

A qualitative exploration of the unmet psychosocial rehabilitation needs of cancer survivors in China

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Abstract

Objective: This study explores the unmet psychosocial rehabilitation needs of cancer survivors.

Methods: Sixty-eight cancer survivors from the Shanghai Cancer Rehabilitation Club in China participated in one of the eight focus groups. These were transcribed verbatim, coded using thematic analysis and analysed using NVivo 10.

Results: Five main themes were identified: the need for (1) better information: Chinese cancer survivors find it difficult to sort and evaluate the overwhelming mass of information with which they are confronted; (2) psychological support: survivors fear cancer relapse and neighbours' discrimination against them; support from other cancer survivors can relieve the stress; (3) support for survivors' families: like the survivors, family members are under great but usually unacknowledged pressure; (4) improved health and medical services: community health service centres provide little medical, informational or psychological support for cancer survivors, who seek and expect more communication with doctors; and (5) assistance with the financial burden: costs of treatment and lack of adequate medical insurance cause substantial financial pressure for survivors.

Conclusions: This study shows that, in addition to their illness, Chinese cancer survivors experience a range of stresses related to their financial circumstances, lack of reliable and summarised information, poor access to support and services (including for their families) and discrimination. Support from families seems to improve survivors' ability to cope. Cancer survivors (and their families) need an integrated package of support from their families, doctors and other service providers, hospitals and communities. These findings can inform approaches to continuing care for cancer survivors.

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Cancer is the leading cause of mortality across China. Nearly two million people die of cancer each year, accounting for one-quarter of all deaths [1,2]. Although the incidence of cancer is rising, remarkable advances in medicine, early detection and treatment mean that cancer patients survive longer [3,4]. Cancer is increasingly regarded as a chronic disease that has a profound influence on survivors' health status, mood and quality of life [5–7]. Cancer survivors face multiple challenges including worsening physical and psychological status and arduous social adjustment that can last their entire lives [8].

Many studies worldwide have explored cancer survivors' psychosocial rehabilitation needs [9–13], but little, if any, has been conducted in China. International studies about cancer survivors' psychosocial needs indicate a desire for ongoing psychological counselling, a lack of availability of complementary and alternative therapies, a need for continuous support, for information about rehabilitation possibilities and for support to the family and need for social support [8–13]. However, peoples' social and

cultural backgrounds have substantial impact on their attitude towards cancer and its causes and on treatment options [14]. For example, among Chinese people, a fatalistic outlook seems to prevent people from participating in cancer screening [15]; further, Chinese people are taught not to express emotions, especially negative emotions. Chinese people tend to think that violating this cultural norm (i.e. expressing negative emotions) is a common adverse effect of cancer and that it might hamper cancer recovery [16].

In China, after inpatient medical treatment, community health service centres are expected to provide all follow-up care [17], but this is inadequate [18]. In Shanghai, as soon as the community health service centres receive the list of cancer patients from Shanghai Center for Disease Control and Prevention, they organise a first visit to the cancer survivors to check their basic information, register them and schedule routine follow-up activity. The frequency of follow-up depends on the patients' Karnofsky Performance Scale Index scores that indicate functional impairment from 0 (dead) to 100 (no evidence

of disease). Internationally, the Karnofsky score is usually used to help guide treatment decisions. However, in China, because community healthcare facilities are so over-worked, cancer survivor follow-up mostly consists of recording administrative and medical details, such as change of address, history of treatment, re-examination, symptoms of relapse and physical and psychological changes [18,19]. The resulting care provided is typically inadequate, often involving no more than a follow-up telephone call [18].

Internationally, comprehensive primary care is now thought the most appropriate follow-up approach, the priority being to help cancer survivors to manage their own illness [7]. Chinese cancer survivors do not receive this support, and their many unmet needs may hamper their rehabilitation [20]. To enhance cancer rehabilitation programmes in China, a detailed and culturally sensitive understanding of the psychosocial rehabilitation needs of Chinese cancer survivors is necessary. As little is currently known, it is appropriate to begin with a qualitative study that can describe key themes and provide in-depth information that can be informative in its own right [21,22]. The aim of this study is thus to scope the unmet psychosocial rehabilitation needs of cancer survivors in China.

Method

Participants

Participants were recruited from the Shanghai Cancer Rehabilitation Club ('the Club'), registered in 1993, a non-government organisation exclusively for cancer survivors. This non-profit self-help support group had 17 affiliates and 13 000 registered members in 2012. It offers regular rehabilitation activities including physical exercise and psychotherapy to improve survivors' quality of life [23]. We contacted all 17 branches of the Club across Shanghai by email or telephone, and eight of them agreed to participate in the study. We sent recruitment advertisements and posters to these eight branches. Recruitment was conducted independently in each branch to obtain maximum variety in gender, age and types of cancer. We recruited a total of 68 voluntarily participating survivors, 50 women (73.53%) and 18 men (26.47%), aged 42–78 years ($M=59.44$, standard deviation = 8.07). They had been living with cancer between 0.17 and 30.67 years ($M=10.68$, standard deviation = 7.20), and 76.49% of the participants were at least 5 years post-diagnosis (Table 1).

Conduct of focus groups

Between September and November 2013, each cancer survivor participated in one of the eight focus groups, each containing 6–10 participants. The focus groups were conducted in Mandarin (by J.W.) and, if participants requested it, also in the local Shanghai dialect. Focus

Table 1. Demographic characteristics of focus group participants

Characteristics	Number (n)	Proportion (%)
Sex		
Male	18	26.47
Female	50	73.53
Primary cancer		
Lung	7	10.29
Breast	31	45.59
Liver	2	2.94
Colorectal	10	14.71
Leukaemia	4	5.88
Gastric	6	8.82
Thyroid	3	4.41
Ovarian	2	2.94
Tongue	1	1.47
Naso-pharynx	1	1.47
Endometrial	1	1.47
Years since diagnosis		
Less than 1	1	1.47
1–2	4	5.88
3–4	11	16.18
5 and more than	52	76.47
Relationship status		
Legally married	59	86.76
Divorced	5	7.35
Widowed	4	5.88
Educational attainment		
Sixth grade or below	2	2.94
Junior high school	23	33.82
Senior high school	24	35.29
Some university or technical school	11	16.18
University graduate	8	11.76
Monthly household income (Chinese yuan)		
Up to 2000	15	22.06
2001–3000	20	29.41
3001–4000	13	19.12
4001–5000	13	19.12
5001 and above	7	10.29

group questions were based on the World Health Organization's definition of health [24] and quality of life [25] and unmet needs identified from published research [9–13]. Open-ended questions were used to optimise participants' opportunity to express themselves [26] focusing on their physical, psychological and social adjustment needs (Table 2). The assistant focus group facilitator (Q.S.) encouraged free-flowing conversation to ensure that all questions had been thoroughly discussed. Participants were also encouraged to introduce any additional topics.

Table 2. Focus group questions

1. Has your general health changed since being diagnosed with cancer and how?
2. Have you experienced any changes in your day-to-day life?
3. What physical and psychological needs do you have, related to your cancer, that are not being met?
4. What do you need in relation to your family and social participation?
5. What are your most important needs to improve your health and quality of life?
6. What else do you think could be done to improve your health and quality of life?
7. Do you have any further comments?

Each focus group was held in the community cancer rehabilitation club common room and lasted approximately 60–90 min. Another member of the research team (T.R.) recorded all discussion using handwritten notes, audio and video. Participants' demographic characteristics were obtained from a questionnaire attached to the consent form. After each focus group discussion, participants each received a small, culturally appropriate gift (a toothbrush and toothpaste). The study was approved by the Institutional Review Board of the School of Public Health, Fudan University. Ethical approval to conduct this study was granted on 23 April 2013 by the Medical Research Ethics Committee of the School of Public Health, Fudan University (protocol number RB #2013-04-0450).

Analytic approach

We followed Braun and Clarke's six phases of thematic analysis which are (i) familiarising yourself with the data, (ii) generating initial codes, (iii) searching for themes, (iv) reviewing themes, (v) defining and naming themes and (vi) reproducing the report [26]. Four different authors undertook this analysis. First, two authors (Z.Q. and C.L.) transcribed the video recording verbatim, and another author (Q.S.) checked these against the handwritten notes and the audio recording. After reading the transcriptions multiple times, to promote detailed familiarity with their content, another author (T.R.) conducted primary coding using thematic analysis. This coding was collated to generate potential themes which were checked back against the original data. This process identified five themes that were reviewed by another author (Q.S.). Finally, the whole Shanghai project team came together to discuss and decide on the final set of themes, including resolving any discrepancies identified in the initial rounds of thematic analysis.

Translation of participants' quotes from Mandarin to English for this paper was conducted by three authors in three main steps (note that professional translators were not used). A Shanghai-based team member (T.R.) undertook the initial translation, and an Australian-based English-speaking native Mandarin speaker (N.D.) checked these under the supervision of the native English-speaking author (H.B.) who undertook all final checking of the translations. The translations were not at any point back-translated. All aspects of English expression, including double-checking of translation, were undertaken by the lead English-language author (H.B.).

Data were analysed using NVivo 10 (QSR International Pty Ltd, Melbourne, Australia).

Results

Cancer survivors' needs were categorised into five themes: the need for (1) better information, (2)

psychological support, (3) support for survivors' families, (4) improved healthcare services and (5) assistance with the financial burden.

Need for better information

Chinese cancer survivors find it difficult to sort and evaluate all the information they confronted. As in other countries, Chinese cancer survivors face an overwhelming and confusing quantity of cancer-related information (and misinformation) from many sources, such as television programmes, newspapers and books, doctors and other medical professionals, other cancer survivors, public talks, drug companies and the Internet.

We need lots of information, of course, but it is difficult for us to understand. We cannot sort through all this information. (M, 5 years living with colorectal cancer)

Some information is not accurate, for example, when provided by private sector companies wanting to market their products.

There are lots of talks all about cancer treatment. We do not believe the information they provide because they are just trying to sell their products: 'oh [they say], I have a magical method to cure your cancer and I can help you get rid of this disease'. In the end, they just want your money. (F, 15 years living with ovarian cancer)

Sometimes, information is simply not available. Participants wanted but could not access relevant information that was responsive to their full range of needs as adults, for example, about exercise, diet, medical facts and sexual activity.

We want someone tell us whether it's OK to have sex. But no-one will tell you that. (F, 9 years living with breast cancer)

Need for psychological support

Survivors fear cancer relapse and neighbours' discrimination against them; support from other cancer survivors can relieve the stress.

Coping with fear of the cancer coming back

Many survivors were terrified of their cancer coming back. Physical symptoms that may signal a recurrence, such as pain or catching a common cold, could cause survivors and their families great worry.

We are so wary of abnormal symptoms: even [if we only have] a little uncomfortable feeling or a little pain, we will

to go and get it checked immediately out of fear of the cancer returning. (M, 4 years living with gastric cancer)

People are strange, aren't they? [I have a] hospital check-up once a year. If I am going to get my blood tests tomorrow, today I am panicking and nervous for no reason. Actually, there is no need to be nervous, is there? I have lasted nine years since diagnosis. I am not sad if I die now. But I still get very nervous. When I eventually see the blood test report, [I think] oh, thank god, it's ok. (M, 10 years living with liver cancer)

As soon as I feel pain somewhere, I think it's the cancer coming back and I'm scared. When this happens, another cancer survivor telling me 'it's okay, don't worry', would be such a great comfort and I wouldn't feel scared any more. If not [if there's no other cancer survivor to reassure me], I just can't stop thinking about it [the pain] and the pain just gets worse and [I worry even more that] the cancer has come back. (M, 12 years living with colorectal cancer)

Dealing with discrimination

Because many Chinese people think that cancer is contagious, survivors sometimes felt isolated and discriminated against. For them, meeting people was therefore not always a pleasant experience.

We cancer survivors sometimes used to go on outings and some of our family members would join us. We shared food together from the same dishes. But [once people knew we had cancer] some of the so-called healthy people would not serve themselves from the dishes once we had taken some, or they only took some before we ate. This kind of thing really happens. (F, 4 years living with breast cancer)

You can do any kind of exercise you like but, if you practice Guolin Qigong,¹ it's just like telling everyone that you have cancer. Doing it with other survivors makes me feel stronger and I don't care what other people think. Otherwise, with the neighbours whispering next door, you have to do it far away [where they can't see you]. We've all had these feelings. (F, 8 years living with breast cancer)

To avoid other people's discrimination, many survivors chose to conceal their illness when making new friends.

If you want to fit where you are exercising, if you join a new group, as long as you don't mention it [the cancer], you will get along fine with them. But if people find out that you have cancer, maybe from neighbours or friends gossiping, they will ostracise you straightaway. They will try to kick you out of the group. (F, 8 years living with breast cancer)

Support from other cancer survivors

Cancer survivors can often relate to each other because of their similar experiences and can find mutual support very important. They would rather talk to other survivors than to their families.

You talk with your family [and] they just do not understand you. They haven't experienced cancer, have they? But it is different talking to other cancer survivors. They know which medicine to take, they know how to take care of themselves, they know when they should be careful and they know what we cannot eat... (F, 5 years living with breast cancer)

Other cancer survivors, working as role models, provide them with confidence and motivation to keep living.

See, oh, you've got it worse than me and you have survived 10 or 20 more years. So I'm more confident, it just gives me an invisible immunity. I have to learn from you and I have to live. (F, 8 years living with breast cancer)

Because peer support is so effective, participants also said that the government should provide more support to cancer rehabilitation clubs.

To make it [the club] better, we want more support from government. You know, we don't have a good place for our activities, the thermos flasks and the television were donated by one of our club members ... We (club organisers) don't need any pay for what we do and that doesn't matter. We just need some money to improve our facilities. (F, 4 years living with gastric cancer)

Need for support for survivors' families

Like the survivors, family members are under great but usually unacknowledged pressure. In China, there is little support, psychological or financial, available to survivors' families. Participants said that, because of this, their families were always under great pressure and had nobody to talk to.

My husband's hair has nearly turned completely grey because of my illness. Really, he has had so much stress. And he hasn't had anyone to talk to about that. (F, 10 years living with lung cancer)

Family members' personalities could even change as a result of the pressure. One participant told us that her son changed from being outgoing to becoming withdrawn. Furthermore, participants feared that cancer would also affect their children's marriage potential. Because cancer is heritable, may relapse and may cause a substantial

future financial burden, participants feared that their children would not be able to find partners or that their children's current partners would decide to end the relationship.

It is difficult to find a girlfriend or boyfriend, you know [when your parent has cancer]. It is a big problem. When your partner finds out, oh god, your parent has cancer, they will break up with you. (F, 4 years living with breast cancer)

Cancer survivors also worried that they would not live long enough to care for their family, particularly their children, or to provide their descendants with sufficient emotional and economic support. Many participants felt sorry for their children and/or grandchildren and said that they could not take good care of them during cancer treatment or buy them a house.

From another perspective, survivors' worries can have a positive effect enhancing their will to survive: living for upcoming milestones in their children's lives can become survival goals.

I have this thought that I need to set goals: I have to live long enough to see my daughter sit her college entrance examination, then to see her have a child, then to help bring up my grandchild. Goals give me the strength to carry on. (M, 14 years living with tongue cancer)

Need for improved health and medical services

Community health service centres provide little medical, informational or psychological support for cancer survivors, who seek and expect more communication with doctors.

Health services from community health centres

Participants were seldom satisfied with the services provided by community health service centres in recovering from cancer because these centres provide little medical, informational or psychological support.

They just call you once a year to find out whether you are still alive. It is their duty; really, they just call to fulfil their duty. (F, 26 years living with breast cancer)

The centres don't have the medicines we [cancer patient] need. We have to go to hospitals to get them. (F, 1 year living with lung cancer)

Prescriptions only for short time periods

Many participants complained that they had to go to hospital pharmacies twice a month to collect their prescriptions because the prescriptions were only for

2 weeks at a time. The hospitals were usually packed, and survivors experience lengthy waits for service. This was considered inefficient because their prescription did not change from fortnight to fortnight.

The prescription only lasts for two weeks. I have to go to the hospital twice a month. It is so crowded. Why not give me a two-month prescription? I just take the same medicine every day. (F, 11 years living with thyroid cancer)

Doctor's caring attitude

Many participants found doctors unfeeling, taking an un-caring attitude towards cancer survivors and showing no concern for their psychological needs.

Medical students and doctors should know that it is not your seniority that matters most but your taking responsibility for patients. If you take your responsibility for we patients seriously, you will become a great doctor one day. Otherwise, even if you are a professor, you just have a useless title. (M, 10 years living with hepatic cancer)

Good communications between doctors and survivors can help improve compliance with treatment regimens and can also promote mental health. Participants also mentioned the need for more care for people with terminal cancer and for better palliative treatment to relieve severe pain.

As to terminal patients, more care is needed. They suffer from great pain. Terminal care is good enough now. If you are prescribed morphine, the doctor only gives you a small amount. It's nowhere near enough. These patients are already weak and they cannot tolerate such great pain. (F, 2 years living with breast cancer)

Need for assistance with the financial burden

Costs of treatment and lack of adequate medical insurance cause substantial financial pressure for survivors.

Insufficient income

Costs of treatment are always financially stressful and can be disastrous for cancer survivors and their families whose income is often inadequate to cover the costs. Discrimination against people with cancer can also lead to loss of income-earning opportunities.

The surgery cost a lot of money. I just couldn't afford it. How can I afford further chemotherapy and Chinese traditional medicine? That was such a hard time and I have a little daughter to bring up who was in elementary school then. (F, 10 years living with lung cancer)

My husband told me, when I was sick, he went to the hospital to hand over a stack of cash to pay for the surgery and treatment, just like throwing out a stack of paper. (F, 2 years living with breast cancer)

After treatment is completed, some cancer survivors in remission would like to return to paid work. However, having cancer can severely affect their employment opportunities, sometimes leading to loss of wages and even to loss of jobs.

What struck me most was not the cancer but what was written on my medical certificate. It said I was no longer able to work. Because of that, I couldn't get back onto a ship [to resume my previous job]. I could only get jobs with the lowest wages at that time in Shanghai. (M, 5 years living with colorectal cancer)

A friend of mine, she once worked for [China's] space program and worked on the design of Shenzhou-eight and nine. She was an extremely capable person with a great deal to contribute to the country. But after her cancer diagnosis, she couldn't get a job and had to retire early. (F, 4 years living with breast cancer)

Some participants said that they therefore preferred to hide their illness on returning to work.

When going back to work after being diagnosed with cancer, people prefer to hide their illness because it does no good to tell the truth. Sometimes, colleagues just think, oh, you got this disease so you will always bring bad luck. So a cancer diagnosis becomes a death sentence. They just want to get rid of you as quickly as possible. (M, 24 years living with colorectal cancer)

Inadequate medical insurance

To reduce the incidence of catastrophic financial consequences, national healthcare arrangements in China have been expanded to cover cancer-related costs. However, participants pointed out that the cancer programme provided care for an unreasonably short period of years with limited coverage of out-of-pocket expenses. For example, the cost of traditional Chinese medications is not included within the scope of medical insurance reimbursements and nor are patients' annual check-ups, both of which caused great financial stress for cancer survivors in the present study.

National health insurance covering traditional Chinese medicine only lasts five years. We have gone through several surgeries and are always in poor health. Sometimes we just want to use traditional Chinese medicine to help with our recovery but it would cost so much compared to how little we earn. We want lifelong insurance to buy traditional Chinese

medicines then we will feel less stressed. At the moment, we just can't afford them. (M, 10 years living with lung cancer)

Participants expressed feeling uncomfortable when applying for reimbursement under the national health scheme mainly because public servants' attitudes were officious, sometimes even refusing to reimburse examinations ordered by doctors.

Each time I applied for a reimbursement, I had to make myself look like a mad woman, messing up my hair, thumping my prescription for morphine injections and my medical certificate showing I had advanced-stage cancer down on the official's desk; only then would he sign the approval. The fact was, I had every right to get his approval: I was in the advanced stage and I already had a prescription from my doctor for morphine. These officials were just inconsiderate and unsympathetic. (F, 10 years living with lymphoma)

Discussion

The unmet psychosocial and related needs of cancer survivors in China have not been well understood. Findings from the present study, while preliminary, show that cancer survivors' needs in China extend well beyond the valuable but nevertheless scant medical care that they receive [17] and that their needs are much the same as survivors' needs in other countries but with some unique differences. Living with cancer affects survivors, their families and their community connections in many ways, including relationships with neighbours, employment opportunities and financial circumstances.

Cancer survivors need continuous and up-to-date information to help them manage their own illness [7], but our sample of survivors from Shanghai expressed severe concerns about the nature, accessibility and credibility of available information. They need trustworthy medical information, for example, about ongoing risks (e.g. the risk of cancer recurrence or metastasis) and the importance of visiting a primary care provider.

Our study shows that having other cancer survivors as role models substantially improves psychological support, helping survivors cope better with stress. This is consistent with findings about the positive effects on cancer survivors of cancer rehabilitation organisations [27]. Given that the Shanghai Cancer Rehabilitation Club has inadequate financial support, providing more support to such organisations would be an inexpensive, efficient and effective way to provide more opportunities for cancer survivors to gain support from others facing similar circumstances.

Cancer survivors in China face discrimination because of public ignorance about cancer. Medical professionals, government leaders and prominent citizens have a responsibility to

act against this damaging stigma by disseminating accurate information about cancer directly countering the common belief that cancer is infectious and a sign of being cursed. They also need to calling for more care and respect for cancer survivors and the provision of friendly rehabilitation environments.

Families play an important role in cancer rehabilitation [28–31] supporting their family member living with cancer and needing care themselves during the treatment and rehabilitation phases [32]. However, support for families is gravely inadequate in China. We have recorded the substantial pressures that survivors' family members can face, including impacts on household finances, personalities, social stigma and children's marriage potential. Further research is required to understand Chinese families' needs and to identify appropriate intervention models.

Costs of treatment are financially stressful and can be disastrous for cancer survivors and their families. National medical insurance reform in China must take account of the long-term nature of cancer rehabilitation. Survivors in this study frequently noted that it was difficult to return to work because of social stigmatisation, and this translated to financial as well as social loss – itself significant because labour-force participation contributes considerably to improved quality of life among cancer survivors [30]. Fees for annual check-ups, costs of medications, loss of income and even unemployment only serve to increase financial stress. For some survivors, these high financial costs are a barrier to treatment.

Hospitals in China themselves present further challenges for cancer survivors, most of whom have to go back repeatedly for check-ups, further treatment and medicines. Oncologists in public hospitals need training to improve their communications skills and capacity to provide emotional support to cancer survivors. In China, the role of providing follow-up care for cancer survivors falls to community health service centres [18], but their services and approach are critically insufficient [17,19]. Some survivors were so dissatisfied with services that they did not attend these services. These centres will need to take greater responsibility and be more creative to satisfy cancer survivors' requirements.

The conclusions that can be drawn from this study are limited to the extent that participants were all recruited from a cancer rehabilitation club and, thus, already receiving at least some psychosocial support; the needs of those not attending such clubs could well exceed those reported here. Further, although the sex ratio of cancer patients approximates 1:1 across China [33], only 30% club members are male, perhaps because women are more open to

participating in social activities [34] or to talking about their experiences. Female participants in our study therefore greatly outnumbered men, and we cannot assume that our findings apply equally to both sexes. Nevertheless, our sample reflected the proportions of women to men in the survivors' clubs, and the comments provided were similar across both sexes and consistent with the international literature on the broadly based needs of cancer survivors. Two other concerns were that few study participants were newly diagnosed (so we can only comment on the needs of those already used to living with cancer) and, because our participants were aged 42–78 years, we cannot comment on the psychosocial needs of young cancer survivors. Finally, we did not allocate participants to different focus groups based on type of cancer (almost one-half had breast cancer), which may mean that we did not detect subtle differences in treatment and rehabilitation experiences of people living with different diagnoses.

Conclusion

Despite its limitations, this study had provided compelling preliminary evidence that it is essential to respond to the psychosocial needs of cancer survivors. Improving the psychosocial experiences of cancer survivors requires a collaborative effort between government, society, communities, neighbours, families and friends, hospitals and doctors. There is much that can be done to alleviate some of the physical and emotional suffering that cancer survivors experience and the cancer-related financial and psychosocial costs to those who support them.

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Note

1. It is one kind of rehabilitation exercise activities in the Club. It is characterised by a slow walking exercise accompanied by arm movements coordinated with slight twisting movements of the waist. Club members are taught to practice it to help with their recovery.

References

1. The China CDC. Chinese health statistical digest, 2012. (Available from: <http://www.chinacdc.cn/tjsj/gjwstjsj/201206/W020120608368277572334.pdf>) [Accessed 12 April 2014]
2. Ferlay J, Shin H, Bray F, Forman D, Mathers C, Parkin DM. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *Int J Cancer* 2010;127(12):2893–2917. DOI:10.1002/ijc.25516.
3. de Martel C, Ferlay J, Franceschi S, *et al.* Global burden of cancers attributable to infections in 2008: a review and synthetic analysis. *Lancet Oncol* 2012;13(6):607–615. DOI:10.1016/S1470-2045(12)70137-7.
4. Parkin DM, Bray FI, Devesa SS. Cancer burden in the year 2000. The global picture. *Eur J Cancer* 2001;37(Suppl 8):S4–S66.

5. Barrera I, Spiegel D. Review of psychotherapeutic interventions on depression in cancer patients and their impact on disease progression. *Int Rev Psychiatry* 2014;**26**(1):31–43. DOI:10.3109/09540261.2013.864259.
6. Scheffold K, Mehnert A, Müller V, Koch U, Härter M, Vehling S. Sources of meaning in cancer patients – influences on global meaning, anxiety and depression in a longitudinal study. *Eur J Cancer Care* 2014;**23**(4):472–480. DOI:10.1111/ecc.12152.
7. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA* 2002;**288**(19):2469–2475.
8. Khan NF, Evans J, Rose PW. A qualitative study of unmet needs and interactions with primary care among cancer survivors. *Brit J Cancer* 2011;**105**:S46–S51. DOI:10.1038/bjc.2011.422.
9. Weis J. Support groups for cancer patients. *Support Care Cancer* 2003;**11**(12):763–768. DOI:10.1007/s00520-003-0536-7.
10. Merckaert I, Libert Y, Delvaux N, et al. Factors that influence physicians' detection of distress in patients with cancer. *Cancer* 2005;**104**(2):411–421. DOI:10.1002/cncr.21172.
11. Abrahamson K, Durham M, Fox R. Managing the unmet psychosocial and information needs of patients with cancer. *Patient Intell* 2010;**2**:45–52. DOI:10.2147/PL.S9442.
12. Piil K, Jarden M, Jakobsen J, Christensen KB, Juhler M. A longitudinal, qualitative and quantitative exploration of daily life and need for rehabilitation among patients with high-grade gliomas and their caregivers. *BMJ Open* 2013;**3**(7e3183). DOI:10.1136/bmjopen-2013-003183.
13. Sammarco A, PhD RN. Perceived social support, uncertainty, and quality of life of younger breast cancer survivors. (C) 2001 Lippincott Williams & Wilkins, Inc. Angela Sammarco is Assistant Professor of Nursing, College of Staten Island, City University of New York, 2001; 212–219.
14. Lim J, Gonzalez P, Wang-Letzkus MF, Ashing-Giwa KT. Understanding the cultural health belief model influencing health behaviors and health-related quality of life between Latina and Asian-American breast cancer survivors. *Support Care Cancer* 2009;**17**(9):1137–1147. DOI:10.1007/s00520-008-0547-5.
15. Kwok C, Sullivan G. Influence of traditional Chinese beliefs on cancer screening behaviour among Chinese-Australian women. *J Adv Nurs* 2006;**54**(6):691–699. DOI:10.1111/j.1365-2648.2006.03872.x.
16. Ho RTH, Chan CLW, Ho SMY. Emotional control in Chinese female cancer survivors. *Psycho-oncology* 2004;**13**(11):808–817. DOI:10.1002/pon.799.
17. Ying Z, Jun H, Peng P. Practice on cancer patient care in community in Shanghai. *China Cancer* 2010;**19**(2):89–92.
18. Xue C. Study on quality of life among community breast cancer survivors and community-based intervention strategy in Shanghai. Fudan University, 2009; 103.
19. Wang J. The status of the quality of life and health education in patients with malignant tumor in communities of Changning District. Fudan University, 2011.
20. So W, Chan C, Choi K, Wan R, Mak S, Chair S. Perceived unmet needs and health-related quality of life of Chinese cancer survivors at 1 year after treatment. (C) 2013 Wolters Kluwer Health | Lippincott Williams & Wilkins: Author Affiliations: Nethersole School of Nursing, Chinese University of Hong Kong (Drs So, Choi, Chan, and Chair); and Department of Clinical Oncology, Prince of Wales Hospital (Mr Wan and Ms Mak), Hong Kong SAR, People's Republic of China, 2013; E23–E32.
21. Smith F. *Qualitative Interviews. Research Methods in Pharmacy Practice*, Pharmaceutical Press: London, UK, 2002.
22. Patton M. *Qualitative Research and Evaluation Methods*, Sage Publication: Thousand Oaks, CA, 2002.
23. Club SCR. A brief introduction to the Shanghai cancer rehabilitation cancer club, 2014. (Available from: http://www.shrc.cn/webs/field_news.aspx?id=35) [Accessed 18 October 2013]
24. World Health Organization. Constitution of the World Health Organization – basic documents, Forty-fifth edition, Supplement. Geneva, 2006.
25. WHOQOL Group. The development of the World Health Organization Quality of Life Assessment Instrument (WHOQOL). In *Quality of Life Assessment: International Perspectives*, Orley J, Kuyken W (eds.), Springer-Verlag: Heidelberg, 1994.
26. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psycho* 2006;**3**(2):77–101. DOI:10.1191/1478088706qp0630a.
27. Mikkelsen TH, Søndergaard J, Jensen AB, Olesen F. Cancer rehabilitation: psychosocial rehabilitation needs after discharge from hospital? *Scand J Prim Health* 2008;**26**(4):216–221. DOI:10.1080/02813430802295610.
28. Duan J, Fu J, Gao H, et al. Factor Analysis of the Caregiver Quality of Life Index-cancer (CQOLC) Scale for Chinese Cancer Caregivers: a preliminary reliability and validity study of the CQOLC-Chinese version. *PLoS One* 2015;**10**(2e116438). DOI:10.1371/journal.pone.0116438.
29. Li Q, Loke AY. The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psycho-oncology* 2013;**22**(11):2399–2407. DOI:10.1002/pon.3311.
30. Main DS, Nowels CT, Cavender TA, Etschmaier M, Steiner JF. A qualitative study of work and work return in cancer survivors. *Psycho-oncology* 2005;**14**(11):992–1004. DOI:10.1002/pon.913.
31. Schroevers MJ, Helgeson VS, Sanderman R, Ranchor AV. Type of social support matters for prediction of posttraumatic growth among cancer survivors. *Psycho-oncology* 2010;**19**(1):46–53. DOI:10.1002/pon.1501.
32. Mellon S, Northouse LL, Weiss LK. A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nurs* 2006;**29**(2):120–131, 132–3.
33. Wan-qing C, Rong-shou Z, Si-wei Z. An analysis of cancer incidence in China: 2003–2007. *China Cancer* 2012;**21**(3):161–170.
34. Fortuijn JD, Meer M. Gender and voluntary work in late adulthood in rural communities in the Netherlands. *GeoJournal* 2006;**65**(4):381–392. DOI:10.1007/s10708-006-0029-6.