending a quaternary metropolitan cancer center in Australia were invited to participate through hand-delivered written invitation or flyers placed in the waiting room. Approximately 1000 people attend the center for care each week. Inclusion criteria included any person with cancer and/or family/friend who attended the hospital during the recruitment period between October 2018 and February 2019. Participants were excluded if unable to participate due to altered cognition at the discretion of the recruiter who was an experienced cancer health practitioner. Participants were offered a variety of times to attend for the sessions and the option of complimentary parking.

Procedures

Participants were invited to attend a focus group to discuss their experience and need of wellness services in relation to their cancer journey. In recognition of the pragmatics of recruiting for a real-world study if participants were unable to attend a booked focus groups, they were offered the opportunity to attend an individual session. Focus groups were conducted by two members of the research team and offered on-site at the treating facility, or off-site at a local research center. Participants were provided with stimulus questions, allowing them time to reflect on their experience before discussing it in session. The focus group explored (i) thoughts and feelings about the definition of wellness, and (ii). wellness needs during the cancer experience [Appendix 1]. The stimulus questions were reviewed for relevance by a consumer advisor. Two hours were set aside for each session. The focus groups were audio recorded and transcribed

Table 1: Cancer wellness descriptive content categories			
Dimensions of wellness	Descriptive content categories	Needs/wants	
Physical	"One way or another, I have to move"	Programs that include Professional support Exercise/gym Complementary therapies (gentle physical movement) Body therapy	
Social	My experience of others	Advice, consultations with health professionals	
	"What can I do for you?" the impact of others		
	Service level factors	Hospital and community	
	Access to	Supported and co-ordinated care information The hospital High-quality community services	
	Connection with the environment	An environment: that feels less medical, allows to connect with people, and supplies reliable information	
	Connection with people		
	Family and pets		
	Online portal		
Occupational	My financial position		
Intellectual	Self-care, meditation, relaxation	Programs that include Mindfulness and relaxation Music	
	Maintaining "normal" - "it meant that things were normal"		
	Wellness is "finding my happy place"		
Spiritual	Spiritual connection		
	Sense of purpose		
	"It's a personal thing"		
	Being with nature		
Emotional	Personal factors (priorities, day to day health)		
	My outlook on life		

Physical- recognizing the need for regular physical activity and gaining knowledge on diet and nutrition. Benefits from this dimension often lead to psychological benefits such as enhanced self-esteem, self-control, determination, and a sense of direction; Social- encouraging a contribution to one's environment and community that can enhance personal relationships, improve one's living space and build a better community, Intellectual- recognizing one's creative, stimulating mental activities and exploring issues related to problem solving, creativity, and learning, Intellectual- recognizing one's creative, stimulating mental activities and exploring issues related to problem solving, creativity, and learning, Spiritual- recognizing the search for meaning and purpose in human existence so that one's actions become more consistent with their own beliefs and values, Emotional- recognizing awareness and acceptance of one's feelings so that feelings can be expressed freely and managed effectively, and Occupational- recognizing personal satisfaction and enrichment in one's life through work. Important components include choice of profession, job satisfaction, career ambitions, and personal performance (COSA, 2016). COSA: Clinical Oncology Society of Australia

verbatim for subsequent analysis. The same interview schedule was used for the one-on-one session.

Content analysis

Descriptive analysis of the sessions was conducted using an interpretive descriptive approach by Thorne.[15] This approach is a qualitative methodology that is used to generate knowledge relevant for the clinical context. The research team has knowledge of the content, being clinical researchers, active members of the hospital cancer wellness initiative, and has visited other established cancer wellness centers. The researchers who undertook the focus groups and theming have extensive qualitative research experience. Initial descriptive analysis was undertaken by two members (JN, BB). The analysis involved a four-step process:[15,17] (1) Comprehending – the team learnt about the experience of the study participants through conducting the focus groups, listening to the audiotapes, reflecting on the rough notes, and reading the transcripts; (2) Synthesizing - this is the sifting process where refining and comprehending the typical or composite patterns within the data helps to form common descriptive content categories from the ten sessions; (3) Theorizing – this step involved mapping

the common descriptors from the sessions against the six dimensions of wellness as recommended for use by the COSA Model of Survivorship care^[5,2] [Appendix 2]; (4) Recontextualizing – the research team further review the synthesized the descriptive content categories into a form that are applicable to the health care context and is presented in both the results and discussion sections.

Results

Participants

Sixteen people with varying cancer diagnoses and ten family/friends attended ten sessions. Sessions ranged from 1 to 4 participants, with an average of 2.6 in each. One session had one participant due to the convenience of the participant. Demographics are described in Table 2. Ages ranged from 39 to 84 years [Table 2]. Over half (56%) of the people with cancer had a family member/friend attend, of which the majority were spouses.

Interviews

Sessions ranged from 29 to 120 min (mean 68 min). Analysis of session content revealed 19 descriptive content

Table 2: Demographic profile of participants		
Characteristics	n (%)	
Person with cancer	16 (100)	
Age (years)		
39-49	3 (19)	
50-60	6 (38)	
61-71	4 (25)	
72-82	2 (12)	
82+	1 (6)	
Gender		
Male	5 (31)	
Female	11 (69)	
Type of cancer		
Breast	8 (50)	
Prostate	2 (12)	
Head and neck	2 (12)	
Liver	1 (6)	
Leukemia	1 (6)	
Other	2 (12)	
Current active treatment		
Yes	11 (69)	
No	5 (31)	
Family/friend attended		
Yes	9 (56)	
No	7 (44)	
Family/friend	10 (100)	
Carer relationship		
Spouse	7 (70)	
Friend	3 (30)	
Number of sessions	10	
Number of participants in sessions		
Range	1-4	
Average	2.6	

categories, and these were mapped across all six dimensions of wellness [Table 1]. Each of these categories contained wants/needs and is reported in detail [Table 1 for overview]. The physical and social dimensions (which include environment) were the two most frequently discussed domains that constituted the meaning of wellness for the group, followed by occupational (including financial), the subsequent dimensions of intellectual, emotional, and spiritual were also discussed however with less frequency.

Physical dimension [Table 1]

A large proportion of the group described that for them wellness before cancer diagnosis, during treatment, and into survivorship was linked to a sense of being physically well and active:

"As far as my wellness goes, I've always done some form of walking-about 40 min to an hour a day" (FG4, male)

"Because wellness, exercise-which is what gives me my wellness-has been shown to increase my survival. So if I don't exercise, then I'm stealing time, potentially, from my family, so I kind of have to look after my own wellness now" (FG3, female).

The majority of the group had a strong understanding of the importance of physical activity in relation to wellness, however expressed that sometimes it was difficult to feel motivated to exercise, and often hard to find services to support them:

"Going through chemo and various things, there are days when I just veg on the couch." (FG3, female).

"For me a big thing was finding services like physio and if there was, I don't know, a wellness clinic or something where you can actually access everything" (FG9, female).

The need for support from health professionals both with advice and guidance, but also access to a gym/formal exercise program was expressed by a large number of the participants:

"Can we have a drop-in gym, like a 24-hour access with somebody there, one of the physios there, just in case, just to keep an eye on you, but you're not necessarily that closely watched" (FG3, female).

Some participants commented on the benefits of activity such as yoga/pilates, and other complementary therapies:

"I think a wider variety of classes as well, so not only the weights and the cardio, but yoga and Pilates" (FG3, female).

Although infrequent, other suggestions for what constituted wellness needs and wants that overlapped across the physical, spiritual, and emotional dimensions, included access to and practices of tai chi, reiki, mindfulness, and the use of music.

Social dimension [Table 1]

The majority of participants discussed the social domain as a reflection of feeling connected to the community of people which included family, friends, health professionals, and the environment that they interact with as a means to support wellness. The value of relationships, advice, and consultation with health professionals, which assisted people to feel supported in making choices that related to wellness was discussed multiple times. As one participant explained:

"If I want to find out something medical, I either go to my GP or I talk to somebody like yourself. I'm not going to go online and go, yes, look that's what's wrong with me, because all that's going to do is cause more problems" (FG10, male).

Participants discussed how the support of the hospital community contributed to the feeling of wellness while having treatment, with descriptions of:

"The staff are amazing-exactly, you do become-really have become my community and my support network" (FG3, female).

In addition to the general hospital community network, participants also highly valued a supported and co-ordinated approach to their care which helped to enable a feeling of wellness:

"Wellness is making all efforts to surround yourself with information and persons, medical and allied health, to enable you to function to the best of your ability by being supported and listened to and given tips and coping strategies to enable a positive outcome to your state of mind, health and wellbeing" (FG8, female).

The other significant impact that participants and families/friends discussed was the social support of others in their local community constantly saying, "What can I do for you?"

"You just can't believe, I mean, how nice people can be when you're in such a shitty place and as I said, nobody-people came and had coffee with me in the morning before I'd go to the hospital and they'd bring meals and-they were just amazing. They were so supportive." (FG8, female).

Participants discussed in addition to getting support from health professionals and community, social well-being meant being able to access support for addressing a variety of needs – which included "access to information," "the hospital," and "high-quality community services." Participants had different experiences with accessing information, with some feeling they had all the information they needed:

"I've never really worried about things that are completely out of my control, so I'm a very pragmatic person and I like lots and lots of information and reading, and once I've got that information, I know that I can just positively move forward to the next day, and just take one day at a time" (FG6, female 2).

In contrast, a small group found an ongoing struggle to get information that was reliable which was subsequently reflected in their feeling of insufficient social support required to support wellness:

"So far the process to get information hasn't been easy. It's been quite a struggle. There hasn't been really any support that has been offered in any way. We've had to go searching for it and looking for it ourselves" (FG5, female).

Access to quality services and information within the hospital and the community were of high importance to participants. Participants identified the want for ongoing professional support including dietitian, physiotherapy, and having Centrelink (i.e., government welfare) assistance on site, with suggestions such as:

"Whether it be a psychologist talking to people about how to break back out into the world or whether it be someone coming from-I don't know, a work-based company coming in and helping people" (FG9, female).

In the social dimension, participants described that not only a strong "connection with people" was essential for wellness, but that the connection with the environment contributed to a feeling of wellness. There were multiple references to the concept that a wellness space must have a strong "connection with the environment:"

"It needs to be modern and cheery. Someplace to go for a coffee would be really, really nice." (FG3, female) "Like the garden

space which is where we had lunch yesterday which was quite cool, so to have – especially because we're in Queensland – to have that more natural element I think" (FG7, female); "I think it helps break down social barriers as well. You sit down next to someone and you're having a cup of tea, you just-it's almost-it breaks down that-it's easy to start a conversation and chat" (FG6, female 2).

Numerous challenges were discussed in meeting social needs. Participants cited many practical challenges such as travel time to access the hospital, but of greater concern was the difficulty and cost associated with parking:

"I think the biggest thing, and what puts a lot of people off coming here, is the parking." (FG9, female); "I find the parking here frustrating. It's so bad" (FG1, female).

Participants discussed the importance connecting socially and that a wellness model should be easy to access in terms of the location, or online, and there must be free parking:

"So, having those things that are either closer in your community or having it accessible in your own home makes a huge difference when you're feeling so unwell" (FG9, female).

A consistent request from the participant group was the need to consider creating wellness supports "online" to optimize access for participants. Participants mentioned the concept of an "online portal," that would help people who had difficult attending in person, whether from a geographical, financial, or health constraints:

"If some people don't actually want to physically come in, they would-they still want to do the program-or access the program but not necessarily physically come in" (FG10, female).

Occupational dimension [Table 1]

The occupational dimension of wellness proposed by Hettler, 1976 is that of occupation which recognizes personal satisfaction and enrichment in life through work:

"If I can be well enough to be able to work, I'm going to work. If I can work, I'm happy" (FG1, male).

Although the financial position is not part of the definition of the occupational dimension, it was raised by a large number of participants when discussing occupation, with some reporting excellent support from work and income protection insurance, which had a positive impact on their ability to engage in wellness:

"I had incredible support from my employers. I had income protection insurance, so I wasn't financially struck or anything like that" (FG6, female 2).

Conversely, another group reported financial hardship made it difficult to access any additional wellness supports, despite the interest in attending things such as exercise group:

"It was really good, but I can't afford to come in all the time. So, it gets back to cost" (FG1, female). Approximately half of the group reflected on occupation/ finances and noted the significant impact of finances on their sense of well-being. Suggestions from participants in regard to support for this dimension included having a health professional who could provide assistance with financial navigation, support getting back to work after active treatment, and onsite social services support system to assist with financial inquiries, as often accessing these services was very challenging while undergoing treatment.

Intellectual dimension [Table 1]

Some of the group expressed that wellness is very individual and varied greatly. The needs addressed by the group in regard to intellectual wellness included practicing personal self-care which may include being kind to oneself, meditation or relaxation. Participants highlighted that wellness is very personal to the individual:

"I just keep coming back to healthy state of mind and healthy body. A state of mind again is a personal thing. It's something that different people feel is different for them. Whether you're a gym junkie or whether you're a couch potato, if you have a healthy mind, it doesn't matter what else you do provide you think right, think clear, think honest, be honest" (FG10, male).

Some participants expressed that the meaning of wellness included being able to maintain a sense of normalcy and that it was important for them to continue to be normal despite the cancer diagnosis, whether this meant going to work, looking after kids, or the way they presented themselves to the world:

"I had my face done every day. In the morning, I'd have a shower and the staff were like wow. They said even though I was on the way out... It meant that things were normal" (FG6, female 1).

The importance of experiencing normalcy with life included time and experience with family and with pets:

"A big thing for me with wellness is seeing my granddaughter's face every morning gets me through my day" (FG9, female).

"My dog. Contentment. He just-he's not a dog, he's a baby" (FG5, female).

Emotional dimension [Table 1]

The emotional dimension of wellness recognizes awareness and acceptance of one's feelings (Hettler, 1976). The groups had a strong focus on the link with happiness and wellness, with this concept being an easy way to explain wellness to the wider population:

"What I would-how I would describe it to my father in law is probably things that make you happy, is probably the only way that he would get it" (FG3, female).

Participants described personal factors that had a direct impact on their experiences of wellness. These included "*My priorities*" where participants described that their own

wellness before the cancer diagnosis did not take priority:

"I go to work, I get the kids, I look after the house, the shopping, the washing....if there's time for me, great; if not, it doesn't matter, so long as everybody else is happy" (FG3, female).

Or that wellness had become more of a priority since their cancer diagnosis:

"You have to take all the things that's happening to you and you have to re-adjust your lifestyle and re-adjust your train of thought to encompass what's happening to you and put that into a better place" (FG10, male).

In addition, there were discussions regarding the outlook people choose to take can influence the wellness that may be experienced, with one participant reporting:

"I can sit in the corner and cry, and don't worry, there are days I do it. But nine times out of 10, unless you get up and go and do something with that day, then you've wasted it" (FG9, female).

The other personal factor discussed was day-to-day health, and how it can be challenging to think about or maintain wellness while undergoing active treatment, however, most participants would counter-balance these challenges with what wellness meant to them at different times of the cancer journey.

Spiritual dimension [Table 1]

A small number of participants described that the meaning of wellness for them was having a sense of purpose in life:

"I think it's just basically about enjoying life and being productive and making sure the people around you are the same" (FG8, male).

Other meanings of wellness discussed by the group included having a connection with nature and the balance of spirituality:

"If I can go and sit on the beach or walk in a cool forest, that's the best" (FG3, female);

"I do respect science and I do love my spirituality and I like that mix" (FG6, female 1).

Although participants discussed spiritual connections and supports, there were no suggestions that this be included as part of health service provision.

Discussion

The 2006 definition of wellness that was based on the WHO, projects that wellness is about the optimal health for individuals, with two main components identified: first, the individual having the potential to realize their fullest ability in the physical, psychological, social, spiritual, and economic sense, and second, being able to fulfill roles to family, community, place of worship, workplace. [3] Reassuringly, the discussions from participants in this study found that wellness needs in 2020 are still consistent with the proposals of what constitutes wellness in the

cancer experience, with a strong focus on the physical, social (connections to health professionals, information and environmental), and occupational dimensions (including financial). These experiences described by people with cancer, and their family/friends, would indicate that wellness during and following cancer treatment is still highly desired to maintain an optimal state of health and that the organizational definition of wellness is consistent with the experience of this group of survivors.

Despite the extensive research supporting the benefits of exercise, [18,19] the published guidelines on physical activity, [18,20] and good understanding from this group about the benefits of physical activity, participants in this study continued to reflect on the challenges of staying physically active. Participants discussed they either did not know where to access safe exercise support that is geographically close to them, or that finances were prohibitive to attending classes/paying for parking at their treatment centers, or sometimes knowing how to get started. While access to reputable exercise services in the community maybe limited, more guidance on where and how to access this information from health professionals is needed. [21] Another more affordable and feasible support option for some cancer survivors might be telehealth exercise interventions or telephone counseling services. [22,23] This suggests the need for cancer services to provide information/registry on reputable, trustworthy exercise classes for cancer patients, or further research into the potential efficacy and/or benefits of an online cancer exercise program.

Participants and families/friends in this study described a high value of social support provided from both health professionals and the community of the hospital in sustaining wellness. An environment that is welcoming and friendly^[11,24] has been identified by participants in this study and in a previous study of 188 patients and carers as being a place that can be relaxing, where you can sit and have tea/ coffee, and chat to other people and health professionals as a means of obtaining support to enhance wellness.[10] Accessible information enables people to increase personal control and be more proactive with wellness than sometimes actual face-to-face services.[24,25] Although participants discussed the hospital environment as needing to provide both practical access through free parking and an environment that felt welcoming, they also discussed the possibility of accessing this wellness environment through an online portal option. To date, there have been minimal reports on whether the provision of wellness support and information needs to be face-to-face, via telehealth, or an online portal, however this is something that needs to be explored further. In the context of the current international coronavirus disease 2019 (COVID-19) pandemic, it would

seem reasonable that a combination of all these options need to be available to support cancer wellness options. [26,27]

A study that interviewed professional stakeholders' views of wellness centers concluded that wellness models do not have to meet all users' needs but be to be able to link the person to options that may already exist – either in the clinical, community, charity, or government sectors. [11] This view was supported by participants in the current study that agreed on the need to obtain reliable information about treatment and support options. The topic of financial challenges came up as a consistent theme with participants in maintaining wellness during cancer treatment. It is clearly reported that financial burden is associated with wellbeing in cancer survivors. [28] Although themed within the dimension of occupation, the authors feel that this is a topic that requires further exploration, and potentially acknowledge this as a separate dimension.

Limitations

As it was conducted in only one Australian health service, the results may not be generalizable beyond the local setting. However, it is noted that many of the outcomes are similar to of the findings from other health service areas and countries, suggesting the data may be applied to a wider population. One of the sessions only contained one participant which potentially reduced the richness of data gathered, however being a pragmatic real-world study, the research team wanted to include all willing participants.

Conclusions

The participants in this study have discussed that what constituted wellness for them is the ability to be physically active, social support of health professional, reliable information and a welcoming environment, and financial safety during a cancer journey. Cancer wellness models should continue to base service models on six dimensions of wellness with the consideration of including a financial domain.

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Conflicts of interest

There are no conflicts of interest.

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Appendixes

Appendix 1: Participant stimulus questions

We are interested in understanding your experience of accessing and engaging in health services and/or programs that promote your "wellness." This may help us provide better access, support, and services so more people with cancer, and their families can receive best-practice health care. This focus group will take 1 h of your time.

- 1. The definition of wellness long used by the National Wellness Institute is as follows: *Wellness is an active process through which people become aware of and make choices toward a more successful existence.*
 - What are your thoughts and feelings about the definition of "wellness"?
- 2. Think about your wellness needs both now, and during your cancer experience. Please write down what things make it easy to support your wellness, and what things are hard.

Appendix 2: Hettler's six elements of wellness

Physical: Recognizing the need for regular physical activity, which can then lead to enhanced psychological benefits such as self-esteem and self-determination;

Social: The person contributes to the community and the environment that enhances personal relationships which helps improve living space and build a better community;

Intellectual: The person recognizes creative, stimulating activities and supporting the exploration of issue related to problem solving, creativity, and learning;

Spiritual: The search for meaning and purpose in human existence, so that one finds connection and consistency with their own personal beliefs and values;

Emotional: Awareness and acceptance of one's feelings so that they can be expressed freely and managed to good effect. Occupational: Personal satisfaction and enrichment in life through work (Hettler, 1976).