Aperito Online Publishing

Palliative Medicine and Nursing

Open Access

Received: Sep 22, 2014
Accepted: Oct 24, 2014
Published: Oct 28, 2014

ISSN 2378-8909-1-103 Research Prof. Gil Bar-Sela, Palliat Med Nurs Open Access 2014, 1:1

Informal Family Caregivers of Dying Cancer Patients- What Kind of Support Do they Need?

Roni Gagin[1], Shiri Shinan-Altman[1,2], Adi Shilat[1,3] and Gil Bar-Sela[3,4*]

[1]Department of Social Work, Rambam Health Care Campus, Haifa, Israel

[2]School of Social Work, Bar Ilan University, Ramat Gan, Israel

[3]Division of Oncology, Rambam Health Care Campus, Haifa, Israel

[4]Faculty of Medicine, Technion-Israel Institute of Technology, Haifa, Israel

Abstract

Studies have shown great physical and emotional vulnerability among informal family caregivers of dying cancer patients as a result of the demanding care they provide. However, many informal family caregivers find it difficult to locate appropriate treatment services to answer their physical and emotional needs. Thus, the aims of the current study were twofold: 1) to identify informal family caregivers' needs in order to improve ways of intervening during the treatment and also after the death of their relative; 2) to examine the emotional implications of taking care of a dying family member by informal family caregivers. Based on a convenience sample, 48 informal family caregivers, 17 men and 31 women, aged 19-75 years participated. A semi-structured questionnaire was used, containing background information on the caregiver and information on treating the patient, quality of the relationship with the sick relative, using formal support, and a hospital anxiety and depression scale questionnaire. Findings indicated that most of the informal family caregivers experienced good feelings about taking care of their dying relative since caring allowed them to feel that they were helping and supporting their relatives and caring for them gave them meaning as well. However, participants expressed relatively high levels of anxiety and depression. Furthermore, participants who received supportive services expressed lower levels of anxiety compared to those who did not receive supportive services. We concluded that the changing needs of informal family caregivers should be examined and structured follow-up programs prepared, to provide information and support according to the family caregiver's changing emotional state.

Keywords: Anxiety; Caring relatives; Depression; Dying cancer patients; Professional services

***Corresponding Author**: Prof. Gil Bar-Sela, Director, Integrated Oncology and Palliative Care Unit, Division of Oncology, Rambam Health Care Campus, POB 9602, Haifa 31096, Israel; Tel: 972-4-8543810; Fax: 972-4-8541810; Email: g_barsela@rambam.health.gov.il

Introduction

Modern medicine has brought with it an increase in the life expectancy of a significant number of patients with advanced cancer [1]. However, in addition to the improvement in life expectancy, there has been a gradual decrease in physical functioning, causing mental, social and economic difficulties, and many cancer patients need a framework that will provide a response to their changing needs [2-4].

Informal family caregivers provide essential support to cancer patients along the illness trajectory [5]. However, studies have shown that there is a great deal of physical and emotional vulnerability among informal family caregivers of dying cancer patients, especially those who provide care on a daily basis [6, 7]. Informal family caregivers' tasks are multifaceted and change along the trajectory of illness in concordance with patients' medical and emotional needs [5]. Alongside with the patients' needs, informal caregivers are also concerned by their own changing needs. Kim, Spillers and Hall [8] provide a categorization of caregivers' needs and concerns by identifying four domains: psychosocial, financial, medical, and activities of daily living. These domains were examined among caregivers 2 months, 2 years, and 5 years after the patients' diagnoses (N =5162, N= 5896, and N= 5608, respectively). The prevalence of unmet psychosocial needs was 68% at 2 months and 36% at 5 years.

Indeed, taking care of a relative who is dying from cancer is often emotionally and physically challenging, and many family members find it difficult to locate appropriate treatment services to answer their needs [9]. Thus, the World Health Organization (WHO), as part of defining palliative care, referred to the patient and his family as a single treatment unit and emphasized the importance of providing treatment and support to both the patient and his family who are dealing with agony, pain, loss and bereavement [10]. Studies have already shown that informal family caregivers report symptoms of depression, anxiety, psychosomatic symptoms, tensions in couple and family relationships, as well as physical and medical problems [11, 12]. In addition, it was found that many informal family caregivers who take care of a dying patient are themselves old or sick, or are older children who have responsibilities toward their own children and their workplace [13, 14].

Surprisingly, it was found that informal family caregivers are not interested in sharing with professionals the difficulties they are coping with [15]. Others do not want to impose on professionals, who often come across as physically and emotionally laden with treating palliative patients [16]. Moreover, it was found that informal family caregivers perceive their role as tangent to that of the professionals and, therefore, they do not feel that their need for support and information is vital [17]. On the other hand, some professionals may not have the skills to discuss dying and death with informal family caregivers [16, 18].

Nonetheless, various studies suggest that informal family caregivers who take care of dying patients need information and professional support during treatment [19-21], and that individual and group intervention programs for those caregivers are important [22, 7]. In addition, it was found that the needs of informal family caregivers change throughout the development of the disease, in a similar way to the patient's changing needs. Therefore, there is a need to examine ways in which the caregivers can receive proper professional-therapeutic care, according to their emotional state [23, 24]. Thus, the aims of the current study were twofold: 1) identify informal family caregivers' needs in order to improve ways of intervening during the treatment and also after the death of their relative; 2) examine the emotional implications of taking care of a dying family member by informal family caregivers.

Method

Participants

The current study included 48 informal family caregivers taking care of a relative who is dying from cancer. Table 1 shows the background characteristics of the study participants. The sample included 17 men (35%) and 31 women (65%), aged 19 to 75 years (average 30 years, SD=15.51). Among the participants were 29 partners of patients (60%), 17 children of patients (35%), and two other relatives (4%). Most of the study participants were born in Israel, married, with an average of 2.98 children (SD=1.52). Over half were unemployed, although only seven participants (15%) were over 65 years. Among the employed participants, approximately half were working full time and approximately half were working part time. When asked for the reason for unemployment or part-time work, 14 participants (38% of those not working full time) stated that they were looking after a sick relative. Most of the others who answered the question reported that they were retired.

Table 1: Distribution of participant characteristics (n=48)

		N (%)
Gender	Male Female	17 (35.4) 31 (64.6)
Country of birth	Israel Asia/Africa Eastern Europe	37 (77.1) 5 (10.4) 6 (12.5)
Marital status	Married Divorced Single	38 (82.6) 3 (6.5) 5 (10.9)
Occupation	Employed Unemployed	21 (43.8) 27 (56.3)
Full time/part time	Full time Part time	22 (44.6) 26 (55.4)
Religion	Jewish Muslim Christian Druze	38 (79.2) 6 (12.5) 2 (4.2) 2 (4.1)
Extent of religiousness	Secular Traditional Orthodox – Religious	27 (57.4) 14 (29.8) 6 (12.8)
Education	Primary school High school Academic degree Other	1 (2.1) 27 (56.2) 15 (31.3) 5 (10.4)
Economic state	Good Moderate Reasonable Other	11 (22.9) 12 (25.0) 15 (31.3) 10 (20.8)
Treatment duration per week	All week Almost all week	16 (34.8) 30 (65.2)
Total treatment duration	1-12 months 1-5 years Over 5 years	26 (56.5) 24 (30.5) 6 (13.0)

Measures

1. Background information about the informal family caregiver – gender, age, marital status, number of children, ethnic origin, religion and extent of religiousness, education, occupation, economic status
2. Anxiety and depression were examined by the Hospital Anxiety and Depression Scale (HADS; [25]). The questionnaire includes two scales, one measured anxiety and the second measured depression. Each scale consisted of 7 items. Participants were asked to rate their feelings of anxiety and depression in the past week on a Likert scale from 0 to 4 (0=low levels on anxiety and depression, 4=high levels of anxiety and depression), and a general index was calculated by summing the answers. The scoring for each scale was done over a range of severity: normal (0-7), moderate (8-14) and severe (15-21), where a score of 8 and above represented high levels of depression and anxiety. The questionnaire was previously translated into Hebrew, Russian and Arabic and was found to have good internal reliability (Cronbach's alpha) (.86 for the depression scale, .91 for the anxiety scale) [26]. Chronbach's alpha internal reliability found in the current study was .85 for the depression scale and .83 for the anxiety scale.
3. Background information about treating the patient – these included the following questions: treatment duration per week, total duration of treatment (in years), receiving information about the patient's condition, receiving details regarding the patient's condition, receiving information about life expectancy with the disease
4. Quality of relationship with the relative – feelings which arise due to taking care of the patient, having talks with the patient about his condition and his future
5. Using support services (e.g. emotional support, economic support)– these included formal support that could have assisted with coping, voicing a desire to have a formal support following the death of the relative, and the desired manner to receive information about such support services
6. A question regarding the informal family caregiver's current physical-emotional state, on a scale of 1 (worst) to 10 (best); A question about recent changes in the informal family caregiver's health, with a dichotomous answer of yes/no.

Procedure

The study was performed in the oncology ward at Rambam Health Care Campus in north Israel, where patients admitted in order to balance their disease symptoms. The study's outline was a cross-sectional study based on a convenience sample, with the consent of the informal family caregivers to participate in the study. A questionnaire was purpose designed for the current study. In a pilot study, 10 questionnaires were delivered to 3 experts in the field of cancer and validation of the questionnaire was performed. Next, in a pre-test, a questionnaire was given to 5 informal family caregivers to test the clarity of the items, identify difficulties in understanding them, and examine the reliability of the questionnaires. Comments from this pre-test contributed to the construction of the final questionnaire, such as changing wording where necessary. The study's questionnaire included a number of open-ended questions designed to initiate discussion around main issues arising from conversations the informal family caregivers had with social workers, and was specifically adjusted to serve this pilot study's purposes. A total of 53 informal family caregivers were addressed, 48 of whom agreed to take part in the study which took approximately 18 months. The 5 informal family caregivers who refused to participate in the study claimed it was long and invasive. After signing informed consent, the questionnaire was given to the informal family caregiver by a social worker who stayed with them while they completed the questionnaire, in order to clarify questions as needed and provide emotional support where required.

Statistical Analysis

The data were coded and analyzed using SPSS-17. Descriptive statistical analysis was performed on demographic characteristics. The distribution of background details regarding taking care of the patient, the relationship with the patient, supportive services, and the relationship with staff members, as well as the distribution of anxiety and depression among the

informal family caregivers, the caregiver's physical-emotional state, and the change in the caregiver's health were described using descriptive statistics. Connections between background details, the details of the treatment, the relationship with the patient, supportive services and the relationship with staff members, as well as between those and the caregiver's anxiety and depression, the caregiver's physical-emotional state, and changes in the caregiver's health were analyzed using chi square test, t-test and Pearson correlation coefficient, according to the nature of the variables.

Results

Table 2 describes the quality of the relationship with the sick relative and the use of supportive services.

Table 2: Distribution of quality of the relationship with the sick relative and using supportive services (n=48)

		N (%)
Quality of the relationship with the sick relative Treating the patient triggers good feelings	Yes	41 (95.3)
Had open conversations with the patient regarding his condition and his future	Yes	22 (51.1)
Shares difficulties with	Partner	13 (28.3)
	Children	10 (21.7)
	Friend	10 (21.7)
	Other	13 (28.3)
Using supportive services There are unanswered needs	Yes	21 (43.8)
	No	17 (35.4)
	No answer	10 (20.8)
Interested in information about supportive services	Yes	17 (35.4)
Do you think that these services will help?	Yes	13 (27.1)
	No	21 (43.8)
	No answer	14 (29.2)
Interested in support services following the death of the sick relative	Yes	15 (31.3))
	No	23 (47.9)
	Other	5 (10.4)
	No answer	5 (10.4
Preferred timing for a future approach	First week	3 (6.3)
	First month	4 (8.6)
	Other	7 (14.6)
	No answer	34 (70.8

The quality of the relationship with the sick relative: Most informal family caregivers experienced good feelings regarding taking care of a sick relative. Approximately half reported that they talked with the patient about his condition and about the future implications of his medical condition. The informal family caregivers shared their difficulties with their partners, children, friends and others.

Using supportive services: Approximately a quarter of the informal family caregivers answered a question regarding the supportive services they received. Over half reported that they have talked with a professional, and the rest reported that they received information or financial help. When asked about services that could have assisted, approximately 68% could not define which services could have helped them, while approximately one-third responded that financial help, a conversation with a professional, information and other relatives could help. Approximately 44% of the informal family caregivers claimed that they had unanswered needs, and 35% stated that they would be interested in information about supportive services. Only one-quarter of the participants thought that these services could be useful to them. Approximately one-third of the participants stated that they would be interested in support services after the death of their loved one, usually by an application of the palliative care team, at different timings.

Anxiety and depression among informal family caregivers

Table 3 presents the level of anxiety and depression among informal family caregivers. Approximately half the informal family caregivers felt high levels of anxiety, and one-quarter more felt anxiety at a moderate level. Approximately 30% of the informal family caregivers felt high levels of depression, and one-quarter more felt depression at a moderate level. Cross-checking the categories indicated that eight caregivers (17%) were at normal/mild levels on both variables, while 22 caregivers (47%) were at moderate/severe levels of both variables, and half had high levels of both variables. Four caregivers (8%) had a moderate/severe level of depressions without anxiety, while 13 caregivers (28%) had a moderate/severe level of anxiety without depression.

Table 3: Distribution of anxiety and depression in caregiving relatives (n=48)

	Anxiety	**Depression**
	N (%)	**N (%)**
Normal	1 (12.8)	9 (19.1)
Mild	6 (12.8)	12 (25.5)
Moderate	12 (25.5)	13 (25.5)
Severe	21 (48.9)	14 (29.8)
Mean (SD)	13.88 (4.70)	11.82 (4.86)

Physical-emotional state of informal family caregivers

The informal family caregivers were asked about their current physical-emotional state, on a scale from 1 (worst) to 10 (best). The 40 who answered this question reported an average physical-emotional state of 4.60 (SD=2.11). Eighteen respondents (45%) rated their physical-emotional state as worst, 15 (38%) as moderate and only 7 (18%) rated it as good. Later, 19 caregivers (44% of 43 respondents) reported that they recently had a change in their health condition.

Table 4 presents the relationships between anxiety, depression, physical-emotional state and changes in the caregivers' health. A positive correlation was found between anxiety and depression and between these variables and a change in the caregiver's health - the higher the anxiety level, the higher the depression level, and then the risks for a change in the caregiver's health increased. Negative correlations were found between the level of anxiety and the level of depression and the caregiver's physical-emotional state, and between the physical-emotional state and a change in the caregiver's health, indicating that the higher the levels of anxiety and depression, the worse the caregivers rated their physical-emotional state, and then the risks for a change in their health increased. In

addition, in examining the relationship between the extent of using supportive treatment services and the emotional state of the informal family caregivers, statistically significant differences were found, according to which the level of anxiety among those who received supportive services was lower than among those who did not receive supportive services. Moreover, a higher level of depression was found among informal family caregivers who had unanswered needs during treatments compared to informal family caregivers who had their needs met during treatment.

Table 4: Relationship between anxiety, depression, physical-emotional state and change in the caregiver's heath condition (n=47)

	Mean (SD)	**Depression**	**Physical-emotional state**	**Change in health condition**
Anxiety	13.88 (4.70)	.40** (n = 47)	-.46** (n = 40)	.31* (n = 43)
Depression	11.82 (4.86)		-.49*** (n = 40)	40** (n = 43)
Physical-emotional state	4.80 (2.11)			-.39* (n = 38)
Change in health condition	0.44 (0.50)			

Notes

*p<.05, **p<.01, ***p<.001

Discussion

The current study examined informal family caregivers' needs in order to improve ways of intervening during the treatment and also after the death of their relative as well as the emotional implications of taking care of a dying patient by informal family caregivers. Generally, it seems that the open-ended questions, facilitated by a face-to-face interview with social workers, who were experts in dealing with the issue of taking care of dying people, allowed the participants to reveal emotional contents and difficulties with the treatments beyond those that were included in the study questionnaire.

As part of examining the implications of taking care of a dying patient by informal family caregivers, we examined whether those caregivers would be interested in maintaining contact with professionals to receive treatment services, support, information and utilization of rights following the death of their sick relative. The findings of the study suggested that only a third of the participants would be interested in this item. We found that most participants did not want information about supportive services and did not think that supportive services would help them. It is possible that, in a situation where family members are busy dealing with the complex treatment of a patient and with the implications of the treatment on different aspects of their lives, they are not free to think of their future needs, after the death of their loved one. Their concern is concentrated on the sick relative and future personal needs are pushed aside. Furthermore, the informal family caregivers had difficulty in defining which services might be of assistance, which made it difficult to determine whether they would need further support services. It is also possible that informal family caregivers focused on the "here and now" and used defense mechanisms, such as denial, and tried not to think of the worst, the future without their relative. However, since emotional reactions and

needs may change after the death of the sick relative, it is advisable to examine emotional reactions of informal family caregivers after the death of their loved one and to provide them with professional treatment, such as targeted therapeutic interventions, if needed.

According to our findings, most of the informal family caregivers reported that they had good feelings regarding the care their dying relative since caring allowed them to feel that they are helping and supporting their relatives and caring gave them a meaning as well. Furthermore, participants were satisfied with the information they received regarding the patient's medical condition and his life expectancy. These findings are in accordance with other studies which found that relatives of dying patients were satisfied with the information they received from professionals, that this information provided them with skills on how to cope with taking care of the patient, and assisted them in making decisions regarding continuation of treatment [27, 28]. The current study's findings are of importance because sufficient information regarding the medical condition may decrease feelings of uncertainty and anxiety in treatments, as well as unrealistic expectations from the treating staff members.

Approximately half the participants reported high levels of anxiety and depression, and about half the participants rated their physical-emotional state as moderate/bad. The literature also reports an increase in the levels of depression, anxiety and psychosomatic symptoms among informal family caregivers as the patient's medical condition deteriorates [11, 12]. These findings have significant implications. Firstly, emotional states of depression and anxiety among informal family caregivers may be manifested in the treatment interaction and may affect the nature of the treatment and the support which they provide to their sick relative who is dying. Secondly, states of depression and anxiety may affect the functional state of the caregivers themselves and may cause them physical and mental illness [29, 30]. Therefore, the literature recommends examining emotional responses of informal family caregivers who are taking care of dying patients and giving those caregivers access to appropriate professional care, such as by designated treatment intervention programs [1].

Limitations

The current study has several limitations. Firstly, the study was based on a convenience sample and not on a representative sample. Relatives who refused to participate were not taken into consideration and, therefore, the sample of the participants in the study is not fully representative of the implications of taking care of a dying relative. Secondly, there is a possibility of a social willfulness bias, so that the participants answered the questionnaire in a certain way in order to create a desired impression towards others or perhaps even toward themselves. Lastly, this pilot study is based on a small sample size and caution is needed about drawing conclusions.

Conclusion

It is evident that there is a gap between the extent of using existing supportive services for relatives taking care of a patient and the caregiver's emotional distress, as manifested in the questionnaires. It is possible that the participants had a low awareness of the services offered by the social workers or that they felt hopeless and were unavailable to use professional services for themselves due to the emotional difficulty of taking care of a dying relative. Therefore, the changing needs of informal family caregivers should be examined, along with preparing structured follow-up plans at set times, so that it would be possible to provide information and support according to the caregiver's changing emotional state, even during the last weeks of the patient's life and after his death.

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