RESEARCH ARTICLE

Supportive Care Needs of Iranian Cancer Survivors and Relationships with Social Support

Safieh Faghani¹, Robab Mohammadian², Azad Rahmani^{3*}, Ali-Reza Mohajjel-Aghdam⁴, Hadi Hassankhani⁴, Arman Azadi⁵

Abstract

<u>Background</u>: Assessment of supportive care needs of cancer survivors and identifying factors affecting such needs is important for implementation of any supportive care programs. So, the aims of present study were to investigate the supportive care needs of Iranian cancer survivors and relationships with social support. <u>Materials and Methods</u>: In this descriptive-correlational study two hundred and fifty cancer survivors participated via convenient sampling methods. The Supportive Care Needs Survey (SCNS-SF34) and Multidimensional Scale of Perceived Social Support (MSPSS) were used for data collection. SPSS software was applied and univariate regression was used for examine relationships of supportive care needs with social support. <u>Results</u>: Participants demonstrated many unmet supportive care needs, especially in health system and information and psychological domains. In addition, participants reported that family members and significant others were their main source of support. Also, social support has a significant correlation with all domains of supportive care needs. <u>Conclusions</u>: There is an indispensable need for establishment of supportive care programs for Iranian cancer survivors. In addition, family members of family members of such survivors are an important resource to help develop such programs.

Keywords: Supportive care needs - social support - survivors - cancer - Iran

Asian Pac J Cancer Prev, 16 (15), 6339-6345

Introduction

Recent advancement in detection and treatment of many types of malignant tumors lead to increase in the number of long-term cancer survivors (Bray et al., 2008; Khan et al., 2008). Traditionally, the cancer survivorship divided into three seasons including acute, extended, and permanent. However, today this term is extended and includes more seasons (Miller et al., 2008). The global burden of five year survival for cancer is reported as 28.8 million people in 2008 (Bray et al., 2008) and this number continue to increase each year (Siegel et al., 2012). By the way, because of delay in diagnosis of malignant tumors, the results of some studies reported that the overall survival rate for Iranian cancer patients is relatively poor (Rezaianzadeh et al., 2009; Sadjadi et al., 2009; Rezaianzadeh et al., 2012). But, it should be noted that there is no any valid statistic about the number of cancer survivors in Iran.

The results of one systematic review showed that cancer survivors experience many problems such as physical, social, psychological, cognitive and sexual difficulties (Valdivieso et al., 2012). So, cancer survivors displayed lower levels of health and more burdens compared with general population (Yabroff et al., 2004). In wide review of related literature, there are no reports about the problems of Iranian cancer survivors. Although, some studies showed that Iranian cancer patients experience many problems including financial and job related difficulties, social problems, and many problems in daily life (Moradian et al., 2012). In addition, the results of two qualitative studies showed that the life of Iranian cancer patients is full of suffering and stress (Nasrabadi et al., 2011) and they have many problems in communication with others (Zamanzadeh et al., 2013).

In recent years the concept of supportive care needs was introduced in the field of caring of cancer patients. This concept has a board meaning and may defines general needs of cancer patients or their caregivers in physical, emotional, psychological, social, informational, and spiritual domains since their journey from diagnosis, treatment, survivorship, palliative care, and grief process (Fitch, 2007). Many studies showed that cancer survivors in non-western (Park and Hwang., 2012, So et al., 2013; Abdollahzadeh et al., 2014; Rahmani et al., 2014) and western (Beesley et al., 2008; Bender et al., 2012; Boyes et al., 2012) countries have many unmet supportive care needs.

¹Faculty of Nursing & Midwifery, Babol University of Medical Sciences, Ramsar, ²Department of Nursing, Islamic Azad University, Maraghe Branch, Maraghe, ³Hematology and Oncology Research Center, ⁴Medical-Surgical Department, Nursing and Midwifery Faculty, Tabriz University of Medical Sciences, Tabriz, ⁵Department of Nursing, Ilam University of Medical Sciences, Ilam, Iran *For correspondence: azad.rahmani@yahoo.com

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Recently, one systematic review summarized all interventions designed for reduce the supportive care needs of cancer patients and interesting this review did not consider social support or seeking for social support as a strategy to reduce supportive care needs of cancer patients (Carey et al., 2012). On the other hand, other studies showed that social support is an important coping mechanism for adjustment of cancer patients (Decker, 2007; Schwarzer and Knoll., 2007). Also, some studies showed that social support has a positive relationship with family well-being (Friedman et al., 2006) and decrease the symptoms of depression and post-traumatic stress disorder in cancer patients (Carpenter, 2006; Cheng et al., 2013). In addition, social support is an important predictor return to work in cancer survivors (Taskila and Lindbohm, 2007). Similarly, the results of some qualitative studies showed that social support, especially support from family members, is an important factor in inspiring hope (Rahmani, 2012) and coping (Taleghani et al., 2006) of Iranian cancer patients. So, there is a need for studies aimed to investigate the relationship of supportive care needs of cancer survivors with social support available for these patients.

As mentioned before, in wide review of relevant literature we found no studies aimed to investigate supportive care needs of cancer survivors in Iran or other Middle Eastern countries and examined its relationship with social support. This means that there is a gap in our knowledge about the supportive care needs of cancer survivors in this region and the effects of social support on meeting supportive care needs of cancer patients. It is clear that such information is vital to planning any supportive care services for cancer survivors in Iran or other countries with similar cultural background. So, the aims of present study were to investigate the supportive care needs of Iranian cancer survivors and its relationship with social support.

Materials and Methods

This descriptive-correlational study was conducted from November in 2013 to March in 2014. Two in-patient wards and out-patient clinic of Ghazi hospital affiliated to Tabriz University of Medical Science was used as the main setting for this study. This hospital is located in Tabriz, the provincial capital of East Azerbaijan Province that located in northwest of Iran. Also, for covering patients with different characteristics the private office of one oncologist in Tabriz was selected as another setting for the study.

Two hundred fifty cancer patients who receive follow up treatments during sampling period in the study settings was invited to participate in the present study. The sample size was calculated based on pilot study on 30 cancer survivors. The inclusion criteria for patient were including: having at least 18 years old; awareness of exact diagnosis of cancer; passing at least 3 month from the first round of cancer treatment; having no any signs of relapse or recurrence of the disease; having no other chronic diseases; physically and mentally ability to participate in the study. In this study the ", the transition from active treatments to careful observation was used as a criteria for survivorship (Miller et al., 2008). It should be noted that during sampling 1123 cancer patients visited and 283 of them meet the research criteria and finally the data of 250 survivors included in the study.

The instrument consists of three parts. The first part was a checklist that designed by researchers and consists of 20 items about some demographic and disease related characteristics of participants. The second part consists of Supportive Care Needs Survey (SCNS-SF34), a valid and reliable 34-item measure that investigates the supportive care needs of cancer patients in five domains including: psychological (10 items), information and health system (11 items), daily living and physical (5 items), patient care and support (5 items), and sexual (3 items) domains. Each item is based on 5- point Likert scale including: no need: not applicable; no need: satisfied; low need; moderate need; and high need that receive scores from 1 to 5 respectively. The final score for each domain was calculated based on score 100 by using following formula: ((sum of individual items minus number of domain questions) \times 100 / (the number of questions in a domain) \times (the value of the maximum response for each item - 1)) (McElduff et al., 2004). This instrument widely used for investigate the supportive care needs of cancer survivors (Nasrabadi et al., 2011; Moradian et al., 2012; Park and Hwang., 2012) and showed good internal consistency (Boyes et al., 2009; Okuyama et al., 2009; Lehmann et al., 2012). The third part consists of Multidimensional Scale of Perceived Social Support (MSPSS). MSPSS is a 12-items scale that assesses the perception of social support from family, friends and a significant other. Each subscales including family, friends, and significant other is assessed with four items. Each item is based on 7-point Likert-type response format from very strongly disagree to very strongly agree that receive scores from 1 to 7 respectively. So, the final score is from 12 to 84. Score from 12 to 48 is considered low perceived support; score 49 to 68 is considered moderate perceived support; score 69 to 84 is considered high perceived support (Zimet et al., 1988). This scale showed good internal consistency in samples of cancer patients, Cronbach's alpha from 0.82 to 0.92 (Cicero et al., 2009; Bozo et al., 2013; Han et al., 2013). Similarly, this scale showed acceptable reliability in previous studies in Iran (Naderi et al., 2009; Naseri and Taleghani., 2012).

For using in the present study, SCNS-SF34 and MSPSS questionnaires were translated into Persian via translate-back translate procedure that conducted by two independent Persian- English translators. Then, face and content validity of translated questionnaires were determined by 15 academic staff from Tabriz University of Medical Science and minor changes was made according to their comments. After that, the reliability of questionnaires was approved using Cronbach's alpha coefficient after pilot study on 30 survivors. The coefficient for subscales of SCNS-SF34 was from 0.79 to 0.86 and for MSPSS was 0.82.

Prior to data collection, the study protocol was approved by Regional Ethics Committee at Tabriz University of Medical Sciences. After obtaining permission from the fields of research, one of researchers and two research assistants were find out cancer patients who met inclusion criteria and invited them to participate in the study. Brief information about the aim and method of the study was given to all patients orally and their informed consent was obtained according to the guideline of local Ethics Committee. For increasing the validity of the study the data of all participants were gathered by private interview by researchers in private settings.

The statistical analysis was performed using SPSS software (version 13, SPSS, Chicago, IL). The descriptive statistic including frequency, percent, mean and standard deviation was used for describe demographic and disease characteristics of participants and their scores on SCNS-SF34 and MSPSS.

Results

Most of participants were female (55.2%), married (91.6%), housewife (42%), educated at under diploma level (44.8%), their income equal to livening expense (52.4%), lived in cities (71.2%), lived with their spouse and children (63.6%), and diagnosed with breast cancer

(40%). Also, the education of most of participants was in under diploma level (36.4%). Most important, 10 and 14 percent of participants had a symptomatic depression and anxiety respectively. The mean age of participants was 47.42 years and the time passed since awareness of exact diagnosis was 3.67 years.

Most top ten frequent meet and unmet supportive care needs of participants are reported in Table 1. As evident in this table nine of top unmet needs are related to health system and information (5 items) and psychological (4 items) domain. In addition, among met needs 3 are related to sexuality domain and 3 are related to Patient care and support domain.

The mean score of supportive care needs in 5 domain

Table 2. The Score of Social Support and its Dimensionfrom the Viewpoint of Cancer Survivors

Domain	Mean (SD)	CI 95%
Support from family	26.10 (2.76)	25.7-26.45
Support from friends	17.48 (8.00)	16.49-18.48
Support from significant others	25.10 (3.58)	24.66-25.55
Total score of social support	68.70 (11.13)	16.49-18.48

		MOST frequent unmet supportive care need			
Rank	Domain Items				
1	Health system and information	Being informed about things you can do to help yourself to get well			
2	Health system and information	Being informed about your test results as soon as feasible			
3	Health system and information	Being given explanations of those tests for which you would like explanations	187 (74.8)		
4	Health system and information	Health system and information Being informed about cancer which is under control or diminishing (that is,remission)			
5	Psychological	Psychological Concerns about the worries of those close to you			
6	Psychological	Psychological Fears about the cancer spreading			
7	Psychological Anxiety				
8	Psychological	Psychological Feelings of sadness			
9	Health system and information Being adequately informed about the benefits and side-effects of treatments before you choose to have them		155 (62.0)		
10	Physical and daily living	Lack of energy/tiredness	147 (58.8)		
	· · · · · ·	MOST frequent met supportive care need			
1	Patient care and support More choice about which hospital you Attend		31 (12.4)		
2	Patient care and support	More choice about which cancer specialists you see	48 (19.2)		
3	Health system and information Being treated in a hospital or clinic that is as physically pleasant as possible		56 (22.4)		
4	sexuality To be given information about sexual Relationships		70 (28.0)		
5	Psychological	Feelings about death and dying			
6	sexuality	Changes in your sexual relationships	87 (34.8)		
7	sexuality	Changes in sexual feelings			
8	Health system and information	Having access to professional counseling (e g, psychologist, social worker counselor ,nurse specialist) if you, family or friends need it			
9	Patient care and support	Reassurance by medical staff that the way you feel is normal	109 (43.6)		
10	Physical and daily living	Pain	111 (44.4)		

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Sexuality			Patient care and support		Psychological			
Р	Beta	B (SE)	Р	Beta	B (SE)	Р	Beta	B (SE)
0.003	-0.18	-0.60 (0.20)	< 0.001	-0.22	-0.51 (0.14)	< 0.001	-0.24	-0.61 (0.15)
Physical and daily living		Health system and information						
Р	Beta	B (SE)	Р	Beta	B (SE)			
< 0.001	-0.28	-0.76 (0.16)	< 0.001	-0.27	-0.69 (0.15)	Social support		

Safieh Faghani et al Table 3. Relationship between supportive care needs and social support among Iranian cancer survivors

of questionnaire was 53.80 for health system and information domain; 46.00 for psychological domain; 40.66 for physical and daily living domain; 39.14 for patient care and support domain, 27.96 for sexuality domain. About social support, the highest scores were for support from family members and significant others and the lower score were for support from friends (Table 2).

The result of univariate regression model is reported on Table 3. As evident, social support has a significant correlation with all domains of supportive care needs.

Discussion

The aims of present study were to investigate the supportive need cares and their relationship with social support among Iranian cancer survivors. Based on the wide review of related literature, this is the first article investigated this topic in Iran or other parts of the world.

The result showed that Iranian cancer survivors had a many unmet supportive care needs in all domains and information and health system and psychological needs were more unmet needs among Iranian cancer survivors. The results of some previous studies showed that informational needs are most popular needs among cancer survivors in South Korea (Park and Hwang., 2012), Hong Kong (So et al., 2013; So et al., 2014), and Singapore (Cheng et al., 2014). Also, some other Western studies showed psychological needs are the most unmet needs among cancer survivors in Australia (Bender et al., 2012; Boyes et al., 2012), Canada (Bender et al., 2012), United States (Knobf et al., 2012), and England (Armes et al., 2009). But, it should be noted that the amount of needs in this study is not comparable with the results of previous studies and this study confirmed that informational and psychological needs are most frequent needs for cancer survivors.

In information and health system domain, the most frequent needs of survivors were about self-care, the results of laboratory tests, and efficacy of treatments. In another Iranian study the most frequent unmet supportive care need of cancer patient was reported as informational needs (Abdollahzadeh et al., 2014). Also, another studies showed that many of Iranian cancer patients tend to receive more information about their disease, especially about side effects of treatments. On the other hand, many of these patients did not have enough information about their daises and unfortunately receive many of this information from unreliable resources such as other patients or their relatives (Valizadeh et al., 2012; Zamanzadeh et al., 2013). In addition, other Iranian study showed that education of cancer patients is weak in Iran and patients need more information about cancer treatments, and risk factors and treatments of cancer (Montazeri et al., 2002).

The second unmet needs reports by participants was psychological needs especially fears about the future of family members, fear of cancer recurrence, anxiety and fears about outcomes of treatments. Other Iranian study showed that 50% of cancer patients experience high levels of fear of cancer recurrence especially fear about family and children (Aghdam et al., 2014). Similarly, other studies showed a high prevalence of anxiety and depression (Malekian et al., 2007; Tavoli et al., 2007; Vahdaninia et al., 2010) and posttraumatic stress disorder (Rahmani et al., 2012) among Iranian cancer patients. It should be noted there is no established supportive care programs for cancer patients in Iran (Afrooz et al., 2014; Seyedrasooli et al., 2014; Nasrabadi et al., 2011).

Also, the results of this study showed that Iranian cancer survivors have less needs in sexual and patients care and support domains. This result is consistent with the results of other Asian studies regarding sexual domain but is different with these studies about patient care and support domain (Park and Hwang., 2012; So et al., 2013; Cheng et al., 2014; So et al., 2014). It seems that this result regarding sexual needs is related to taboo nature in Iran (Farnam et al., 2008) and maybe many of our participants did not report their needs in sexual domain. However, report of low levels of unmet sexual needs among participants do not necessarily means no real needs of them. This may be related to Asian culture and particularly Persian cutler that considered sexual matters as a taboo subject (Farnam et al., 2008). However, more research is needed to confirm this finding.

The results showed that Iranian cancer survivors perceive high levels of social support. These findings are consistent with studies in Western countries (Petersen., 2008; Sammarco and Konecny., 2010; Zhou et al., 2010; Forsythe et al., 2014) and South East Asian countries such as China (Cheng et al., 2013). No previous studies investigated social support in cancer survivors in Iran or other Middle Eastern countries. However, other studies in Iran (Heydari et al., 2009; Taghavi et al., 2011; Naseri and Taleghani., 2012; Nikmanesh et al., 2013) and other Middle Eastern countries, such as Turkey (Ogce et al., 2007), reported high levels of social support in cancer patients. This finding is consistent with the findings of present study. However, in these studies, cancer patients in all stages of disease, from early treatment to end of life stages, have been studied and their findings are not limited to cancer survivors.

The results of present study showed that these patients considered family members and significant others as a main source of social support and placed less importance to their friends and relatives. Similarly, in previous studies conducted on cancer survivors in Asian countries like China survivors reported that they received more support from their family members. However, in studies conducted in Western countries cancer patients considered their family members and friends as the most important sources of support available for them to the same extents (Zebrack et al., 2007; Corey et al., 2008; Forsythe et al., 2014). However, interestingly unlike these studies Survivors participating in this study reported that they receive little support from their friends. Another interesting point in this study is that the majority of patients believed that their family members are also their only important people in their lives. It seems that this is consistent with the findings of previous studies that showed that in Iranian culture, family is the main source of support for cancer patients (Faghani et al., 2014; Abdullah-Zadeh et al., 2011).

The results of regression analysis showed that there was statistically significant relationship between social support and all aspects of supportive care needs. In this case, by increase in the score of social support the need of patients in psychological, information and health system, daily living and physical, patient care and support, and sexual domains reduced. Although according to a review of the literature there was no studies investigated the relationship between social support and supportive care needs of cancer survivors, however, other studies have been conducted on the effects of social support for cancer survivors. The results of these studies indicate the positive effect of social support. For instance, in some studies the relationship between social support and quality of life was investigated. These studies showed those who received more social support had better quality of life (Cheng et al., 2013; Huang and Hsu., 2013; Paterson et al., 2013). Also, some studies have shown that social support is moderated the psychological problems like depression and stress (Imran et al., 2009). Additionally, social support at the time of diagnosis predicted the inflammation and pain during and after treatment (Hughes et al., 2014).

The results of this study have some application in providing supportive care for cancer survivors. The results showed that Iranian cancer survivors have many unmet needs especially in health system and information and psychological domains. It confirms that there is an urgent need for establishing supportive care programs for these survivors. Such programs should cover all aspects of survivors' supportive needs especially their informational and psychological needs. Also, the results of present study showed that Iranian cancer survivors

This study has some limitation. This study was conducted in one educational center and private office in Northwest of Iran and it is difficult to generalize its finding to other parts of Iran. In addition, in this study the perceived social support was investigated and this may not represent the actual level of support received by patients. So, it is a need for other studies in other parts of Iran or other Middle Eastern countries.

Acknowledgements

This article is the result of a master thesis in nursing submitted to Tabriz nursing and midwifery faculty. This study was funded by the Research deputy of Tabriz University of Medical Sciences, Iran. Thanks to all cancer survivors who agreed to participate in the study.

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