



# The experiences of older caregivers of cancer patients following hospital discharge

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## Abstract

**Purpose** This study addressed the experiences of older caregivers of cancer patients in the 2 weeks following a hospital discharge. It sought to understand the challenges they face in providing supportive care to patients at home.

**Methods** Qualitative descriptive interviews with a narrative approach were conducted with each caregiver at 1 and 2 weeks following the patient's discharge from the hospital. A thematic analysis approach was used to identify the themes that emerged from the caregiver interviews.

**Results** Caregivers were primarily Caucasian (77%), were mostly 68 years of age or older (62%), and were primarily caring for a spouse (69%). Three key themes emerged from the qualitative analysis: caregiver and patient wellness are connected, caregivers' struggle with control issues, and challenges in communication with health professionals.

**Conclusions** These findings highlight psychosocial changes that caregivers experience over the 2-week time period following hospital discharge. Implications include the need to identify interventions to better prepare caregivers for the post-discharge period.

**Keywords** Qualitative research · Hospital/ambulatory care · Care coordination · Caregiving · Transitions in care

## Introduction<sup>1</sup>

Caregivers are an integral part of the care system for cancer patients. Research has shown that informal caregivers (e.g.,

family members, friends) tend to be older, with the vast majority (48%) caring for their loved one at home [1]. A greater risk of mortality has been related to caregiving [2], with high levels of strain being positively associated with a greater risk of death [3]. Older caregivers specifically experience greater burden, have poorer physical health [4], and are vulnerable for various health and mental health issues, including depression, poor nutrition, and loneliness [5, 6]. Furthermore, older caregivers have reported more awareness of their future death and health issues as related to the caregiving experience [7].

Cancer caregivers may be at particular risk of adverse effects due to their involvement in providing high levels of care [8] that are often associated with high physical strain. Such tasks cover a range of care from obtaining/dispensing medication, preparing meals, and adhering to prescribed treatments, to more complex activities, such as monitoring and interpreting symptoms and side effects [9].

In addition, caregivers experience stress attributed to the stigma associated with cancer diagnoses. Cancer caregivers have reported individuals being unsure of how to interact with them or the patient, or people distancing themselves from the caregiver because they fear the patient's death and in turn their

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own mortality [10–13]. For some caregivers, dealing with patient mortality is an added stressor and area where emotional support is needed [14].

Many aspects of cancer caregivers' needs are poorly understood, including the experience of older caregivers caring for adult cancer patients at a crucial time in the care trajectory, immediately following discharge from the hospital. Understanding these needs is key, as cancer ranks fourth among illnesses associated with home caregiving, and informal caregivers tend to be older themselves, with one study showing 53% of them being 50 years of age or older [1].

The hospital discharge process is important, as cancer patients often continue to experience treatment and disease-related effects when returning home. Considering how treatment effects or symptoms persist upon discharge and the associated challenges in caregiving [15], understanding what occurs post discharge is important in informing the development of strategies to ease hospital to home transitions, and to improve caregiver and patient outcomes.

This study explored the home caregiving experiences of a sample of older informal caregivers of cancer patients in the 2 weeks following a hospital discharge. Examining this particular discharge time point is important as caregiver needs are often unmet at 1 week and persist after 2 weeks of hospital discharge [16, 17].

## Methods

### Setting and sample

Research was conducted within the solid tumor and malignant hematology inpatient units at Duke University Hospital (DUH), in Durham, North Carolina. Patients and their caregivers (defined as a “dyad”) were recruited through the following means. The patient's nurse or other health care provider was approached by the primary author (AS) and asked to inform the patient about the study and inquire if they may be interested. This step was important in reducing the possibility of coercion, as AS approaching the patients first might have made them feel obligated to participate. If interested, the patient was then approached at bedside by AS who described the study.

Eligible patients included individuals who were admitted to one of the two units for cancer treatment or treatment-related/cancer-related complications, were at least 18 years of age, had no diagnosis of cognitive impairment, and had a pending discharge to home. Eligible informal caregivers included individuals who were at least 55 years of age and were identified by the cancer patient as the primary source of assistance. As of 2015, the average age of a family caregiver in the USA was 49.2 years [1], and previous research [6] has included caregivers in this age range. By recruiting individuals 55 years of age and older, we hoped to capture the experiences of

representative caregivers. The dyad did not have to be related, but both had to be English-speaking.

### Study procedure

A qualitative descriptive design (QD) was used as it supports understanding older cancer caregivers' everyday experiences without use of “manipulation of variables, and no prior commitment to any one theoretical view of a target phenomenon” (p. 255) [18]. The QD interpretation process is “low-inference,” summarizing subject experiences in common terms (p. 335) [19], and analysis is “a rich, straight description of an experience” (§ 7) [20]. QD includes a naturalistic inquiry worldview whereby understanding is gained by observing events in their natural setting without influencing what occurs [21, 22]. Furthermore, QD design and is useful in translating findings into interventions [23].

**Data collection** Baseline data were collected at bedside prior to discharge after dyads completed the consent process. Qualitative interviews with the caregiver were completed via phone or in person at 1 and 2 weeks after the patient's discharge from the hospital. Interviews lasted from 45 min to 2 h and were digitally recorded for transcription. Table 1 provides examples of questions from each interview guide.

**Interview process** In the first interview, caregivers were prompted to share what caregiving was like for them since the patient returned home. They were also asked what could have been explained or provided to them prior to discharge to address any challenges they might be experiencing, assistance sought since returning home, and patient symptoms. In the second interview, caregivers had the opportunity to share anything that changed since their first interview and indicate what unmet needs persisted or developed.

### Analysis

The primary author (also the interviewer) transcribed 42% of the interviews, and the remaining interviews were transcribed by study personnel. Thematic analysis was implemented using processes described by Braun and Clarke and Nowell et al. [24, 25]. Two study team members completed an initial read of the transcripts and pre-coded (e.g., underlined) any statements of interest [26], thus enabling themselves to become familiar with the data [24, 25]. Then, a second read was completed and transcripts were coded using *in vivo*, descriptive, structural, and simultaneous codes [26]. Next, the individuals met to discuss what and how they coded the data, and disagreements were discussed and resolved. Although disagreements were resolved, a third team member was available if agreement was not reached. Next, each transcribed interview was imported into NVivo version 10 qualitative analysis software

**Table 1** Interview guide and exemplary questions

Interview guide	Exemplary questions
1 week post discharge	<ol style="list-style-type: none"> <li>1. What do you know now that you wished you knew when your loved one was discharged/when you returned home?</li> <li>2. What challenges in caring for your [relative/friend] have you experienced since returning home from the hospital?</li> <li>3. What could have been explained or provided to you before your [relative/friend] was discharged that would have helped you manage these challenges when you returned home?</li> <li>4. What have you learned that might help other caregivers caring for their loved one within that first week of coming home from the hospital?</li> </ol>
2 weeks post discharge	<ol style="list-style-type: none"> <li>1. How have you and your [relative/friend] been since I saw you last week? Tell me about what this week has been like for you and your [relative/friend].</li> <li>2. Has anything changed since we last spoke in regard to ...</li> <li>3. Have some things become easier in caring for your [relative/friend] this week? <ol style="list-style-type: none"> <li>a. If yes, what?</li> <li>b. Why was it easier?</li> </ol> </li> <li>4. Was anything harder in caring for your [relative/friend] this week? <ol style="list-style-type: none"> <li>a. If yes, what?</li> <li>b. Why was it harder, what exactly about that was harder?</li> </ol> </li> </ol>

[27] where coded sections of data were highlighted and identified with a node (NVivo's version of codes). Then, an NVivo report was run on each node providing output of text associated with each node. The output was reviewed to identify patterns or overlaps of codes that were then collapsed into themes [24].

**Qualitative rigor** Lincoln and Guba's elements of trustworthiness or rigor were maintained throughout the research process [21]. Three aspects addressed credibility: (1) the second interview was an opportunity to clarify any responses participants made during the first interview (member checking), (2) contacts with participants began prior to hospital discharge and included two interviews (prolonged engagement), and (3) selected aspects of the interviews were shared with the research team to solicit feedback (peer debriefing). Memos concerning ideas and questions related to data collection and analysis and based on correspondence with team members were maintained (confirmability) [28], and various iterations of the analysis process (e.g., hand coding, NVivo data files, memos) were retained (dependability) [25]. The manuscript development process incorporated thick description [21] of the data providing insight into how the findings may be transferrable to similar subpopulations of caregivers (transferability) [21, 25].

## Results

Twenty-three dyads were recruited, 7 self-withdrew or were withdrawn from the study for (1) no longer being interested in

participating ( $n = 1$ ), (2) readmission to the hospital prior to the 1-week post discharge interview ( $n = 5$ ), and (3) hospice referral at discharge ( $n = 1$ ). Of the remaining 16 caregivers, 3 did not complete the second interview as the patient was re-hospitalized. Only caregivers who completed both interviews, a total of 26 interviews, served as the basis for this analysis.

The transcript analysis yielded three key themes concerning the experience of caregivers over the post discharge time period, including (1) caregiver and patient wellness are connected, (2) caregivers' struggle with control issues, and (3) changes in communication with health professionals.

Table 2 provides characteristics of the caregivers and patients who completed the study. The mean age of caregivers was slightly higher than of patients (68.2 and 63.2, respectively), and the dyads were predominantly Caucasian. The majority of patients and caregivers had some college/a college degree or some graduate/graduate school training.

### Theme 1: caregiver and patient wellness are connected

Caregivers experienced a dynamic process of adjustment between the two interviews as there was an improvement in their emotional wellness/affect at the second interview. Often, this progress was connected to the improved health of the patient. During his first interview, Mr. F, a Caucasian 70-year-old gentleman, was asked to explain what bothered him or had been most challenging in caring for his wife. Mr. F explained:

**Table 2** Dyad descriptive data<sup>a</sup>

Variable	CG (n = 13)			PT (n = 13)		
	% (n)	Mean (SD)	Range	% (n)	Mean (SD)	Range
Female	77(10)			46(6)		
Age		68.2(7.4)	55–78		63.2(13.0)	31–78
Time caregiving (months)		28.8(52.9)	1–168			
Race						
White	77(10)			77(10)		
African American	15(2)			23(3)		
Other	8(1)			0		
Educational attainment						
Less than high school/HS/GED	15(2)			23(3)		
Some coll/trade/assoc.	24(3)			16(2)		
College degree	31(4)			15(2)		
Some grad/grad	31(4)			46(6)		
Employment status						
Full-time	8(1)			15(2)		
Not currently working	8(1)			8(1)		
Retired	77(10)			62(8)		
On disability	0			8(1)		
Other	8(1)			8(1)		
Marital status						
Never Married	0			23(3)		
Married	77(10)			69(9)		
Divorced/separated	8(1)			0		
Widowed	15(2)			8(1)		
Perceived income <sup>b</sup>						
1	0			17(2)		
2	8(1)			17(2)		
3	33(4)			8(1)		
4	58(7)			58(7)		
Relationship to patient						
Spouse	69(9)					
Sibling	8(1)					
Parent	15(2)					
Friend	8(1)					

CG caregiver, PT patient

<sup>a</sup> Only includes those caregivers who completed all interviews and are basis of qualitative data analysis; any percentages over 100 are due to rounding

<sup>b</sup> 1 = You are having difficulty paying the bills, no matter what you do, 2 = You have money to pay the bills, but only because you have cut back on things, 3 = You have enough money to pay the bills, but little spare money to buy extra or special things, 4 = After paying the bills, you still have enough money for special things you want

*I tend to walk fast like...and I can't do that all the time... she necessarily has to move slowly ...I have to wait sometimes... it's kind of frustrating for me. But I understand why it's happening and I remind myself about that.*

However, during the second interview, after being asked by the interviewer how things had been since the first interview, Mr. F appeared less frustrated and responded by describing the

improvement in his wife's physical ability, and his return to his regular pace:

*This week improved as we went along. She had a lot of fluid buildup especially in her legs. And as the week went on that finally started leaving. I could tell her energy improved... and her appetite, well it started improving...and it kept improving.*

In addition to these improvements, caregivers also began to return to a somewhat regular routine by the second interview. They reported feeling more comfortable leaving the patient at home alone to complete errands or other activities. During her first interview, Mrs. T, a 62-year-old Caucasian woman caring for her husband, was visibly distraught and frequently in tears. In addition to cancer, her husband had a perforated gall bladder that left him fairly bed bound and required Mrs. T to complete multiple health care-related tasks. Mrs. T described a “meltdown” she had the day before while trying to wash her husband:

*...the pain started really badly and he needed to go back to bed...And I was like, "You have to sit up!"...I was frustrated because I felt like he wasn't fighting hard enough to get well. He just wanted to stay in bed and sleep for 20 hours...he's always been a really strong fighter...his nickname at work was like bulldog...but he's so sick right now and I was so frustrated because I can't make him eat. I can't make him walk.*

By the second interview, Mrs. T reported a marked change in her husband, “he’s actually um, eating better- or drinking- he’s on a liquid diet. But drinking better without me having to just ask. I mean like I go in and before he’d just you know make all these faces and whatever.” Mrs. T also noted how, “a couple of the days he called me on the phone and said, ‘Okay I think I need to try to get up now.’” Her words allude to her seeing her husband’s sense of “fight” return. When asked if leaving him alone at home was something that has become easier, she reported,

*Yeah, 'cause I went to bible study... when I went to bible study it was the morning and um, so he slept in. And when I got home, then he got up and everything...So it's just 2 hours, and I'm five minutes away.*

This was a great departure from her first interview where Mrs. T reported that she would not leave him alone.

Mr. J, an African American 61-year-old man caring for his wife, reported a similar experience in terms of increased comfort with leaving his wife at home alone. During interview one, he reported

*I help her up the steps, she come down the steps, but she has a hard time going up... that's another hard thing 'cause when you look at somebody that was as active as lively as she was before this, uh, it's kind of hard to deal with her being that tired all the time and her sleeping a lot.*

Prior to the second interview, at a follow-up appointment, the oncologist and nurse urged Mr. J to get out of the house more

by stating, “you need to go and watch ballgames, so give her some space. You don’t need to be there 24/7...go to your friend’s house... You really need to do that.” This was an important moment for Mr. J who indicated, “I needed somebody to tell me that.” Mr. J heeded the advice given to him, and reported at his second interview:

*I went over to [friend's] and watch the game...it's been easier for me to not have to be here- you know that strength is coming back a little ...for instance last Tuesday and Thursday...she would stay upstairs until I got home. But I got [home] today and the door was open and she was downstairs...And when she does that- the more she exercises – it's going to bring that appetite back.*

## Theme 2: caregivers’ struggle with control issues

Caregivers often discussed issues related to recognizing a lack of control over the disease and its ultimate outcome. While this was frustrating, their responses indicated they learned one controllable aspect—their reaction to the patient’s illness. Understanding they were in control of their reaction helped caregivers accept not having control over what might happen to the patient—death or remission. As stated by Mr. S, a Caucasian 76-year-old man caring for his wife,

*[You] come to the realization that a) uh there comes an end of everything, and b) uh, you don't have control over it, and c) the best thing that you can do for your loved one is uh make sure that they enjoy every moment they can.*

Caregivers generally had a routine in place at home for the patient’s care by the second interview, again illustrating that home cancer caregiving is a dynamic process over the 2-week post discharge period. This included activities such as managing medications and cancer-related symptoms. During her second interview, Mrs. P, a 55-year-old Caucasian female caring for her husband, indicated that in addition to her husband’s pain decreasing, she along with her sister, had a “system” in place. Mrs. P explained, “We’ve got a system down better...we coordinate- who sleeps, who goes to bed. We did the drugs together- so now she [sister] knows them... You know it's not so- it's not so frantic.”

Some caregivers came to various conclusions about the lack of control over the cancer and acceptance of it over the course of one interview. Mrs. Y, a 70-year-old African American female caring for her husband, provided a metaphor for what it was like to deal with cancer during her second interview,

*I think that's what wears most caregivers down is the fact that they, um, that it's a long-term thing for a lot of*



*people- not everybody, but in my case, it's a long-term thing. And after a while you know- it gets very um, tiring... 'Cause it's like you're ... just walking in place, you can't [go] forward, you can't go back.*

When asked how one moves forward, Mrs. Y replied, “You don’t, because you can’t. There’s too many unknowns. Anytime you got this many unknowns it’s no way for you to move forward. Because if you do- you’re going to probably be disappointed.” At the end of her first interview, Mrs. Y explained another viewpoint on her husband’s illness:

*You kinda get used to what you need to do. And you have some semblance of how to get it done. So, you feel a little more comfortable ... you feel just a little bit more in control than you do when you first get that diagnosis. It seems like things start to clear up a little bit ...eventually you just accept it and just you know, try to figure out how you can juggle all these things to the best of your ability.*

### **Theme 3: challenges in communication with health professionals**

Some of the caregivers discussed issues related to communicating with health professionals (e.g., not knowing what questions to ask). To address this, some caregivers altered the way they communicated so they could more effectively manage and understand the illness. This theme reinforces the dynamic nature of caregivers’ adjustment over time, showing the growth in either their own ability to communicate their needs, questions, or concerns to health professionals or their reliance on a chosen proxy to do so.

For example, Mrs. X, a Caucasian 78-year-old female caring for her spouse, explained during her first interview that she had trouble accessing medical information. During her first interview, she explained,

*They know so much and a little bit above my head and so I try to listen but now I have to depend on my daughter, she asks things... I need to talk to a doctor more...I need to ask more questions. I really do, because I have not. Now this surgeon ...to find out whether that was malignant, the surgeon drilled a hole...in top of his head and went in there and got a biopsy and found out it was malignant. But I thought that was, that was kinda drastic.*

During her second interview, Mrs. X explained further about why she does not feel comfortable asking questions. She stated,

*I don't know as much about what they're doin' maybe as I should, so I think I need to ask more questions but I just think they are so educated and well, maybe I don't know, you know, what I'm talkin' about...And maybe I'd say I don't think I'm educated enough. But you know, you don't want to sound dumb.*

While she mentioned she depends on her daughter at times during the first interview, her dependence became more apparent during the second interview: “[Daughter] is always there when we go in...she always gets off from work. So, I’m dependin’ on her which I don’t know whether I should because I’m there more than she is...But anyway, I just, I guess I just leave it to her.” While Mrs. X was still questioning her reliance on her daughter at the second interview, she seemed more comfortable with having her daughter ask all necessary questions.

Care coordination issues were also expressed by some, along with concern about how it could negatively impact patient health and recovery. For example, although prescriptions are provided to patients prior to discharge, getting them filled immediately at their local pharmacy could be challenging. As described by Mrs. P (discussed earlier),

*We came home with all the prescriptions and I took him to the drugstore because that's where we filled them last week. They didn't have any of those drugs....so the pain pills that he needs, the morphine, I don't have enough between over the weekend, so I am jerking around the other medication that he's got to cover it. Because I've called all the Walgreens drug stores... only way to get this stuff is that when you're over at the Cancer Center, is to go to their pharmacy because they carry it all, but no one explained that to me.*

As a result, Mrs. P initially gave him medications she uses for her own chronic illness. This type of response adds risk for the patient and, in this case, was ultimately ineffective. By the second interview, she reported that the pain had been so bad that her husband had to have a pain pump implanted.

In addition, while several patients received home health care following discharge, some caregivers did not understand what this service was supposed to provide and were upset when the visits did not occur. Mrs. Q, a Caucasian 68-year-old female caring for her friend, explained during the first interview that a home health nurse was supposed to come and change her friend’s bandages. However, no one had come yet. When Mrs. Q mentioned this at a doctor’s appointment, she was told that “they didn’t order it. And so, when the girl came out for physical therapy today she ordered it. She called the [Dr. name] office, so that was that slack with [Dr. Name] office.” At the second interview, the issue had not yet been resolved. Mrs. Q said,

*I know we see like one nurse and one P.A. and [Doctor's name]. So, I don't know who's ordering what and who's not in there, and what is said. But Monday I'm gonna say, "Look, they sent all the sterile stuff for the home health nurse to change the bandages. We've got the proof, we've got the box it came from...Now we want the nurse to come" ...we'll see, come Monday...If not, I think I'm gonna scream a little bit.*

Her response during the second week interview showed that Mrs. Q felt more empowered to voice her frustration that post discharge care was not going as planned, specifically the home health support.

## Discussion

Findings from this study provide more detailed information about the experience of cancer caregivers during the hospital-to-home discharge phase. We found that caregiver emotional health can be closely tied to the patient's physical health. While some studies show negative impacts on caregivers' health and mental health [29, 30], we identified positive impacts for some participants: improvement in a patient's health appeared to be associated with improvements in the caregiver's well-being. This finding is supported by previous studies using quantitative methods that show how patient health is positively associated with caregiver well-being and health [31–34], and how the dyad's influence on one another is reciprocal [35]. The use of qualitative methods facilitated a greater understanding of the associations between patient and caregiver emotional health. Knowing that the dyad's mental health/health is reciprocal [35], a continued focus on supporting caregiver self-care is important, as they may ignore their own needs [36–39], which in turn may impact the patient.

A second important finding relates to caregivers feeling a loss of control since they cannot impact the patient's cancer diagnosis. We found that caregivers' acceptance of the lack of control was somewhat ameliorated when they realized they could control their reaction to the patient's illness. Based on the experiences presented, the 2-week post-discharge time point is important in a caregiver's ability to regain some sense of control and demonstrates their ability to control one aspect in an uncontrollable situation. Additional research investigating existing interventions that are effective in supporting caregivers cope with feelings of control is warranted.

Finally, this study reinforced previous literature related to the challenges of communication between health care professionals, patients, and their family members [40–42]. Of particular concern is the potential for negative patient outcomes related to communication issues, particularly those associated with medication use and home health services.

## Limitations and future research

Despite enhancing our understanding of the experiences of older cancer caregivers, there were several factors that were unaccounted for that could have affected caregiver experiences, including formal in-home assistance, length of time caregiving, caregiver sex, dyad type socioeconomic status, and whether this was the first-time caregiving. The last factor may have differentially impacted experiences as caregivers' ability to adapt to the patient's illness trajectory may be related to caregiving knowledge gained during prior pre- and post-hospitalization periods. In addition, our dyadic sample was predominantly white and well educated, and findings may differ among a more diverse sample. Future research should purposively sample caregivers to account for these factors.

## Conclusion

Our findings provide a detailed and rich description of the experiences of older cancer caregivers following hospital discharge, while supplementing the quantitative literature on this topic. The experiences presented here open a dialog about how services provided to caregivers can be improved upon and expanded to increase both their quality of life and that of the person they care for in the community setting.

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## Compliance with ethical standards

**Ethical approval** All procedures performed in the study involving human participants was in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**IRB approval** Approval from the DUH Institutional Review Board was obtained prior to study commencement.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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