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Responsibilities and Difficulties of Caregivers of Cancer Patients in Home Care

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ÜNİVERSİTESİ





Introduction

- Home care of cancer patient is growing rapidly in the world.
- Caregivers have to undertake the responsibility of the cancer patient's at home.
- It is a great burden on the shoulders of caregivers.



Caregiver

- The caregiver is defined as the person who most often helps the patient with cancer and is not paid to do so.
- *In most cases, the* primary caregiver is a spouse, partner, parent, or an adult child.



Caregiver

- The caregiver has a key role in the patient's care.
- These roles change as the patient's needs change during and after cancer treatment.
- Good caregiver support is crucial to the physical and emotional well-being of patients with cancer.



The responsibilities of a family caregiver

- personal care (hygiene, feeding)
- domestic care (cleaning, meal preparation)
- auxiliary care (shopping, transportation)
- social care (informal counselling, emotional support, conversing)
- nursing care (administering medication, changing catheters)



Challenges

It is reported that caregivers experience challenges

- pain management
- patient mobilization
- daily life activities
- communication with health personnel
- symptom management
- home medicine treatment
- the management of emotional reactions of the patients

(Given et al., 2001; Hendrix and Ray, 2006; Meeker et al., 2011; Serfelova, 2012).



Caregiver...

- It is reported in the literature that caregivers are not prepared sufficiently before the patient is discharged.
- The period after discharge is important for the management of the symptoms of cancer patients.

(Altun, 1998; Wen and Gustafson, 2004; Karabuga, 2009; Serfelova et al., 2012).



Home Care in Turkey

There are different organizations of home care in Turkey.

In 1996, private organizations started to deliver home care services.

- totally paid by the patients
- no legal regulation



Turkey

- "The Transition of Health Project" made elementary changes in primary care by Ministry of Health.
- Hospital based home health services have been started in 2004.
- "Home Health Services" delivered in 2010.

(Turkish Prime Ministry. Home Care Services Offer, No. 25751, March 10, 2005. <http://www.saglik.gov.tr/TR/belge/1-570/eski2yeni.html>. Accessed September 11, 2015).



Turkey

- “Home Health Services Program” has been initiated in all the cities by mobile teams for the rural areas.
- The mobile team consist of
 - Doctor (1)
 - Nurses (2)
 - Driver

(Mergen H et al., Home Health Care Management & Practice 25(3) 104-109).



Home Care

- Any patient who is in need of home care can directly call on to these teams.
- If any family physician or any specialist doctor (e.g. general surgeon, internal medicine) needs home care for their patients, they can get in touch and involve the team in patient care.



Home Care

- Home care teams are responsible for simple acute measures such as pain relief, constipation, wound dressing and parenteral drug administration.
- They will take care for the patients who are not sufficiently mobile.



Turkey

- Home Care Services are limited in Turkey.
- The caregivers face many potential tasks when caring for cancer patients at home.
- There is limited research about caregivers problem at home.



- **Materials and Methods**



Aim of the study

- The aim of this study is to investigate challenges that caregivers encounter in the home care of patients and the reasons for these challenges.



Sample

- The research sampling consisted of 137 voluntary caregivers of patients.
- The caregivers,
 - aged 18 and older,
 - spoke Turkish,
 - lived in the same house with their patients,
 - had given care for more than three months.
 - primary school graduates
 - did not receive financial support for their caregiving service.



Descriptive Characteristics of Caregivers

- 70.80% of caregivers were female
- 31.40% were in the 40-50 age group
- 42.30% were primary school graduates
- 81.80% were married
- 96.30% had health insurance
- 57.70% gave care for one year
- 49.60% were the spouse of the patient
- 70.80% had no chronic disease
- 56.93% did not receive any help during caregiving process .



Data Collection

- Data collection tool was developed by the researchers from the literature.
- Data were collected with face-to-face interviews in the oncology outpatients clinic.
- Caregivers were informed about the aim of the research and the voluntary ones were included in the study.



Research Ethics

- Ethics Committee approval was taken from University.
- Caregivers and their patients were informed about the research and their approval was taken as well.
- No financial support was received from any institution or agency to conduct this research.



Results and Discussion

- The home care of cancer patient requires extra effort and management.
- In this study, it was found that many needs of cancer patients were met by caregivers and caregivers report some difficulties during this process.

Auxiliary care (shopping, transportation)

DLA for which caregivers provide help	(%)*	Reasons of challenges
Shopping	75.91	Patient's being alone at home
Taking the patient out, bring her/him to hospital	71.53	Patient's physical mobility restriction Patient's risk of fall
Providing suitable resting environment	69.34	Tiredness of caregiver



Shopping

- It was found that 75.91% of the caregivers need help to shop for patient and house needs.
- The caregivers have concerns about the patient's being alone at home.



Taking the patient out

- It was found that 71.53 % of the caregivers need help to
 - **taking the patient out**
 - **bring her/him to hospital**
- The caregivers have concerns about the
 - **Patient's physical mobility restriction**
 - **Patient's risk of fall**



Environment

- It was found that **69.34 %** of the caregivers need help to
 - **Providing suitable resting environment.**
- The caregivers feel
 - **Tiredness of caregiver.**



Auxiliary care (shopping, transportation)

- The caregivers reported that they have difficulty in giving the patients' auxiliary care.
- The findings are similar to the results seen throughout the literature.

(Kim et al.2006; Honea et al.2007; Krepa et al., 2008; Adams et al., 2009).

Findings : Personal care (hygiene, feeding)

DLA for which caregivers provide help	(%)*	Reasons of challenges
Changing clothes	51.82	Presence of pain in patient Patient's physical mobility restriction
Body hygiene	44.53	Patient's risk of falling Tiredness of caregiver
Nutrition (including cooking)	54.01	Patient's loss of appetite Patient's nausea and vomit Patient's nasogastric tube feeding
Oral hygiene	26.28	Patient's unwillingness to use solutions

Changing clothes

- It was found that **51.82 %** of the caregivers need help **changing clothes**
- The caregivers have concerns about the
 - **presence of pain in patient**
 - **patient's physical mobility restriction**

Body hygiene

- It was found that **44.53** % of the caregivers need help to **body hygiene**
- The caregivers have concerns about the
 - **patient's risk of falling**
 - **tiredness of caregiver**

Nutrition (including cooking)

- It was found that **54.01** % of the caregivers need help about nutrition.
- The caregivers have concerns about the
 - **patient's loss of appetite**
 - **patient's nausea and vomit**
 - **patient's nasogastric tube feeding**



Personal care (hygiene, feeding)

- The caregivers reported that they have difficulty in giving the patients' personal care.
- The findings are similar to the results seen throughout the literature.

(Altun, 1998; Roberts et al., 2002; Ugur, 2006; Northouse et al., 2012; Serfelova, 2012).

Nursing care (administering medication, changing catheters)

DLA for which caregivers provide help	(%)	Reasons of challenges
Medicine use	50.36	Patient's challenge in swallowing medicines Patient's nausea and vomit
Control of patient's pain	50.36	Non-efficiency of caregiver's practices
Control of patient's body temperature	48.18	Non-efficiency of caregiver's practices 15 (22.73)



Pain

- It was found that **50.36** % of the caregivers need help to **control of patient's pain**
- The caregivers have concerns about the
 - **Non-efficiency of caregiver's practices**

Medicine use

- It was found that **50.36 %** of the caregivers need help to **medicine use**
- The caregivers have concerns about the
 - **patient's challenge in swallowing medicines**
 - **patient's nausea and vomit**



Nursing care (administering medication, changing catheters)

- The caregivers reported that they have difficulty in giving the patients' nursing care.
- The findings are similar to the results seen throughout the literature.
- (*Roberts et al., 2002; Yildirim, 2006; Northouse et al., 2012; Serfelova, 2012*).



Discussion

- According to Turkish general customs, families and relatives of patients prefer caregiving in their own social environment.
- In Turkey, family caregivers have an important place in the health care system.



Discussion

- Therefore, it is important to develop effective coping attitude for the caring period to be perceived positively by both the patient and the caregiver.
- In this study, the caregivers reported that they have difficulty in giving the patients' nursing care .
- Because the home care team is consist of a doctor, 2 nurses.
- There is a lack of visiting nurses to support patients and instruct caregivers.



Discussion

- In the literature, it is reported that caregivers should be supported regarding pain control, medicine management, medicine dosage, pain assessment, and the management of side-effects of medicines.

(Silver and Wellman, 2002; Todd et al., 2002; Jansma et al., 2005; Sapountzi-Krepa et al., 2008; Adams et al., 2009; Meeker et al., 2011; Stajduhar, 2013).



Discussion:

- Given et al. (2001) found that caregivers need to be informed about the disease, treatment, management of symptoms and emotional problems of patients, household management, developing problem solving strategies and supporting the patient's mobility.

(Given et al.2001. CA ancer J Clin, 51, 213-31).



Discussion:

- Hendrix et al. (2006) found that planned and practical training given to the caregiver for the home care of cancer patients reduces challenges and stress.

(Hendrix C, Ray C . 2006. Informal caregiver training on home care and cancer symptom management prior to hospital discharge: a feasibility study. Oncol Nurs Forum, 33, 793-8.).



Discussion

- In this study, it was found that 56.93% of caregivers do not receive any assistance.
- There is not a housekeeper in the home care team and the government doesn't pay .



Discussion

- In the literature, it was reported that caregivers who are directly responsible for patient care should receive support from external institutions regarding household management.

(Chamber et al., 2001).



Conclusion and suggestions

- Family caregivers face many problems.
- There is inadequate support for relatives who care for cancer patients at home.
- Inefficient home care increases the heavy burdens on families.
- Nurses should teach caregivers about the care of the patients at home before patients discharge.



Conclusion and suggestions

- The government should increase the number of nurses for the home care team.

- The government should pay for the housekeeper.

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- Thank you...