



Original Research

Perspectives of Participation in Daily Life From Cancer Survivors: A Qualitative Analysis



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KEYWORDS

Cancer;
Occupational Therapy;
Qualitative research;
Quality of Life;
Rehabilitation

Abstract Objective: To characterize how survivors of cancer define participation.

Design: Cross-sectional qualitative study.

Setting: Participants were enrolled from a large academic medical center in the Midwestern United States. Interviews were conducted over Zoom or phone.

Participants: Survivors of cancer (N=40) with brain, breast, colorectal, or lung cancer (n=10 per group). Participants were purposively sampled to maximize variation in the study sample. Participant ages ranged from 26-83 years, with a mean age of 55 years. Seventy percent of participants were receiving active cancer treatment at the time of the interview.

Interventions: Not applicable.

Main Outcome Measures: Participant perspectives gathered from 1-on-1 semistructured interviews. Qualitative description and thematic analysis were used to analyze interview transcripts and develop themes from the data.

Results: Survivors described participation as doing valued activities and highlighted 4 common aspects: (1) control; (2) social connection; (3) engaging in various contexts; and (4) cultivation of joy and purpose. Fully participating in life involved being able to do what they want to do without restrictions or limitations. Survivors' perspectives of control outlined how competence, choice, adaptations, and locus of control influence broader feelings of control and participation. Interviews highlighted that participation remains central to daily life among survivors of cancer.

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The research was conducted at Washington University in St Louis School of Medicine, Department of Occupational Therapy and Siteman Cancer Center

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Conclusions: Rehabilitation researchers and clinicians need to establish a standard and comprehensive definition of participation. Rehabilitation providers need to consistently evaluate how participation is affected among survivors of cancer and use measures that include core aspects of participation identified in this study and previous research. Comprehensively defining participation will improve the design and selection of measurement tools and support comprehensive assessment of survivor experiences.

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Participation is recognized as the ultimate goal of rehabilitation,¹ yet there remains no universally accepted definition or standard approach to its measurement.¹⁻⁵ Participation was defined as “involvement in a life situation” in the International Classification of Functioning, Disability, and Health,^{6(p10)} but this broad definition does not fully encompass the construct.⁷ Continued challenges defining and measuring participation may contribute to its limited uptake beyond the field of rehabilitation.

Survivors of cancer, identified as survivors at diagnosis,⁸ are a rapidly growing population⁹ and a key group of individuals among whom we need to better understand participation and rehabilitation needs.¹⁰ While researchers, clinicians, and survivors recognize the need to support survivors in returning to work, school, and life activities,¹¹ they do not identify these as domains of participation. Cancer care does prioritize quality of life,¹² a related, but separate construct from participation.^{13,14} Ultimately, how rehabilitation scientists explain participation to other disciplines may support or further hinder its clinical integration¹⁵ and opportunities to refer survivors of cancer to rehabilitation.

As we work toward integrating participation into cancer care, we first need to understand what participation means to survivors of cancer. To further elucidate this complex construct we aimed to characterize how survivors of cancer with brain, breast, colorectal, and lung cancer define participation. Secondly, we aimed to describe how cancer affects survivors' perspectives of participation.

Methods

The institutional review board and protocol review and monitoring committee at Washington University in St. Louis School of Medicine approved this cross-sectional study.

Study sample

This study was conducted with patients of a large academic medical center located in the Midwestern United States. Participants included adults (older than 18 years) with any stage/grade brain, breast, colorectal, or lung cancer. Eligible individuals were in any phase of treatment or post treatment. We included multiple common cancer types¹⁶ to evaluate variations and commonalities across diagnoses. We aimed for 10 participants per stratum (N=40), which is typically a sufficient number to reach thematic saturation,¹⁷ the point when new themes are no longer emerging from the data.¹⁸ Individuals were excluded who were not English-

speaking or had aphasia because their ability to engage in a conversation would be limited. Purposive sampling was used to maximize variation, identifying individuals on and off treatment and with varying participation challenges. Potential participants were informally screened by the medical and research team to develop a basic understanding of their participation restrictions. A purposive sampling approach was used to ensure we were not gathering a sample of extremes or overrepresenting the perspectives of 1 group of individuals, for example, those with severe impairments.

The oncology treatment team approached patients about the study during clinic visits. Contact information of interested patients was shared with the study lead. One individual was recruited via snowball sampling. Verbal informed consent was completed over the phone. Most participants selected a preferred date and time of interview at the time of consent.

Data collection

Individual semistructured interviews were conducted over Zoom with video (n=16), without participant video (n=4), or over the phone (n=20) between September and November 2020. All participants were in a private location, typically the home, during the interview. A researcher not part of the treatment team conducted all interviews (mean, 57 minutes; range, 30-81 minutes). An interview guide (online supplement appendix) was developed based on previous research⁷ and clinical knowledge to understand the effect of cancer on survivors' daily lives. Interviews were audio recorded, transcribed verbatim, and deidentified. Participants self-reported demographic characteristics and treatment history.

The data presented in the current report are part of a broader mixed-methods research study focused on the participation experiences of survivors of cancer. The interview guide is divided into 2 sections in which participants first discussed their participation experiences and then provided feedback on 3 measures of participation. Please refer to the online supplement for additional details on the quantitative participation measures completed before the interviews. The entirety of each transcript was coded and included in this analysis, but only data specific to our current research question are presented.

Data analysis

Data were analyzed through an iterative team-based process by 5 researchers. Guided by qualitative description¹⁹ and thematic analysis,²⁰ a primarily inductive approach to coding was used.²⁰ Thematic analysis is a process through which

researchers synthesize participant experiences to identify collective meaning within the data.^{20,21}

Codes and definitions were documented in a codebook that was piloted by the team (A.L., A.M., A.T., N.H.) on 4 transcripts. The codebook was modified to improve clarity and tested on 1 additional transcript. Two coders independently coded each transcript; 1 team member reviewed coded text and coding discrepancies. When indicated, team discussion was used to resolve coding discrepancies; the single code reconciler (A.L.) made the final decision on text coding. Themes were developed (A.L., N.S.) by continuously analyzing and reviewing coded text to identify data patterns.²⁰ Data were coded using NVivo 12 software.^a For additional methodology, see the online supplement.

Results

Sixty-one survivors of cancer were contacted to participate after expressing interest in the study during an oncology clinic visit. Ten could not be reached, and 6 were no longer interested (reasons: request of spouse, too busy, did not feel their life was affected by cancer). Forty-five consented; 3 were lost to follow-up, 1 withdrew because of time limitations, and 1 wanted an in-person interview, which was not possible because of COVID-19 research restrictions. Throughout the data collection process, ongoing data analysis was conducted to

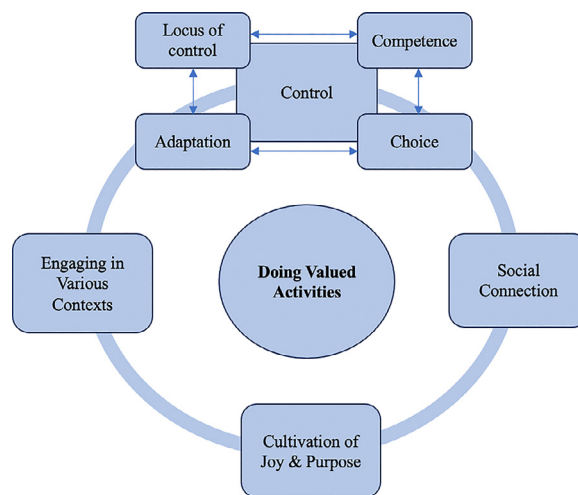


Fig. 1 Core aspects of participation.

identify emerging themes and assess saturation. After 35 interviews, we determined no new themes were emerging; however, only 6 individuals with colorectal cancer had participated. To ensure themes unique to the colorectal group were not missed, additional interviews were completed for an equal sample of 10 per group. Forty survivors aged 26-83 years participated (table 1).

Table 1 Participant Demographics

Participant Characteristic	Total sample n= 40	Brain n= 10	Breast n= 10	Colorectal n= 10	Lung n= 10
Current age, mean (range)	54.8 (26-83)	47.1 (26-67)	53.2 (37-67)	54.2 (33-66)	64.6 (41-83)
Years since first diagnosed with cancer, mean (range)	5.9 (0-24)	2.2 (0-5)	9.3 (1-24)	4.3 (2-9)	7.8 (0-24)
Sex (female)	27 (68)	4 (40)	10 (100)	5 (50)	8 (80)
Marital Status					
Single	6 (15)	2 (20)	2 (20)	0 (0)	2 (20)
Divorced	3 (7)	0 (0)	2 (20)	1 (10)	0 (0)
Married	29 (73)	8 (80)	6 (60)	8 (80)	7 (70)
Widowed	2 (5)	0 (0)	0 (0)	1 (10)	1 (10)
Race					
African American or Black	6 (15)	1 (10)	4 (40)	0 (0)	1 (10)
Asian	1 (3)	0 (0)	0 (0)	0 (0)	1 (10)
White	33 (82)	9 (90)	6 (60)	10 (100)	8 (80)
Receiving treatment at time of interview	28 (70)	8 (80)	9 (90)	4 (40)	7 (70)
Disease Stage (total n=30)					
I	2 (6)	N/A	1 (10)	0 (0)	1 (10)
II	6 (20)		2 (20)	3 (30)	1 (10)
III	5 (17)		2 (20)	2 (20)	1 (10)
IV	17 (57)		5 (50)	5 (50)	7 (70)
Treatment history,					
Chemotherapy	35 (88)	10 (100)	9 (90)	7 (70)	9 (90)
Surgery	26 (65)	10 (100)	8 (80)	2 (20)	6 (60)
Radiation	21 (53)	6 (60)	6 (60)	7 (70)	2 (20)
Hormone therapy	6 (15)	0 (0)	6 (60)	0 (0)	0 (0)
Immunotherapy	10 (25)	4 (40)	1 (10)	1 (10)	4 (40)

Abbreviation: N/A: not applicable.

Survivors described participation as doing what they find important or meaningful in their daily lives. No standard set of activities was valued by all individuals, but participation encompassed both what people wanted and needed to do in their lives and is summarized as the central idea of “doing valued activities.” Interviews revealed 4 common aspects of participation: (1) control; (2) social connection; (3) engaging in various contexts; and (4) cultivation of joy and purpose in daily life (fig 1). The final theme highlighted that participation remains central to daily life among survivors of cancer. Themes were assessed for differences across diagnosis groups, but no major differences were observed.

Control

Participants emphasized their desire to do what they want to do without restrictions. They wanted control and choice over what, how, and when they participate: “To physically be able to do whatever it is I want to do. Um, whatever that may be. Not to have any limitations.” (50 years, male, colorectal.) Embedded within control were the concepts of competence, or the skills or abilities needed to participate, locus of control, adaptation, and choice.

Competence (skills and abilities)

Cancer dominated the lives of many participants. Thus, their cancer experiences were often embedded within how they defined participation:

I did a lot of cooking and baking. Um I loved doing that for my family [voice cracks and gets high-pitched] and I can't really do that now because—and all of this is difficult because my left side is affected. The motor function has been um affected. . .so a lot of things have been lost.” (62 years, female, brain.)

Survivors' definitions emphasized treatment and disease adverse effects (eg, fatigue, colostomy issues, etc) and cancer-related limitations. Cancer and its treatment resulted in a change in the underlying skills of many individuals. With a change in skills, such as inability to raise an arm or stand for 5 minutes, survivors experienced a loss of control over their ability to do what they valued in life.

Participants felt they needed certain skills (eg, physical, cognitive) to be competent and able to fully participate:

“To feel physically strong enough and um mentally strong enough [is what] I feel like I need to, to take part in life fully.” (67 years, female, breast.)

Perceptions of what skills are needed to participate can be highly individual and yield different perspectives of participation. These differences are related in part to an individual's locus of control.

Locus of control

Two perspectives of control, internal and external loci, were apparent within survivors' definitions of participation. With an external locus of control, cancer was often in control of

the individual's life and survivors felt unable to change their abilities:

“I'd want to get rid of my physical restraints and go back to doing things.” (65 years, male, brain.)

Many felt that if they had specific abilities they would be able to participate:

“More and more, I come to think up of, well, if I could breathe, I used to like to work in the yard . . . I used to plant bulbs and flowers . . . I just absolutely can't do that anymore.” (75 years, female, lung.)

A loss of skill was often associated with the cancer experience and seen as outside of an individual's control.

With an internal locus, some survivors had a “don't let cancer stop me” mentality. These individuals focused on pushing past challenges to participate in life. An internal locus was also more dominant among survivors who experienced fewer adverse effects and participation restrictions. Overall, the complexity of survivors' experiences often highlighted both loci of control:

Most of it feels outside of my control. Yeah, I guess there's always more you could do. You know you could be a lot more self-motivated . . . I could take more chances, you know with the getting out of the house than I do. But I mean even yesterday, like I ran to [store], which is probably 5 minutes from our house and I had an accident, you know, while I was out so it kind of discourages you from wanting to get out.” (59 years, female, colorectal.)

Some survivors were still processing what control they had over their participation. Negative experiences often reinforced the control that cancer had over their lives.

Adaptation

Adapting, putting forth effort, or making specific plans to participate were strategies used by some to support participation. Adapting was a way to take action, control a situation, and control their participation. Some struggled to problem solve through how, when, or what to adapt to participate. After thinking through multiple ways to modify a leisure activity, a 39-year-old female participant with a brain tumor explained: “There's no way I could do that [activity] right now.” Despite wanting to adapt to participate many survivors expressed they were restricted in what or how they could participate because of a lack of control over their abilities and circumstances.

Choice

There was also an emphasis on having opportunities to choose to do what they want to do, another way of expressing they want control over their participation. However, many felt limited control over their lives because of their cancer experience. When an external locus of control was dominant, participants expressed they had fewer choices in what and how they participated.

Participants felt personal control when in a more stable situation with their disease and when they had the skills and

resources needed to participate. Resources provided choices and helped survivors participate in what they desired.

Social connection

Participation often involved doing activities for or with others, typically family and friends. Examples included cooking, going out with friends, or having a game night. Participation was often discussed in the context of life roles, such as being a spouse, parent, grandparent, or friend.

There was a desire among participants to be present and visit or spend time with others. Family members (spouse, children) were frequently identified as survivors' primary motivation and support to participate. Even when a few individuals discussed more solitary activities (eg, writing), some still connected these activities to other individuals (eg, motivated by other people enjoying her stories). For many, their cancer experience highlighted the importance of relationships and some made it a priority to participate with others:

"I just spent more time trying to do things with other people . . . I had a kayak for a year by myself and I was like, 'why am I doing this by myself?' So I got my wife a kayak." (26 years, male, brain.)

Communicating and socializing were central to participation and were important throughout the entire cancer continuum:

"To be able to interact with others and um being able to talk with them back and forth." (67 years, male, brain, considering hospice.)

Survivors expressed their desire to form connections with others through participation, but these opportunities sometimes became limited after a cancer diagnosis:

I used to be able to get up and do stuff, I was interacting with people, um you know, seeing them at the university, seeing them at church, you know what I mean? I was always interacting with people. Um, now I don't at all, and it's been [short pause, sounds emotional] something I really, I'm sorry about." (75 years, female, lung.)

Engaging in various contexts

Survivors discussed the importance of doing valued activities in various contexts such as the home, neighborhood, city, and work. For a subset of the sample, their concept of full participation included doing valued activities outside the home. Examples included golfing, shopping, driving, walking outdoors, traveling, and going to restaurants and appointments. Survivors wanted to "go out" to do things with others and to enjoy life:

"Be able to travel and see things and experience the things in nature that I would like to enjoy." (49 years, male, colorectal.)

Some survivors acknowledged that their cancer experiences limited their participation outside the home because of physical challenges, body image or infection concerns, bathroom urgency, and shifts in what they found important in life. For some, their home environment became their place of safety,

and they became hesitant to participate outside the home. When engaging less outside the home, social networks also became smaller, as discussed in the previous theme.

Survivors rarely focused on engaging with the broader community. While some discussed volunteering, valued activities outside the home were often done independently or with close family and friends, with little emphasis on broader community-focused activities:

[Being sick from chemotherapy was] when I realized how much I'd like to participate. Not necessarily in like group or community activities but just the basics, going to the store, uh you know, going shopping, taking the dog for a walk again, golfing with my kids, hanging out outside with my kids." (50 years, male, colorectal.)

Cultivation of joy and purpose in life

Survivors described participation as a meaningful and important component of their daily lives. They emphasized the personal value and satisfaction they derived from participating and how participation brought joy and energy to life and opportunities to learn:

"It means everything, um, it's extraordinarily, extraordinarily important . . . it's what keeps you young and it's what keeps you healthy, not to put any limits on yourself." (66 years, female, colorectal.)

Participation was linked to improved physical symptoms and mental health. Several participants suggested that participating served as a distraction from their cancer and improved their mental status:

"Once I find myself getting up and getting out and not thinking about [cancer] and doing things . . . to take my mind off of it and I think once I do that, I feel a lot better." (54 years, female, breast.)

Participating in life supported feelings of accomplishment, which helped establish a sense of purpose and meaning and could improve an individual's morale. While some felt accomplished when doing things for themselves, there was also an emphasis on wanting to contribute, from helping their spouse with a simple task to volunteering. Contributing was a way to have an effect on the world and promoted life satisfaction. However, opportunities to contribute were sometimes limited because of physical limitations or others' expectations of what is safe for a survivor of cancer to do:

I deal with . . . suggestions from my doctor to my family to my friends. 'You shouldn't do this' . . . That's all I hear you know all the time. Um, like I still wanna help others, but everybody thinks like now because I have this, I'm the one that needs to be helped. People don't want me helping." (43 years, female, breast.)

Participation remains central to daily life among survivors of cancer

Even when dealing with a variety of adverse effects and a life-threatening diagnosis, survivors still prioritized

participation. Participants explained they wanted to continue to live life and do what they enjoyed even while dealing with cancer. There were phases when participating was very limited for some, but it was still something they highly valued and fought to continue to do. Participating in life was identified as a priority among survivors. When participation restrictions were experienced, distress was common.

Cancer altered many survivors' perspectives of what was important in life and their participation priorities:

"My interest and desire for things that used to be there, it just kind of dropped off . . . I guess that the analogy of before it was a floodlight and now it's a focused pin light on what I find enjoyable." (49 years, male, colorectal.)

While some developed a narrower focus, others broadened their horizons and cancer was a catalyst to participate more fully:

"I think I've found my purpose . . . before I was just alive. And now I think I am living. I am doing more exciting things . . . and seeing different things that I've always wanted to see. And I love it." (54 years, female, breast.)

Survivors repeatedly emphasized their focus on not taking life for granted and appreciating life, which was central to how they viewed and defined participation.

Discussion

Research aiming to broaden the conceptualization of participation has historically focused on the perspectives of individuals who receive intensive rehabilitation after an injury or illness (eg, spinal cord injury, stroke). This study is the first to investigate how survivors of cancer conceptualize participation. Survivors' perspectives confirmed previous findings about core aspects of participation including control, choice, competence, social connection, community engagement, and meaning generation.^{1,2,7,22}

Findings also highlight how perspectives of participation may vary among individuals with different types of disabilities or medical conditions. The study by Hammel et al examining what participation means to individuals with disabilities primarily included individuals with spinal cord injury, stroke, or traumatic brain injury.⁷ Societal perceptions were emphasized in the participation values outlined by Hammel, including societal inclusion, rights to resources, and the meta theme of respect and dignity.⁷ The current study did not confirm these findings among survivors of cancer. Participants in Hammel's work likely had more permanent and static disabilities than survivors of cancer. Cancer is a dynamic process²³ and can result in a disability experience that is constantly evolving. Instead of focusing on how society views them and can adapt to their needs, many survivors are occupied by their disease, treatment, and associated changes within their body. Survivors identify the source of their cancer-related impairments (eg, fatigue) as coming from within; consequently, environmental adaptations and societal influences are underrecognized.

Disability^{7,24} and survivor of cancer identities^{23,25} can further shape perspectives of participation and rehabilitation.²⁶ Cancer-related disability is common,¹⁶ but it is

unknown whether survivors see themselves as people living with disabilities. Many of the disabling conditions experienced by survivors (eg, cognitive impairments) result in hidden disabilities. The hidden nature of these disabilities may explain why participants' perspectives of participation did not reflect the respect and dignity meta theme.⁷ Survivors may not see themselves as having disabilities, and neither does society, so survivors may not face the stigmatization experienced by other groups living with disabilities.

Survivors also frequently anticipate resolution of cancer-related symptoms once they have completed treatment. They expect, and are often told by medical providers, it may take time to get back to their "old self" and return to normalcy.²⁷ However, the complexities of cancer-related disability make it difficult to assess when and if patients will return to baseline and resume participating. Participation is a critical outcome of rehabilitation,²⁸ and we have demonstrated it is important to survivors of cancer.

Future research needs to define participation for a broad group of individuals with varying disabilities. Facets of participation identified in this study and previous research^{7,22,29} need to be systematically tested to develop an accepted comprehensive definition of participation. Measurement tools can then be refined and tested to support the clinical integration of participation measurement. Evaluating variability in participation experiences can help providers identify individuals who may benefit from rehabilitation.¹⁰

Study limitations

Environmental influences were rarely discussed by survivors. This may be because of the interview guide design; we were seeking to understand participation broadly and did not probe on environmental factors. However, survivors did not discuss environmental factors when asked about barriers or supports to participation, suggesting survivors may be less aware of environmental influences on participation. Prior to the interviews, survivors completed 3 quantitative participation measures because a portion of the interviews focused on engaging survivors in providing feedback on these measures. The content of the participation measures may have primed survivors about what the construct of participation means, as defined by assessment developers. It is unclear how this conceptualization of participation by survivors translates to all survivors of cancer and other populations. Our sample was intentionally broad to capture a wide range of experiences. It is encouraging that the core aspects of participation identified in this study are consistent with previous research.

Conclusions

Rehabilitation researchers and clinicians need to establish a standard and comprehensive definition of participation, which will support the design and selection of measurement tools. Rehabilitation providers need to consistently evaluate how participation is affected among survivors of cancer and use measures that include the central aspects of participation identified in this study and previous research.

Suppliers

- a. QSR International, NVivo Version 12.

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