

Family Caregivers' information and burdens regarding patients with cancer

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Abstract:

Background:

A patient diagnosed with cancer may have significant impact not only on them self's, and health care providers but also on their family members. Family caregivers are often the primary source of social and emotional support for patients. In addition, they have a major role in helping the patient to manage their health problem that faced during receiving palliative care.

Objective: The main objective of this study was to determine the information of Family Caregivers for patient with cancer, and Palliative Care, to describe socio demographic data and to find out the relationship of information with some socio demographic data.

Method: A cross-sectional descriptive study was done. Family Caregivers Questionnaire (FCQ); which was created based on the review of literature, and health care needs context. The total number of interviewed caregivers was 200.

Results: 82.5% of caregivers only heard about cancer without having sufficient information about it, (51%) of them thought that cancer could be treated. Tiredness and fatigue were the most physical problem faced to the caregiver, which was (65.5%). In addition, (75%) of the participant was complaining of worry about the progress of the disease. Furthermore, pain was also the most difficult burden of cancer patient, which faced to them, was about (62.5%), and there was significant association between age, level of education with information of caregivers about cancer.

Conclusion: The findings of this study showed that family caregivers are not knowledgeable about cancer and palliative care. The lack of education and experience may have contributed to the caregiver's low level of knowledge cancer and palliative care.

Background:

Cancer is a major disorder which affects many people directly or indirectly, the course of cancer is shifting from an acute disease with a prompt outcome usually death due to chronic disease with long term treatment (Rob et al, 2000).

A diagnosis of cancer has a significant impact not only on the patients, but also on their family members. Family caregivers are often the primary source of social and emotional support for patients and play a major role in how well patients manage their illness (Bultz et al., 2009; Zobra et al., 2000).

Cancer is a challenge for patients, family caregivers and the health care system. The incidence of cancer is increasing from year to year duo to better diagnosis, an ageing population, and long life expectancy (WHO, 2013).

According to research center in the UK 2012, over half (53%) of all cancers are diagnosed in adult age (50-74) year.

Care giving can involve administrating medications manage side effect, providing nutrition, equipment care example infusion pump (intravenous), managing of activities the patients has forgone because of illness. Caregiver may also have to accompany patients on frequent clinic visits for treatment as well as for the management of adverse events, patients may require care for long time and in many cases caregiving ends with the death of loved one, which is followed by the stress of bereavement (Moore et al., 2004).

Several studies reported that family caregiver experience social and emotional problem in addition to caring of person with cancer also care of children they worry about the patient when they are not with him or her as a result they try to do it all at work at home and with the patient (Coristren et al, 2003).

Methodology

Study design and population

A descriptive cross-sectional study Quantitative design was conducted to assess the knowledge of caregivers or family members of the patients who were diagnosed with cancer.

One of the caregivers from family member who had been designated as caregiver of the patient that had cancer was interviewed.

Data Collection and Setting

Family caregivers of those patients who had received chemotherapy from the Hewa Hospital were identified through visiting them during they received oncologic care from Hewa Hospital. It is located at Province of Sulaimania, in Kurdistan Region/Iraq. It is publicly funded agency that is mandated to provide an oncologic care services. Formally, Caregivers asked to participate in the study, those who were wishing to participate then interviewed, and the questionnaire filled out. The data was collected from February 2nd2015 to April 10th 2015. No follow-up occurred to non-responders.

The Family Caregivers Questionnaire (FCQ) was created and used to obtain caregivers' information regarding cancer, and it is impact on those who provided care to the terminally ill patients with cancer. This instrument consists of 6 main sections, which is contained 15 items.

Data analysis

Frequencies and percentage were used to describe caregiver demographic characteristics. They were also used to describe caregiver reports on each question that are provided in the questionnaire. Descriptive analyses were conducted on all responses by using (SPSS V20).

Result and Discussion:

Two hundred caregivers participate in this study from these 118 were male and 82 were female; the highest percentage of caregivers (28.5%) were at age (21-30) years, most of them were married (47.5%), most of them level of education were secondary school (29.5%), Employee occupation of caregiver were (36%). As it is illustrated in the (Table 1)

Table 1: Socio-demographic characteristic of Caregivers

Socio-demographic characteristics of caregivers	Frequency	Percentage
Age groups		
≥20	54	27%
21-30	57	28.5%
31-40	41	20.5%
≤ 41	48	24%
Total	200	100%
Gender		
Male	118	59%
Female	82	41%
Total	200	100%
Occupation		
Employee	72	36%
Self emplye	65	32.5%
Jobless	45	22.5%
Retirement	18	9%
Total	200	100%
Level of education		
Illiterate	40	20%
Primary school	49	24.5%
Secondary school	59	29.5%
Institute	37	18.5%
College and Post-graduated	15	7.5%
Total	200	100%
Marital status		
Single	75	37.5%
Married	95	47.5%
Divorce	7	3.5%
Widowed	23	11.5%
Total	200	100%

Table 2: Family Caregivers information regarding cancer

Family Caregivers information regarding Cancer	Know	Don't Know	Uncertain
	F (%)	F (%)	F (%)
Have you heard of cancer	165 (82.5%)	35 (17.5%)	0 (0%)
Is it common in this environment	155 (77.5%)	35 (17.5%)	10 (5%)
Can be detected early?	20 (10%)	57 (28.5%)	123 (61.5%)
Can early detection improve chance of survival	102 (51%)	72 (36%)	26 (13%)
Do you have family history with cancer	23 (11.5%)	123 (61.5%)	54 (27%)
Is cancer can be treated	102 (51%)	72 (36%)	28 (14%)

More than two third (82.5%) of caregivers had heard about cancer, as shown in table (2), but almost all they do not have satisfactory information about of cancer and burdens of cancers' patient. 51% of them believe that cancer is treated. Knowledge is one of the most essential, and magic keys for caregivers, who take care of cancer patients. Specifically, in the alleviating and minimizing of symptoms that had developed from side effect of chemotherapy and physical care in particular at home.

In the studies which were conducted by Aslan, et al.(2006), Beaver and Witham, (2007) asserted that family caregivers described not knowing what their information needs where until a crisis occurred when information was not provided by clinicians, family caregivers felt frustrated and helpless.

Table3: Impact of physical health on caregivers

Impact on physical health	Frequency	Percentage
Tiredness and fatigue	131	65.5%
Back neck and shoulder problem	86	43%
Blood pressure and heart problem	37	18.5%
Digestion and bowel problem	38	19%
Lack of sleep	51	25.5%

Caregivers are exposed to a considerable burden as a result of the many responsibilities they handle for long period. Care is often a difficult, disruptive impact on physical health. This study is discovered that the most prevalent physical problems reported by caregivers as present in table (3) including Tiredness and fatigue (65.5%), back, neck and shoulder problem (43%), blood pressure and heart problem (18.5%), digestive and bowel problem (19%), lack of sleep (25.5%), which is very similar to the Stenberg, et al.(2010) study. In which the common physical problem of caregivers include tiredness and exhaustion (54.5%), leg and foot problem (4.6%), heart problem (12.6%) and arthritis (10%). Except of the digestive and sleep problem. It is believed that fatigue and exhaustion resulting in decrease ability to concentrate and decrease motivation. While, back and leg pain caused by heavy lifting with the further physical strain when the patient was incontinence of urine and feces due to increase amount of washing.

The impact of constancy of care for physical needs was exacerbated by continual lack of sleep if patients needed care during night.

According to Vitalano et al and Haelyin (2000) in their study say, Stress may have negative effect on the function of the immune system, blood pressure, and lipid profile of caregivers and high level of stress in older adult's spousal caregivers may be a risk factor for death.

Table 4: Emotional problem and reactions of Caregivers

Emotional problem and reactions	Frequency	Percentage
Anxiety for my own health	78	39%
Not wish to leave the patient	92	46%
Always worry	150	75%
Possibility of getting cancer (Fear)	50	25%
Fear from losing the patient	95	47.5%
Fear of recurrence of the cancer	82	41%
Fear of the metastasis	69	34.5%
Hopelessness	79	39.5%
Feel upset (Anger confused)	64	32%
Feeling inadequacy (Wish to do more)	97	48.5%

Table (4) concentrated that 39% of caregivers have anxiety of their own health, 47.5% fear of losing the patient and 48.5% fell of inadequacy or wishing to do more. Lamert et al in 2012 founded that more than one third of caregivers reported borderline or clinical level of anxiety even %17 reported of clinical depression also Price et al. (2010) founded that significantly higher prevalence of clinical anxiety and depression among caregivers compared with the patients rate and community norms.

Caregivers experience anxiety most commonly from fear of losing the patient; they could have difficult expressing these fears to others.

In addition to caring the person with cancer also should care of children or aging parents these caregivers often felt stretched in many directions at once, they worry about the patient that reported in this study it was (%75), when they are not with him or her and they worry about other family member when they are with the patient.

As a result they try to do it all at work, at home, and with the patient, our study showed that (48.5%) felling inadequacy and they wish to do more.

Table 5: Positive Emotional Experience of Caregiver

Positive Emotional Experience of Caregiver	F	Percentage
Appreciate the time together	32	15.5%
Brought the Whole Family Closer	52	26%
Greater Sense of Connectedness	61	30.5%
Feeling very good about doing it	70	35%

Caring is a complex process that has both beneficial and costs, positive and beneficial aspect of caring with consequence for interpersonal relationship between patient and caregivers,

this study was founded that even caregivers have burden and emotional problem but some caregivers reported a positive emotion they said we are appreciate time together, brought the whole family closer, grating sense of connectedness, felling very good about doing it. It was (15.5%, 26%, 30.5%, 35%) respectively, as shown in table (5).

Kim et al (2007) were supported our findings they reported that caring of cancer patients that families bound together during the illness, they learned a lot experience the caregiving as meaningful, purposeful and satisfying also reported that caregiving as positive for their self-esteem.

The primary source of support for patients with cancer are family caregivers and the first respond to changes in the patient situation throughout each phase of cancer, the sample study provided a great deal of clinical care they help patients and try to manage symptom such as nausea, vomiting, fatigue or pain.

Based on Dobratzet al and Fainsinger et al (1999), Pain is the symptom commonly experienced by patients receiving palliative care, our study founded (62.5%) have pain. Present in table (6).

Table 6: **Burden related to the responsibility and impact on daily life.**

Burden related to the responsibility and impact on daily life.	Frequency	Percentage
Assisting with mobility	98	49%
Assisting changing dressing	102	51%
Assisting change dipper, Give bath	88	44%
Difficulty in Managing Patients Symptoms		
▪ Frequent Urination	75	37.5%
▪ Pain	125	62.5%
▪ Fever	58	29%
▪ Difficulty Breathing	45	22.5%
▪ Diarrhea	77	38.5%
▪ Constipation	55	27.5%
▪ Nausea	88	44%
▪ Vomiting	68	34%

Education for patient and family is the foundation for good pain control and can be the responsibility of both physician and nurse, the concept of regular medication dosing for regular pain control can be taught. Family caregivers are such assist the patients without any training to control all symptoms so as burden and impact of daily life.

Table 7: Relationship between some Socio-demographic characteristics of caregivers and information of caregivers

Socio-demographic characteristics of caregivers	Caregivers information about Cancer				P value
	Know	Don't Know	Uncertain	Total	
Age groups					
≥20	30	20	4	54	0.0066
21-30	41	11	5	57	
31-40	17	20	4	41	
≤ 41	28	10	10	48	
Gender					
Male	78	15	25	118	0.2554

Table (7) shows that there was significant association between age group, level of education and information of caregivers, those who have young caregivers (21-30) age group, collage and post graduate level of education have good information, also the study was done by (Bradly and Sherwood, 2010), was support our findings.

Young age spend much of their lives in educational setting, and their experience in school, collage can shape much of their subsequent lives, to date duo to vast majority of mass media such Television, Internet they can get information more easily what they want.

However the study was done by (Oberst et al, 2011), was opposite our findings they showed that older caregiver had significantly higher challenge and information about cancer, they believe that older group have grater patience, experience and knowledge from a life time of decision making.

Conclusion

To date the oncologic care system has not fully incorporated into community health care services. In addition, family members, and caregivers knowledge regarding the oncologic care, and process of the cancer is deprived. The findings of this study showed that family caregivers are not knowledgeable about palliative care. The lack of education and experience, as well as some cultural limitations, may have contributed to the caregiver's low level of knowledge about palliative care.

Recommendation

These findings suggest that caregivers' information about palliative care can be improved by establishing specific palliative care educational program to focus on end-of-life care. The majority of the caregivers requested to understand the process, and the progression of the diseases. This can be achieved through a specific educational program about palliative, and end of life care. A health care institution requires incorporation of palliative and end-of-life care into oncologic care in Kurdistan region.

Ethical Consideration:

The Ethics and scientific review committee of the School of nursing at Raparin University in Kurdistan region/Iraq approved the study.

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زانیاری ئەندامی خیزانی نهخۆش و بارگرانیهکانی ئەو نهخۆشانهی که شیرپهنجهیان ههیه پاشخان:

ئەو نهخۆشانهی که شیرپهنجهیان ههیه کاریگهريهکی بهرچاو نهک ههەر له سهەر خودی نهخۆشهکه بهلکو له سهەر کارمهندانى تهندروستی ههروهها ئەندامانى خیزانهکهی ههیه. ئەندامانى خیزان ههموو کات سهەرچاوهی سههرهکین له پالپشتی کردنى نهخۆشهکه له رووی کۆمهلايهتى و سۆزداریهوه. سههرهپایی ئەمهش پۆلیکی بهرچاو دهبینن له یارمهتی دانی نهخۆشهکه بۆ باسترکردنى ئەو کیشه و گرفتانهی که رووبهرووی نهخۆشهکان دهبنهوه له ماوهی وهرگتنی چارهسهری درێخایهین.

ئامانج:

ئامانجی سههرهکی لهم تووێژینهوهیه بهدهستهینانی زانیاریه له ئەندامانى خیزانى ئەو نهخۆشانهی که شیرپهنجهیان ههیه و چارهسهری درێخایهینان بۆ دهکرییت، ههروهها بۆ باسکردنى زانیاریهکانیان دهبارهی شیرپهنجه و پهيوهندیان لهگهڵ زانیاریه ديموگرافیهکان.

میتۆد:

تووێژینهوهیهکی وهسفیه، و راپرسیهک به ناوی (FCQ) بهکارهاتوو به مهبهستی کۆکرنهوهی زانیاری له ئەندامانى خیزانى ئەو نهخۆشانهی که شیرپهنجهیان ههیه.

ئهنجام:

له ۸۲.۵% ئەندامانى خیزانى نهخۆشهکان تهنها گووبیستی شیرپهنجه بوون، به بئ ههبوونی زانیاری تهواو و پيوست دهبارهی شیرپهنجه. له ۵۱% ئەوان بیان وایه که شیرپهنجه دهتوانرێ چارهسهربکرییت. داهیزران و مانبوون کیشهی جهستهی زۆربهی بهشداربوون بوو که رووبهرویان دهبیتهوه له کاتی چاودیریکردنى نهخۆشهکان. سههرهپایی ئەمهش ۷۵% بیان زۆر دوو دل و پارا بوون دهبارهی باش بوون و بهرهوپپچوونی نهخۆشیهکه. زیاتر له مهش ههبوونی ئازار که بارگرانیکی تره به بهردهوامی رووبهرووی ئەندامانى خیزانى نهخۆشهکان دهبوو که ریزهکهی له ۶۲%. به دهر له مانهش پهيوهنديهکی زانستی بهرچاو ههبوو له نیوان تهمن و ئاستی خویندن ئەندامانى خیزانى نهخۆشهکه و زانیاریهکانیان دهبارهی شیرپهنجه .

دهرئهنجام:

زانیاریه بهدهستهاتوووهکان ئەوه دهردهخن که کهس و کاری نهخۆشهکان زانیاری دروست و تهواویان نیه دهبارهی شیرپهنجه و چارهسهری درێخایهین و چاودیریکردنى نهخۆشهکان.

معارف واعباء العوائل المعينة بالمرضى المصابين بالسرطان

الخلفية:

المرضى المشخصين بمرض السرطان ليس لهم تاثير كبير فقط على انفسهم والمزودين لهم بالخدمات الصحية بل يشمل اعضاء عوائلهم ايضا. والعوائل المعينين للسرطان هم دائما المصدر الاولي والاساسي للمساند الاجتماعية والعاطفية للمرضى، بالاضافة الى ان لديهم الدور الاكبر في مساعدة المريض لادارة وتدبير المشاكل الصحية التي تواجههم خلال تلقيهم العلاج التلطيفي.

الاهداف:

الهدف الرئيسي لهذه الدراسة هو تحديد معارف العوائل التي تعنتي بمرضى السرطان، وخدمة العلاج التلطيفي وكذلك وصف المعطيات الديموغرافية والاجتماعية وايجاد العلاقات بين المعارف والمعطيات الديموغرافية لعينة البحث.

المنهجية:

اجريت دراسة وصفية استعراضية بواسطة وضع استبانة مستحدثة لهذا الغرض من خلال الاعتماد على مراجعة البحوث والدراسات السابقة وايضا في ضوء احتياجات الخدمات الصحية . والعدد الكلي للمتقابلين من المقدمين للعاية لغرض العينة هم ٢٠٠ عينة.

النتائج:

٨٢.٥ ٪ من مقدمي العنايه والخدمات سمعوا بالسرطان ولايملكون المعلومات الكافية عن المرض، (٥١٪) منهم يعتقدون بإمكانية علاج السرطان.

يعتبر التعب والاعياء من اهم المشاكل الجسمية التي تواجه مقدمي الخدمات وبنسبة (٦٥.٥٪) منهم. بالاضافة الى ان (٧٥٪) من المشاركين كانوا يشكون من تطور المرض. وكذلك كان الالم من اكثر المؤثرات الصعبة لمرضى السرطان والتي كانت تواجههم وبنسبة (٦٢.٥٪)، وكانت هناك علاقة كبيرة بين العمر والمستوى الثقافي من جهة وبين معلومات المقدمين للخدمات والعنايه للمرضى.

الاستنتاج:

وجدت الدراسة ان العوائل المزودين بالخدمات والعنايه بمرضى السرطان لايمتلكون المعارف الكافي بمرض السرطان والعلاج التلطيفي له. ونقص الثقافة والمهارة ربما تتداخل مع قلة ونقصان المعارف للمقدمين للخدمات والرعاية لحالات السرطان والعلاج التلطيفي.