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“Life Without Symptoms” or “Being Able to Enjoy Life”: What does it Mean to be “Well” After Cancer?

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Abstract

Objective: To achieve wellness in cancer survivorship, researchers and clinicians need a better understanding of what it means to live “well”, from the perspective of cancer survivors themselves. **Methods:** Australian and UK cancer survivors (N=376) diagnosed in the previous five years, were asked “*What does it mean to be well?*”, with an open-ended text response. Responses were coded using content analysis. Demographics, time since diagnosis, coping style and symptom level were also assessed. **Results:** Descriptions of what it meant to be “well” were coded as *absence-focused* (living *without* negative impacts of illness, 32.7%) or *presence-focused* (living *with* health, function, or wellbeing, 37.8%). A further 29.5% of responses contained both elements. Lower symptom level and higher use of a fatalism coping style were associated with presence-focused definitions of being well. **Conclusions:** More meaningful conversations with cancer survivors about their goals for care would be facilitated by a better understanding of what it means to them to be “well”. As symptoms change over the course of survivorship, it may be necessary to re-examine each survivor’s goals of care.

Keywords Cancer · Wellness · Survivorship · Patient-centred care

Patient-centred care can improve the quality of care that patients receive, empower patients to be active participants in decision-making, and lead to better health outcomes [1, 2]. The involvement of patients in care requires healthcare staff to understand and address patients’ priorities, life preferences, and overall goals. Healthcare systems are often designed to address clinical needs, with less focus placed on a patient’s non-clinical needs or broader goals. However, these non-clinical goals can be just as important to patients [3, 4]. Moreover, without explicit discussions of these issues, there may be misunderstandings from the perspectives of both patients and clinicians [5, 6].

In the area of cancer survivorship, modern advances in cancer detection and treatment have resulted in increasing chances of survival, with an overall five-year survival rate of 70% [7]. With more people surviving cancer, there is a growing need to address the persistent physical, psychological and social issues that many survivors experience [8]. In response, there has been an increasing focus on fostering “wellness” during survivorship.

The Clinical Oncology Society of Australia (COSA) Model of Survivorship Care incorporates the support of wellness as a key element of survivorship care [9] and there has been increasing development of wellness centres offering supportive care services [10–12]. However, only a small percentage of patients will be referred to, and subsequently use, these services [13]. Moreover, despite heightened interest in helping survivors to live well after cancer, researchers and clinicians still need a better understanding of what this means from the perspective of cancer survivors themselves.

A recent Australian focus group study examined what wellness meant to cancer survivors [14]. This study asked patients at a single cancer centre about their understanding of wellness in the context of health service provision, finding that survivors’ responses mapped onto Hettler’s six dimensions of wellness; physical, social, intellectual,

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spiritual, emotional and occupational [15]. Whether this definition applies to “wellness” outside of the context of service provision, for instance, for survivors many years from diagnosis and treatment, requires further investigation.

Another recent study examined this issue among a sample of survivors of adolescents and young adult (AYA) cancer [16]. AYAs’ definitions of wellness tended to focus on living a “normal” life in which the young survivor experiences similar challenges and rewards to their peers. The extent to which this focus, identified in a youth sample, is shared with adult cancer survivors, or whether the definition of “normal” life is the same, remains unknown. Certainly, life’s goals vary significantly with life stage [17, 18].

The aim of this paper was to explore what it means to live well as an adult following a cancer diagnosis by examining definitions of wellness provided by cancer survivors. A secondary aim was to examine the relationship between these definitions and time since diagnosis, current level of symptoms and coping style. A better understanding of these issues will help medical professionals, allied health clinicians, and caregivers work together to design care that prioritises survivors’ goals.

Methods

The study was approved by the La Trobe University Human Research Ethics Committee (HEC18534). Informed consent was obtained from all participants. Data collection occurred between July and October 2019.

Participants & Procedure

This paper uses the definition of “survivor” endorsed by the Clinical Oncology Society of Australia; a person is a survivor from the time of diagnosis, for the remainder of their life [19].

Participants were eligible if they were diagnosed with cancer in the preceding five years, aged 18 years or older, resided in Australia or the United Kingdom (UK), and were able to read and write in English. Participants were recruited through a market research company and a crowdsourcing online research panel and were reimbursed for their time. Survivors of early-stage melanomas or non-melanoma skin cancers were excluded because these cancers may follow a different treatment pathway than other cancers (e.g., day surgery). Participants were sent the link to an online questionnaire to complete at their leisure. This paper presents selected data from a larger survey, with methods reported elsewhere [20] and summarized below.

Measures

Demographic and diagnostic information were recorded, including age, gender, country of residence, cancer diagnosis and time of diagnosis.

Wellness

Participants were asked “*What does it mean to be “well”?*” Responses were made with an open-ended text response option. Additional explanatory text to prompt participants read, “We are asking for your own individual opinion about what it means to be a “well” person. This might differ from person to person”.

Coping

Coping strategies were measured using the Mini-Mental Adjustment to Cancer scale (Mini-MAC) [21]. The scale consists of 29 items measuring five subscales; helplessness-hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance, and fatalism. Items were rated on 4-point likert scales from 1 (Definitely does not apply to me) to 4 (Definitely applies to me) and were summed to create subscale scores.

Current Symptom Level

The Edmonton Symptom Assessment Scale (ESAS) [22] was used to examine participants’ current experience of nine key symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath). Ratings were made from 0 (none) to 10 (worst possible severity). Items were summed to create a total score.

Statistical Analysis

Participants’ text responses to the open-ended *Wellness* question were coded using content analysis [23]. Content analysis is well-suited to the descriptive analysis of short text-based responses that allows quantitative counts of the resulting codes [24]. Categories were derived directly from the data using a bottom-up, inductive approach. The responses were discussed in detail by two authors (CW and GS) during preliminary coding, resulting in several smaller codes being combined into larger categories. Final codes were then allocated by one author (GS) and 10% were double coded by another author (CW).

To examine factors associated with participants’ definitions of wellness a binary variable was created to indicate whether a participant’s definition contained a presence-focused response (either with or without an absence-focused

element, $n=253$) or not (i.e. an absence-only response, $n=123$). A second variable indicated whether responses contained an absence-focused response (either with or without a presence-focused element, $n=234$) or not (i.e. a presence-only response, $n=142$). Two logistic regressions examined whether these outcomes were related to time since diagnosis, current level of symptoms, and coping style. Age, gender, education and location of residence were also included. Analyses were conducted in STATA V17.

Results

Of the 459 initial participants who returned a survey, 63 were excluded due to extensive missing data or an insufficiently long response time to indicate a valid attempt. A further 20 people did not answer or misinterpreted the main variable of interest in this study and were excluded.

In brief, 315 Australian and 61 UK cancer survivors, aged 20–83 years ($M=62.81$, $SD=12.99$), participated. They were an average of 35.74 months post-diagnosis ($SD=18.57$, Range 0–67). 69% had completed treatment at the time of the survey. Most participants had a tertiary education (36.2%) or vocational training (34.0%). Participants were mostly female (52.3%) and were diagnosed with a range of cancers, with the most frequent being breast (23.4%), prostate (19.4%), haematological (10.4%) and

melanoma skin cancers (10.4%). The sample reported low levels of each symptom measured by the ESAS (Table 1).

What does it Mean to “Be Well”?

Themes and example quotes are provided in Table 2. Participants’ descriptions of what it meant to be “well” broadly reflected two themes: (1) the *absence* of illness, negative effects, mental stress, fear, ongoing treatment or restrictions (absence-focused; $n=123$, 32.7%), and (2) the *presence* of health, normal function, or positive mood (presence-focused; $n=142$, 37.8%). One-hundred and eleven people (29.5%) identified both absence- and presence-focused responses in their answers.

The most frequently cited absence-focused definitions of being “well” were living without symptoms or pain ($n=119$, 31.6%) and living without illness ($n=92$, 24.5%). The most frequently cited presence-focused definitions of being “well” were being able to do the things you wanted to do and be productive ($n=95$, 25.3%) and feeling good, positive and hopeful ($n=85$, 22.6%).

Relationship with Symptom Level and Coping Style

As shown in Table 3, defining being “well” in presence-focused terms (partly or wholly), was associated with a lower level of reported symptoms and greater use of fatalism

Table 1 Descriptive statistics for the mini-mental adjustment to cancer scale and the edmonton symptom assessment scale

Variable	Overall sample (N = 376)		Participants who provided absence-focused responses	Participants who provided presence-focused responses	Participants who provided both absence- and presence-focused responses
	Mean(SD) ^a	Range	Mean(SD) ^b	Mean(SD) ^c	Mean(SD) ^d
Mental adjustment to cancer (mini-MAC)					
Helplessness-Hopelessness	12.80 (4.86)	8–32	13.19 (5.27)	12.39 (4.42)	12.89 (4.94)
Anxious Preoccupation	17.46 (6.01)	8–30	17.82 (6.46)	16.80 (5.48)	17.91 (6.14)
Fighting Spirit	11.15 (2.54)	4–16	10.81 (2.63)	11.35 (2.42)	11.27 (2.60)
Cognitive Avoidance	9.71 (2.66)	4–16	9.69 (2.77)	9.71 (2.72)	9.74 (2.47)
Fatalism	12.87 (2.75)	5–20	12.40 (3.08)	12.82 (2.61)	13.45 (2.45)
Symptom level (ESAS)					
Pain	2.22 (2.51)	0–9	2.56 (2.66)	1.99 (2.49)	2.12 (2.35)
Tiredness	4.33 (2.85)	0–10	4.93 (2.79)	4.12 (2.74)	3.95 (2.96)
Nausea	1.11 (2.07)	0–10	1.17 (1.97)	1.20 (2.18)	.92 (2.02)
Depression	2.81 (2.99)	0–10	3.27 (3.08)	2.51 (2.81)	2.68 (3.07)
Anxiety	3.00 (2.96)	0–10	3.50 (3.15)	2.55 (2.78)	3.05 (2.90)
Drowsiness	2.86 (2.80)	0–10	3.25 (2.78)	2.73 (2.70)	2.59 (2.90)
Appetite	2.69 (2.48)	0–10	2.87 (2.44)	2.54 (2.54)	2.69 (2.47)
Wellbeing	3.49 (2.36)	0–10	3.96 (2.32)	3.13 (2.35)	3.42 (2.34)
Shortness of breath	2.50 (2.83)	0–10	2.88 (3.09)	2.24 (2.54)	2.41 (2.87)

^a Mini-MAC N = 373, ESAS N = 371

^b Mini-MAC N = 121, ESAS N = 121

^c Mini-MAC N = 142, ESAS N = 142

^d Mini-MAC N = 110, ESAS N = 108

Table 2 Categories identified from responses to the question “what does it mean to be well?” (N = 376)

Theme		Number (%) of cases	Example quote
Absence-focused	Living without symptoms or pain	119 (31.6%)	<i>Not suffering from pain or symptoms</i>
	Living without illness	92 (24.5%)	<i>I'm well because I am cancer free.</i>
	Living without anxiety, stress, mental illness or fear	46 (12.2%)	<i>Being well means not having to constantly worry about my health and not think about the worse case scenarios</i>
	Living without restrictions	23 (6.1%)	<i>Well means that my cancer (and it's ongoing side effects) aren't stopping me from doing anything...</i>
	Living without treatment	15 (4.0%)	<i>not needing to see doctors or visit hospitals</i>
	Living without fear of recurrence	5 (1.3%)	<i>Not having to think about the cancer coming back</i>
Presence-focused	Able to do normal things, function well and live a full life	95 (25.3%)	<i>It means that I am able to do all the things that I wish/like to do each day.</i>
	Feeling good, positive, and hopeful	85 (22.6%)	<i>Being able to enjoy life, be happy...</i>
	Being healthy and well	71 (18.9%)	<i>To be in a good state of health, physical and mental</i>
	Physically active & energetic	33 (8.8%)	<i>to have enough energy to live an active life</i>
	Back to normal	12 (3.2%)	<i>Going back to the person I was before after all of this - healthy...</i>
	Peace of mind and acceptance	9 (2.4%)	<i>To ... be aware, but, not concerned with illness</i>
	Ability to cope and take care of yourself	8 (2.1%)	<i>To be able to care for yourself [sic] even though you suffer from other illnesses</i>
	Sense of future	4 (1.1%)	<i>... Having a sense of a future</i>
	In control of your body	4 (1.1%)	<i>It means I am on top of things and in control of my body emotional and physically</i>
	Alive	3 (0.8%)	<i>To be well means to be alive and be healthy</i>
	Financial independence/ security	3 (0.8%)	<i>Being able to enjoy life, be happy, earn money to keep yourself supported</i>
	Better appreciation for life	2 (0.5%)	<i>Having a better appreciation for life [a]fter [sic] major illness</i>
	Sleeping well	2 (0.5%)	<i>Able to sleep deeply and undisturbed...</i>
	Quality of life	2 (0.5%)	<i>that you have quality of life</i>
	Sense of wholeness	1 (0.3%)	<i>...Having a sense of wholeness...</i>
Normal life expectancy	1 (0.3%)	<i>... life expectancy [sic] to be as per normal for your age group</i>	

Note. N = 376. Participants' responses could be given multiple codes

as a coping strategy. Interpreted another way, defining being “well” in solely absence-focused terms (without any presence-focused elements) was associated with a higher level of symptoms and lower fatalism. Additionally, defining being “well” in presence-focused terms (partly or wholly), was weakly associated with younger age, although this result was not significant at $p = .062$. As shown in Table 3, defining being “well” in absence-focused terms (partly or wholly) was unrelated to participants' demographics, time since diagnosis, coping style or symptom level.

Discussion

This study examined cancer survivors' qualitative definitions of what it means to be well. Additionally, the quantitative analysis provides further insight into the potential reasons behind survivors' differing conceptualisations of what it means to be well. We found that the majority of survivors (approximately 70%) provided a definition that focussed on *either* the absence or the presence of some significant challenge or opportunity. In the context of an absence-focused definition, survivors were keen to overcome acute challenges that threatened their current quality of life (e.g., “*Not suffering from pain or symptoms*”).

Table 3 Logistic regressions identifying factors associated with a presence-focused or absence-focused definition of being well (1=yes/0=no) (N=370)

Presence-focused ^a	OR	95%CI	p
Symptom level	0.83	0.72, 0.97	0.015
Helplessness-Hopelessness	1.03	0.96, 1.11	0.445
Anxious Preoccupation	0.99	0.93, 1.05	0.666
Fighting Spirit	1.04	0.94, 1.16	0.451
Cognitive Avoidance	0.96	0.86, 1.06	0.410
Log(Fatalism) ^b	4.63	1.33, 16.07	0.016
Time since diagnosis	1.01	0.99, 1.02	0.361
Age	0.98	0.96, 1.00	0.062
Gender			
Female	ref		
Male	0.84	0.51, 1.40	0.509
Education level			
High school	ref		
Tertiary education	0.74	0.41, 1.32	0.305
Vocational training	0.72	0.41, 1.28	0.265
Location of residence			
Australia	ref		
United Kingdom	0.70	0.33, 1.50	0.360
Intercept	0.28	0.02, 4.98	0.386
Absence-focused^c	OR	95%CI	p
Symptom level	1.10	0.96, 1.27	0.182
Helplessness-Hopelessness	0.98	0.91, 1.05	0.595
Anxious Preoccupation	1.03	0.97, 1.09	0.343
Fighting Spirit	0.94	0.85, 1.04	0.234
Cognitive Avoidance	0.96	0.87, 1.06	0.400
Fatalism	1.05	0.95, 1.16	0.326
Time since diagnosis	1.01	0.99, 1.02	0.317
Age	1.01	0.99, 1.03	0.518
Gender			
Female	ref		
Male	1.05	0.65, 1.71	0.831
Education level			
High school	ref		
Tertiary education	0.99	0.57, 1.72	0.976
Vocational training	1.05	0.62, 1.80	0.848
Location of residence			
Australia	ref		
United Kingdom	1.49	0.71, 3.11	0.288
Intercept	0.73	0.10, 5.33	0.758

^aModel fit (LR $\chi^2(12)$ 22.41, $p = .03$) McFadden's $R^2 = 0.048$

^bThe Fatalism subscale of the MAC violated the assumption of linearity, as assessed by the Box-Tidwell test. The log transformed variable was used to address this problem and indicated the same pattern of results in the regression model as the untransformed variable. The transformed variable is presented here and the untransformed version of the model is presented in Supplementary Materials 1 (Table S1) to aid interpretation

^cModel fit (LR $\chi^2(12)$ 9.21, $p = .685$). McFadden's $R^2 = 0.019$

Conversely, presence-focused definitions highlighted the importance of doing things routinely; living life normally (e.g., “It means that I am able to do all the things that I wish/like to do each day”).

At least half of the sample in this study did not define living well as the absence of cancer or symptoms. Instead, they defined it in presence-focused terms, which centred around ability, productivity and a positive outlook. Definitions of being well that contained at least some presence-focused elements (either partly or wholly) were more likely among participants with fewer symptoms or those who made use of a fatalistic coping style. This could suggest that when symptom levels are lower, some patients may focus less on the acute experience of disease and may consider goals that go beyond the absence of cancer and its effects.

The Fatalism subscale of the Mini-MAC includes items such as “I’ve had a good life, what’s left is a bonus”, “I count my blessings”, and “At the moment, I take one day at a time”. Our results suggest that a more fatalistic attitude towards one’s cancer diagnosis is associated with an outlook on wellness that is more than just morbidity and reflects broader attitudes towards life and purpose. This may reflect a more optimistic focus on the present with a willingness to let the future take care of itself.

Overall, the results suggest that there is no one-size-fits-all approach to defining wellness and discussions with survivors need to consider patient outcomes holistically. This also needs to be an ongoing conversation between survivors and clinicians that is revisited at regular milestones. We found no association between wellness definitions and time since diagnosis and, while for some patients achieving wellness may require a strong focus on treatment and symptom management, it should not be assumed that this is the case for all patients at the same stage.

Recent Australian research found that cancer survivors defined wellness as encompassing Hettler’s six dimensions; physical, social, intellectual, spiritual, emotional and occupational [14, 15]. Those findings draw some parallels to the current study: both studies identified an element of wellness as being physically active, and several of the presence-focused categories identified here align with elements of the other dimensions reported in Nixon, Chan [14]. For example, taking care of yourself and getting “back to normal”, both presence-focused responses in the current study, were elements of the intellectual dimension of wellbeing in Nixon, Chan [14]. However, there were also some notable differences. The current study identified a greater focus on the absence-focused definitions of wellness; living without illness, symptoms, anxiety, restrictions, treatment or fear. The open-ended written question provided in this study may have facilitated a broad range of responses, absent of any context such as wellness service provision. As such, one interpretation is that the findings here provide an assessment of what it means to “be well” rather than what it takes to achieve wellness.

The current study also draws some similarities to recent research examining how AYA cancer survivors define “living well”, which identified three dimensions; living mindfully, living an identity as a healthy young person, and spending time with friends and family [16]. Living mindfully incorporated living without depression and fear of the future, which aligns with the absence-focused themes identified in the current study. This dimension also incorporated being able to do the things that make oneself happy without worrying about anything or anyone else, which draws some similarities to the presence-focused theme of being able to do things, function well and live a full life. Living an identity as a healthy young person incorporated living as if they never had cancer, which aligns with the presence-focused themes of being healthy and well, and getting back to normal. Finally, spending time with friends and family incorporated engaging in a variety of outdoor activities, which draws some similarities to the theme of being physically active and energetic. Compared to the current results, young people reported more focus on control over their own body, making their own decisions and building/fostering relationships [16]. The current study reported a more explicit focus on being cancer free, which is interesting since both studies included participants who were still undergoing treatment.

Limitations and Future Research

The main variable of interest was assessed using a single-item question asking what participants thought it meant to “be well” after cancer. A strength of the study is the large sample size and the ability to examine the relative size of each category making up the definition of “being well”. However, a deeper and more nuanced understanding of these issues would be gained from further qualitative explorations of the topic.

A further strength is the combination of qualitative and quantitative approaches. We found that only symptom level and Fatalism were related to the choice of a presence-focused strategy and impact of the increased difficulty being related to the absence-focused terms (with a family presence-focused element). This association with a higher prevalence of symptoms of depression and anxiety in defining “being well” also suggests that future research (which will explore all roads associated with younger age, although this result was not statistically significant) should be shown in Table 3. Interestingly, living an identity as a healthy young person in defining “being well” reported absence-focused terms (partly by the absence-focused late participants’ demographics, only reported by 31 people [9.8%]). Our research could explore the importance of language in how this outcome is framed, and how this influences survivors’ expectations and psychosocial outcomes.

Conclusions

A survivor’s care goals will influence what course of action they consider appropriate, including treatment decisions and end-of-life care, and which support services they may choose. These expectations can also influence survivors’ perceptions of treatment success [25]. Importantly, our findings suggest that being cancer free, while important, was not the only definition of being “well” and a large number of people defined it as the ability to do the things that mattered to them.

Framing this as a question about what it means to “be well”, rather than how to treat illness, may be a simple way to start a conversation about the goals of care. As noted by Schreiner, Grosseohme [16], conversations about “living well” open the door to further conversations about emotional and mental wellbeing. Framing this as a question of wellness may also empower survivors to participate more actively in achieving this outcome and may encourage both clinicians and patients to consider the use of supportive care services. Overall, our findings suggest that asking survivors what being “well” means to them may help inform the goals of a survivor’s cancer care, beyond curing them of disease.

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Data Availability Data are not available due to ethical restrictions.

Declarations

Conflict of Interest The authors have no relevant financial or non-financial interests to disclose.

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