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Survivorship issues following treatment completion—results from focus groups with Australian cancer survivors and health professionals

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Abstract
Background The number of cancer survivors is increasing dramatically. Many survivors report long-term psychosocial, physical and other consequences. To understand the issues faced by Australian cancer survivors we conducted focus groups with cancer patients and health professionals.
Methods Patients were identified through a peer support program at a major cancer treatment center (Peter Mac). Health professionals were also recruited from Peter Mac. Focus groups followed a semi-structured format based on themes identified from the literature. Questions focused on treatment completion, and 1 year post-treatment. Participants were also asked to suggest solutions to address identified issues. Focus groups were taped, transcribed, cross-checked for accuracy, and analyzed independently.
Results The most common needs (in terms of both frequency and intensity) reported at treatment completion by both survivors and professionals were dealing with fatigue, anxiety about cancer recurrence, others expecting you to be back to normal, having to create new expectations about physical ability, and anxiety about leaving the hospital system. The most common needs at 1 year were anxiety about check-ups and results, and going into early menopause. The most frequently suggested ways of meeting these perceived needs were reassuring survivors the way they feel is normal and putting them in contact with others who have been through the same experience.
Discussion There was a high level of congruence in the themes identified by survivors and health professionals.
Implications for cancer survivors These results provide a clear direction for the development of resources to support cancer survivors following treatment completion.

Keywords Survivors · Cancer · Social adjustment · Long term survivors

Introduction

In Australia, 5-year relative survival following treatment for cancer was 63% in 1997 [1]. In the USA and the UK, the proportions are similar [2, 3]. Advances in early detection, and improved treatments, coupled with an ageing population, have given rise to a burgeoning number of cancer survivors. Given the rising numbers of people surviving cancer and the emerging awareness of their needs, there is now an urgent call to understand and address the issues and concerns faced by cancer survivors [2].

The term 'cancer survivor' has been used in the literature in a wide variety of ways [2]. Currently, the most commonly accepted definition is the one advocated by the National Coalition for Cancer Survivorship [4], which is "the experience of living with, through, and beyond a diagnosis of cancer" and includes family members and

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friends affected by the experience. While endorsing this broad definition, much of the research in this area has focused on people who have completed potentially curative treatment [2], which is also the focus of this paper.

For many people, post-treatment survivorship entails considerable and life-long effects [5], although there is wide variation in outcomes and illness trajectories [6, 7]. However, there is limited information on the prevalence, duration and precise nature of the medical and psychosocial effects arising during cancer survivorship. In terms of ongoing health, those who have completed potentially curative treatment are not only at risk of recurrence and possible second cancer, they may suffer other illnesses as a consequence of cancer treatments, such as ischemic heart disease, renal impairment, hypertension and osteoporosis [2]. In addition, treatments can be associated with adverse physical sequelae, such as pain, fatigue and bodily disfigurement. Although there are only limited longitudinal studies, it is known that these sequelae, termed long term effects, can be persistent or even permanent [2]. Some sequelae, termed late effects, such as lymphedema, may arise some time after treatment completion. These physical effects can contribute to and compound the psychosocial impact of surviving cancer.

Depending on the type of cancer, treatments and an individual's circumstances, survivors can experience a multitude of psychosocial effects post-treatment [7]. Fear of recurrence and death is probably the most commonly reported psychological impact of a cancer diagnosis [8]. This fear is closely linked to anxiety about separating from the health care system, particularly when discharged from regular medical follow-up [9]. More generally, feelings of uncertainty about the future are common, including inability to make long term plans [10]. While estimates vary [2], a sizeable minority of cancer survivors will experience clinically significant depression, anxiety or adjustment disorders [5, 11], and many more cancer survivors experience periods of psychological distress [10]. Other psychological issues include changes to self-identity and existential or spiritual concerns. However, not all psychological consequences are negative, with many people reporting positive outcomes, such as an enhanced appreciation of life, personal growth and positive lifestyle changes [12].

Social, occupational and relationship functioning are also commonly affected. Many survivors do not return to full-time work [13, 14], some experience reduced social integration [15], and some experience changes, both positive and negative, in their intimate relationships [16–19]. Sexuality and fertility issues can also affect survivors. Adverse outcomes in this domain are particularly prevalent following treatment for breast, prostate or gynecological cancer [20–23].

In Australia and the UK government-funded health care systems provide universal access to health services free at the point of service. However, having cancer can still impose a significant financial burden. Cancer treatment can limit work capabilities, leading to decreased work or prompting early retirement [2]. Furthermore, a changed outlook on life could prompt some to change careers, potentially resulting in a reduced income.

To date, most of the limited research on cancer survivorship has been conducted in the USA. This study provides a qualitative, in depth exploration of the issues, and potential solutions, faced by Australian cancer survivors from two different perspectives: the survivor and the health care professional. The results of this research were used to develop a DVD resource for cancer patients completing treatment for cancer [24].

Method

Participants

Cancer survivors were identified by two means. Firstly, patients who were within 1 year of completing cancer treatment and currently undergoing follow up were approached through doctors and nurse consultants at the Peter MacCallum Cancer Centre (Peter Mac), a major cancer center in Victoria, Australia. Secondly, letters were mailed to volunteers participating in the Cancer Connect program, a service of The Cancer Council Victoria. This is a one-to-one telephone-based peer support program. Volunteers are a minimum of 2 years post treatment and are apparently free from cancer. Volunteers in the Cancer Connect program represent the broad spectrum of long-term cancer survivors. Health professionals were all recruited from Peter Mac, by sending targeted email invitations to each of the cancer services. Medical, nursing and allied health professionals were approached.

Procedure

The Peter Mac Ethics Committee approved the study and all focus group participants provided signed, informed consent. The same facilitator (AP) and note taker were present for each group. The focus groups followed a semi-structured format based on themes identified from a previous literature review. Participants were asked to focus on two time points, first, treatment completion, and second, 12 months post-treatment. Questions and discussion emphasized psychosocial aspects of cancer survivorship and covered: the most difficult and challenging things; support and information; impact of the experience on self and family, physical symptoms, quality of life, emotions, and follow-up care. Participants were also asked about suggested solutions or strategies to meet the issues and needs identified. Focus groups were taped, transcribed, cross-checked for accuracy, and analyzed independently.

Analysis

The process of analyzing the data involved an examination of the material supplied, development of the coding system and then the transcripts were principally analyzed by one individual and then checked by another.

The experiences, concerns and needs of cancer survivors were collapsed into two main groups: (1) those reported by cancer survivors (three focus groups) and, (2) those reported by health care providers (four focus groups). For both groups, perceived needs and concerns were interpreted in terms of their frequency and intensity.

Frequency was defined as the number of times a need was stated across each focus group (within a main group), as well as the number of times a need was stated within each focus group by different individuals. The need was not recounted if it was raised a number of times by the same individual.

An intensity score of between 1 and 4 was allocated to each need statement, based on the perceived intensity of the descriptive language surrounding that need (1 = low intensity, 2 = moderate intensity, 3 = high intensity and 4 = very high intensity). For example, a need reported in a context that it is “fairly important” would be allocated an intensity score of 2 (moderate intensity), whereas a need reported to be “catastrophic” would be allocated an intensity score of 4 (very high intensity). A standardized dictionary was developed prior to analysis (see Table 1). The subthemes were given a score based on frequency and intensity (frequency x intensity) and have been listed in this order (see Table 3). Subthemes that had a frequency of 1 and were mentioned by one group (cancer survivors or health professionals) at one time point have not been reported. Finally, need statements were grouped into broad themes both at treatment completion, and at 1 year post-treatment. The suggestions of how the identified needs could be addressed were coded in terms of frequency but not intensity, as most suggestions were proposed with low intensity.

Results

Participants

Three focus groups involved 22 survivors; details are shown in Table 2. Four focus groups involved 20 health professionals: doctors (two groups—medical and radiation oncologists and hematologists); nurses (one group) and allied health professionals (one group—social workers, a dietician and occupational therapist).

Identified issues or unmet needs

The concerns expressed by survivors and health professionals immediately following and 1 year after treatment completion tended to fall into 12 broad themes (Table 3). There was reasonably high concordance between the issues raised by survivors and those raised by health professionals at both time points.

1. Managing everyday routines and responsibilities

For survivors, this theme included aspects such as fitting back into normal life and losing daily structure and the routine of cancer treatments.

> You sort of go to work and you say “Oh, well, you know, I’m good for the job but I don’t know how much time I’m going to need off or…” You just can’t sort of prepare yourself for that (cancer survivor).

Professionals also described difficulties returning to normal, returning to work and meeting associated medical costs.

> And how many challenges they have to face to get back to normal. Like, as you were saying before, some of your patients, it takes for ever and ever to get back to their work life or to whatever they were doing before. Whereas, with some of my patients, it’s much easier (nurse).

Table 1 Categorization of descriptive language by intensity

Intensity	Score	Descriptive language
Very high	4	Extraordinary, absolutely, terribly, really really, very very, extremely, totally, the hardest, the biggest, the most, the worst, huge, enormously, overwhelmingly, drives you crazy, dreadful, catastrophic, always, constantly, obviously, definitely, particularly, number one, major, main
High	3	Quite, very, really, pretty, certainly, more, so, a lot, virtually, often, big, usually, many
Moderate	2	A bit, sort of, sometimes, kind of, might, some
Low	1	No descriptive language

Table 2 Demographics of cancer survivors participating in focus groups

		N value
Sex	Male	7
	Female	15
Age	<30	1
	30–60	13
	>60	8
Time since completing treatment	<12 months	6
	1–2 years	3
	2–10 years	8
	>10 years	3
Cancer types	Breast	7
	GI tract	5
	Lung	3
	Lymphoma/leukemia	3
	Others[a]	4

[a] One patient each with cancer of the larynx, testis, ovary and with sarcoma

This was the only theme that was not mentioned at 1 year post treatment completion.

2. Managing treatment side-effects and medications

Dealing with fatigue was the area that cancer survivors most frequently reported needing help with at treatment completion. It was also rated as being a 'most intense' need (scoring 4).

> I think I as well wasn't expecting to feel so tired for so long after treatment. I started Uni again in the March after finishing the year before, and I used to come home after a few hours and even then I would still be buggered, like, just in a heap, going "I don't know what's wrong with me; I can't function like a normal 21 year old. Everyone's doing stuff, and I spend a day at Uni and, you know, need to sleep for hours." And I wasn't expecting that kind of tiredness to linger on… (cancer survivor).

Professionals also reported fatigue to be an important problem at both time points, rating it highly in terms of both frequency and intensity.

> Well, I could say, definitely just fitting back into their life as they knew it before. That's always a difficulty because of fatigue (nurse).

Other side effects such as coping with hot flushes and sweats, and with poor concentration and memory were also 'intense' needs reported immediately post and 1 year after treatment completion.

> I'm going through menopause, like lots of females… surely there's somewhere we can go for advice, you know, really good advice on how to deal with, like, an instant rapid menopause. But, most people who don't have cancer, don't experience, it's a more gradual thing. Whereas, when you're on chemo, it's bang, you're in it; it's happening and it's happening quick and you've got everything happening (cancer survivor).

> My memory was…absolutely shot…but once the treatment had all finished, it had all gone. I just couldn't keep things in my head (cancer survivor).

3. Support

Together with concerns around the management of fatigue, survivors rated 'losing the support and reassurance of hospital staff' as the most common issue around treatment completion, in terms of both frequency and intensity. Professionals also recognized this as a common issue.

> I felt that I'd had this team around me for this very intense period of time, and all of the sudden I was told "Just go back to your life" as if nothing had happened to some extent (cancer survivor).

> And also the feeling that they're moving into, from a supported or a supportive environment of care to something they think will be a bit unknown; not as supportive (allied health professional).

Both cancer survivors and health professionals also described friends and family thinking that support was no longer needed once treatment was completed. This was described with high intensity 1 year after treatment completion.

> There is that sort of sense of pressure from other people too to put it all behind…(cancer survivor).

> I think a lot of families expect that that person's just going to spring back into their roles and spring back into their, you know, being just the same old good old Dad or whatever as they were. So, it's sort of expectations of families, and sometimes it's not what reality is (allied health professional).

4. Coping with changes to self-identity

This theme included 'having different outlooks, priorities, and attitudes towards life,' 'altered expectations about physical ability,' 'coming to terms with being diagnosed' as well as change in identity brought about by not being able to work, not being able to have children and, for some women, other consequences of early menopause.

> For me it was a totally different attitude to life. Before that, I'd been totally focused on my career and my

Table 3 Themes identified by cancer survivors and health professionals

Theme	Subthemes	Reported by		Time point reported at	
		Cancer survivors	Health care providers	At treatment completion	One year post treatment completion
Managing everyday routines and responsibilities	Returning to work		X	Y	
	Fitting back into normal life	X	X	Y	
	Meeting medical costs		X	Y	
	Losing the daily structure and routine of treatment	X		Y	
Managing treatment side-effects and medications	Fatigue	X	X	Y	Y
	Hot flashes, sweats	X	X	Y	Y
	Poor concentration or memory	X		Y	
	Changes in weight		X	Y	Y
	Trouble sleeping	X	X	Y	Y
	Painful intercourse/sexual health issues		X	Y	
	Loss of taste and smell		X		Y
	Not being able to eat		X	Y	Y
	Medications	X		Y	
	Pain	X	X	Y	
	Nausea		X	Y	
	Skills to use medical equipment (e.g. feeding tube)		X	Y	
	Trouble swallowing		X	Y	
	Teeth falling out		X		X
	Dry mouth		X	Y	Y
	Diarrhea		X	Y	Y
	Painful urination		X	Y	Y
Support	Losing the support and reassurance of hospital staff	X	X	Y	Y
	Having someone to talk to who has been through a similar situation	X	X	Y	Y
	Friends and family thinking support is no longer required	X	X	Y	Y
Coping with changes to self-identity	Going into early menopause	X	X	Y	Y
	Having different outlooks, priorities and attitudes towards life	X	X	Y	Y
	Not being able to do the things you used to	X	X	Y	Y
	Expectations about physical ability	X	X	Y	
	Not being able to go back to work	X	X	Y	Y
	Expecting yourself to be back to normal	X	X	Y	Y
	Feeling like a different person	X	X	Y	Y
	Coping with changes in appearance (body image)		X	Y	Y
	Coming to terms with being diagnosed	X	X	Y	
	Never being able to do some things again (e.g. speak)		X	X	X
	Being dependent on others	X	X	Y	Y
	Not being able to have children	X	X	Y	Y
	Strains or changes in relationships or friendships		X	Y	Y
	Having to go on a pension	X	X	Y	Y
	Change role in friendships or relationships	X			Y
Fear and anxiety	Going for tests/check-ups or waiting for results	X	X	Y	Y
	Leaving the system (not knowing what to do, who to contact)	X	X	Y	
	Cancer recurrence	X	X	Y	Y
	The future (uncertain)	X	X	Y	Y
	Whether the treatment has worked		X	Y	
	About minor illness or aches and pains		X	Y	
	Loss of control	X	X	Y	
	Returning to work		X	Y	Y

Table 3 (continued)

Theme	Subthemes	Reported by		Time point reported at	
		Cancer survivors	Health care providers	At treatment completion	One year post treatment completion
	About long term side effects		X	Y	
	Whether bosses/managers will be supportive		X	Y	
	Being told different things by different health care providers		X	Y	
	How you are going to earn money	X	X	Y	
	That you won't have enough time to do the things you want to.	X			X
	Family and friends emotional well-being	X	X	Y	Y
Sadness and loneliness	Feeling low, flat, down, depressed	X	X	Y	
	Feeling isolated/alienated	X	X	Y	
	Feeling over emotional (crying, empathy for others)	X			X
	Feeling vulnerable	X	X	Y	
	Not feeling happy or relieved when treatment is over	X	X	Y	
	Being reminded of having cancer by the media or others	X	X		Y
	Staying positive	X		Y	
	Feeling guilty that it was your fault you got cancer	X	X	Y	Y
	Feeling guilty about what you've put your family through/passing cancer on to your children	X	X	Y	Y
	Not being able to feel normal again	X		Y	
	Feeling like you don't fit in or belong	X		Y	
	Feeling sadness for time lost	X		Y	
Lacking confidence	To set long term goals or make long term plans	X	X	Y	
	About appearance (body image) or physical problems	X	X	Y	Y
	That the cancer has gone away	X	X	Y	Y
	Wanting to have regular check-ups	X	X		Y
	In yourself	X		Y	Y
Information needs	How to prevent cancer in the future		X	Y	
	What to look out for (sign of cancer returning)	X	X	Y	Y
	Who to contact if you have a question or problem	X	X	Y	
	How your body will change	X		Y	
	How to get better and achieve goals		X	Y	
	What to do once treatment ends	X		Y	
	Whether the treatment has worked	X	X	Y	
	How to look after yourself	X		Y	
	In languages other than English		X		Y
	About whether you can have children		X	Y	Y
	The difference between being in remission and cured		X	Y	
	How much time you'll need off work	X	X	Y	
Coping with the behavior of others	Others expecting you to be back to normal	X	X	Y	Y
	Others expecting you to feel happy, positive, relieved or grateful	X	X	Y	Y
	Others not understanding what you are going through	X	X	Y	Y
	Others not knowing what to say or how to behave	X		Y	Y
	Others not being able to cope	X		Y	Y
	Friends and family not understanding that you have changed		X	Y	Y
	Other not understanding your physical abilities have changed	X	X	Y	Y
Relating to others	Not being able to relate to or connect with others	X	X	Y	Y
	Not knowing how to talk to others about: how you feel, how you have changed or what it is like	X	X	Y	Y

Table 3 (continued)

Theme	Subthemes	Reported by		Time point reported at	
		Cancer survivors	Health care providers	At treatment completion	One year post treatment completion
Health services	Feeling abandoned, pushed out, cast adrift by the system	X	X	Y	
	Doctors over-reacting to minor illnesses and aches and pains	X			Y
	Finding counseling or support groups	X		Y	Y
	Treatment finishing suddenly	X		Y	
	Setting short term goals for improvement or rehabilitation	X	X	Y	Y
Positive experiences	Celebrate good news or test results		X		Y
	Reward yourself for finishing treatment		X	Y	
	Do nice things with your family		X	Y	
	Time to reflect on what you've achieved		X		Y
	Being able to celebrate (e.g. when reaching goals)	X	X	Y	Y

> work and climbing the corporate ladder and doing all those sorts of things and working yourself into the ground, and suddenly I come out of hospital and "Gee, now it's me."…I think in a lot of cases it's a matter of suddenly realizing that there is more to life (cancer survivor).

> And, I think for some of my patients, the patients that were premenopausal, certainly that issue about not being able to have children, being postmenopausal, all of those things actually hit home and it really, it's usually at around about that twelve months, you know, relationships become very strained and difficult for them (nurse).

> I think people often reset their priorities, too, as a result (allied health professional).

5. Fear and anxiety

As described in the literature, focus group participants described several fears around treatment completion. For both survivors and health professionals, the three areas most commonly reported were worries about leaving the health care system, fears about cancer recurrence, and uncertainty about the future. The latter two were fears that persisted at 1 year after completion of treatment. Other fears concerned side effects and follow-up as well as more practical aspects such as financial security.

> I didn't feel relief, I felt quite scared, wondering if it was going to come back again; clinging on to, I suppose, the support that I'd had in hospital as well as the support that I had outside; clinging onto my oncologist, metaphorically speaking, I suppose (cancer survivor).

> The thing that the patients always say is that they get very anxious the few days before the appointment, and very relieved when there's nothing found. So, it's a very ambivalent feeling, I think, the follow up. On the one hand they want to come and be told that there's nothing wrong, but they also get very anxious just before it. So, I mean, I think that living with the uncertainty is really very real, and something I talk a lot about with them because, you know, it doesn't matter what percentage risk you give them for the cancer coming back, as long as it's not 100% that it won't come back, then there's always going to be a risk (medical oncologist).

> I often tell them that when they finish the treatment, you know, it's very common for the fear of recurrence to be at the forefront of their mind, and that as time goes on, they'll find it moves to the back of their mind and the times that they think about it will come less often and less severely. And so I guess I try to give them a pattern of what a lot of patients describe to you as a way of trying to reassure them that it is normal to worry about recurrence, that that's not unusual, and basically they've got to find a way of pushing it back out of the front of their mind to the back of their mind (medical oncologist).

6. Sadness and loneliness

The most common statement reported by both main groups was around feeling low, flat, down or depressed. At 1 year post treatment the most common statement was feeling over-emotional and being reminded of having cancer by the media and others.

> Yeah. I felt a bit flat when I'd finished treatment. So, it wasn't the sense of relief that I was expecting, and my family was expecting me to feel (cancer survivor).

Both main groups also described the experience of not feeling happy or relieved when the treatment is over. Others described feeling isolated, vulnerable and alienated.

> I just fell in a bit of a heap, I think, I think because I'd been so focused on getting through my treatment, that I still had a lot of grief there that I hadn't really dealt with (cancer survivor).

> But when they cease the direct involvement, they can often feel a bit abandoned I think. That they've had something to occupy their mind, coming and going to hospital every day, and it sort of seems like they're working on the cure, if you like, or on the treatment, and then when it's all finished, they've got nothing to do but worry, "Has it been successful?" or "Are these reactions going to be permanent?" I think there's the immediate period right after the intensive interaction (medical oncologist).

7. Lacking confidence

Very commonly survivors talked about lacking confidence that their cancer had indeed gone away.

> But once it was all finished, I thought "Right, well," you know, "I'm OK now, supposedly. Now what do I do? Just wait? Does it come back? Do I get on with it?" you know, "They're telling me it's gone. OK. Do I believe it?" (cancer survivor)

Members of both groups also reported that survivors may lack the confidence to set long term goals or make long term plans. Survivors also may lack confidence about their ongoing health, appearance (body image) or related to other physical problems.

> A real traumatic experience that's made you rethink your priorities, what's important, all that sort of thing, and your uncertainty and lack of confidence in your body, where you think you can control most things around, but this body's doing things that you don't want it to do. I think that's the difference; that's what causes it (cancer survivor).

> She'd (a patient) come to the end of treatment and she didn't have any goals anymore because her goal was to finish treatment and she was hoping to survive the treatment, kind of thing, and she had no goals in life and she just felt totally swamped and had no idea of which way she was going to go…It was quite overwhelming for her (allied health professional).

> Well, external appearance is a big issue for some patients, especially if they've had major surgery before their radiotherapy, and you know, even having a laryngectomy, although it doesn't alter your facial appearance, it certainly can be very embarrassing if you get into a coughing fit or something in a restaurant or whatever, and you're trying to control a stoma. For people whose external appearance is not much altered, they can still be socially isolated by function, not being able to swallow properly or talk properly or articulate because they've only got half a tongue or whatever. So, I don't think appearance is just visual appearance, it's functionality, and yet you get other people who can look lopsided or whatever after surgery or have a big scar but they do well; it's a mental attitude (radiation oncologist).

8. Information needs

Both main groups noted the need for information around the time of treatment completion. Information needs raised by participants included what to look out for (signs of cancer returning), what to do once treatment has ended, how to get better and prevent cancer recurrence as well as practical information such as who to contact with questions or problems. At 1-year post treatment survivors wanted to know that the way the felt was normal and needed more information about where to find resources.

> For the next five years I was waiting to be spitting up blood again, until I finally did. So I came back here, and they said, "Don't worry about it. It happens." Now, if somebody had told me that five years before, I wouldn't have been worried about it coming back so much (cancer survivor).

> I think, actually, I don't know whether when patients finish their treatment they get a support sort of pack of information. There's probably no…But, that would be a good time to give out information, I think, because when they're first diagnosed, and they're bombarded with information, they have to make decisions under stress, they have their treatment, quite a stressful time, it's not really necessarily a time that they're seeking a lot of information. They don't know what they need to know, and at that point of discharge from treatment, like, you know, your active treatment, that might be a good time to have a pack that just gets given to people on their last treatment day to say, you know, "These are for finishing treatment. Congratulations!" kind of thing, and you know, "Here are some things that might be useful for you in the next few months." (allied health professional).

9. Coping with the behaviors of others

Again, there was considerable agreement at both time points between survivors and professionals around this theme. Statements coded under this theme included ‘others expecting you to be back to normal’ and people not knowing what to say and not understanding what the cancer survivor has experienced. Participants also described others expecting people to feel happy, positive or relieved.

> I think there’s a certain amount of peer expectation, that you’ve been through that and they see you walking around and they expect you to be back to normal (cancer survivor).

> And other people’s expectations are that you’ve finished treatment. And so, “What’s wrong with you now?” (cancer survivor)

> I think once the, well, some people that I’ve seen, once the physical, objective sides of cancer had gone, you know, the appearance goes back to normal, hair grows back, you’ve got your eyebrows again, you know, all of that type of thing, that often people around the patient, we’ll call them the patient, do expect the person to be just the same as they were before, and even though, you know, it’s touched them as well, that they kind of have the expectation that that person’s going to be the same, but they’re not. So, you know, there can be some issues there with, I guess, again, unrealized expectations or unrealistic expectations from the family, that they just are going to slot into their old roles and be their own jolly old self and, you know, life’s going to be good, you know, good how it was (allied health professional).

10. Relating to others

Associated with the above theme, several survivors in particular described not being able to relate to or connect with others. Both groups mentioned difficulties in talking to others about how they had changed because of their cancer experience. These persisted 1 year after completion of treatment.

> I’ve got older sisters that have all got kids and got friends that have all got kids and when I went back to going, sort of, trying to relate to them, I couldn’t relate to them, because they told me I couldn’t have kids after the chemotherapy (cancer survivor).

> It makes you feel more, you know, more isolated, that people don’t understand what you’re going through and don’t understand what you’ve been through, and so I think it makes you withdraw (cancer survivor).

11. Health services

Survivors frequently and with intense language described feeling abandoned, pushed out or cast adrift by the health care system at the time of treatment completion. This was also commonly reported by healthcare professionals.

> It’s such an intense relationship with all the treatment practitioners for that length of time, and then you’re sort of just cast off and, you know, they’re onto the next patient and you’re just left to flounder yourself. Whereas, that structure had been built around a lot of support and a lot of contact, the treatment, and then you were just sort of cast adrift, as you said. So there was a real sense of abandonment (cancer survivor).

> Just the uncertainty, feeling like your safety net’s now gone, which is the hospital, the staff, the chemo (cancer survivor).

Some survivors talked about the need and importance for them of finding counseling or support groups because of this abrupt change in relationship:

> I went searching for support groups, and they’re few and far between (cancer survivor).

> One of the things that I’ve found really useful was that I had participated in a research project that was, it was built, the part that I was on, was built around peer support. So, it was a group of ladies that got together and talked about their experiences. And when that finished, we kept in touch, and we would go out for lunch maybe once every three months. And just being able to talk to those ladies that had all been through the same thing and were still going through the same thing was enormously valuable (cancer survivor).

> I mean, link them in with some, like, extra resources and things like that, because sometimes even up until twelve months, you know, a support group just isn’t in the plan for them. So, sometimes those things can be helpful (nurse).

12. Positive experiences

Some focus group participants described reward and positive experience at treatment completion, though this was not a common statement. At 1 year post treatment completion these statements were repeated by health professionals.

> I felt that it had, I won’t say been a worthwhile experience, but that it had been quite a good experience for me. It gave me a chance of understanding other people better. I felt for my own personal

> development, it had not been a negative experience at all…it's been a rounding of my character, if you like, to some extent (cancer survivor).
>
> I think, also, amidst all of that sort of negative stuff, though, I know our group do tend to plan a weekend away or plan to do nice things with their family, I mean, I think that's when the support of family and community is what they call upon. Without them, there is to break that, or to reward themselves for getting through the treatment (nurse).

Suggested strategies to meet the identified needs

Suggestions for how the needs of cancer survivors could be met were grouped by who could potentially be responsible for changes to the psychosocial care of cancer survivors. As seen in Table 4, five major groups were identified.

Both the survivor and health care professional groups stressed the importance of providing reassurance to survivors that the way they feel is normal. Both groups commonly suggested putting the cancer survivor in touch with someone with similar experience, either through a 'buddy' or through a support group. Both groups also supported the notion of a transition from active treatment to the post-treatment survivorship phase: through a 'treatment completion' session; telephone follow-up and improved liaison with primary care doctors. Both groups also stressed the importance of providing adequate information about issues related to survivorship, including what to expect during different time frames, as well as adequate emotional and psychological support. Survivors could also assist themselves by setting goals and resuming pre-diagnosis activities.

Professionals emphasized the need for routine post-treatment psychosocial screening, whereas this was not mentioned by survivors. Interestingly, some professionals pointed to issues with the current model of care, noting that short review appointments hindered ideal survivorship care.

Although Australians have access to a free, universal public health system, and also to sickness benefits, participants considered governments to have additional responsibility to ensure optimal survivorship outcomes. As examples, survivors mentioned the need for ongoing sick leave provision and professionals spoke of the need for local government to provide assistance with household tasks.

Discussion

This study contributes to the literature in two important ways. First, the issues faced by survivors are explored from two different perspectives: the survivor and health professionals. This provides a subjective and also perhaps more objective insight into the experiences of survivors. Interestingly, there was a high level of congruence in the themes that emerged from the focus groups, conducted separately,

Table 4 Some suggestions of how the needs of cancer survivors could be met

Responsible group	Suggestion
Hospitals, treatment centers, or clinics	Being buddied or put in contact with a cancer survivor who has been through the same thing (CS[a]/HP[a])
	Having a health care provider who rings you at home to check how you are going, and who you can ring if you have any concerns (CS[a]/HP)
	Establishing a transition group between finishing treatment and going home (CS/HP)
	Having routine psycho-social screening (HP[a])
	Being connected to a support group (CS/HP)
Health care providers	Being reassured that the way you feel is normal (CS[b]/HP[a])
	Being encouraged to see a psychologist or counselor (CS/HP)
	Having a more specific plan or time-line for physical rehabilitation (CS/HP)
	Ask patients questions or inviting them to bring up a concern, don't wait for them to bring up a concern (HP)
Cancer survivors	Setting achievable short and long-term goals (HP)
	Resuming activities you did before treatment (HP)
Government bodies or agencies	Ensuring that cancer survivors can still receive sick leave after treatment has finished (CS)
	Getting help for household tasks (HP)
National, state and area health services	Information in a variety of media (written, internet etc) (HP[a])
	Information about what to expect at different time frames (CS[a]/HP)
	Information about the disease and treatment side-effects (CS/HP)
	Information about how to talk to others about cancer, including young children (CS)

CS cancer survivor, HP health professional

[a] Subthemes mentioned by five or more focus group participants

[b] Subthemes mentioned by ten or more focus group participants

with survivors and with health professionals. In order to develop effective psychosocial interventions, the first hurdle requirement is that the intervention be viewed as both acceptable and appropriate, both from the perspective of patients/survivors and that of health professionals, to ensure optimal uptake [25]. A second key contribution from this study, therefore, is the determination of strategies for addressing the needs of survivors, elicited from both groups.

The major survivorship issues identified in this study mirror the themes described in previous, primarily US studies [2], suggesting a great commonality to the survivorship experience. The most prominent, frequently experienced concern is the fear and anxiety people experience at treatment completion. This relates to fears about cancer recurrence, worries about leaving the health care system and uncertainty about the future, reported in our study, echoing earlier work [2, 8, 9]. Sadness and loneliness also emerged as prevalent emotional reactions. This sits in juxtaposition to the perceived expectations of family and friends that the cancer survivor should get ‘back to normal’ and/or feel happy that treatment is over. This difference in perspective was further demonstrated by survivors frequently reporting that others don’t know what to say or know how to behave with them. Both professionals and survivors discussed the struggle that many individuals have in coping with changes to self-identity following treatment completion, particularly having a different outlook, priorities, and attitude towards life. Also, as has been found in previous work [13–15, 17], role functioning and relationships with friends and family can alter. Finally, there can be persisting long term and late physical effects for survivors. Fatigue was mentioned with high frequency and intensity as the most troublesome side effect at treatment completion. One difference between these results and previous work in this area is that no one raised any issues related to gaining employment or insurance [2]. This is likely to be due to the socio-political differences between the USA and Australia.

There was broad agreement between health professionals’ views and those of cancer survivors. However, some aspects within each of the twelve domains tended to be emphasized by some groups e.g. health professionals highlighted particular physical complaints. As an example, professionals with experience managing patients with cancers of the head and neck region spoke about the potential for loss of taste and smell, difficulty with swallowing, problems with teeth and the need to develop skills to use medical feeding equipment. Only one survivor in the focus groups had been treated for a cancer of this region (laryngeal cancer). In studies such as this, it may not always be possible to achieve good representation from survivors of all cancer types. To adequately understand issues for survivors it may be necessary to corroborate the views of survivors and health professionals.

Professionals emphasized the need for routine post-treatment psychosocial screening, whereas this was not mentioned by survivors. This may reflect professional knowledge or experience; could be a result of under sampling of survivors, or may indicate that survivors were unaware of the potential for ongoing psychological distress.

Interestingly, there were no clear domains that were identified by survivors, that were not considered by the health professional groups, suggesting good awareness by professionals of survivorship issues. That does not necessarily imply that survivors are receiving ideal post-treatment care. Both groups noted a lack of information, support, services and effective models of care.

In order to meet the array of needs, a broad range of suggestions were offered by survivors and by health professionals. The two most frequent suggestions proposed by both survivors and by health professionals were targeted at the emotional consequences of post-treatment survivorship. The first was that survivors should be reassured by health care providers that the way they feel is normal. Without trivializing the significance of their experience, normalizing a person’s emotional reactions might help reduce the sense of fear, loneliness and sadness which was so commonly expressed by survivors. This relates to the second most frequently reported suggestion, to be put in contact with a survivor of the same cancer to provide understanding that can only be provided by someone who has “been through the same thing and (is) still going through the same thing”.

Both groups used different language in proposing ongoing monitoring of survivors to identify issues early. Health professionals suggested routine psychosocial screening of survivors; whereas survivors suggested having a health care provider ring survivors at home to monitor concerns. Both groups stressed the importance of ongoing, personalized information relating to past, present and possible future issues. These results provide support for the first three elements of the IOM’s individualized ‘survivorship care plan’. The IOM report [2] concluded that there are four essential elements to survivorship planning: prevention of recurrent and new cancers; surveillance for new or recurrent cancers, medical and psychosocial late effects; intervention for the physical and psychosocial consequences of cancer and its treatment; and coordination between specialists and primary care providers.

While an individualized care plan may be one solution to the complex and multifaceted needs that survivors face, this intervention is currently untested and may be difficult and expensive to actually implement and disseminate in a portable health care system. Indeed, some of the issues may be addressed quite easily and with more generic resources. Basic information and reassurance about the common issues faced by survivors might be successfully delivered using a variety of media as proposed by both survivors and professionals in our study. A variety of media have been successfully used for the delivery of patient information, predominantly targeted around the diagnosis and active treatment phases, including print, audiotape, telephone, the Internet and audio-visual media such as videotape, DVD and CD-ROM [26, 27]. It is critical that information resources are developed specifically for the post-treatment survivor phase, ideally employing a range of media to account for different preferences. Using the qualitative data reported in this paper, we have recently completed development of an informational DVD [24] and a companion booklet, designed for survivors who have completed potentially curative treatment. As information is required by all patients [28], developing these resources is a necessary first step. A tiered framework of supportive care delivery holds that many people will require further assistance to meet their needs, some will benefit from more intense input and a few will require highly specialist services to deal with complex problems [28]. Hence, there is considerable effort required to develop effective interventions to address the array of issues faced by survivors. Some focus group participants spoke of difficulties with current models of care, which places little emphasis and affords only very limited time for post-treatment care. As supported by the IOM report [2], it will be necessary to consider alternative models of care to ensure optimal survivor outcomes.

Limitations

We acknowledge that there are potential concerns with the use of frequency and intensity in the analysis of the focus group themes. The accuracy of the frequency analysis may be flawed in two ways. Firstly, if a need is raised by one individual in a group, then it is perhaps less likely to be raised again by another individual, despite its importance. Secondly, although the audio files record any verbal agreement with statements, non-verbal agreement, such as the nodding of heads etc, is not recorded. Therefore, the frequency of statements calculated from the audio transcripts may not present an entirely accurate picture. For this reason the measure of intensity was also included. A second limitation of the work is the recruitment methods employed may have influenced the results. In particular, as a substantial proportion of survivors were volunteers in a one-to-one telephone-based peer support program run by the Cancer Council, it is possible that they may overemphasize the need to receive and the potential benefits of peer support. However, the issues raised by these volunteers were also raised by survivors recruited directly from the hospital. Third, not all cancers and not all health professionals were represented in the focus groups, however, a good spread was achieved. Finally, a set number of focus groups were performed; hence, strictly speaking saturation may not have been achieved. However, there was considerable repetition over the series of focus groups, with the main sub themes recurring frequently and in the final focus group very few new sub themes were identified.

Conclusion

There was a very high level of agreement between cancer survivors and health care professionals concerning the issues that survivors face at treatment completion, and in the first year after treatment. The fears, sadness and loneliness that survivors experience, the disparity in perceptions between the survivor and their family, ongoing physical issues, changes in identity, role functioning and relationship changes mirror themes reported in earlier work and summarized in the Institute of Medicine report [2]. The suggestions offered by cancer survivors and health care professionals support three of the four core elements of the IOM proposed survivorship care plan. Particularly, the importance of normalizing, without trivializing the emotional experience, providing peer support, instigating ongoing monitoring to identify ongoing and emerging physical and psychosocial issues, and the delivery of tailored information by the survivor's preferred media. Currently, intervention research in this field is in its infancy. Clearly, rigorous trials of acceptable interventions are required to address the serious concerns of this large and growing group.

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