

# Use of Outside Services and Other Needs of Informal Caregivers of Adult Oncology Patients

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## BACKGROUND

This qualitative study is a follow-up to a previous quantitative, descriptive study “Caregiver Reactions in Oncology and Other Chronic Illnesses”. Key findings of the initial study being explored further in this study are:

- 78% of informal caregivers reported not using any outside services in providing care
- Informal caregivers reported that providing emotional and psychological support to the patient is the most challenging caregiving activity

**Informal Caregiver:** an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.



## OBJECTIVES

The purpose of this study is to explore the experiences and needs of informal caregivers of adult oncology patients.

Primary aims of the study:

1. Identify what information caregivers need and desire in relation to outside services to assist them in their role
2. Describe barriers to use of outside services by informal caregivers

Secondary aims of the study:

1. Explore experiences and needs of caregivers relative to providing emotional and psychological support to the patient
2. Describe how caregiver experiences and needs change over time

## METHOD AND STUDY DESIGN

Qualitative description

Demographic questionnaire

Structured, open-ended individual interviews – audiotaped

Recruitment: Presentations at nursing councils and leadership meetings, e-News notices to all employees, flyers distributed throughout the institution, notice on institution web site

## DATA ANALYSIS

Transcribed interviews read in one sitting

Tables constructed with questions, themes and illustrative comments

Interview transcripts and data tables reviewed by second investigator (a social worker) for concordance and validation

Coding table created

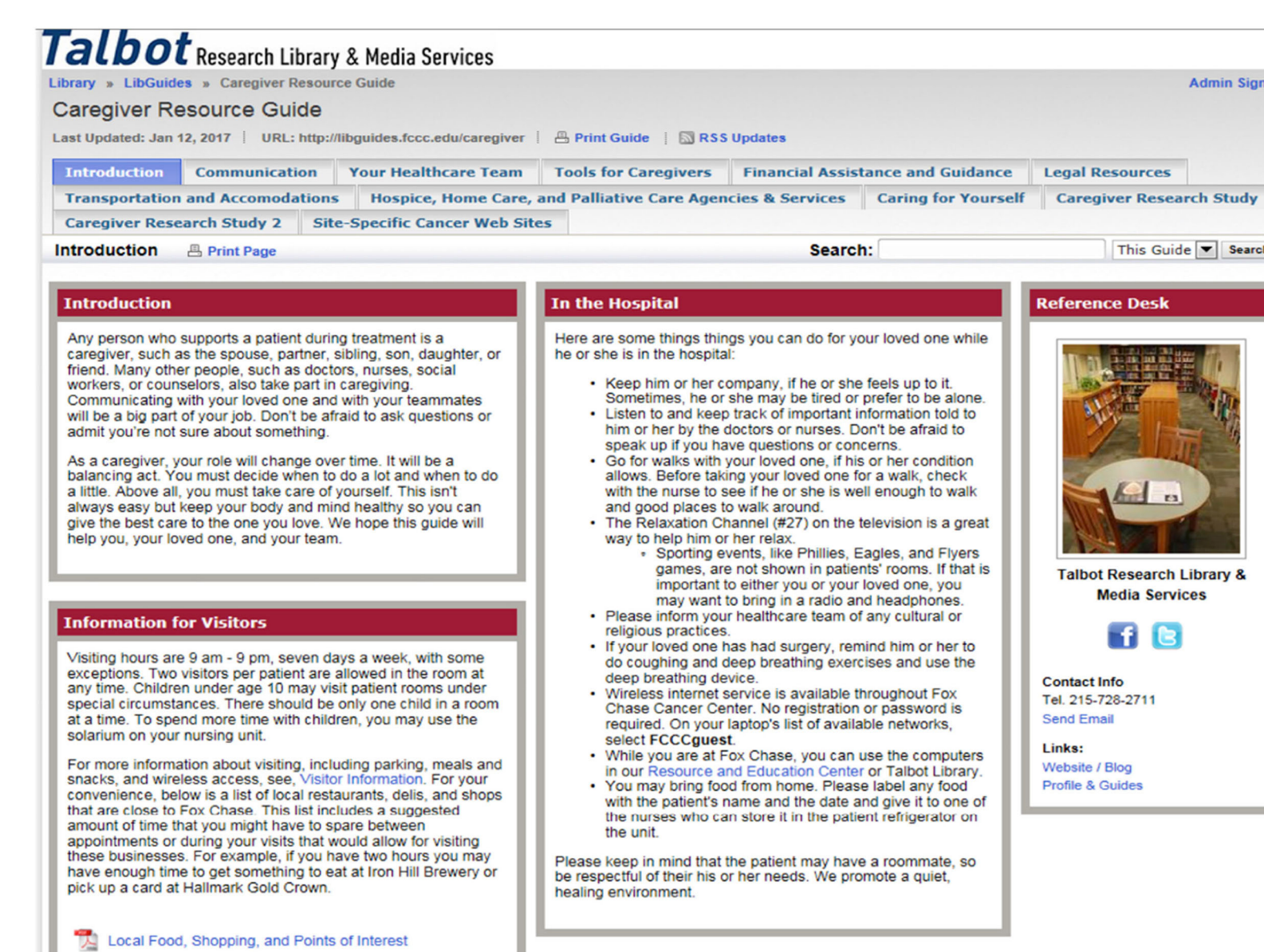
Narrative description of the findings

## RESULTS (To date - 13 caregiver interviews)

Do not use outside services – Why?	Not needed (6)
What information about outside services would be helpful?	What is available (7) Financial (3)
When is the best time to receive information about outside services and resources?	In hospital before discharge
What methods are most helpful to receive this information?	Written (5)    Verbal (4) Phone (3)    Email (3)
Is providing emotional and psychological support to the patient challenging for the caregiver? -What would help?	Yes (9)  Very individualized responses; Social work (2); Online community forum (2)
How are the caregiver’s emotional and psychological needs being addressed?	Prayer, worship, faith (4) Medication (4)
Fears that caregivers report	Being able to take care of the patient (4) Fear of the unknown (3)
Changes in the caregiver experiences and needs over time	None (3)  Some had been in the caregiver role for a short time  Very individualized responses - “Learning what cancer patients go through” “Put things in perspective” “Made me more sensitive, resilient, flexible”
Impact on caregiver’s schedule	Very individualized responses - “Everything revolves around the patient’s schedule”  “Retired so no issue” Impact on work, school, children, grandchildren
Impact on caregiver health	10 identified some impact Most frequent – stress and stress-related health problems
What can we teach nurses and other health care professionals that would help caregivers?	Communication-related (6) Take care of yourselves (2)
Do you know about the <i>Caregiver Resource Guide</i> on the Fox Chase Cancer Center website?	No (8)

## Fox Chase Cancer Center Caregiver Resource Guide

[www.foxchase.org/caregiver](http://www.foxchase.org/caregiver)



## REFERENCES

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