Family caregivers voice their needs:
A photovoice study

JENNIFER ANGELO, PH.D., O.T.R./L., N.Z.R.O.T.,[1] AND RICHARD EGAN, PH.D.[2]

[1]Otago Community Hospice, Dunedin, New Zealand, and School of Physiotherapy, Division of Health Sciences, University of Otago, Otago, New Zealand
[2]Cancer Society Social and Behavioural Research Unit, Te Hunga Rangahau Ārai Mate Pukupuku, Department of Preventive and Social Medicine, University of Otago Medical School, Dunedin, New Zealand

ABSTRACT

Objective: Caregivers often are unprepared for their role yet serve as the frontline in the provision of palliative care services. The aim of our study was to explore family caregivers' experiences from their perspective as they cared for dying relatives.

Method: Using the Photovoice methodology, ten unpaid family caregivers took photographs depicting issues they experienced as informal caregivers of an ill family member who had less than a year to live. Each participant met with the first author individually four to six times and explained their role as caregiver through photographs and stories.

Results: The results were clustered into seven themes: physical demands, emotional/spiritual stress, preparing for the future, securing help, medication management, navigating the agencies, and relationships.

Significance of results: Caregivers perform a variety of tasks, often under stress. This study highlights the main areas where problems lie and the areas that palliative care health professionals need to be aware of so they can assist and educate caregivers, with the goal of finding solutions to the burdens of care. The themes were found to be intertwined, showing the complexity of the caregiving role.

KEYWORDS: Caregivers, Family support, Palliative care, Photovoice

INTRODUCTION

Palliative care services rely on family members to provide for the practical, day-to-day needs of ill relatives. Family members who become informal caregivers are considered to be the "frontline of primary care" (Milligan, 2006). In Canada, family caregivers provide 80 to 90% of care in home settings (Romanow, 2002). In Australia, family caregivers outnumber paid care providers five to one (Australia Institute of Health and Welfare, 2003). Cares Australia estimates that, if formal care were substituted for family-provided informal care, the cost would be $40 billion (Carers Australia, 2010). In the United Kingdom, approximately 6.4 million people over the age of 65 years provide care (Age UK, 2011). In New Zealand, there are approximately 419,300 informal caregivers (Ministry of Business Innovation and Employment, 2010), and in the United States, more than 50 million Americans annually care for a family member (Stambor, 2006). Informal caregivers are the backbone of social care delivery (Stajduhar et al., 2010). Services are moving toward outpatient care, which means increased involvement for family caregivers (Aoun et al., 2005; Grande & Ewing, 2008).

Informal caregivers are often unprepared for the multiple and varied tasks of tending to family members with life-limiting illnesses (Andershed, 2006; Linderholm & Friedrichsen, 2010). Responsibilities can include independently handling complex medical procedures, performing demanding physical tasks, managing finances, advocating for the patient,

Address correspondence and reprint requests to: Jennifer Angelo, Otago Community Hospice, 293 North Road, North East Valley, Dunedin 9010, New Zealand. E-mail: jangelo@jangelo.com

making decisions, providing emotional support, and coordinating care (Stajduhar et al., 2008). The conclusions of many studies have shown that informal caregivers feel unprepared and desire more support, guidance, and information (Bevan & Pecchioni, 2008; Hudson, Aranda, & McMurray, 2002; Morris & Thomas, 2002).

During this time, family members experience increased stress levels and physical ailments, demonstrating how they have unmet needs (Barazzetti et al., 2010; Empeno, 2013; Tsigaroppoulos et al., 2009). Collectively, studies have confirmed that providing sufficient information is critical to meeting informal caregivers' needs and assisting families through this stressful time. Recent research concluded that group education was an effective way of supporting informal caregivers (Applebaum & Breitbart, 2013; Hudson & Aranda, 2013; Hudson et al., 2005; 2013). Further, a Cochrane report noted that providing community care services, including caregiver education, was beneficial in allowing patients to die at home, if that was their choice (Gomes et al., 2013). Providing sufficient information appears to be a key to increasing comfort levels and reducing anxiety levels (Broback & Bertero, 2003; Cain et al., 2004; Demiris et al., 2009; Elde, 1986; Henriksson & Årestedt, 2013; Kessler et al., 2005).

Research groups have acknowledged the need for extensive work in this area. According to the National Institutes of Health State-of-the-Science Conference (NIH, 2004), there is a paucity of research that comprehensively defines the needs of informal caregivers. At the International Symposium on Supportive, Palliative, and End-of-Life Care, Hagen and colleagues (2006) described approaches employed in Canada, the United Kingdom, and the United States. Symposium research attendees from all three countries recognized the need for research in the family/informal caregiver support category. Information was seen as key to supporting families and identifying families at risk for adverse health and emotional/spiritual consequences. But what information do caregivers want? What do caregivers say their needs are?

Findings in other studies have focused on the need for education in the areas of handling unfamiliar or new tasks so that informal caregivers perform these tasks without increasing their stress levels while simultaneously maintaining their own health. Sekelja and coworkers (2010) and Tsigaroppoulos and colleagues (2009) noted that families appreciated receiving practical help and solutions when handling difficult tasks. Tamayo and colleagues (2010) found that informal caregivers wanted better communication in the areas of symptom management and medication administration. Further, those who pre-pared for grief were more likely to feel in control and ready to handle it (Rando, 1986; Lin & Tsao, 2004).

These findings point to the need for education. Education empowers caregivers and helps them better fulfill their roles (Broback & Bertero, 2003). Collectively, the studies discussed above confirm that providing sufficient information is critical to meeting informal caregivers' needs and assisting families through this stressful time.

Authors' Statements

The authors drew conclusions from primary data and literature; however, they recognize that their backgrounds inevitably influenced this work. The first author grew up in the United States, where 10 years ago her mother utilized hospice services. She has been trained in occupational therapy and educational psychology. She emigrated to New Zealand in 2009 and works in a hospice. The second author is a *pakeha* (European New Zealander), middle-aged male with training in theology, education, public health, and health promotion. For this study, both authors come from the background of the stance of a naïve observer (Pillow, 2003).

Aim

The aim of our study was to explore family caregivers' experiences from their perspective as they cared for their dying relatives.

METHOD

Research Design

We selected a methodology that would enable caregivers to develop their own voice and stories around their experiences. Photovoice, a participatory method, fit the criterion of allowing caregivers to speak freely about their role. Participatory methods can help researchers create knowledge that is more closely centered on the experiences of individuals with illness and disability (Letts, 2003). Further, it creates a partnership between researcher and participants (Lal et al., 2012). It enabled participants to show and describe their contexts, providing relevant information as to the issues caregivers face (Andonian & MacRae, 2011).

We employed Photovoice (Wang & Burris, 1997), a qualitative research method in which participants are given cameras to take photographs representing the topic under investigation. A narrative analysis approach, Photovoice provides rich insight into first-hand experiences and allows for exploration from various angles (Bingley & Clark, 2008). Visual data

alone may be difficult to interpret; however, when explained through stories, the visual images reflect the realities and experiences the participants face (Harper, 2002). The visual data compel participants to reflect on and discern their own perspectives (Gold, 2004). Further, this type of methodology allows participants, rather than the researcher, to determine both the subject and meaning of a photograph (Carlsson, 2001; Hurworth, 2003; Radley & Taylor, 2003).

Photovoice was a useful tool in the current study because the informal home caregivers were alone much of the time when stressful situations arose. Using the camera, they captured the situations in photographs and later recalled the related stories. They were able to illustrate their experiences, speak freely about their concerns, introduce issues, and communicate their experiences. Participants photographed objects and situations depicting their tasks and concerns and later discussed them with the first author. This allowed for many aspects of the informal caregiver role to emerge. The method helped capture concerns that may have been previously overlooked, ignored, or not conceptualized, yet were integral to the informal caregiver's well-being. Photovoice provided an insider's perspective. This "insider's view" has been successfully used to uncover areas unrecognized in other investigations (Marshall & Rossman, 1999). The insider's perspective can be seen in investigations of such things as the activities of the elderly (Mahood et al., 2012; Rush et al., 2012), problems faced by homeless women (Bukowski & Buetow, 2011), and the outlook of cancer survivors (Yi & Zebrack, 2010). The current authors believe that this is the first time Photovoice has been used with caregivers.

Participants

Each informal caregiver was over the age of 18, lived with the ill family member, and was the main person responsible for care of the ill person within the home. The person being cared for had a terminal illness, was predicted to live less than a year, and was enrolled in the Otago Community Hospice (Dunedin, New Zealand). Hospice community coordinators serving the local urban/suburban community recruited informal caregivers. The study sample consisted of a convenience sample of 10 caregivers. Some 12 caregivers were approached. The first 10 potential participants who agreed to participate were accepted into the study. After an explanation of the study, two caregivers chose not to participate. Both reported that they wanted to concentrate on traveling and living as the ill family member's health permitted. Living to these two caregivers meant participating in recreational and social activities. They realized that participating in our project could help them reflect and contemplate their current situation, but they chose to spend their time pursuing other options. They were thanked for their interest.

Ethics approval was obtained from the Lower South Ethics Committee (Health and Disability Services Policy Group, the Population Health Directorate, and the Ministry of Health). We employed pseudonyms for all participant names to protect confidentiality.

Data Collection

Six sessions were initially to be conducted in two focus groups of five participants each. However, 8 of the 10 participants felt uncomfortable leaving their family member unattended or with a volunteer. Therefore, data collection procedures were modified. The first author met eight of the participants privately in their homes, with all other family members in other rooms out of hearing range. The ninth participant's husband rested on the couch during sessions without making comments. The first author met with the tenth participant in a coffee shop of their choosing. The acoustics of the selected shop allowed for private conversation. All participants took part in five or six sessions, except for one caregiver who died after session four. See Figure 1 for a study flowchart.
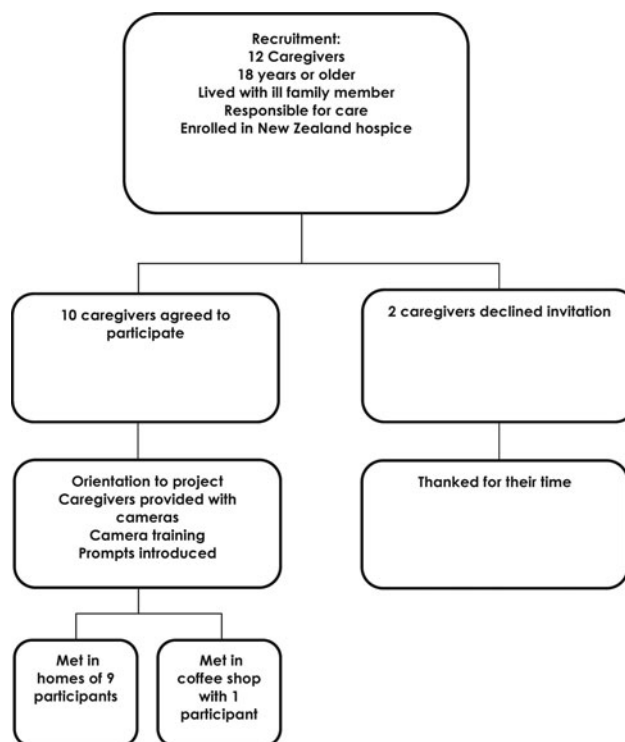

Fig. 1. Study flowchart.

During the orientation session, the first author explained the purpose of the study, showed examples of the types of photographs being sought, gave a tutorial on digital camera operation and shot composition, and answered all questions.

At the end of the orientation session, a prompt was given to guide participants as to the type of information the authors were interested in learning. A prompt was given at the end of subsequent sessions as inspiration for the following week's pictures. Prompts to help participants understand the nature of the project and what was being asked of them were developed (Rose, 1996; Wang, 1999). The prompts were: (1) take photos of things that show what your life is like; (2) take photos of things that concern you; (3) take photos of tasks you do now that you didn't used to do; (4) take photos that show how you are feeling; and (5) take photos that show what you will be doing when all this is over (i.e., after the relative died). It was made clear to participants that they were free to use or ignore the prompts, and they were encouraged to introduce new topics. At the beginning of each session, the pictures taken since the previous sessions were downloaded to a computer. The participant and first author viewed each photograph while the participant told the accompanying story. Interviews were digitally recorded.

Data Analysis

All interviews were transcribed and checked for accuracy of transcription. They were analyzed using Atlas.ti (2009). Interrater reliability was achieved by having the authors and two occupational therapists with graduate degrees each read through three of the interviews and code them. A coding scheme was developed with agreement consistent or variances resolved. Similarly, the authors and two occupational therapists independently reviewed the codes and developed themes. Data were grouped into meaningful patterns so as to the understand major and minor themes that ran through the transcripts.

Analysis followed a "generic qualitative research" process (Caelli et al., 2003). A growing number of studies employ generic approaches, particularly in applied research. Thus, the process included reflexive thinking, transcribing, coding, developing themes, and extracting quotes to support the themes.

RESULTS

Participants

Ten New Zealand European informal caregivers who were caring for family members with less than a year to live participated in our study. Ten participants were chosen because the number matched the available resources (e.g., cameras); provided sufficiently rich data to explore research needs; and reached saturation within the sample frame. Participants' names have been changed to protect their anonymity. Participant demographics are reported in Table 1.

The participants produced 961 photographs and shared them with the first author during 51 individual interviews lasting from 50 to 90 minutes each. Seven themes emerged (Table 2).

Physical Demands

Tasks described under the physical demands category were preparing meals, addressing personal hygiene (toileting, showering, and washing bed linens), performing household chores, and using technology to assist with tasks. Female participants described how they managed tasks that they were physically unable to accomplish. For example, one female participant described the physical demands of stacking wood, a point illustrated by a photograph of firewood in a jumbled pile on the front lawn and a photograph of firewood neatly stacked against a fence:

> Neil used to stack all the wood, and he can't do it anymore. So we have a boy who comes up after school, and he stacks it for a few dollars and a Pavlova [a New Zealand dessert]. —Lesley, age 59

Moving heavy trash bags to the curb on collection day was another physical demand that a female

Table 1. *Caregiver demographics*

Gender	Ethnicity	Age	Education	Occupation	Relationship	Diagnosis of Patient
8 females	New Zealand Europeans	Range: 30–80 years	7 high school	6 retired	7 spouses	8 cancer
2 males		Mean: 57 years	3 tertiary or university degree	3 working part time (1 on leave) 1 university student	3 daughters	1 chronic obstructive pulmonary disease 1 kidney failure

Table 2. *Themes*

Themes	Number of Times Coded
Physical demands	75
Emotional/spiritual stress	70
Preparing for the future	61
Securing help	54
Medication management	51
Navigating the agencies	48
Relationships	44

participant described. She photographed a home-made dolly on wheels:

> I've got a frame out there; my brother made it for my father. He had arthritis. So I've now got this wee frame. It was made from a rim of a car. It's got two wee wheels and a wee handle. So I put my recycle bin on it and my rubbish and wheel it out. —Donna, age 55

Emotional/Spiritual Stress

Topics under the emotional/spiritual domain centered on emotional stress. Emotional and spiritual concerns were combined because their differences were not clearly discernible. Contemporary mental health definitions (Keleher & Armstrong, 2005; Lindridge, 2007) justify combining these themes, and findings on spirituality's correlations with and contributions to other domains of human wellness are increasingly reported in the literature of the social and behavioral sciences and the health-related professions (Moberg, 2002). Situations that caused stress ranged from the small amounts of food the ill family member was eating to which medical service to call or visit when new symptoms emerged (the general practitioner, the oncologist, the hospice physician, or the hospital's emergency department). Much of the time, caregivers grappled with these situations under duress (e.g., when the family member had uncontrolled pain or was experiencing breathlessness or the caregiver was in a sleep-deprived state).

The following story illustrates an emotionally stressful situation. The accompanying photograph was of the caregiver's husband sitting in the car with his seatbelt on, a water bottle nestled between his thighs:

> His breathing is getting worse. We went out to the school sports in [a nearby town] on Wednesday, and he had two breathing attacks. I thought he was all right, so I sent him inside [upon returning home],

and I said, "I'll get the mail." And he had a really bad breathing attack, and was panicking when I came inside, and he'd wet everywhere. The doctor came yesterday and gave him a morphine spray and some more tablets. The district nurse is going to come to talk to him about the incontinence. Last night, he said he realized it was getting harder. —Deborah, age 55

Participants also mentioned lack of sleep, as in the following transcription excerpt:

> The hard part is the lack of sleep. Sometimes in the middle of the night you have an "oopsie" [bowel movement]. So in the middle of the night you get up, and you change the sheets, and you take the blankets off. You then have to work out how you are going to clean the blanket. The last couple of nights I haven't gotten a lot of sleep. One night she had breathing difficulty. Rest—rest is paramount for her, and for me to get enough rest would be good, but it is easier said than done. That's what life is about, and a whole night's sleep is not part of it. —Tom, age 65

Participants also discussed the ill family member's loss of appetite, a state that caused caregivers emotional stress:

> Like when my wife wasn't eating. You feel you should be doing something. If they don't eat, they don't (. . .) you know, they'll lose strength, they'll lose weight. It's difficult to keep your hand out of that and say well, you know. You've got to. It's difficult to find that balance. To encourage, but not to push. —Andrew, age 66

Participants' spiritual needs were expressed through individual and inclusive activities that suggested the ways they found meaning in their lives. Some enjoyed playing bowls (a sport similar to the Italian game of bocce) with friends, walking along the beach, or working in their gardens, or, for example, taking a picture of her potted plants next to a fence. One participant reported,

> I like being outside on a nice day. It's therapeutic, and I suppose it's a sense of it [the garden] looking nice when it was messy to start with and then you think, Oh, that's better. —Tina, age 55

Preparing for the Future

Regarding future plans, five participants looked at the future as an opportunity to travel. Traveling was seen as an activity that they were delaying while

in the role of caregiver but looked forward to pursuing once their responsibilities were completed. The other five participants had no specific plans for the future.

Securing Help

All participants mentioned securing help, illustrating that assistance from others was a significant concern. Four had successful experiences, but six had difficulty either asking for help or accepting offers of help. One participant described her resistance to accepting help and finally accepting it, illustrated by a photo of a sawed-off tree trunk:

> Friends of mine told me, "Look, Patricia, you've got to accept help." Because I just wasn't. And then a friend texted me, "I've got my chainsaw; I'll be coming around. What can I do?" That kind of help is great. And you say, "Well, I'd love this tree trunk chopped down." Half of the garden was dead and the trestle had fallen over. On Saturday, my friend with the chainsaw arrived with a whole lot of people. They just arrived. I burst into tears. It was lovely. —Patricia, age 47

The brothers of two female participants wanted their fathers to be placed in nursing homes. The sisters (the participants) understood that caring for and living with their fathers meant they were going against their brothers' wishes:

> My brother said, "We will do what we [he and his wife] can do, but we cannot do what you do. And if your husband comes down and you need to ask for help, then Dad will go into a rest home." I took the information in and thought, How can I ever ask for help? The whole reason I'm here is so Dad is not in a rest home. I rung my brother back just to confirm what I'd heard. So I said, "Thank you for saying that you can't commit to the level I've committed, and you can't—including your wife—do what I do. And if I need help from 5:00 Friday to 7:00 Sunday, Dad will have to go into a home." And he said, "Yes. That would be the bottom line." —Fiona, age 55

Both participants were resolute in their actions. They would care for their fathers, despite limited emotional and physical support from their brothers.

Medication Management

Caregivers spent time managing several aspects of medications. Participants described increased visits to the pharmacist and frustrations when the pharmacist did not have their entire order ready, meaning additional trips. Donna took a photo of medication bottles and a pillbox she was filling:

> Today, I just finished doing that for the whole week. So I keep all the pills in the box and then put them into individual days of the week, and then it is done for the whole week. Because he has so many to take. That is what that photo is about. —Donna, age 55

The simplicity of Donna's quote demonstrated that the depth of feeling and desire to stay on top of the medication regime become part of the everyday caregiver experience.

Navigating Agencies

All participants discussed government benefits for which they or their family member might be entitled. One participant described the Work and Income New Zealand (WINZ) sickness benefit, which her husband was entitled to due to a life-threatening heart condition. WINZ paid for this particular participant's phone line. The phone was considered essential in case the patient needed immediate medical attention. Another participant applied for and received funding for a nebulizer to ease her husband's breathing.

Two participants noted that filling out the paperwork was laborious. Another participant, whose husband needed a ramp into his house, realized it would take more than a year for the work to be completed using the public system. She and her sons, who were familiar with woodworking jobs, decided to fund and complete the task themselves rather than wait for a government subsidy.

Relationships

The relationships category included all discussions concerning families, friends, and health professionals. One participant found that his wife's declining health meant she could no longer engage with their grandchildren:

> Suddenly, grandchildren who were the sole focus of our lives, it's no longer that way. And they have to adjust to that. "Can we go see Nanny now?" No, you can't see Nanny at the moment. Maybe later on. Suddenly it's very hard for them as well. Nanny just lived for the grandchildren, and now Nanny can't cope with the grandchildren. That is quite a stressful part of our lives. —Tom, age 65

Another participant developed new ways to connect with friends and family.

I have a friend I meet up with. And three of the ladies [from church], we went out to lunch. That's probably why I'm putting on weight: too many lunches and coffees. These are people outside my own family. And, of course, we have a routine going there, too. The kids come out every Thursday night and I cook. It's automatic. We know it is going to happen every Thursday, unless we have an earthquake. —Gary, age 68

Patricia, who was caring for her husband, used a photograph of a three-dimensional artwork of intertwining ribbons to discuss concerns about the interconnections of refusing help from her mother and the relationship with her mother:

This is a piece of artwork in the hospital entrance. It's the whole burdensome thing, really. It's the twisty bits in it. And life is quite burdensome a lot of the time. There are so many parts to it all. It's the hospital system. It's dealing with my family and my mother and her wanting to help but not knowing how to help and instead of just arriving saying, "Here I am, what can I do?" wanting to know what it is that she should do before she comes. And finding that too difficult to deal with, saying to her, "No, everything is fine," when it is not at all fine. And so she does not get a true picture of what is going on. —Patricia, age 47

All participants spoke of family and friends, who were part of their normal interactions, either face to face or through phone calls and email messages. Participants found these interactions either helpful and strengthening or stressful. The photographs and stories demonstrated concern, support, and the complexities and stresses involved in relationships.

DISCUSSION

Our study was undertaken to identify informal caregivers' concerns about caregiving from their point of view. The results were grouped into seven themes: physical demands, emotional/spiritual stress, preparing for the future, securing help, medication management, navigating the agencies, and relationships.

Physical Demands

Physical demands generated a great deal of concern. Female participants spent time in problem solving ways to finish jobs they were not physically strong enough to complete. For instance, Deborah began carrying the trash cans to the curb when her husband could no longer manage this weekly task. However, the cans were too heavy for her to carry. In her garage, she found a dolly with wheels, a device her brother had made years earlier. Using this device, she effortlessly wheeled the cans to the curb. For weeks, she lifted the heavy cans and suffered from sore arms and back before realizing the solution was in the back of the garage. For Lesley, the solution for having her wood chopped and stacked was bartering. She used a small portion of her personal funds and then used her baking skills to make up the difference.

Our results confirmed the findings of other studies. Physical demands are burdensome for caregivers (Emlet, 1996; Ferrario et al., 2004; Given et al., 2011). The burdens listed were fatigue, tiredness, exhaustion, poor health, and decreased time for rest. Formal training has been shown to help reduce these burdens (Donelan et al., 2002; Hudson et al., 2005). Grande and Ewing (2009) suggested that respite can be beneficial. However, Ingleton and colleagues (2003) noted that there is no clear evidence to support that rest reduces caregiver burden or improves mental health. Studies have been imprecise as to the implementation stage to reduce the burden of physical demands. Education might provide a solution. In one review paper, Applebaum and Breitbart (2013) found that interventions— which included components of psychoeducation, communication training, education regarding cancer treatments, problem solving, and coping skill training—had lower attrition rates. One conclusion was that the participants benefited from the sessions. Listening to caregiver problems and brainstorming potential solutions may help decrease the burdens caregivers feel—like using the trolley stored in the back of the garage or using one's cooking skills to bake a Pavlova.

Emotional/Spiritual Stress

Our findings confirm the findings of other studies on the emotional burden placed on caregivers (Applebaum et al., 2013; Hopkinson et al., 2012; Hudson & Aranda, 2013; Moore et al., 2013; Northouse et al., 2012). In our study, emotional toll was related to several situations. For example, caregivers suffered sleep deprivation due to getting up one or more times at night to manage the needs of the ill family member. Another stress was related to observing and monitoring the general decline of a patient's health and the decreasing number of activities in which they could participate. Watching a relative lose the ability to perform tasks can cause emotional pain (Beach et al., 2000; Harding et al., 2012). Another area that caused stress for participants in our study was watching the family member lose interest in food and lose weight. This stress

related to reduced food intake was confirmed by the findings of Hirdes and coworkers (2012). Similarly, Stajduhar and colleagues (2010) reported that the majority of quantitative studies found moderate to high levels of emotional/psychological stress. Funk and coworkers (2010) reached the same conclusion when reviewing qualitative studies. Caregivers certainly suffer from increased emotional turmoil and stress.

It is acknowledged by the current authors that the emotional/spiritual theme is strongly interconnected with the relationship theme. Due to the emotional tone of the stories and the stress involved, the authors placed these stories under the rubric of the emotional theme.

Securing Help

A major worry after emotional/spiritual concerns focused on securing help from others, which fell into two categories: being reticent to ask for help when needed and being reluctant to accept help when offered. The reluctance of caregivers to accept help has been reported in other studies. The National Alliance for Caregiving (2004) noted that relying on others was seen as a loss of independence. Tang (2009) found that caregivers were reluctant to ask for help despite having friends. No further explanation was provided for this phenomenon.

The current Photovoice study revealed various reasons and motivations for caregivers' reluctance to ask for help despite their burdens and challenges. Some participants ignored the need for help to avoid additional stress, while others ignored the need to prevent increasing tension among family members. Further, asking for assistance may have added a new dimension to an already complex, stressful life.

Two female participants asked their brothers for help. The brothers wanted the fathers to live out their remaining days in a nursing home. The two female participants wanted to care for their fathers themselves, but they also desired support from their brothers. This support was not forthcoming. The two female participants faced the complexity of caring for dying fathers at home while simultaneously navigating through sensitive family dynamics. They were on their own while caring for their fathers. Fiona had to promise her brother that, if she needed support, she needed to call New Zealand's emergency telephone number or put their father in a nursing home. The brothers in these two instances appeared emotionally detached. However, the circumstances that lay behind their actions were unknown.

The two female participants were satisfied with their decisions, yet they knew they did not have family assistance, should they need it. Plans should be in place at the beginning of the caring role for a second caregiver (Angelo et al., 2013). In this way, when the primary caregiver needs a break, requires respite, or becomes incapacitated, a second caregiver is ready to step up.

In Patricia's situation, her need for help with her overgrown garden was caught in a web of concerns that were difficult to separate. Initially, it was easier for Patricia to ignore her garden rather than organize a work party: "I find it too difficult to deal with, so I end up saying everything is fine when everything is not fine." However, in her particular case, her friends stepped in to help despite her protests.

Another common reason for not requesting help was the tension it caused between caregivers and patients. One participant wanted the fence painted but would not ask anyone to paint it because that was her husband's job. Asking for help would have called attention to her husband's declining health. Ignoring the fence caused less stress than addressing the fence's poor condition.

Although asking for assistance can be psychologically difficult, it is essential that caregivers, already burdened with tasks, learn how to ask for help. Asking and receiving help can relieve some caregiver burden and assist them with continuing in their primary role: looking after the ill family member. "More than a million: Understanding the UK's carers of people with cancer" (Ipsos MORI & Macmillan Cancer Support, 2011) reported that the most frequent support comes from family (44%) or friends (28%).

When asking family members for assistance is not possible, as seen with two of the female participants in our study, health professionals can educate caregivers by helping them identify other resources, such as friends or neighbors. Health professionals can also provide information on volunteer organizations that can assist. Social workers can educate caregivers as to which government agencies can provide financial assistance.

Caregivers may need education on how to tap into community resources. Caregiver fatigue may obscure the ability to identify where support might come from—that is, family, friends, or church groups. They may need assistance with learning how to ask or allowing friends to help. Health professionals can help caregivers strategize, identify others who could help, and assist in putting a plan into place. Caregivers could receive such help as asking someone to fill in during a weekly afternoon off, having someone come in on a regular basis to clean or cook, or organizing a week's respite for the ill family member in a nursing home.

Medication Management

Participants in our study worried about giving the medications in the prescribed amounts at the correct

time. If a family member was in pain, participants wanted to be sure they administered the correct dosage. They also wanted to know what to do if they gave an incorrect dosage. Other medication issues they were constantly monitoring included how many pills were left and if they would have enough. They also found keeping up with the ever-changing medication regimens exhausting. Many other studies have confirmed these findings (Connell et al., 2013; Hirdes et al., 2012; Payne & Hudson, 2008; Tang, 2009).

Relationships

Relationships form the basis of society and help define who we are. A change in relationships due to a change in health status can cause stress and/or sadness in the affected parties. In Tom's story, his wife's failing health negatively affected her relationship with their grandchildren, as she could no longer engage in family activities. Her withdrawal heightened the grandchildren's concern for their grandmother and Tom's concern for his wife. Patricia's story showed the complexity of relationships and their effect on caregivers' lives. Gary's story represented the positive effects of friendships and how friends helped him cope with his wife's illness.

Many of our caregivers' were interconnected. The emotional toll was connected to the physical demands and to participants' relationships. Patricia's gardening story exemplified how stress, physical demands, and social and spiritual issues intertwine, demonstrating the Te Whare Tapa Whā principle of interconnection (Cherrington, 2009; Durie, 2001). Gardening, a physical task (*tinana*), has a social component when friends help to weed and plant. The garden cleanup becomes a social (*whanau*) event that benefits the entire family (*whanau*). In the end, the overgrown garden is transformed into a haven for spiritual (*wairua*) renewal. The importance of connecting with nature and awe-inspiring experiences are noted elsewhere in the literature (Barton et al., 2003; Norfolk, 2000). MacKinlay (2006) found that the spiritual, understood as one's ultimate meaning, is mediated through relationships, religion, and the environment, including gardens.

Patricia's story about how visits from her family were stressful events demonstrated not only how relationships play an important part in caregivers' lives but also how the securing help and relationships themes are interconnected. According to Patricia, visits from her parents, who lived in another town, would have been unhelpful. When speaking to her parents on the phone, Patricia chose her words carefully. She informed them of her husband's condition yet did not share the seriousness of the illness. She refrained from asking for help as, in her eyes, hosting them in her house for a week would be a burden.

Caregivers had different emotional responses to relationships. Tom expressed sadness when his wife could no longer engage with their grandchildren. Gary was able to keep the family connected by organizing a weekly family dinner. However, Patricia found the relationship with her mother too difficult and avoided the encounter.

Through education, palliative team members may be able to facilitate caregivers' relationships with their families and others. Palliative care health professionals can help identify relational obstacles. Through this identification, the health professional can help caregivers find solutions that may ease stress and lead to developing ways of managing other difficult relationships. Further, palliative care health professionals can refer caregivers to palliative care counseling services.

Financial issues were raised in other studies (Jorgensen et al., 2010; Stajduhar et al., 2010) and indirectly permeated the participants' stories in our study. As discussed earlier, one caregiver baked food in exchange for a boy chopping and stacking her wood. Another discussed the expense of hiring a cleaning lady. In another family, the son constructed a wheelchair ramp and deck for his father. The family received a quote from a builder but decided to do it themselves due to the expense. Participants expressed concern and indirectly stated how they were being careful with their personal funds. In lower socioeconomic groups, the financial burden may have been more pronounced.

STRENGTHS AND LIMITATIONS

Nine of the participants met with the first author five to six times, thus fostering a productive relationship. Participants chose the subject matter they photographed and the stories they shared, directing the research to the areas that were significant, pressing, and of concern to them. When taking photographs, they were free to employ the prompts provided by the first author or to introduce new issues. Further, the Photovoice methodology may have been an empowering experience.

The participants were all New Zealand Europeans. Further research is required with other ethnic groups in New Zealand. Eight of the participants' family members had cancer. Thus, the needs of family members with relatives who have life-limiting illnesses other than cancer are not well represented by our findings. Photovoice is inherently a retrospective method. Caregivers recalled how they felt and what their experiences were based on photographs they had taken the previous week. Though the

timespan was short (a few days) between when the photograph was taken and the interview, a recall bias may have been introduced. Furthermore, the sample size was small. With these limitations in mind, the findings are not generalizable, but they may be transferable.

CONCLUSIONS

This study contributes to the literature on caregiver roles and responsibilities. The themes were physical demands, emotional/spiritual stress, preparing for the future, securing help, medication management, navigating the agencies, and relationships. These themes were found to be intertwined, highlighting the complexity of caregiving. This complexity impacts the ability of caregivers to provide quality care for their dying relatives. Our study also offers insight into understanding the issue of accepting help as being complex.

It is well known that caregivers want support and information. Further research should focus on the effectiveness of interventions in the three areas this study identified. The interventions could be in the form of group education, responsiveness of palliative care health professionals, or the impact of providing practical solutions for physical demands and help with handling relationships.

Further study regarding barriers to accepting help may assist palliative care professionals in helping caregivers increase their ability to accept help. On a practical level, this research may inform palliative care teams how to educate caregivers about overcoming obstacles to securing help. Meeting the needs in this area would be expected to reduce caregiver stress and burden, resulting in fewer adverse health and emotional consequences. In turn, the ill family member would receive better palliative attention from the family caregiver. Attending to the needs of caregivers has the potential of improving the quality of care that patients receive. Clinicians need to be aware of caregivers' needs and intervene to allow for the best possible outcomes.

REFERENCES

Age UK (2011). *Later life in the United Kingdom*. Available at http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true.

Andershed, B. (2006). Relatives in end-of-life care, part 1: A systematic review of the literature of the five last years, January 1999–February 2004. *Journal of Clinical Nursing*, *15*(9), 1158–1169.

Andonian, L. & MacRae, A. (2011). Well older adults within an urban context: Strategies to create and maintain social participation. *British Journal of Occupational Therapy*, *74*(1), 2–11.

Angelo, J., Egan, R. & Reid, K. (2013). Essential knowledge for family caregivers: A qualitative study. *International Journal of Palliative Nursing*, *19*(8), 383–388.

Aoun, S.M., Krisjanson, L.J., Currow, D.C., et al. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine*, *19*, 551–555.

Applebaum, A.J. & Breitbart, W. (2013). Care for the cancer caregiver: A systematic review. *Palliative & Supportive Care*, *11*, 231–252.

Applebaum, A.J., Farran, C.J., Mariziliano, A.M., et al. (2013). Preliminary study of themes of meaning and psychological service use among informal cancer caregivers. *Palliative Medicine*, *13*, 1–10.

Atlas.ti (Producer) (2009). Qualitative data analysis software. Retrieved from www.atlasti.com.

Australia Institute of Health and Welfare (AIHW) (2003). *Australia's welfare 2003*. Canberra: AIHW. Available at http://www.aihw.gov.au/publication-detail/?id=6442467539.

Barazzetti, G., Borreani, C., Miccinesi, G., et al. (2010). What "best practice" could be in palliative care: An analysis of statements on practice and ethics expressed by the main health organizations. *BMC Palliative Care*, *9*, 1.

Barton, J., Grudzen, M. & Zielske, R. (2003). *Vital connections in long-term care: Spiritual resources for staff and residents*. East Peoria, IL: Versa Press.

Beach, S.R., Schulz, R. & Yee, J.L. (2000). Negative and positive health effects of caring for disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging*, *15*(2), 259–271.

Bevan, J.L. & Pecchioni, L.L. (2008). Understanding the impact of family caregiver cancer literacy on patient health outcomes. *Patient Education and Counseling*, *71*(3), 356–364.

Bingley, A. & Clark, D. (2008). *Palliative care developments in the region represented by the Middle East cancer consortium: A review and comparative analysis*. Bethesda, MD: National Cancer Institute, U.S. Department of Health and Human Services, National Institutes of Health.

Broback, G. & Bertero, C. (2003). How next of kin experience palliative care of relatives at home. *European Journal of Cancer Care*, *12*(4), 339–346.

Bukowski, K. & Buetow, S. (2011). Making the invisible visible: A Photovoice exploration of homeless women's health and lives in central Auckland. *Social Science & Medicine*, *72*(5), 739–746.

Caelli, K., Ray, L. & Mill, J. (2003). "Clear as mud": Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, *2*(2), 1–13.

Cain, R., MacLean, M. & Sellick, S. (2004). Giving support and getting help: Informal caregivers' experiences with

palliative care services. *Palliative & Supportive Care*, 2(3), 265–272.

Carers Australia (2010). *The economic value of informal care in 2010*. Available at http://www.carersaustralia. com.au/storage/Economic-Value-Informal-Care-Oct-2010.pdf.

Carlsson, B. (2001). Depicting experiences. *Scandinavian Journal of Educational Research*, 45(2), 125–144.

Cherrington, L. (2009). *Te hohounga: Mai i te tirohanga māori, the process of reconciliation: Towards a māori view*. Wellington: New Zealand: Ministry of Social Development. Available at http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=0CDYQFjAB&url=http%3A%2F%2Fwww.msd.govt.nz%2Fdocuments%2Fabout-msd-and-our-work%2Fpublications-resources%2Fresearch%2Fconduct-problems-best-practice%2Fcherrington-report-dec-2010.doc&ei=m8OSUvSEK8SOigf834H4CQ&usg=AFQjCNEZIdLp-pOnAy9t7JMLUo8jh0LjWg&sig2=QFtSGLI5ddgVaiZaGxA4xA&bvm=bv.56988011,d.aGc.

Connell, T., Fernandez, R.S., Tran, D., et al. (2013). Quality of life of community-based palliative care clients and their caregivers. *Palliative & Supportive Care*, 11, 323–330.

Demiris, G., Oliver, D.P. & Wittenberg-Lyles, E. (2009). Assessing caregivers for team interventions (ACT): A new paradigm for comprehensive hospice quality care. *The American Journal of Hospice & Palliative Care*, 26(2), 128–134.

Donelan, K., Hill, C.A., Hoffman, C., et al. (2002). Challenged to care: Informal caregivers in a changing health system. *Health Affairs*, 21(4), 222–231.

Durie, M. (2001). *Māori ora: The dynamics of māori health*. Australia: Oxford University Press.

Elde, C. (1986). The use of multiple group therapy in support groups for grieving families: A model of bereavement support for a hospice program. *The American Journal of Hospice & Palliative Care*, 3, 27–31.

Emlet, C.A. (1996). Assessing the informal caregiver: Team member or hidden patient? *Home Care Provider*, 1(5), 255–275.

Empeno, J. (2013). The impact of additional support services on caregivers of hospice patients and hospice social workers. *Omega*, 67 (1–2), 53–61.

Ferrario, R.S., Cardillo, F., Vicario, F., et al. (2004). Advanced cancer at home: Caregiving and bereavement. *Palliative Medicine*, 18, 129–136.

Funk, L., Stajduhar, K., Toye, C., et al. (2010). Home-based family caregiving at the end of life, part 2: A comprehensive review of published qualitative research (1998–2008). *Palliative Medicine*, 24(6), 594–607.

Given, B.A., Sherwood, P. & Given, C.W. (2011). Support of caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiology, Biomarkers & Prevention*, 20, 2015–2021.

Gold, S.J. (2004). Using photography in studies of immigrant communities. *American Behavioral Scientist*, 47, 1551–1572.

Gomes, B., Calanzani, N., Curial, V., et al. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *The Cochrane Database Systematic Reviews*, 6, CD007760.

Grande, G. & Ewing, G. (2008). Death at home unlikely if informal carers prefer otherwise: Implications for policy. *Palliative Medicine*, 22(8), 971–972.

Grande, G.E. & Ewing, G. (2009). Informal carer bereavement outcome: Relation to quality of end of life support

and achievement of preferred place of death. *Palliative Medicine*, 23(3), 248–256.

Hagen, N.A., Addington-Hall, J., Sharpe, M., et al. (2006). The Birmingham International Workshop on Supportive, Palliative, and End-of-Life Care Research. *Cancer*, 107(4), 874–881.

Harding, R., Epiphaniou, E., Hamilton, D., et al. (2012). What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer*, 20, 1975–1982.

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies*, 17(1), 13–26.

Henriksson, A. & Årestedt, K. (2013). Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliative Medicine*, 27, 639–646.

Hirdes, J.P., Freeman, S., Smith, T.F., et al. (2012). Predictors of caregiver distress among palliative home care clients in Ontario: Evidence based on the interRAI palliative care. *Palliative & Supportive Care*, 10(3), 155–163.

Hopkinson, J.B., Brown, J.C., Okamoto, I., et al. (2012). The effectiveness of patient–family carer (couple) intervention for the management of symptoms and other health-related problems in people affected by cancer: A systematic literature search and narrative review. *Journal of Pain and Symptom Management*, 43(1), 111–114.

Hudson, P.L., & Aranda, S. (2013). The Melbourne family support program: Evidence-based strategies that prepare family caregivers for supporting palliative care patients. *BMJ Supportive & Palliative Care*, 1–7. Available at http://spcare.bmj.com/content/early/2013/06/04/bmjspcare-2013-000500.abstract.

Hudson, P., Aranda, S. & McMurray, N. (2002). Intervention development for enhanced lay palliative caregiver support: The use of focus groups. *European Journal of Cancer Care*, 11(4), 262–270.

Hudson, P.L., Aranda, S. & Hayman-White, K. (2005). A psycho-educational intervention for family caregivers of patients receiving palliative care: A randomized controlled trial. *Journal of Pain and Symptom Management*, 30(4), 329–341.

Hudson, P.L., Trauer, T., Kelly, B., et al. (2013). Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial. *Psycho-Oncology*, 22(9), 1987–1993.

Hurworth, R. (2003). Photo-interviewing for research. *Social Research Update*, 40(1), 1–4.

Ingleton, C., Payne, S., Nolan, M., et al. (2003). Respite in palliative care: A review and discussion of the literature. *Palliative Medicine*, 17(7), 567–575.

Ipsos MORI & Macmillan Cancer Support (2011). *More than a million: Understanding the UK's carers of people with cancer*. Available at http://www.macmillan.org.uk/Aboutus/News/Latest_News/Overamillioncancer-carersmissoutonvitalsupport.aspx.

Jorgensen, D., Parsons, M., Jacobs, S., et al. (2010). The New Zealand informal caregivers and their unmet needs. *New Zealand Medical Journal*, 123, 9–16.

Keleher, H. & Armstrong, R. (2005). *Evidence-based mental health promotion resource*. Melbourne: Department of Human Services and VicHealth.

Kessler, D., Peters, T.J., Lee, L., et al. (2005). Social class and access to specialist palliative care services. *Palliative Medicine*, 19(2), 105–110.

Lal, S., Jarus, T. & Suto, M.J. (2012). A scoping review of the Photovoice method: Implications for occupational therapy research. *Canadian Journal of Occupational Therapy*, *79*(3), 181–190.

Letts, L. (2003). Occupational therapy and participatory research: A partnership worth pursuing. *American Journal of Occupational Therapy*, *57*(1), 77–87.

Lin, W.C. & Tsao, C.J. (2004). Information needs of family caregivers of terminal cancer patients in Taiwan. *The American Journal of Hospice & Palliative Care*, *21*(6), 438–444.

Linderholm, M. & Friedrichsen, M. (2010). A desire to be seen: Family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, *33*(1), 28–36.

Lindridge, A. (2007). *Keeping the faith*. London: Mental Health Foundation.

MacKinlay, E. (2006). Spiritual care recognizing spiritual needs of older adults. *Journal of Religion, Spirituality & Aging*, *18*(2/3), 59–71.

Mahood, A., Chaudhury, H., Michael, Y.L., et al. (2012). A Photovoice documentation of the role of neighborhood physical and social environments in older adults' physical activity in two metropolitan areas in North America. *Social Science & Medicine*, *74*, 1180–1192.

Marshall, C. & Rossman, G.B. (1999). *Designing qualitative research*. Thousand Oaks, CA: Sage.

Milligan, C. (2006). Caring for older people in the 21st century: "Notes from a small island." *Health & Place*, *12*(3), 320–331.

Ministry of Business Innovation and Employment (2010). *Labour market characteristics of unpaid carers*. Wellington:: Department of Labour. Available at http://www.dol.govt.nz/publications/research/characteristics-of-unpaid-carers/summary.asp.

Moberg, D.O. (2002). Assessing and measuring spirituality: Confronting dilemmas of universal and particular evaluative criteria. *Journal of Adult Development*, *9*(1), 47–60.

Moore, G., Collins, A., Brand, C., et al. (2013). Palliative and supportive care needs of patients with high-grade glioma and their carers: A systematic review of qualitative literature. *Patient Education and Counseling*, *91*, 141–153.

Morris, S.M. & Thomas, C. (2002). The need to know: Informal carers and information. *European Journal of Cancer Care*, *11*(3), 183–187.

National Alliance for Caregiving and AARP (2004). *Caregiving in the U.S*. Available at http://www.caregiving.org/data/04finalreport.pdf.

National Institutes of Health (2004). *Statement on improving end-of-life care*. Bethesda, MD: NIH. Available at http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm.

Norfolk, D. (2000). *The therapeutic garden*. New York: Bantam.

Northouse, L., Williams, A., Given, B., et al. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, *30*(11), 1227–1234.

Payne, S. & Hudson, P. (2008). Assessing the family and caregivers. In *Palliative medicine*, 1st ed. C.A. Walsh et al. (eds.), pp. 320–325. New York: Elsevier.

Pillow, W.S. (2003). Confession, catharsis, or cure? Rethinking the uses of reflexivity as a methodological power in qualitative research. *Qualitative Studies in Education*, *16*, 175–196.

Radley, A. & Taylor, D. (2003). Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Health Research*, *13*(1), 77–99.

Rando, T. (1986). *Loss and anticipatory grief*. Lanham, MD: Lexington Books.

Romanow, R.J. (2002). *Building on values: The future of health care in Canada*. Ottawa: Government of Canada.

Rose, G. (1996). Teaching visualized geographies: Towards a methodology for the interpretation of visual materials. *Journal of Geography in Higher Education*, *20*(3), 281–294.

Rush, K.L., Murphy, M.A. & Kozak, J.F. (2012). A Photovoice study of older adults' conceptualizations of risk. *Journal of Aging Studies*, *26*(4), 448–458.

Sekelja, N., Butow, P.N. & Tattersall, M.H. (2010). Bereaved cancer carers' experience of and preference for palliative care. *Supportive Care in Cancer*, *18*(9), 1219–1228.

Stajduhar, K., Allan, D.E., Cohen, S.R., et al. (2008). Preferences for location of death of seriously ill hospitalized patients: Perspectives from Canadian patients and their family caregivers. *Palliative Medicine*, *22*(1), 85–88.

Stajduhar, K., Funk, L., Toye, C., et al. (2010). Home-based family caregiving at the end of life, part 1: A comprehensive review of published quantitative research (1998–2008). *Palliative Medicine*, *24*(6), 573–593.

Stambor, Z. (2006). Caring for caregivers. *Monitor on Psychology*, *37*(10), 46–47.

Tamayo, G.J., Broxson, A., Munsell, M., et al. (2010). Caring for the caregiver. *Oncology Nursing Forum*, *37*(1), E50–E57.

Tang, W.R. (2009). Hospice family caregivers' quality of life. *Journal of Clinical Nursing*, *18*(18), 2563–2572.

Tsigaroppoulos, T., Mazaris, E., Chatzidarellis, E., et al. (2009). Problems faced by relatives caring for cancer patients at home. *International Journal of Nursing Practice*, *15*(1), 1–6.

Wang, C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, *8*(2), 185–192.

Wang, C. & Burris, M.A. (1997). Photovoice: Concept, methodology, and use for participatory needs. *Health Education & Behavior*, *24*(3), 369–387.

Yi, J. & Zebrack, B. (2010). Self-portraits of families with young adult cancer survivors: Using Photovoice. *Journal of Psychosocial Oncology*, *28*(3), 219–243.