



Adjustment and perceived needs of cancer survivors: a qualitative exploratory study in a Portuguese island region

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Received:

13 October 2020

Last revised:

16 November 2023

Accepted:

24 November 2023

Abstract

Background: Cancer survivors from rural or isolated areas may experience psychosocial adjustment issues and needs following treatments. The adjustment and the perceived needs of cancer survivors in the Azores have not been investigated.

Goals: To explore the adjustment to survivorship and perceived needs of cancer survivors from a Portuguese archipelago region.

Methods: Cancer survivors from São Miguel Island (Azores archipelago) took part in this qualitative exploratory study. Three focus groups were carried out, which were transcribed, coded through thematic analysis, and analyzed using NVivo 12.

Results: The sample comprised twenty-two cancer survivors. Five main themes emerged: 1) Current adjustment to diagnosis; 2) Barriers to current adjustment; 3) Promoters of current adjustment; 4) Post-diagnostic growth; and 5) Perceived needs and suggestions for improvement. The results revealed that the factors influencing cancer survivors' adjustment and their perceived needs and concerns are similar to those of survivors from other rural or isolated regions. However, some differences were found, such as the perceived trauma related to the follow-up spaced-out period and the displacement to Portugal mainland to perform cancer therapy as a promoter of adjustment in survivorship. Beyond the financial and social concerns, the psychosocial support and continuity of care needs were also expressed by cancer survivors.

Discussion: Assessing and monitoring survivors' needs during different stages of the disease could inform health and psychosocial care providers on how to better support cancer survivors from the Azores, preparing them for survivorship. A multidisciplinary approach which recognizes cancer survivors' difficulties and unmet needs can promote optimal care delivery, improving their adjustment.

Keywords: Oncology, Survivorship, Adjustment, Needs, Azores

Introduction

The remarkable advances in cancer treatments have led to an increase in cancer survivors worldwide. In Portugal, the survival rate for oncological disease has been increasing (Allemani et al., 2018). Global survival report data indicates survival rates of 60-69% for colon and rectal cancers, 85% for breast cancer, and approximately 90% for prostate cancer, the most

common types of cancer in Portugal (Allemani et al., 2018). In the Azores, a Portuguese archipelago, the survival rate five years after diagnosis has increased for cancer patients in general (e.g., about 93% survival rate for prostate cancer patients) (Allemani et al., 2018).

Cancer survivors have been described as those who have recovered from any evidence of disease, are at a

stage with no risk or minimal risk of recurrence and who have restored their health in its physical, psychosocial, and developmental domains (World Health Organization, 2008).

Following treatments, cancer survivors may experience physical and psychosocial issues (e.g., fertility, emotional distress, fear of recurrence, returning to work; Banard et al., 2016; Baker et al., 2013; Burton et al., 2015; Livaudais et al., 2010; Penrose et al., 2012) which can lead to depression or anxiety (e.g., Brandão et al., 2017; Brandenbarg et al., 2019; Inhestern et al., 2017; Naughton & Weaver, 2014; Oancea & Cheruvu, 2016). In Portugal, a study conducted with osteosarcoma patients revealed that participants in the follow-up stage, even though in an intermediate sub-clinical level they display anxiety (21,3%) and symptoms of depression (6,6%) (Paredes et al., 2011).

Moreover, once treatment has finished, a range of needs may arise (i.e., necessities for which they will need some sort of help or support; Campbell et al., 2011) which, if remained unmet, may lead to mental health morbidity (Oberoi et al., 2017a; 2017b). Previous studies about cancer survivors' needs indicate lack of information about available emotional, practical, or financial support services, need for continuous support or rehabilitation (Cavers et al., 2013; des Bordes et al., 2016; Dsouza et al., 2018; Khan et al., 2011; Walton et al., 2010; Wang et al., 2016). In the Azores-Portugal, in a quantitative study developed by Sousa et al. (2021), the unmet needs most reported by cancer survivors were those related to emotional issues associated with the disease (e.g., how to deal with the fear of recurrence).

When considering cancer survivors from more isolated or remote areas, some factors can present additional challenge to their adjustment, such as geographic isolation, greater distance to healthcare services, limited access to oncology, psychology and/or social support services and limited transportation options (Roder et al., 2013), as it happens in the Azores. The Azores archipelago comprises nine islands, but only three have a local hospital. These three hospitals, disperse among them, include oncology services, but due to geographical constraints,

understaffing and unavailability of certain treatments (e.g., radiotherapy, transplants), cancer patients are frequently displaced to mainland Portugal to perform cancer therapy and other complementary or surveillance tests. Those factors may contribute not only to poorer mental health outcomes (Butow et al., 2012; Charlton et al., 2015; Lashbrook et al., 2018), but also to higher levels of unmet needs. Previous qualitative studies have explored the needs of cancer survivors from rural or more isolated areas, finding that they experience more needs in accessing health services, a need for continuity and coordination of care and for socioeconomic and emotional support; Grimison et al., 2013; O'Connor et al., 2019; Walton et al., 2010). To our knowledge, however, the adjustment and needs of cancer survivors in the Azores have not been investigated. So, it is important to explore their experiences to better understand potential facilitators or barriers to adjustment and identify any gaps in care delivery, to inform regional healthcare providers to better support survivors' needs and promote their mental health. Since this is the first study to be carried out in the Azores and much remains unknown, this study is based on a qualitative methodology which is the most appropriate methodology for identifying the main themes and obtaining more in-depth information on these processes.

The goals of this exploratory study are a) to explore the perception of cancer survivors regarding their adjustment in survivorship, b) to understand factors influencing cancer survivors' adjustment, c) to explore the perceived needs of the Azorean cancer survivors, and d) to determine cancer survivors' suggestions for improvement.

Methods

Participants and Procedures

Participants were recruited from the Medical Oncology Service of the Divino Espírito Santo Hospital of Ponta Delgada, EPE and from Regional Center of the Azores of Portuguese League Against Cancer – Delegation of São Miguel. The Ethics Committee and Direction Boards of these institutions approved the

study. The participants have already participated in the principal investigator's PhD project and had given their prior consent to be contacted in the future. The researcher contacted the participants by phone to determine their interest and availability to collaborate. The recruitment was conducted aiming to obtain variety regarding gender, ages, tumour types, treatments performed and years of survivorship. However, the survivors who have been showing willingness to participate were more homogeneous in their socio-demographic and clinic characteristics and it was not possible to ensure the desirable heterogeneity of the sample. Participants were eligible to participate if they had completed treatments, not showing clinical signs of oncological disease, confirmed by the appropriate complementary diagnostic tests, or being followed up; were >18 years; were from São Miguel Island and Portuguese speaking. Cancer survivors were ineligible if they were unable to speak and understand Portuguese or had any cognitive, physical and/or psychological damage which might influence participation in the study.

Data Collection

Three focus groups were conducted. This methodology allowed us to access and explore, in a descriptive, reflexive, and interpretive way, perceptions that are shared by a set of people going through similar experiences, with cancer survivors being the best sources of information regarding the sensitive processes to be studied (adjustment and perceived needs in survivorship). The existing guidelines for conducting, development and implementation of focus groups were followed (Braun & Clarke, 2006). The focus groups were conducted to saturation, which was reached after the third focus group. Although there are no defined rules regarding the optimal number of groups to be used (Stewart et al., 2007), conducting two to four focus groups with different participants allows the researcher to confirm the responses of the initial group (Bortree, 1986; Goodman, 1984) or to predict the participants' responses (McQuarrie & McIntyre, 1987). The objective is to obtain enough groups until the data are repetitive and no new relevant information, concepts or themes is

obtained - saturation (Fush & Ness, 2015; Malterud et al., 2016).

A single interview session was held with each group in the meeting room of the São Miguel Island Health Unit, in April 2019. Each focus group lasted approximately two hours. A written informed consent was obtained, both for the interview and its recording. The principal investigator initiated each of the focus groups, encouraging free-flowing conversation to ensure that all questions had been thoroughly discussed. A second mental health researcher (J.C) was also present to act as an observer in each session, recording non-verbal responses that could possibly arise, using handwritten notes. Open-ended questions were used to optimize participants' opportunity to express themselves, focusing on their adjustment and needs, and to allow the joint discussion and reflection on the topics to be addressed. Participants were also invited to present any additional comments.

Measures

Questionnaire on sociodemographic and clinical information

Sociodemographic data (e.g., age, gender, education) and clinical data (e.g., diagnosis, treatments received) were collected and evaluated using a questionnaire developed by the study authors.

Focus group interview script

This script was developed by the researchers of the study based on a bibliographic review of the topics under study and its objectives. Open-ended questions were used to allow full accounts of survivors' experiences to be shared and to optimise discussion between participants ("*How do you feel about and adapt to survivorship?*"; "What kind of changes have you been experiencing after the diagnosis?"; "*As a survivor of an island region, what needs do you have?*"; "*How do you evaluate the available of health resources to survivors in the Azores?*"; "*What do you think could be done to improve your adjustment?*"). At the end of each session, participants were invited to make any additional comments related to the topics addressed ("*Do you have any further comments?*").

Data analysis

Descriptive statistics were used for participants' sociodemographic and clinical information. The data from focus groups were analysed using QSR NVivo 12 software. We followed through Braun and Clarke's six phases of thematic analysis, which consists of identifying, analyzing, and reporting patterns (themes) within the data (Braun & Clarke, 2006). Following each of these phases, the recordings of each focus group were transcribed (*verbatim*), ensuring the anonymity of all the verbalizations and speech transcribed. Subsequently, the researcher (M.S.) reviewed the transcript of each focus group session to identify meaning patterns and themes of interest in the data. Another researcher (J.C) checked the transcript against the handwritten notes and the audio recording. After the familiarization with the data, the creation of codes began, and these were constantly reviewed during the data analysis. After this phase, the codes were organized to create categories and subcategories until the main themes were identified. This process was subsequently reviewed by another author (C.B.C). A final discussion between the authors were performed to decide on the final set of themes, solving any discrepancies identified in the initial steps of thematic analysis.

Translation of participants' quotes from Portuguese to English for this paper was conducted by three researchers in three main steps. The principal researcher undertook the initial translation, and an English-speaking native checked the translations (S.L). Then, a third researcher back translated the texts to Portuguese (C.B.C).

Results

Twenty-two cancer survivors showed interest in collaborating and agreed to participate voluntarily in the study after having been explained its goals. Participants had an average age of 55.6 years, with the majority being women ($n = 14$, 63.6%), married ($n = 12$, 54.5%) and performing paid work ($n = 9$, 40.9%). No significant differences were found between the three focus groups (see Table 1).

Most participants were breast cancer survivors ($n = 10$, 45.5%) and had a survival time greater than 5 years ($n = 9$, 40.9%). Most of the sample underwent surgery ($n = 12$, 54.5%) and adjuvant chemotherapy and radiation therapy ($n = 11$, 50%). There were no significant differences between the three focus groups, except for diagnosis, which the participants of focus group 1 were mostly survivors of digestive cancer ($n = 3$, 33.3%). The clinical characteristics of the sample are shown in Table 2.

Five main themes were identified: current adjustment to diagnosis, barriers to current adjustment, promoters of current adjustment, post-diagnostic growth, perceived needs, and suggestions for improvement.

Theme 1: Current Adjustment to Diagnosis

Participants described their experiences with the diagnosis. They discussed the impact felt in different life domains due to a cancer diagnosis. This theme is represented by five categories: psychological impact, physical impact, family impact, socioeconomic and professional impact, and no impact.

Psychological impact

Most participants discussed the perceived trauma associated with the diagnosis. These participants described their experiences regarding mental health morbidity, given the uncertainty about the future and the fear of cancer relapse.

Today, I have a trauma; in fact, I have a trauma regarding hospitals... (E, 49-year-old female, lymphoma cancer survivor, focus group 1)

Moreover, currently, I have a serious depression, after all that... (P, 52-year-old female, breast cancer survivor, focus group 2)

When we feel something, discomfort, or pain, we feel nervous. We think it is the cancer coming back and we get scared... (F, 69-year-old female, breast cancer survivor, focus group 3)

Physical impact

The participants discussed a variety of physical symptoms that emerged after the cancer diagnosis. Some cancer survivors reported the loss of strength and the scars as the most impacting to their adjustment.

Table 1. Sociodemographic characteristics of participants in the focus groups

	Total sample (n = 22)	Focus Group 1 (n = 9)	Focus Group 2 (n = 7)	Focus Group 3 (n = 6)
Women n (%)	14 (63.6)	4 (44.4%)	4 (57.1)	6 (100)
Age (years) M(SD); range	55.59 (10.02); 41-78	56.11 (9.00); 44-68	51.43 (7.93); 41-66	59.67 (13.10); 46-78
Marital Status n (%)				
Single	4 (18.2)	2 (22.2)	1 (14.3)	1 (16.7)
Living together	1 (4.5)	0 (0.0)	0 (0.0)	1 (16.7)
Divorced	4 (18.2)	1 (11.1)	2 (28.6)	1 (16.7)
Widow/widower	1 (4.5)	1 (11.2)	0 (0.0)	0 (0.0)
Married	12 (54.5)	5 (55.6)	4 (57.1)	3 (50)
Education n (%)				
Elementary school	6 (27.3)	3 (33.3)	2 (28.6)	1 (16.7)
Middle school	5 (22.7)	2 (22.2)	3 (42.9)	0 (0.0)
Junior high school	2 (9.1)	2 (22.2)	0 (0.0)	0 (0.0)
High school	5 (22.7)	2 (22.2)	1 (14.3)	2 (33.3)
College	3 (13.6)	0 (0.0)	1 (14.3)	2 (33.3)
Other	1 (4.5)	0 (0.0)	0 (0.0)	1 (16.7)
Employment n (%)				
Employed	9 (40.9)	3 (33.3)	4 (57.1)	2 (33.3)
Retired	5 (22.7)	1 (11.1)	2 (28.6)	2 (33.3)
Retired due to disability	4 (18.2)	3 (33.3)	0 (0.0)	1 (16.7)
Unemployed	1 (4.5)	1 (11.1.)	0 (0.0)	0 (0.0)
Other	3 (13.6)	1 (11.1)	1 (14.3)	1 (16.7)
Income n (%)				
Less than 500 euros	2 (9.1)	1 (11.1)	1 (14.3)	0 (0.0)
From 500 to 900 euros	10 (45.5)	3 (33.3)	5 (71.4)	2 (33.3.)
From 901 to 1300 euros	4 (18.2)	2 (22.2)	0 (0.0)	2 (33.3.)
From 1301 to 1700 euros	1 (4.5)	0 (0.0)	1 (14.3)	0 (0.0)
From 1701 to 2100 euros	1 (4.5)	1 (11.1.)	0 (0.0)	0 (0.0)
From 2101 to 2500 euros	1 (4.5)	1 (11.1)	0 (0.0)	0 (0.0)
From 2501 to 2900 euros	2 (9.1)	1 (11.1.)	0 (0.0)	1 (16.7)
From 2901 to 3300 euros	1 (4.5)	0 (0.0)	0 (0.0)	1 (16.7)

Table 2. Clinical characteristics of participants in the focus groups

	Total sample (N = 22)	Focus Group 1 (n = 9)	Focus Group 2 (n = 7)	Focus Group 3 (n = 6)
	n (%)	n (%)	n (%)	n (%)
Diagnosis/Type of Cancer				
Breast	10 (45.5)	2 (22.2)	3 (42.9)	5 (83.3)
Haematologic (Non-Hodgkin's lymphoma, Hodgkin's lymphoma, Leukemia)	2 (9.1)	2 (22.2)	0 (0.0)	0 (0.0)
Digestive (stomach, intestine, pancreas, gallbladder, esophagus, rectum)	5 (22.7)	3 (33.3)	2 (28.6)	0 (0.0)
Reproductive (ovaries, cervix, testicles, prostate, penis)	1 (4.5)	1 (11.1)	0 (0.0)	0 (0.0)
Respiratory (nasopharynx, oropharynx, larynx, lung, oral cavity)	3 (13.6)	1 (11.1)	1 (14.3)	1 (16.7)
Endocrine (submandibular adenocarcinoma, adrenal glands, thyroid)	1 (4.5)	0 (0.0)	1 (14.3)	0 (0.0)
Having other chronic disease	6 (27.3)	2 (22.2)	3 (42.9)	1 (16.7)
Survivorship (years)				
< 5 years	7 (31.8)	3 (33.3)	2 (28.6)	2 (33.3)
> 5 years	9 (40.9)	4 (44.4)	2 (28.6)	3 (50)
Unknown	6 (27.3)	2 (22.2)	3 (42.9)	1 (16.7)
Having done surgery	12 (54.5)	4 (44.4)	4 (57.1)	4 (66.7)
Adjuvant Treatments				
Only chemotherapy (CT)	2 (9.1)	1 (11.1)	1 (14.3)	0 (0.0)
Only radiotherapy (RT)	3 (13.6)	1 (11.1)	0 (0.0)	2 (33.3)
CT and RT	11 (50)	3 (33.3)	5 (71.4)	3 (50)
CT and transplant	1 (4.5)	1 (11.1)	0 (0.0)	0 (0.0)
None	2 (9.1)	3 (33.3)	1 (14.3)	1 (16.7)

My life became limited, I can't push on the stove, I can't push to wash a pan, (...) I lost the full strength of my arms... (V, 54-year-old female, breast cancer survivor, focus group 2)

You have scars, this is very difficult... I'm not the woman I used to be anymore... (E, 64-year-old female, breast cancer survivor, focus group 1)

Family impact

Most of cancer survivors participating in the focus groups have discussed the difficulties in maintaining or developing affective or intimate relationships. These participants also perceived a negative impact of the disease on the emotional management of other family members.

Changed me a lot, in my affective life... (I, 51-year-old female, breast cancer survivor, focus group 1)

I got a divorce, after one year... (P, 52-year-old female, breast cancer survivor, focus group 2)

They [the family] get it worse than we do... (M, 46-year-old female, lung cancer survivor, focus group 3)

Socioeconomic and professional impact

The challenges brought by the disease in terms of family income were discussed. The loss of family income is related to patients' absence from work or to difficulties in returning job or finding employment opportunities after the end of treatments. Many cancer survivors also discussed the perceived stigma felt in the island region. In their opinion, in the Azores some people still think that cancer is contagious or is a death sentence, so sometimes they felt discriminated against.

I am retired and I live on a very small retirement of three hundred and such euros, I am not ashamed to say... (M, 66-year-old male, intestine cancer survivor, focus group 2)

Because the attack of people and the verbalization is so negative and points the finger, it seemed that I was a person excluded from society... (M, 46-year-old female, lung cancer survivor, focus group 3)

No impact

While aware of the impact caused in some life domains, some survivors experienced no impact resulting from the cancer diagnosis. Many survivors accepted the challenges brought by the disease and began to adjust to it during the post-treatment period.

I've never had restrictions. I did my walks on weekend, I ran... (F, 69-year-old female, breast cancer survivor, focus group 3)

I keep working, I keep doing everything... (S, 42-year-old female, renal cancer survivor, focus group 2)

Theme 2: Barriers to Current Adjustment

Cancer survivors explored several constrains regarding the adjustment to survivorship, which are presented by the following four categories: information and previous experiences, available resources, displacement, and health care providers communication skills.

Information and previous experiences

Many participants reported how difficult is to distinguish between trustworthy and misinformation they found in social media (e.g., television, internet). These participants voiced they are overwhelmed and confused with the quantity of cancer-related information from many sources and sometimes the information is not available. In addition, when there is no previous knowledge or experiences regarding a cancer diagnosis, the adjustment can be challenging.

The internet knows, informs, but to us who do not have education in medicine it can harm a lot! It has already hurt many people, sometimes we talk about it... (F, 63-year-old male, nasopharynx cancer survivor, focus group 1)

When you don't know anything, you go into the unknown... (M, 45-year-old female, leukemia survivor, focus group 1)

No one else has ever had something similar... (S, 42-year-old female, renal cancer survivor, focus group 2)

Available resources

Cancer survivors discussed the availability of resources to assist them in adjusting to survival stage. Although some participants recognized the government subsidies already offered, they discussed negative experiences related to financial and social assistance which is perceived as limited when family income is often insufficient to cover all expenses. The

lack of financial and social support from non-profit entities was also perceived as a barrier for many survivors. Furthermore, the change in social benefits a few years after the end of treatments or in the follow-up stage cause substantial financial pressure for survivors.

Some participants also stated that unavailability of some services (e.g., oncology emergency services) and of their oncologist in the emergency room as another barrier. When it happens, survivors are seen or evaluated by another health professional who is unaware of their clinical situation, or the treatment is delayed if the oncologist was not immediately available.

In monetary terms there is support... but I think it may not be enough... (G, 50-year-old female, breast cancer survivor, focus group 3)

The Cancer League doesn't offer us anything, does it? We don't even have support to order a bra (H, 49-year-old female, breast cancer survivor, focus group 3)

From eighty [percentage of disability] I came to twenty and now every time I need to come here for an appointment, I pay two and a half euros... (V, 54-year-old female, breast cancer survivor, focus group 2)

My concern is that we get to the hospital and don't have our doctor, even in the emergency room... (V, 54-year-old female, breast cancer survivor, focus group 2)

How is possible that in the emergency room there is not an oncologist available? (P, 41-year-old male, lung cancer survivor, focus group 2)

Displacement

Most participants discussed the displacement to Portugal mainland to perform cancer-therapy or medical reviews as a complex process with a great financial burden which are not met by the competent entities. Even though these participants recognized the need for displacements when the resources are unavailable in the Azores, they prefer to perform their follow-up care in the island where they live.

When there are no [treatments], we must accept our conditions of the Azorean, archipelago... but do not take me out of here! Do not take me out of here! (A,

63-year-old male, penis cancer survivor, focus group 1)

My husband was on medical leave to go with me for two months and two weeks. The first fifteen days did not earn a cent. And how many [people] go alone... (V, 54-year-old female, breast cancer survivor, focus group 2)

Health care providers' communication skills

Some participants discussed the lack of trained health care providers in communication skills at oncological settings. These survivors perceive some oncologists or nurses to have inadequate skills to communicate bad news.

We deal with many people who are not yet prepared, there are many health technicians who do not know how they will react and react worse than we who are sick... (F, 68-year-old male, intestines cancer survivor, focus group 1)

Some people just can't..., but some doctors, nurses, therapists just can't... and this is a failure in their training... (E, 64-year-old female, breast cancer survivor, focus group 1)

Theme 3: Promoters of Current Adjustment

Cancer survivors reported on important aspects which help them to adjust to survivorship. This theme is represented by five categories: other success cases, coping strategies, available support, health care professionals and services, and displacement.

Other success cases

Some participants discussed their experiences with other cancer survivors, who being succeed in cancer fight, promote confidence and motivation to keep living.

I want to hear good things. I want to hear that a guy had it and recovered, that he suffered, or his hair fell out, but there he is, he remade his life. That's it what gives us that engine, the motivation... (E, 64-year-old female, breast cancer survivor, focus group 1)

We don't want to know about people who died. I don't want to know, I don't. I just want to know

about who is alive... (V, 54-year-old female, breast cancer survivor, focus group 2)

Coping strategies

Most participants reported to have employed a range of coping strategies to help them deal with their current situation. Among these, willpower, desire to live, proactive stance, optimism, religion, and faith were evident and enabled these survivors to adjust to their new situation.

We need to have willpower (V, 54-year-old female, breast cancer survivor, focus group 2)

We must face up to it, do not accommodate (J, 44-year-old male, esophagus cancer survivor, focus group 1)

It is always very important for me to think positively (M, 45-year-old female, leukemia survivor, focus group 1)

Religion helped me and still helps (P, 41-year-old male, lung cancer survivor, focus group 2).

Available support

Many survivors discussed the importance of sharing experiences with other cancer peers who faced similar experiences which normalise experiences and promote adjustment. These participants greatly valued support received from family, partners and friends enabling them to adjust to the disease. Professional and religious reassurance and support in the form of availability and listening were also important for survivors' adjustment.

Family members, acquaintances, and people like you that I didn't know from anywhere, that gave me strength to fight and to be here... (E, 64-year-old female, breast cancer survivor, focus group 1)

And your experience of life can also fit with the experience of the other person and there is a topic of conversation... (J, 44-year-old male, esophagus cancer survivor, focus group 1)

Doctor M. is not a doctor for us, she is a friend, a family member (A, 63-year-old male, penis cancer survivor, focus group 1)

The pastor was there talking to me, while he was talking, I was calming down (P, 52-year-old female, breast cancer survivor, focus group 2)

Health care professionals and services

Many participants discussed their regarding to professional qualities and skills. These survivors were often satisfied with the medical services provided in the Azores and with the health teams, whose caring attitude towards cancer survivors and time spent answering questions were recognized. The health team was felt to do a good work.

Everyone who works at the oncology service loves people, much more loving than others from different services are... (E, 64-year-old female, breast cancer survivor, focus group 1)

They are much more sensitive people; they are much dearer to the sick. The patient feels, feels that... (G, 50-year-old female, breast cancer survivor, focus group 3)

We have always had good professionals here... (F, 68-year-old male, intestines cancer survivor, focus group 1)

Even at the level of assistants, their psychology, their training... nurses, doctors, there is an evolution... (J, 44-year-old male, esophagus cancer survivor, focus group 1)

Displacement

Even though the displacement to mainland to perform cancer-therapy was perceived as a barrier, some cancer survivors discussed how it worked to promote their adjustment, especially during the period away from home. These survivors perceived that they felt valued by the services and professionals of the health units outside their area of residence.

I had to move to the Portuguese mainland to perform radiotherapy, and I've never felt excluded or discriminated against. In Porto, I was there one month, almost two, performing radiotherapy and I didn't feel excluded for being Azorean... (J, 44-year-old male, esophagus cancer survivor, focus group 1)

They [nurses] have a little more attention that is special because they know that the person is displaced and is in a situation that is at least a little more fragile than usual... (M, 46-year-old female, lung cancer survivor, focus group 3)

Theme 4: Post-Diagnostic Growth

Cancer survivors shared their experiences about moving forward from the disease, which are represented by three categories: lifestyle adjustments, perception of the self and perception of the world.

Lifestyle adjustments

Some participants reported making major lifestyle changes by adopting healthy behaviors or habits (e.g., exercise, nutrition), minimizing and even eliminating health risk factors (e.g., alcohol, tobacco, sugar consumption).

I worry a little more about physical exercise, more walks... (A, 63-year-old male, penis cancer survivor, focus group 1)

I didn't eat carrots... nothing. Nowadays, I eat everything, such as beets, carrots, sunflower seeds. I bake my whole grain bread, smoothies, I do everything at home... (V, 54-year-old female, breast cancer survivor, focus group 2)

Perception of the self

The opportunity to experience a positive change in themselves was described by many cancer survivors. Many participants found they were born again, as if it were a new opportunity to live after the cancer diagnosis. This life-threatening situation brought out their human qualities and the desire to be a testimony and a role model to others around them.

We become more sensitive... we see the most beautiful things. Little things that we didn't value, we started to value... (J, 44-year-old male, esophagus cancer survivor, focus group 1)

We change, our feelings change... (M, 46-year-old female, lung cancer survivor, focus group 3)

I think it was a new beginning (E, 64-year-old female, breast cancer survivor, focus group 1)

I think I care less about the things that I feel I don't have to give so much importance to... (M, 46-year-old female, lung cancer survivor, focus group 3)

We become more human. We become more aware of people... (F, 78-year-old female, breast cancer survivor, focus group 1)

I am happy to talk about my past. Today, after all this, I feel lucky, a warrior... (M, 45-year-old female, leukemia survivor, focus group 1)

Perception of life

Some participants discussed the way they developed a stronger appreciation of life. These survivors learned to incorporate meaning from their cancer diagnosis into their lives by re-assessing their personal and life values and re-signifying everyday situations that were previously perceived as threatening.

In addition, after that we see life differently, which is another thing that I think is positive. (F, 69-year-old female, breast cancer survivor, focus group 3)

We have another perspective about life... (P, 41-year-old male, lung cancer survivor, focus group 2)

Theme 5: Perceived Needs and Suggestions for Improvement

Cancer survivors described their experiences regarding unmet needs. They discussed the domains of needs that are unmet and reported on the suggestions to meet those needs. This theme is represented by three categories: need for assistance with financial and social burden, need for information and improved continuity of care and need for psychological support.

Need for assistance with financial and social burden

Most of the participants discussed the lack of medication and transportation support, even during displacements. Some challenges were mentioned regarding the availability of information about financial supports such as government reimbursement. These survivors agreed that government should provide more subsidies or revise those which already exist. In the case of the patients who are displaced to Portugal mainland or within islands, it was felt that the

governmental travel and accommodation subsidies were inadequate in reimbursing, public transport, accommodation, and meals. Suggestions were made for better provision for travel, accommodation, and medication financial aid. Designated accommodations for displaced patients were highly valued, especially, if it is possible to provide food services.

It's a lot of medication, many things we need... (P, 41-year-old male, lung cancer survivor, focus group 2)

But one of the things we also face is transportation... (P, 52-year-old female, breast cancer survivor, focus group 2)

So, in the case of the Northeast, if I don't drive, I must pay for a taxi, because afterward... at the beginning, they help with taxis, they help eighty percent, but if I come to appointments, it's no longer possible... (P, 52-year-old female, breast cancer survivor, focus group 2)

In other words, it was necessary, if only for the other patients on the other islands a place where they could stay and receive support for special food... (M, 46-year-old female, lung cancer survivor, focus group 3)

Need for information and improved continuity of care. Many cancer survivors discussed the lack of information about what is going to happen during the post-treatment period. The uncertainty and fears expressed about cancer recurrence, lead to a need for information and reassurance about unexplained symptoms, cancer surveillance and future care in allaying these. They recognized the importance of requesting medical care whenever necessary, recognizing that they must take an active role regarding their health. Moreover, these survivors agreed upon they had less frequent follow-up. In their opinion, the follow-up in survivorship should maintain the continuity, the same level of depth and demand as appears in the active stage of the disease. Follow-up appointments were seen as anxiety-provoking and even traumatic, so the extended period over the years is a factor that should be reviewed by healthcare providers.

When you feel something strange, go and insist with your doctor, even if the doctor says no... (P, 41-year-old male, lung cancer survivor, focus group 2)

My surveillance is annual now. I think is too much time, because six months is okay. However, one year, I think is too much, it's traumatic I think... (M, 46-year-old female, lung cancer survivor, focus group 3)

I felt more supported in consultations even every 6 months. Nevertheless, I feel, like, a little helpless. A little insecure, not sure if something happens to me... (G, 50-year-old female, breast cancer survivor, focus group 3)

Need for psychological support

Most cancer survivors participating in the study feared cancer relapse and did not know how to deal with the emotions associated with the disease. Sometimes they are unsure about what to think, feel or do, causing psychological and emotional issues. The participants suggested the inclusion of the psychologist into the multidisciplinary team and in the entire path of the disease (diagnosis, surgery, and treatments) to better help patients to adjust to their disease. They also advised of the usefulness of screening patients for unmet needs during the entire path of the disease to early identify difficulties and prevent clinical levels of mental issues in the future. Psychological support through the active stage of the disease and continually during follow-up would be important to promote adjustment.

What could be better for me maybe at this moment after the operation, during chemotherapy, to have someone, to have a psychologist available, available to speak with us... (E, 64-year-old female, breast cancer survivor, focus group 1)

After the cancer's trajectory... I think that when a person is ill and undergoing treatments... I think we should have either psychological support or other support, right... (P, 41-year-old male, lung cancer survivor, focus group 2)

I think that it is necessary to have more psychological and social support... (G, 50-year-old female, breast cancer survivor, focus group 3)

Discussion

The adjustment and perceived needs of Azorean cancer survivors have not been studied before. The results of this qualitative exploratory study suggested some factors that influenced Azorean cancer survivors' adjustment experiences and perceived needs. Five themes were identified: the current adjustment to diagnosis, barriers to current adjustment, promoters of current adjustment, post-diagnostic growth perceived needs and suggestions for improvement. Findings from the present study, while preliminary, have been replicated in other studies conducted with cancer survivors from other countries, but some differences emerged.

Current Adjustment to Diagnosis

Our study showed that survivor from the Azores were impacted in different life domains when face with a cancer diagnosis. This is consistent with previous studies about the physical and psychosocial challenges faced after the diagnosis (Banard et al., 2016; Baker et al., 2013; Burton et al., 2015; Livaudais et al., 2010; Penrose et al., 2012). Interestingly, in the present study the stigma was perceived as an attack by others. This result deserves more attention in future studies, especially those conducted in regions geographically similar to the Azores. Health care providers, government and the community in general has an important role to disseminate accurate information about cancer to avoid the stigma and the discrimination felt by survivors in the Azores. Our results also suggested that some survivors have not face any impact resulting from the diagnosis, which is in line with previous studies suggesting that after the end of treatments patients incorporate cancer experiences in their lives (Naughton & Weaver, 2014; Raque-Bogdan et al., 2018; Yi & Syrjala 2017). Since this study was conducted in survival stage, similar studies can be planned and would assist in understanding any other factors that influence the adjustment in different stages of the disease, especially, when patients are moved to other places to perform cancer-therapy, to perceive possible differences when compared to survivorship.

Barriers to the Current Adjustment

Participants reported difficulties in dealing with the credibility the information available about cancer and resources (e.g., financial, social, medical) available to help them adjust to their new circumstances, as reflected in the wider cancer literature, namely that conducted in more remote or isolated areas (e.g., Cavers et al., 2013; Charlton et al., 2015; Odahowski et al., 2019; Wang et al., 2016; Zahnd et al., 2018). Overall, participants recognized the government effort in defining financial and social support. However, our sample of cancer survivors expressed concerns about the way social and financial support is defined by regional government and from non-profit entities. This support was perceived as limited, especially for patients who had to move to other islands or to mainland and their companions whose support is not sufficient to cover all the costs involved in the displacement (White et al., 2011). In addition, Portuguese cancer survivors face changes in the percentages of disability aid which is also perceived as inadequate. The barriers identified by our sample of cancer survivors can impact the help-seeking behaviours, since survivor may believe do not have enough socioeconomic and health resources to meet their needs (e.g., Dsouza et al., 2018; Grimison et al., 2013). The displacement to Portugal mainland to perform cancer-therapy was also perceived as a barrier to adjustment. This result is consistent with findings about the negative effect of the displacements on familiar, social and in financial domains (Butow et al., 2012; Charlton et al., 2015; Grimison et al., 2013; Livaudais et al., 2010; Loughery & Woodgate, 2015; White et al., 2011). To prevent some financial or social burdens, patients often decide to make the outward and return journey on the same day (White et al., 2011), as is the case of some patients/survivors from the Azores who move between islands. Another barrier identified was related to the lack of trained professional communication skills, especially in bad news communication. Communication and relationship skills are a central aspect of oncology care, and the lack of training of professionals (e.g., nurses, oncologists) directly influences a patient's adjustment (e.g., Stovall, 2015; Tomkins et al., 2016; Wang et al., 2016).

Promoters of Current Adjustment

Other success cases, adaptive coping strategies, the support received by professionals, family and friends, the qualities of the services and caring attitudes from health care providers were reported by participants as facilitators of their adjustment, which is consistent with previous research (e.g., Cavers et al., 2013; Gall & Cornblat, 2002; Gallagher et al., 2019; Kahana et al., 2016; Li & Loke, 2013; Raque-Bogdan et al., 2018; Schroevers et al., 2010; Wang et al., 2016). Interestingly, our results suggested that the displacement to Portugal mainland, despite being a barrier, is also perceived as a protective factor for survivors' adjustment. Our sample of cancer survivors might have established a bond with healthcare providers during the period away from home that still exists. In addition to the establishment of significant support networks, they perceived they were accommodated in comfortable and safeness facilities adapted to their needs, being followed in hospitals and by teams specialized in oncology (Loughery & Woodgate, 2015), which makes this experience important to current adjustment. Maintaining the continuity of supportive care even after patients return home or linking survivors through support groups can be positive ways to prevent isolation or other relational needs (Livaudais et al., 2010; Tomkins et al., 2016).

Post-diagnostic Growth

Some cancer survivors from the Azores perceived positive changes resulting from the experience of a cancer diagnosis. As identified in previous research, a cancer disease can lead to positive perceptions about oneself and life (Raque-Bogdan et al., 2018; Tedeschi, Park, & Calhoun 1998), strength relationships (Canavarro et al., 2015; O'Connor et al., 2008; Raque-Bogdan et al., 2018) and recognition resilience or self-efficacy in maintaining physical and emotional health (Raque-Bogdan et al., 2018). One aspect that stood out among the participants was the fact that they value more their commitment to maintaining healthy lifestyle habits. This result may be due to the growing number of awareness-raising activities campaigns in the Azores about the adoption of healthy lifestyles to promote health and prevent diseases.

Perceived Needs and Suggestions for Improvement

Our results highlighted the perceived financial and social needs. The costs of medications, alongside loss of family income increase the financial burden (Charlton et al., 2015; Grimison et al., 2013; Livaudais et al., 2010; Wang et al., 2016). Our sample of cancer survivors expressed concerns about the patients from the other islands, who need to travel by air or sea to central hospitals and must deal with the additional costs for accommodation and food. When traveling within the region and to mainland, participants perceived a need for more financial and social support by regional government and social services whose support is not enough in view of all the expenses that travel involves, particularly for the companions of these patients, for whom financial aid when travelling is very low or, in some cases, non-existent. The burden of travelling and related financial cost emerges as particularly challenging for many patients (Charlton et al., 2015; Grimison et al., 2013; Livaudais et al., 2010; Wang et al., 2016). Many participants agreed with accommodations prepared for patients displaced from other islands, in which they have prepared meals, realising them from this task which can be difficult after long days performing treatments. Providing more financial and social support to patients and their companions would be an important way to provide better conditions to those facing a life-threatening situation and give them the same opportunities to be accompanied with a significant person during this process. The interventions or programmes to assist patients who travel for cancer-therapy should be appropriate, including screening and monitoring of health and supportive needs to prevent poor health outcomes (Dsouza et al., 2018; Tomkins et al., 2016). The participants also expressed concerns about information and continuity of care, specifically during the period between follow-up appointments which is spaced out. This was perceived as traumatic for many participants and can be due given the physical focus of traditional follow-up and to a diminution in the care and attention they had received at diagnosis and through treatment (Tomkins et al., 2016). As new models of survivorship care rely on self-monitoring, efforts will need to be made after treatment to ensure patients are well informed and aware of signs and symptoms of recurrence and its

emotional or psychological related issues, of what to expect from their follow-up care and where to turn for advice and support (Tomkins, et al., 2016). Knowing the difficulties in accessing health services in an island region, given the long distances to health care which sometimes is out of the island region, this aspect of follow-up gains more importance, because in the face of a perceived difficulty or symptom, survivors may feel that they do not have the medical support they urgently need (Tomkins et al., 2016). As identified in previous studies, survivors also wanted ongoing care from the consultant they saw during treatment, more scans and monitoring (e.g., Tomkins et al., 2016). Azorean cancer survivors reported the perceived need for psychological support. Previous studies have shown that cancer survivors value psychological support as a way of improving their mental adjustment, especially the management of fear of recurrence (Dsouza et al., 2018; Raque-Bogdan et al., 2018; Wang et al., 2016). A suitable psychological support, including the assessment of emotional and psychological needs may help health care providers reduce mental health morbidity, performing an adequate response to those needs and fostering adaptive adjustment in survivorship. It is also important that other studies that are carried out in island regions also understand how aspects such as displacement can work as a traumatic event that must be prevented and evaluated, especially in the early stages of the disease.

Limitations and Clinical Implications

This study is not without limitations. First, the conclusions that can be drawn from this investigation are limited to the participants who participated in it, and the needs of survivors from other islands in the archipelago could exceed those reported here. This study was conducted with a convenience sample of survivors from the island of São Miguel and not from other islands in the archipelago, who may have other perceptions of adjustment to survivorship and other needs. Second, the number of female participants exceeded the number of male participants, so we cannot assume that the results are equitable for both genders. Since the sample is mainly female and, therefore, the most common diagnosis was breast cancer, this aspect also limits the conclusions that can

be drawn for other types of cancers. Third, the fact that there are no other qualitative studies conducted in Portugal limits the comparison of our results.

Despite these limitations, this study constitutes an important contribution in terms of knowledge of the perception of some survivors of a Portuguese island region regarding adjustment and perceived needs since this is the first study in our country. Although the results are in line with those found in previous studies, some specific themes from the Azores region emerged (e.g., stigma as a personal attack from other, follow-up perceived as traumatic experience), which should be considered in the development and implementation of psychological interventions intended to meet those needs. Improving the psychosocial outcomes of cancer survivors is a relevant and necessary effort between the government, the community, patients, family members, hospitals, and health care teams (e.g., Dsouza et al., 2018; Wang et al., 2016) in the sense of relieving the patients' emotional suffering when insularity issues intensify it. Social workers, psychologists, and healthcare workers, within a multidisciplinary approach, are in a key position to consider how best to recognize the survivors' needs and assist them with their adjustment during cancer survivorship. Moreover, providers of survivors' health and psychosocial care should consider whether sufficient support is available to cope with the burdens faced by Azorean patients before and after treatment, and into survivorship, designing appropriate interventions to meet survivors' needs and promote their adjustment. Further research is needed to evaluate intervention strategies to assess how to meet the needs of survivors across different islands and survivorship timespan. This study can also be a relevant contribution to the research to be carried out in other island regions of the world and, due to geographic similarities with the Azores, can benefit from the results of this work.

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