



Insights on emotional distress following cancer, sources of support and the unmet needs in a setting with limited supportive care services for people living with cancer

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Abstract

Introduction Delivery of supportive cancer care is often deemed a low priority in resource-limited settings. We aimed to explore the sources of emotional distress, the related support and the unmet needs of cancer survivors in Malaysia, where cancer survivorship services are presently limited.

Method Twenty focus group discussions were conducted with 102 cancer patients from diverse ethnic and socioeconomic backgrounds. Thematic analyses were performed.

Results Patient narratives suggested that emotional distress arose from direct and indirect stressors. Direct stressors comprised physical and cognitive side effects of cancer surgery and therapies, and fear of recurrence. Indirect stressors included worry over dependent family members, financial distress following cancer, working with cancer and lack of practical support at home. Distress from altered physical appearances, fear of recurrence and lack of practical support were mainly raised by women, implying that men and women may have disproportionate emotional needs. Emotional support largely came from informal sources including self, family, friends and religion. While formal emotional support from professional counsellors and cancer support groups was acknowledged as important, it appeared to be largely lacking. Unmet needs in coping with fear of recurrence, financial distress, workplace discrimination and household chores were particularly highlighted.

Conclusion The unmet needs revealed in this study provide insights to initiate actionable changes to improve the emotional wellbeing of people living with cancer in settings where cancer survivorship services are still in its infancy.

Keywords Cancer · Emotional distress · Unmet needs · Supportive care need

Implication for cancer survivors Our findings will facilitate development of supportive care services addressing wider aspects of wellbeing following cancer.

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Background

Emotional distress is common across the cancer trajectory, setting in before the point of cancer diagnosis and extending throughout the survivorship phase [1]. According to the National Comprehensive Cancer Network, ‘distress’ can be defined as an unpleasant experience of emotional or psychological nature, including depression, anxiety and other mood and adjustment disorders [2]. Distress in cancer patients is associated with suboptimal cancer-related decision-making, non-adherence to treatment, poor quality of life and higher mortality [3–5]. Emotional distress has also been found to increase the burden on the oncology team and the healthcare system [6, 7].

While a great deal of emphasis on cancer control in the low- and middle-income countries is rightly focused on promoting early detection and improving survival rates of

patients with cancer, delivery of supportive cancer care is often regarded as low priority in these settings [4]. This is corroborated by findings of the ASEAN Costs in Oncology (ACTION) study, which revealed that cancer survivors in resource-limited settings continued to experience impaired health-related quality of life and also high levels of anxiety and depression at 1 year after diagnosis [8]. This was also true for upper-middle-income economies such as Malaysia, where cancer survivorship services are presently limited [9].

We therefore aimed to explore the emotional distress experienced by people living with cancer in Malaysia, and the sources of support to cope with the distress. The study also aimed at gaining in-depth understanding of unmet emotional needs following cancer. Given the scarcity of evidence in this area in the low- and middle-income countries, our findings are expected to facilitate the development of holistic cancer survivorship services addressing wider aspects of wellbeing in people living with cancer in resource-limited settings.

Methodology

Data for the present study was derived from a wider study with a broader aim of identifying the needs of cancer survivors living in resource-constrained settings where supportive cancer care services are presently underdeveloped [10].

Participants

Participants comprised multiethnic patients who were diagnosed with either primary colorectal, prostate, cervical or breast cancer. To ensure adequate representation of participants from diverse ethnic and socioeconomic backgrounds, recruitment was conducted in three public (National Cancer Institute, Kuala Lumpur Hospital, University Malaya Medical Centre) and two private hospitals (University Malaya Specialist Centre, Subang Jaya Medical Centre) across the Klang Valley in Malaysia.

Data collection

Patients were invited to join focus group discussions (FGD), which were conducted separately for men and women. A focus group topic guide relating to the research objectives was developed and validated in a pilot study, and subsequently used by study moderators throughout the FGDs. The FGDs were conducted in either English or Malay language subject to the participant's choice. All FGDs were conducted by two researchers, namely a moderator and a co-moderator who have been trained. Discussions that were conducted in the Malay language were forward translated into English. Towards the end of the focus group discussion, the moderator summarised participants' opinions to ensure that the identified

essence resonated with the participants' experience and clarified any unclear points during the course of the discussion. A standard forward and backward translation was also performed. Each discussion lasted nearly two hours and was audio-recorded and transcribed verbatim. Supplemental notes were also taken. The concept of theoretical saturation using phenomenological methods was implemented to assure that no new conceptual information was appearing from further discussion and the data collection continued until data saturation was reached

Ethical approval

The study was approved by the Medical Research Ethics Committee (NMRR-17-3361-39122), University Malaya Medical Research Ethics Committee (201831-6061), and Ramsay Sime Darby Health Care Independent Ethics Committee (201809.2). Written informed consent was obtained from all participants.

Data analysis

The team members transcribed the audio-recordings. All transcripts were reviewed independently at least twice by two team members. Following data familiarisation, codes were generated for each of the main themes (sources of emotional distress, sources of emotional support) to determine the relevant subthemes. NVivo V.12 was used for analysis. Persistent comparisons, researcher triangulation and checks were conducted by team members to assure the consistency and accuracy of coding.

Results

Data saturation was achieved after 20 FGDs: 12 FGDs with 64 women and 8 FGDs with 38 men. Many of the participants were from low-income families (Table 1). The average age of study participants at diagnosis was 53 years (men: 66 years, women: 49 years). Time since diagnosis ranged from 2 to 240 months (median: 20 months).

Themes

Sources of emotional distress along the cancer journey (Table 2)

Dealing with physical and cognitive side effects of cancer surgery and therapies Study participants recounted that the physical and cognitive impairments associated with administration of cancer therapies, such as chemotherapy and radiotherapy were a major source of emotional distress for both male and female participants. Physical effects such as pain,

Table 1 Characteristics of study participants

Characteristic	Women (n=64)	Men (n=38)
Age		
Below 40 years	15 (23.4%)	4 (10.5%)
40–59 years	40 (62.5%)	10 (26.3%)
60 years and above	9 (14.1%)	24 (63.2%)
Marital status		
Married	49 (76.6%)	30 (78.9%)
Single	6 (9.4%)	4 (10.5%)
Others	9 (14.1%)	4 (10.5%)
Ethnicity		
Malay	36 (56.3%)	8 (21.2%)
Chinese	16 (25.0%)	21 (55.3%)
Indian	11 (17.2%)	6 (15.8%)
Others	1 (1.6%)	3 (7.9%)
Monthly household income*		
B40 (bottom 40: lower than USD1045)	35 (54.7%)	19 (52.8%)
M40 (middle 40: USD2306)	18 (28.1%)	7 (19.4%)
T20 (top 20: more than USD2306)	11 (17.2%)	10 (27.8%)
Missing	0	2
Educational background		
Tertiary	28 (43.8%)	20 (52.6%)
Secondary	31 (48.4%)	18 (47.4%)
Primary	5 (7.8%)	0
Type of cancer		
Breast	30 (46.9%)	-
Colorectal	22 (34.4%)	20 (52.6%)
Cervical	12 (18.8%)	-
Prostate	-	18 (47.4%)
Type of hospital		
Public (Ministry of Health)	37 (57.8%)	20 (52.6%)
Public (university)	16 (25.0%)	9 (23.7%)
Private	11 (17.2%)	9 (23.7%)
Cancer stage at initial diagnosis		
I	7 (11.7%)	3 (12.0%)
II	21 (35.0%)	6 (24.0%)
III	20 (33.3%)	8 (32.0%)
IV	12 (20.0%)	8 (32.0%)
Missing	4	13
Time since diagnosis (months) [‡]		
Median (25th, 75th percentile)	18 (10, 28)	27 (14, 61)

*Household income classification based on the Malaysian Department of Statistics' Household Income and Basic Amenities survey of 2019.

[‡]Primary school (students begin their primary school at age of seven (standard 1) until the age of 12 (standard 6). Secondary school (student enrolled as (form 1) at age of 13 until (form 5) at age of 17). At the tertiary level of education, students enrolled in undergraduate or postgraduate courses in public or private universities

nausea, diarrhoea, extreme fatigue and limitations in range of motion often hindered the participants' ability to carry out

their daily activities, resulting in feelings of frustration and hopelessness. Chemotherapy-induced cognitive impairments, ranging from subtle to severe memory, attention and thinking problems, were also major emotional stressors for some participants as it affected their self-esteem and self-worth. Participants with colorectal cancer highlighted extreme distress associated with wearing stoma bags due to the fear of leaks and the constant need to change the bags. As a result, many patients remained largely homebound and had substantially fewer social outings. Female participants were often in tears when talking about changes in their physical appearances and disfigurements. For many, hair loss from cancer treatment was emotionally challenging as it affected their self-image in the eyes of their loved ones and also within their social circles. Female participants, especially those who were younger who had mastectomies or hysterectomies, expressed grief. To many, these were equivalent to losing part of their femininity. Male participants appeared to be less affected by the physical changes that they had to endure following cancer treatment (Table 2).

Fear of cancer recurrence Almost all participants shared that hospital follow-up visits for screening for recurrence of cancer provoked tremendous fear and anxiety. Most cancer survivors further acknowledged that they do worry about cancer recurrence in their daily lives. Nonetheless, more men than women in this study shared stories of being resilient and generally being able to cope well (Table 2). A handful of female cancer survivors on the other hand reported that they lived in constant fear of recurrence, which was deemed as debilitating.

Worries over dependent family members Most women in this study expressed grave concerns and worries about the care and future of their children in the event of their deaths. Women with young children were especially more distressed because they could not spend time with their young children due to cancer and the side effects of cancer therapy. The men too expressed distress, but over the financial wellbeing of their families upon their demise (Table 2).

Financial distress following cancer The high expenditures incurred after being diagnosed with cancer namely the high costs of certain cancer therapies (targeted therapies), coupled with reduction in household income were raised as important emotional stressors. High costs of cancer care were especially a challenge for patients who sought treatment in private hospitals and had inadequate medical insurance coverage. These patients recounted being referred to the public hospitals to continue cancer therapies upon exhausting their insurance limits, which was perceived as humiliating and stressful. Patients who were treated with expensive targeted therapies in some public hospitals also expressed emotional distress, with some of

Table 2 Subthemes for sources of emotional distress along the cancer journey

Sources of emotional distress

Dealing with physical and cognitive side effects of cancer surgery and therapies

'The children will run and say ghost is coming. I was all bald with no eyebrows.' (50-year-old female with breast cancer)

'My hair and everything were gone, when my friends wanted to come and visit, I didn't let them come, I am not ready for them to see me.' (60-year-old female with breast cancer)

'I kept having diarrhoea. I was outside and I had the urge to go to toilet, you know public toilets have many people and it just passed. Imagine, a 30 plus year old (soiling her clothes)... I called out for my husbands to buy me pants. When I reached home I cried as I felt so ashamed. I didn't go out anymore until my treatment ended.' (39-year-old female with cervical cancer)

'No matter how painful the treatment, I didn't cry in front of my children, I didn't want them to be sad.' (64-year-old female with breast cancer)

After I underwent mastectomy, I lost my confidence and have no mood for sexual relationship and I felt so embarrassed to face my husband. I felt incomplete.' (38-year-old female with breast cancer)

'Even though people say it's okay, but I have already lost one side (breast), so I felt really lacking. Till I got depression. I was moody and ashamed to meet people.' (40-year-old female with breast cancer)

'When I see other women, I will think why am I like this? I feel sad and don't like being in this situation. No matter what, we will definitely feel like we are lacking. Like me, I have a bag on me. My pants cannot be too tight; I have to wear loose pants.' (38-year-old female with colorectal cancer)

'Cervical cancer is very difficult and we feel shy to tell people because it is loss of femininity. We don't get our period, we can't conceive a baby, and we lost our uterus.' (35-year-old female with cervical cancer)

'I have had castration. Before castration, I was worried of the side effects I find that it is all rubbish. I don't feel any lack of self-confidence when I am around people.' (77-year-old male with prostate cancer)

'We are limited. Like sometimes when we go out, we have to be quick to go back just because of the stoma bag, we need to change it... We have to wear really loose and baggy pants. There is always a tendency that you rip or lose the thing'. (68-year-old male with colorectal cancer)

'Low energy after surgery. Not active as previously so I limit my activities.' (46-year-old male with colorectal cancer)

'Most of the time I have to stay at home. Lack of mobility and. I have to clean my waste.' (76-year-old male with colorectal cancer)

'I find that it is not the cancer that affects you, it is the treatment. I have been through chemo. I am still fighting to get my brain functioning as I want it too.' (77-year-old male with prostate cancer)

'Some of us (men) don't feel it (physical changes) because we are not bothered..' (79-year-old male with prostate cancer)

'Those days when I was under hormone therapy. One of the side effects was breast enlargement. I dare not go to the swimming pool, as my breasts were enlarged. The hormone injection also caused the belly to grow. I felt embarrassed.' (79-year-old male with prostate cancer)

Fear of cancer recurrence

'It has been 9 years now, and the fear is always there.' (60-year-old female with breast cancer)

'Every day I am scared, even if I have a small headache, I become worried, when my legs hurt a bit, I become worried.' (49-year-old female with breast cancer)

'I do think of recurrence. A few of my friends passed away, too. So, I try to eat organic food, try to change lifestyles, anything that I could. But of course, I am afraid too.' (47-year-old female with breast cancer)

'Regarding fear of recurrence, in my case, it does come..... Creeping fear maybe yes once in awhile but I can brush it off.' (72-year-old male with prostate cancer)

'I don't feel it (fear of recurrence)' (70-year-old male with colorectal cancer)

Worry over dependent family members

'I have responsibilities. I have a wife with three children. I am the only one who is working, my wife is housewife.' (34-year-old male with colorectal cancer)

'My son is just 2 years old and this is the age that he should get pampered by me, but my condition doesn't allow me to do so, or even to carry him...

Whenever I cough, my child will run and get the dustbin for me.... it really makes me sad.... Every night, I cry thinking about all these and the limited time spent with my child. I pity my child.' (35-year-old female with cervical cancer)

'I was in denial plus I have small kids I couldn't take it. I kept thinking what will happen to my kids if I die? It was stressful period.' (41-year-old female with breast cancer)

Financial distress following cancer

'The hormone tablets used to be free, now it is RM400. They (public hospital) charged me RM400 because they say I am private case (referred from private hospital)... I told them I cannot afford it, I have two kids to take care. So I told them I cannot do anything... Usually they will just give me 3 boxes for free but after that the doctor told me 3 boxes I have to pay RM1200, I was so shocked.' (47-year-old female with breast cancer)

'The doctor said that this medicine is really expensive, so they don't subsidize. I had to pay and claim. And you know, for the government, when you pay and claim, it takes months before being reimbursed. I had to sell my car, my house.' (49-year-old female with breast cancer)

Working after cancer

'.. our boss may not understand our situation as a cancer patient. Like after our operation, we mentioned that we cannot lift heavy things but they keep stressing us up.... Sometimes I feel like I don't even know who I can complain to so that my boss can understand that they need to give suitable tasks for cancer patients.' (37-year-old female, with breast cancer)

'They demoted my position from executive technician. My boss commented that I cannot work and pestered me to resign. He openly said that he is frustrated looking at me. I resigned on my birthday.' (26-year-old male with colorectal cancer)

When I told this (cancer diagnosis) to my superior and requested to be transferred to another department, they did not understand and said that if I really could not work, why not just leave. I felt so stressed and disappointed'. (38-year-old female with breast cancer)

Lack of practical support at home

'We have become people with disabilities, so our energy level is not 100%. Like our husband will expect that after coming home (from work), why not just go and cook. But he doesn't know that when we get home, we also have to entertain our kids and then cook...so, he doesn't understand all these. He forgets that I am sick.' (37-year-old female with breast cancer)

them resorting to selling personal assets in order to pay for their treatment.

Working with cancer Several participants who were in paid employment expressed distress over the discrimination that they had to endure at the workplace due to their cancer diagnosis, such as being demoted or having their salaries frozen. Unreasonable employer expectations during and after their cancer treatment were also deemed as leading to feelings of distress and helplessness.

Lack of practical support at home Female participants highlighted that a lack of support at home was a source of distress as many claimed that their spouses or partners failed to assist them in performing household chores and childcare. In contrast, this issue was not brought up by any of the male participants (Table 2).

Sources of support to cope with emotional distress (Table 3)

Self Different forms of self-reliance methods and psychological adaptations to handle emotional distress were discussed during the FGDs. Participants who felt inferior following physical changes after cancer indicated a preference to isolate themselves from friends and relatives. These patients opted to deal with their emotional distress alone and reported feeling better if no one could see them (Table 3).

Long-term cancer survivors tended to believe that time could heal their emotional distress. These patients expressed the notion of ‘moving on with life’ and ‘accepting the new normal’ as time passed. Patients with family history of cancer especially vouched for self-reliance. Having witnessed their close relatives experience cancer made them realise that they had less control over their cancer predisposition and were more accepting of ‘fate’. Participants also frequently reported that with time, they learned some coping mechanisms to alleviate emotional distress such as by keeping busy, as well as by practicing optimism.

Family members Most male cancer survivors stated that their first source of emotional support was their wives. While female participants appreciated the important role of their families in providing emotional support following surgery and adjuvant cancer treatment, many did not view spousal support as being their most important, unlike their male counterparts (Table 3).

Friends Although the majority of study participants noted that they received primary support from a spouse or first-degree family members, some viewed the additional support from friends as equally helpful in strengthening their emotional coping mechanisms, in particular, if the friend was also living with cancer. Female participants especially preferred to seek

Table 3 Subthemes for sources of emotional support along the cancer journey

Sources of emotional support
Family
‘My wife is the biggest support. I am thankful for the support that I received from her.’ (55-year-old male with colorectal cancer)
‘..every time there is something (issue), the whole family will come. If my kids are working, they will take leave.’ (58-year-old female with cervical cancer)
‘My sister has cancer too, she shared a lot of her experiences and I gain my strength from her.’ (34-year-old female with colorectal cancer)
Friends
‘I share a lot with my good friends, not with my husband. I never cried in front of my husband or family, never! I pity them... I don’t want to give him (husband) more burden.’ (34-year-old female with colorectal cancer)
Self-reliance
‘I just want some space and be alone. I feel more stressed when people see me.’ (48-year-old female with breast cancer)
‘..So, we have to keep ourselves busy. Go out or go to work, I am happy when we forget about it (cancer).’ (60-year-old female with breast cancer)
‘I just take it positively and move on.’ (38-year-old female with breast cancer)
Religion
‘I prefer staying alone or go to church, sit there and be connected to God, I prefer spiritual healing.’ (48-year-old female with breast cancer)
‘Good prayers do help... Prayers help me to be in peace.’ (55-year-old female with colorectal cancer)
Professional support
‘I feel that counselling sessions are really important for patients and also for their spouses.’ (38-year-old female with breast cancer)
‘I prefer the counselling part to come from the doctor as well.’ (41-year-old female with breast cancer)
‘As the pressure becomes depression.... I wasn’t referred for counselling and I didn’t request for it. I personally thought that mentally I can choose a more positive attitude, self-counselling...’. (77-year-old male with prostate cancer)
Cancer support group
‘I am lucky because I am part of a support group.... My strength come from there’. (60-year-old female with breast cancer)
‘The (support) groups consist of have breast cancer, colon cancer or any cancer survivors. Can search in FB (Facebook)’. (50-year-old female with colorectal cancer)
‘When you have cancer and have undergone cancer treatment, you don’t mix much with people. Your activities are cut down... So, this (cancer support group) is an opportunity to mix around, make friends and talk to somebody.’ (78-year-old male with prostate cancer)
‘I feel that hospital should give information about support group and they should direct us to the support group.’ (34-year-old male with colorectal cancer)
‘I came to know about the support group too late. The doctors all never mentioned... If I had known earlier... Support group really helps.’ (71-year-old male with prostate cancer)
‘I did notice the advertisement about support group. The activity is every Saturday. But I don’t have time to join because of my busy schedule.’ (46-year-old male with colorectal cancer)

emotional support from friends rather than immediate family members, as they were mindful of protecting their spouses and children emotionally whom they perceived to have ‘already been through enough’ (Table 3).

Religion Irrespective of their religion, most participants reported attaining inner peace and finding comfort in spirituality. Seeking religious consolation was in fact raised as a common coping mechanism (Table 3).

Professional support All participants generally agreed that professional counselling was very important as it helped them to manage their psychological and emotional challenges better. The unmet needs for emotional support from psychologists/ counsellors were raised by some patients, and some noted that they would prefer to be counselled by their physicians. A number of patients who were not referred for counselling however stated that they chose to not request for it, as they preferred to rely on themselves (self-support) (Table 3).

Cancer support groups Participants also expressed their views that joining cancer support groups and sharing feelings and common issues with other members helped them to cope better with the emotional challenges that they were facing. However, some participants did not have access to support groups as they were not aware of the availability of support groups, and also due to other barriers including lack of mobility and logistical issues (Table 3).

Discussion

In summary, the patients’ narratives suggested that emotional distress following cancer tended to arise from direct and indirect stressors. Direct stressors were physical and cognitive side effects of cancer surgery and therapies, and fear of recurrence. Indirect stressors comprised worry over dependent family members, financial distress attributed to cancer, working while living with cancer and lack of practical support at home. It was interesting to note that altered physical appearance, fear of recurrence and lack of practical support at home were cited as sources of distress, mainly or exclusively by the female participants, implying that these stressors disproportionately affected men and women. These in turn may be reflective of disparities in terms of expected roles and responsibilities corresponding to both gender and age differences. Emotional support largely appeared to come from informal sources including family, friends, one’s own self and religion, and formal sources such as professional counsellors and cancer support groups. Formal emotional support although deemed important was cited as generally lacking. Unmet emotional needs in coping with the fear of recurrence, financial

distress, workplace discrimination and household chores were highlighted.

Altered physical appearances from cancer surgery and anticancer therapies may have disproportionately affected female participants due to the concept of ‘self and body’ and societal expectations of femininity whereby the breasts and hair are often considered physical symbols of womanhood [11]. From a clinical perspective, this finding stresses the importance of ensuring that women with cancer have access to items like wigs, breast prosthesis and mastectomy bras, especially those who come from lower socioeconomic backgrounds where the costs of these items may serve as major barriers [12]. These essential items may go a long way in restoring the cancer patients’ self-esteem. On the same note, access to immediate breast reconstruction surgery following mastectomy should also be improved in the low- and middle-income settings, as disparities continue to prevail due to a combination of health system-related factors and patient-related factors [13].

Nonetheless, it remains possible that the apparent differences in the emotional distress experienced by the men and women in this study are to some extent explained by age differences. Notably, the women in this study were much younger than were the men, therefore making it likely for physical changes associated with cancer and cancer treatment exerting a greater psychological impact on the women. This is particularly pertinent given the more overt physical changes women undergoing treatment may experience such as the loss of breasts and hair compared to the changes experienced by older men who may have received limited adjuvant treatment as in the case of prostate cancer. The generally younger age of women in this study also calls attention to concerns that are specific to women in their child-bearing years and in this culture where the bulk of domestic responsibilities fall largely onto females [14]. The impact of cancer and its treatment on fertility and child-rearing are thus likely to be of significant concern for women in this age bracket, which must be taken into account by the cancer care providers.

Physical and cognitive impairments are relatively common among cancer survivors and have been shown to impair self-worth and quality of life in a way that interferes with their ability to lead a normal life [15]. This may have disproportionately affected the women, as shown in the present study where the lack of support to cope with household duties was cited as a source of distress following cancer treatment. In many parts of the world, irrespective of their working status, socioeconomic background or even marital status, women are often expected to be the primary caretaker of their households and end up bearing full responsibilities in managing chores, running errands, parenting and childcare [16]. Our findings are in line with previous studies, which had revealed that women with less tangible support, especially in performing household chores and running errands, reported having higher

depressive symptoms and less emotional support [17]. Notably, the lack of support from family members and the burden of unshared responsibilities may also hamper return to work after cancer treatment [18].

Cancer survivors often express a strong desire to return to work, not only to provide for their families but also to return to normality [19–21]. As previously reported in our prior work exploring the employment experiences of cancer survivors and also in other studies, returning to work after cancer can be a daunting emotional experience for patients due to effects of cancer itself or the treatment, which may hamper work ability, as well as due to the stigma and discrimination in their respective workplaces [22–24].

The finding that financial difficulties after cancer is an important emotional stressor in this present study is supported by recent findings from a qualitative study among Canadian cancer patients, which also showed that financial struggles following cancer resulted in emotional distress [25]. The investigators had further recommended that regular monitoring of patients for financial distress and its sources may aid in early identification of those who are experiencing financial difficulties for provision of appropriate interventions [25].

Our findings also corroborate results from research conducted in high-income settings where coping with the fear of cancer recurrence has been acknowledged as an unmet need [26, 27]. Prior research among clinical and psychosocial professionals in affluent oncology settings had shown that patients with high levels of fear of cancer recurrence are not routinely referred for psychosocial care [26]. Such patients may benefit from novel psychotherapeutic interventions as have been proven by randomised controlled trials that were conducted in the Netherlands and Australia. The interventions, namely a blended cognitive behaviour therapy and a theoretically/empirically based intervention called Conquer Fear were found to be effective in reducing the high fear of recurrence among survivors of breast, prostate and colorectal cancers [28, 29]. Nonetheless, in multicultural settings, it is paramount that any of such interventions are tailored and evaluated via a participatory approach to ensure success.

It appears that social support plays a pertinent role in buffering the emotional distress experienced by people living with cancer. In this middle-income setting, many participants expressed that emotional support from informal sources such as family, friends, one's own self and religion helped them to cope better. However, support from formal sources appears to remain largely unmet including access to professional counselling and cancer support groups. Although psychosocial oncology support, counselling and social support services are presently available for patients in need in Malaysian public hospitals, disparity in access may be an issue. Likewise, our findings also suggest that access to patient support groups that are offered by the various local non-profit organisations may be limited due to both system-related factors, i.e. lack of

availability of services in rural areas, and patient-related factors i.e. physical disabilities, job insecurities, competing family and financial priorities

The current study findings point towards the urgent need for more psycho-oncology professionals in our settings. This in turn implies that there is an overall need for investment in ramping up mental health workforce capacities in the low- and middle-income countries. The above is further supported by a growing body of evidence underscoring the economic rationale to support investment in clinical services focussing on provision of emotional and psychological support for patients with long-term conditions such as cancer [30]. Psychological interventions will help to improve the quality of life of patients through reduction of psychological distress and enhanced self-management, which can lead to reduced healthcare costs [30]. On the same note, helping patients with cancer cope with the emotional distress arising from financial issues implies that resources must be put aside to develop appropriate financial navigation services for those in need [31]. Achieving the above ultimately requires strong political will. Nonetheless, some of the other unmet needs are low-hanging fruits, which can be addressed via coordinated partnerships with external stakeholders. The inclusion of multisectoral stakeholders including the civil societies, non-health government sectors and also private industries in the delivery of mental health and social support services may be the most pragmatic way to fill the existing gaps in resource-limited settings. Examples include (i) formation of community-based cancer support groups offering face-to-face or online emotional support, which are guided by mental health professional bodies and funded by the private sector, and (ii) provision of free or near-free house cleaning/childcare services for cancer patients via collaboration between the private sector and volunteers: 'Cleaning for a Reason' for instance is a non-profit organisation that provides free house cleaning services in the USA and Canada for women undergoing cancer treatment, via partnerships with the local maid agencies [32].

This qualitative study nonetheless has its limitations. Participants hailed from a broad range of time from diagnosis which extended up to 20 years in some cases, which may have influenced participant recall of emotional distress hence increasing the risk of recall bias. Cancer survivors with a longer duration of survival might be more adapted compared to individuals who were more recently diagnosed [33]. As study participants were largely from urban settings, findings may not necessarily reflect the experiences in rural settings, particularly patients with cancer residing in the East Coast of Malaysia and East Malaysia [34]. However, it is believed that inclusion of over 100 men and women from various demographic backgrounds with different types of cancers and cancer stages provide rich insights into the emotional experiences and the unmet needs arising along the cancer journey in settings with limited supportive care services. Another potential

limitation of this study is that we did not match the gender of the moderators with the gender of study participants. As such, discussions led by female moderators in the FGDs, which were attended by male participants, may potentially have made some of them uncomfortable in expressing themselves.

Conclusion

The unmet needs highlighted in the present study provide insights to initiate actionable changes to improve the emotional wellbeing of people living with cancer in settings where cancer survivorship services are still in its infancy.

Author contribution Harenthri Devy Alagir Rajah: data curation, formal analysis, data interpretation, writing—review and editing. Caryn Chan Mei Hsien: formal analysis, data interpretation, writing—review and editing. Yek-Ching Kong: data curation, writing—review and editing. Li-Ping Wong: data interpretation, writing—review and editing. Ros Suzanna Bustamam: data curation, writing—review and editing. Gwo-Fuang Ho: data curation, writing—review and editing. Kelly Ming-Ying Lai: data curation, writing—review and editing. Cheng-Har Yip: data curation, writing—review and editing. Nirmala Bhoo-Pathy: conceptualisation, funding acquisition, formal analysis, data interpretation, writing—review and editing.

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Availability of data and material Data that supports the finding of this study is available upon reasonable request from the authors.

Code availability N/A.

Declarations

Ethics approval This study was performed in line with the principles of Helsinki Declaration. Ethics approval was granted by the National Medical Research Ethics Committee (MREC) and the respective institutional review boards. The study was approved by the Medical Research Ethics Committee (NMRR-17-3361-39122), University Malaya Medical Research Ethics Committee (201831-6061) and Ramsay Sime Darby Health Care Independent Ethics Committee (201809.2).

Consent to participate Written informed consent was obtained from all participants.

Consent for publication N/A

Informed consent Informed consent was obtained from all study participants.

Conflict of interest The author declare no competing interests.

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