

## RESEARCH ARTICLE

# Cancer Care Burden among Primary Family Caregivers of Iranian Hematologic Cancer Patients

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### Abstract

**Background:** Providing care for hematologic cancer patients may lead to many negative complications in different aspects of life in their family caregivers. Based on a wide review of relevant literature, there are limited data about the burden of giving care for hematologic cancer patients on their primary family caregivers in Iran or other Middle Eastern countries. Therefore, the aim of this study was to investigate the cancer care burden on primary family caregivers of hematologic cancer patients, in terms of physical, psychological, social, spiritual, and financial aspects. **Materials and Methods:** In this descriptive study, 151 primary family caregivers of hematologic cancer patients referred to two cancer care centers in East Azerbaijan Province in northwest of Iran participated. The Financial Distress/Financial Well-being Scale, Hospital Anxiety and Depression Scale, Vaux Social Support Questionnaire, Spiritual Well-being Scale, and SF-36 were used for data collection. Data analysis was performed with SPSS software. **Results:** The findings of this study indicated that the primary family caregivers experience a high level of financial distress and a significant percentage of them suffered from anxiety and depression. In addition, the physical quality of life in these caregivers was moderate. On the other hand, spiritual health and social support of participants was at an acceptable level. **Conclusions:** Iranian primary family caregivers of hematologic cancer patients experience many problems in physical, psychological, and financial aspects of their life. Therefore, developing care plans for reducing these problems appears necessary.

**Keywords:** Cancer - cancer burden - primary family caregiver - hematologic cancer -Iran

*Asian Pac J Cancer Prev*, 16 (13), 5499-5505

### Introduction

The diagnosis of cancer may change all aspects of patients' life, and these effects are not comparable to any other disease (Kearney and Giulio, 2012). In reality, cancer patients may experience many problems in physical, psychological, social, financial and spiritual aspects of their life (Massie, 2004; Aghabarari et al., 2007; Hoseini-Yazdi et al., 2012).

It should be noted that cancer diagnosis not only interrupts the life of effected patients but also has various negative effects on different aspects their caregivers' life (Hodges et al., 2005). In fact, today a number of factors have extended the role of family caregivers of cancer patients. First, considering the advances in medical technology, hospitalization period of cancer patients has decreased considerably and patients spend more time with their family caregivers (Given et al., 2001). Second, medical policies have diverted their focus from professional care to non- professional care which needs an earlier discharge of cancer patients from hospital (Nijboer et al., 2001). Third, by considering patients' preferences

and financial pressure, many cancer patients tend to receive outpatient services from their family members (Pitceathly et al., 2003; Francis et al., 2010). In result, family caregivers of cancer patients have an essential role in providing care for these patients (Girgis et al., 2013). On the other hand, cancer patients' caregivers possibly experience many changes in various aspects of their life including physical, emotional, social, financial, and spiritual aspects which are considered as a cancer care burden (Northouse et al., 2000; Haley et al., 2001; Guadalupe et al., 2010).

Generally, the cancer care burden is a distress that caregivers experience as a result of caring of cancer patients (Guadalupe et al., 2010). There are some studies investigated the different aspects of cancer care burden on family caregivers of cancer patients (Max et al., 2003; Cotrim and Pereira., 2008; Guadalupe et al., 2010). For example, the study of Stenberg et al. (2010) in Australia demonstrated that caregivers of cancer patients report several physical symptoms such as fatigue, back problems, heart problems, high blood pressure, arthritis and weight related problems (Girgis et al., 2013). Other studies have

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reported that depression, anxiety, helplessness and fear of death of loved ones are the most important psychological effects of cancer on family caregivers (Massie, 2004). Also, other studies have been reported the effects of cancer care on financial status, job return (Longo et al., 2006), and spiritual health of family caregivers (Rahnama et al., 2012).

In previous studies some problems that Iranian cancer patients faced such as fear of cancer recurrence (Aghdam et al., 2014), inappropriate family function (Barzanjeh, 2014), incorrect perception of prognosis (Seyedrasooli, 2014), and many supportive care needs (Abdollahzadeh, 2014; Rahmani et al., 2014) have been reported. Also, other studies reported that the quality of life among Iranian cancer patients were moderate (Abdollahzadeh, 2012). On the other hand, other studies reported that Iranian cancer patients had high levels of hops (Abdollahzadeh., 2011; Afrooz et al., 2014) and social support (Faghani et al., 2014).

Regarding the effects of cancer care on family caregivers, only one study found that reported the quality of life in the family members of Iranian cancer patient was

a moderate (Fotokian et al., 2005). In addition, it should be noted that hematologic neoplasms due to high death rate and need for frequentative hospitalizations made more problems for cancer patients and their family members (Bakhshi-Binia et al., 2013). Furthermore, assessing the cancer care burden on family caregivers of hematologic cancer patients is essential for establishing any care programs aimed to increase the quality of life among these caregivers. Accordingly, the aim of this study was to investigate the cancer care burden on primary family caregivers of hematologic cancer patients, in physical, psychological, social, spiritual, and financial aspects.

## Materials and Methods

This descriptive study was carried out in in-patient wards and out-patients clinics of two cancer care center in East Azerbaijan Province. These two centers are the main cancer care centers in northwest of Iran. The participants of this study were primary family caregivers of hematologic cancer patients with the following inclusion criteria: having at least 18 years old; definite

**Table 1. Demographic Characteristics of Participants**

Variable	Groups	Frequency	Percent
Sex	Male	85	56.3
	Female	66	43.7
Education of caregiver	Illiterate	19	12.6
	Primary	46	30.4
	Diploma	55	36.4
	University	31	20.5
Job of caregiver	Unemployed	9	6
	Handworker	18	11.3
	Governmental staff	14	9.3
	Housewife	46	30.5
	Self-employment	42	27.8
	Other	22	14.6
Marital status	Married	129	85.4
	Single	22	14.6
Financial status	Income > expense	10	6.6
	Income = expense	58	38.4
	Income < expense	83	55
Education of patient	Illiterate	47	31.1
	Primary	54	35.7
	Diploma	37	24.5
	University	13	8.6
Job of patient	Unemployed	46	30.5
	Handworker	8	5.3
	Governmental staff	9	6
	Housewife	43	28.5
	Self-employment	27	17.9
	Other	18	11.9

diagnosis of hematologic cancer in one of main family members; being chiefly responsible for taking care for patient, at least three months passed since diagnosis, and mentally and physically able to be enrolled in the study. The sample size of 145 primary family caregivers was calculated based on pilot study on 30 potential participants. Then, 170 primary family caregivers was invited to participate in the study and finally the data of 151 caregivers were collected (participation rate = 88%).

For data collection a questionnaire consisted of six main parts was used. The first part gathered some demographic characteristics of participants. Most of these characteristics were collected based on a private interview or by reviewing the patients' medical records.

The second part was Financial Distress / Financial Well-being Scale which consisted of 8 items that were based on 10-response Likert scale ranging from 1 (severe financial distress) to 10 (no financial distress). Ultimately, the scores of all items are added and divided by 8. The final score were scaled from 1 (the most severe financial stress) to 10 (no financial distress) (Prawitz et al., 2006).

The third part was Hospital Anxiety and Depression Scale which consisted of 14 items, 7 of them were regarding depression, and others examine the anxiety. Each item was based on 4-response Likert scale from 0

to 3. So, the final score for each two sub-scales was from 0 to 21. A score of 11 and above indicates the existence of clinical depression or anxiety; scores between 8 to 10 demonstrates a borderline disorder; and the score 7 or lower indicates the absent of disorders (Bjelland et al., 2002).

The fourth part of questionnaire was Vaux Social Support Questionnaire (Fakhri et al., 2012). This 23- item scale examine the perception of receiving social support from family members, friends, and significant others. The response to each item is based on 5-reponse Likert scale and the total score was varied from 23 to 115. More score indicate higher level of social support. Also, the score of each domain can be computed separately (Fakhri et al., 2012).

The fifth part of the questionnaire was Spiritual Well-being Scale. This 20-item scale was based on a 6-point Likert scale from completely disagree to completely agree, which the scores 1 to 6 was respectively dedicated to them. The final score was ranging from 20 to 120. The higher score indicate higher level of spiritual health (Paloutzian and Park., 2005).

The sixth part of the questionnaire was physical dimension of SF-36 questionnaire. This scale consists of 36 items in 8 sub-scales including physical functioning,

**Table 2. Participants Response to items of Financial Distress/Financial Well Being Scale**

Questions	Mean	SD
Feeling about level of financial stress today	3.26	2.08
Mark satisfaction with present financial situation (on stair steps from 0 to 10)	2.85	1.89
Feeling about current financial situation	2.8	1.72
Worries about being able to meet normal monthly living expense	3.86	2.09
Confidence to find or borrow about \$1,000 for a financial emergency	2.6	2.39
Limiting recreational activities because can't afford	4.33	2.65
Frequency of living paycheck to paycheck	4.41	2.8
Perceived stress about personal finances in general	2.63	2.1
Total financial distress score	2.94	1.52

**Table 3. Participants Response to items of Spiritual Well-being Scale**

Questions	Mean	SD
I find much satisfaction in private prayer with God	5.58	0.8
I know who I am, where I came from, or where I'm going	5.28	0.96
I believe that God loves me and cares about me	5.67	0.74
I feel that life is a positive experience	5.07	1.03
I believe that God is impersonal and not interested in my daily situations	5.57	0.76
I do not feel unsettled about my future	3.84	1.35
I have a personally meaningful relationship with God	5.51	0.74
I feel very fulfilled and satisfied with life	4.1	1.45
I get much personal strength and support from my God	5.53	0.76
I feel a sense of well-being about the direction my life is headed in	4.02	1.41
I believe that God is concerned about my problems	5.53	0.85
I enjoy much about life	3.36	1.39
I have a personally satisfying relationship with God	5.43	0.87
I feel good about my future	4.15	1.38
My relationship with God helps me not to feel lonely	5.57	0.77
I feel that life is full of conflict and unhappiness	2.62	1.45
I feel most fulfilled when I'm in close communion with God	5.52	0.76
Life have much meaning	5.11	1.14
My relation with God contributes to my sense of well-being	5.52	0.79
I believe there is some real purpose for my life	5.3	0.98
Total score	98.63	12.21

**Table 4. Participants Response to items of Hospital Anxiety and Depression Scale**

Questions		Mean	S
I feel tense or 'wound up':	A	1.64	1.15
I feel as I am slow down	D	1.49	1.07
I still enjoy the things I used to enjoy:	D	1.97	0.99
I get a sort of frightened feeling like 'butterflies in the stomach'	A	2.02	0.99
get a sort of frightened feeling like something awful is about to happen	A	2.05	0.97
I have lost interest in my appearance:	D	1.83	1.13
I can laugh and see the funny side of things:	D	1.44	0.86
I feel restless as if I have to be on the move	A	1.79	0.96
Worrying thoughts go through my mind	A	1.84	1.15
I look forward with enjoyment to things	D	1.01	0.91
I feel cheerful	D	1.82	0.95
I get sudden feelings of panic:	A	1.44	0.93
can sit at ease and feel relaxed	A	1.61	0.92
I can enjoy a good book or radio or TV programme	D	1.57	1.07
Anxiety	A	11.11	4.96
Depression	D	12.47	5.02

**Table 5. Participants Response to items of Vaux Social Support Questionnaire**

Questions	Mean	SD
I am respected by his friends	4.37	0.72
My family gave me a lot of attention	4.43	0.74
Others do not give importance to me	3.97	0.98
I am respected by my family	4.43	0.76
I considered among family and friends	4.36	0.63
I can rely on my friends	3.35	1.26
My family has always admired me	4.3	0.81
My relatives attend me	4.03	0.97
My family loves me sincerely	4.76	1.11
My friends do not respect my well-being	3.78	0.89
My family relay on me	4.06	0.98
I have a lot of dignity	4.02	0.91
I do not have the support of my family	4.04	1.08
My relatives admire me	3.94	0.91
I feel I love my friends so much.	3.89	0.91
I receive a lot of support from my friends	3.52	1.12
Others consider much value for me	3.91	0.69
My family really respect me	4.36	0.79
Relationships with friends in this period is important for me	3.79	0.97
I want the attachment to others	3.62	0.94
If I die tomorrow, few people are missing for me.	3.63	1.04
I feel like I'm close with my family	4.03	0.88
Me and my friendship each other in hard days	3.83	1.06
Support from family	34.73	6.59
Support from friends	25.56	5.27
Support from significant others	31.52	4.36

social functioning, physical role performance, emotional role play, mental health, vitality, bodily pain, and general health (Ware et al., 1992). Considering the goal of this study, only the physical health dimension was used. This dimension consists of 4 sub-scales including physical functioning, role impairment due to physical health, pain, and general physical health. The participants' score in each sub-scales varied from 0 to 100 and the higher score indicate better quality of life in that sub-scale. The validity and reliability of this questionnaire was approved in Iranian population (Montazeri et al., 2006).

In this study for using these scales the English version of them was translated into Persian by using translate-back translate procedure by two independent expert translators.

Then, the face and content validity of scales were approved by 15 academic staff from Tabriz University of Medical Sciences and some changes were applied in based on their comments. Then, the reliability of all scales was determined after pilot study on 30 potential caregivers by using internal consistency method. The Cronbach's alpha coefficient for all scales was greater than 0.83.

Before data collection, the study protocol was reviewed and approved by Regional Ethics Committee at Tabriz University of Medical Sciences. Then, researchers referred to the study settings and identified all hematologic cancer patients who passed three month from their exact diagnosis. Next, the patients were asked about their primary family caregivers. Thereafter, these primary

family caregivers were contacted about their participation in the study. Then, in the next hospital visit researchers carried out a private interview with these caregivers and the data of all participants, literate and illiterate, were gathered via private interview. Data collection lasted from July to February in 2014.

Data analysis was performed by using SPSS software (version 13). To describe some demographic characteristics of participants and some disease - related characteristics of their patients and also, describe the response of participants to all 5 scales descriptive statistics including frequency, percentage, mean, and standard deviation were used.

## Results

Some demographic characteristics of participants are reported in Table 1. As evident in this table, most of participants were male, housewives, married, educated at high school level, and their living expense was more than their income. Regarding patients, most of them were educated at primary level and unemployed. The average time passed from exact diagnosis was 25 months.

The participants' response to each items of Financial Distress / Financial Well-being Scale are reported in Table 2. The mean score of participants in this scale was 3.94, which indicate high level of financial distress. Also, the Participants' responses to items of Spiritual Well-being Scale is represented in Table 3. As evident, the mean score is 98.63, which suggest high level of spiritual health.

Participants' response items of Hospital Anxiety and Depression Scale are conveyed in Table 4. The mean of anxiety score was 11.11, and the mean of depression was 12.47. Further analysis showed that 17.9%, 18.5%, and 63.6% of participants have no depression, borderline symptoms and clinical depression, respectively. Also, 25.2%, 21.2%, and 53.6% of participants have no anxiety, borderline symptoms, and clinical anxiety, respectively.

Finally, the responses of participants to items of Vaux Social Support Questionnaire are displayed in Table 5. As evident in this table, participants received high levels of social support, especially from family members. In regards to the physical dimension of quality of life, participants have moderate level of quality of life in pain and physical activity dimensions. On the other hand, the participants have low score in role impairment due to physical health dimension.

## Discussion

The main goal of this study was to investigate the cancer care burden on primary family caregivers of Iranian hematologic cancer patients in physical, psychological, social, spiritual, and financial dimensions. According to extensive review of relevant literature, this study is one of the first studies investigated this subject among family caregivers of hematologic cancer patients in Iran or other Middle Eastern countries.

One important finding of present study is that participants experiences high levels of financial distress. In this regard, the results of a previous systematic review

demonstrated that diagnosis of cancer made high level of financial distress for both cancer patients and their family members even in developed countries (Grunfeld et al., 2004; Longo et al., 2006; Hanratty et al., 2007). Also, results of a study in Iran demonstrated that Iranian cancer patients endure high levels of financial distress (Fathollahzade et al., 2015). Conversely, the results of a study in Netherlands illustrated that family members of cancer patients experience low levels of financial distress (Nijboer et al., 2000). Therefore, it seems that although the level of financial distress that experienced by cancer patients and their caregivers is different among countries, however, financial distress is a common phenomenon among cancer patients and their family members worldwide.

Another important finding of present study is that 64% and 54% of primary family caregivers of Iranian cancer patients have clinical symptoms of depression and anxiety respectively. The results of some previous studies in Norway (Grov et al., 2005), Cyprus (Papastavrou et al., 2009) and South Korea (Rhee et al., 2008) also approved that psychological symptoms are common among caregivers of cancer patients. Interestingly, the results of a study in United States showed that most of family caregivers of cancer patients require psychological support (Vanderwerker et al., 2005). It should be noted that, high level of anxiety and depression reported by participants of present study need immediate attention.

Another goal of this study was to assess the level of social support among family caregivers of Iranian cancer patients. In this regards, the results showed that participants reported high levels of social support. Previous studies reported appropriate level of social support among family members of cancer patients in Australia (Ownsworth et al., 2010) and Taiwan (Shieh et al., 2012). Similarly, some previous studies indicated high level of social support among Iranian cancer patients (Afrooz et al., 2014; Faghani et al., 2014). But, this article is the first reported high level of social support perceived by primary family caregivers of Iranian cancer patients.

The other goal of this study was to investigate the spiritual health of family caregivers of Iranian cancer patients. In this respect, the results showed that the spiritual health of participants was at a high level. The review of previous studies revealed that cancer patients and their family members in Western countries have an acceptable level of spiritual health (Kim et al., 2011), but also still experienced many spiritual needs (Taylor, 2006). Likewise, the results of some studies showed that the spiritual health of cancer patients was relatively high (Sadat- Aghahosseini et al., 2012; Seyedrasooly et al., 2014). Thus, in relation to these findings, the primary family caregivers of Iranian patients diagnosed with hematologic cancers have a high level of spiritual health.

Another goal of this study was to investigate the quality of life of primary family caregivers of hematologic cancer patients in physical domain. In this regards, the results showed that the physical quality of life of participants was at average level in two sub-scales of pain and physical activity dimensions. However, regarding role impairment due to physical health dimension the quality of



life of participants was lower than average. The results of a study in the United States displayed that the total physical quality of life and physical functioning of cancer patients' caregivers was relatively low (Weitzner et al., 1999). The results of other studies also confirm the negative physical health impact of caring for cancer patients on the quality of life of family caregivers. Other results also confirm that cancer not only threatens the physical health of cancer patients but negatively impacts the physical health of their family members (Kim, 2008). In this regard, the results of a study in Iran demonstrated that the quality of life of cancer patients is at a moderate level (Abdollahzadeh et al., 2012). Therefore, in regards to the physical status, it was clear that primary family caregivers of hematologic cancer patients need a supportive care programs to enhance their quality of life.

The results of this study have many clinical applications in developing guidelines for care of family caregivers of hematologic cancer patient or patients with other types of cancer. It was evident that caring for hematologic cancer patients has vast negative financial, physical and psychological impacts on their family caregivers. Thus, any programs for caring the family caregivers of cancer patients should emphasis more on these aspects. Furthermore, the health care system and health insurances should provide more financial support for cancer patients and their family members. On the other hand, family caregivers of cancer patients receive the appropriate social support and have high levels of spiritual health. Therefore, we can utilize these points of strength to develop a plan of care for the family members of hematologic cancer patients.

The findings of this study have some limitations which limit its implication. Only the caregivers of hematologic cancer patients participated in this study and its results cannot be easily generalized to other kinds of Neoplasms. In addition, this study was conducted in only one province in the northern western of Iran; and cannot completely cover the cultural diversity in Iran.

## Acknowledgements

This article is based on a Master of Science thesis submitted to nursing faculty of Tabriz University of Medical Sciences, Iran. Thanks to all primary family caregivers of hematologic cancer patients for their cooperation.

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