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**Reported Self-Care Practices and Perceptions of Well-Being in Caregivers of
Children with Cancer**

An Honors Thesis submitted in partial fulfillment of the requirements for Honors in the
School of Nursing.

By
Rachel Siclare

Under the mentorship of Dr. Sheri Carey

ABSTRACT

Thousands of American children are diagnosed with cancer annually. Cancer does not only affect these children, but also those that care for them. This study examined quality of life issues facing caregivers of children with cancer as a beginning effort in the investigation of this ongoing problem. Caregivers were surveyed at a pediatric hematology-oncology clinic. The surveys assessed caregiver burnout and level of self-care. Data was assessed using IBM SPSS software to determine signs of distress and decreased well-being in these participants. The results of this project will hopefully inspire other individuals to continue research in this field of study.

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Reported Self-Care Practices and Perceptions of Well-Being in Caregivers of Children with Cancer

In children who are one to fourteen years old, the second leading cause of death is due to cancer (American Cancer Society, 2016). In the United States, about 10,380 children between the ages of zero and fifteen will be diagnosed with cancer in 2016 and about 1,250 of those children will die (American Cancer Society, 2016). Cancer does not only affect the children, but also those that care for them. This paper will discuss a baseline examination of quality of life (QOL) issues facing caregivers of children with cancer as a beginning effort in the investigation of this ongoing problem.

Background

Burden and Burnout

“Caregiver burden is defined as the strain or load borne by a person who cares for an elderly, chronically ill, or disabled family member or other person” (Kasuya, 2000, p. 119). Without assistance and support, caregiver burden can lead to burnout (Huang, Mu, & Chiou, 2008). “Caregiver burnout is the progression of caregiver burden to the point where the experience is no longer a viable or healthy option for either the caregiver or the person receiving care” (Kasuya, 2000, p. 119). A caregiver feels highly responsible for the ill individual, especially if the caregiver has a close relationship with the person they are caring for; for example, a child, spouse, sibling, or parent (Beheshtipour, Nasirpour, Yektatalab, Karimi, & Zare, 2016).

Two of the most common signs of burnout include heightened anxiety and stress (Kasuya, 2000). The caregiver might tell someone about these problems early on, or may hide them because of embarrassment (Beheshtipour, Nasirpour, Yektatalab, Karimi, &

Zare, 2016). Mental signs of burnout include “irritability, insomnia, social isolation, greater use of sarcasm, and increased ingestion of alcohol or other drugs” (Kasuya, 2000, p. 120). Other signs of burnout are appetite changes, headaches, indigestion, feeling tired, loss or gain of weight, having a hard time concentrating, and an untidy appearance (Kasuya, 2000). Some of these symptoms may be mistaken an illness, which can delay the caregiver from receiving the help and support that is needed.

Parents providing around the clock caregiving to children with cancer can become emotionally and physically exhausted (Gurková, Andraščíková, & Čáp, 2015). While assessing the terminally ill child, healthcare providers should not forget to also assess the health status of the primary caregiver. If the caregiver is having a difficult time caring for himself or herself, he or she will eventually not be able to appropriately care for the child (Beheshtipour, Nasirpour, Yektatalab, Karimi, & Zare, 2016).

Single parent households can experience more stressors than a two-parent household (Huang et al., 2008). Instead of using two incomes to pay for the healthcare bills, there is only one income to cover the medical expenses. A single parent is responsible for completing more tasks as compared to a caregiver who has a spouse. Single parents have less help, which results in increased responsibility (Huang et al., 2008). An overbearing workload can lead to greater fatigue as well as less energy to provide for the ill child (Beheshtipour, Nasirpour, Yektatalab, Karimi, & Zare, 2016).

It has been suggested that parents caring for school age children with cancer who receive spiritual-educational interventions will report a lower burnout score compared to parents who did not receive any interventions (Beheshtipour et al., 2016). Parents who receive teaching and support are more likely to have a decrease in burnout, which

improves self-care (Kasuya, 2000). Therefore, interventions should be planned so that caregivers do not feel alone or carry all of the weight on their shoulders.

Self-Care and Well-Being

Based on previous research, caregivers should not isolate themselves (Beheshtipour et al., 2016; Gurková et al., 2015; Huang et al., 2008; Kasuya, 2000). Support is important during this challenging time and has proved to be beneficial. Ways to gather support include participating in hobbies with friends, going to a support group, and getting involved in church if the caregiver is religious (Kasuya, 2000). Establishing a support group may help the caregiver with grieving if the loved one passes away. If the caregiver does not have any support, necessities such as adequate sleep, healthy meals, and regular exercise may decline (Huang et al., 2008).

Due to the possible negative effects of caregiving, it is crucial to establish and maintain self-care. Self-care is defined as “activities that individuals initiate and perform on their own behalf to maintain their own health and well-being” (Orem, 2011). Well-being is “an inner attitude of acceptance of the wholeness of one’s Being” (American Holistic Nurses Association and American Nurses Association, 2007). There is little published about self-care or well-being of parents of children with cancer. Using the search terms caregiver burnout, caregiver well-being, pediatrics, and oncology, there were only a few published articles found on this topic (Beheshtipour et al., 2016; Gurková et al., 2015; Huang et al., 2008; Kasuya, 2000). This project will explore these areas further because they are necessary for caregivers in order to prevent burnout.

Purpose

The purpose of this research study is to assess the self-care practices and perceptions of well-being in caregivers of children with cancer. This study was guided by the following research questions. In caregivers of children with cancer: 1) does caring for an ill child create feelings of isolation for the caregiver?; 2) is socioeconomic status related to an improved or diminished level of self-care?; and 3) does caring for a younger child result in less self-care and/or decreased well-being?

Hypothesis/Aims

It is hypothesized that being a minority (non-Caucasian), having a low annual income, lacking medical insurance, and caring for a child who is elementary school aged or younger will result in a decreased level of self-care and feelings of isolation. Consequently, it is also hypothesized that being Caucasian (non-minority), having a high annual income, possessing medical insurance, and caring for a child who is middle school aged or above will result in an increased level of self-care and feelings of support. The aim of this project was for caregivers to discover any signs of caregiver burden or burnout, which could result in less than optimal care provided for their children.

Significance of Study

This research study addresses the topic of caregiver burnout and self-care, specifically evaluating the well-being of caregivers of children with cancer. This is an important issue to explore because pediatric oncology caregiving is emotionally draining (Gurková, Andraščíková, & Čáp, 2015). If caregivers do not keep themselves well, the care they provide could be insufficient and inadequate (Huang et al., 2008). As caregivers completed their surveys, they identified and reflected on their own health and well-being.

With more research being conducted on this topic, awareness of caregiver burnout can be raised, which will hopefully increase well-being in these individuals.

Methods

Research Design

A descriptive study was used to assess perceived caregiver strain and burnout in caregivers of children with cancer. The participants completed a demographic survey (see Appendix A) and a Caregiver Strain Survey (see Appendix B) to measure these concepts.

Research Methods

Caregivers of children with cancer, who were eighteen years or older, were asked if they would like to complete a voluntary survey. Each participant took anywhere from five to fifteen minutes to complete the survey. Before the completion of the surveys, the caregivers were informed that they must be at least eighteen years of age. The Caregiver Strain Survey contained quantitative data that consisted of statements that the caregivers ranked on a scale that ranged from one to four. The statements assessed how frequently each item occurred and how much of a hassle it was for them. Caregiver strain assessment statements included, “Experiencing loss of sleep due to caring for my child” and “Feeling physically drained by caring for my child (e.g., bathing, feeding, cleaning, etc.)” Demographic data collected included age, ethnicity, gender, annual income, and medical insurance status of the caregivers. The caregivers were also asked for their number of hours of sleep per night, their number of days of exercise per week, and the number of meals consumed per day. For this study, at least seven hours of sleep per night, five days of exercise per week, and three meals per day were identified as healthy behavior patterns. The research data was interpreted using IBM SPSS software. This is a

trustworthy software program that allowed the researcher to accurately form connections between the data that was collected.

Ethical Considerations

The Institutional Review Board (IRB) at Georgia Southern University and Memorial University Medical Center approved this study. After the approval process, the data was gathered at a Pediatric Hematology-Oncology clinic in Savannah, Georgia during January and February of 2017. As caregivers were being recruited to complete the surveys, the researcher explained that participation was voluntary and anonymous. They were also told that by filling out a survey, they were giving passive consent. The project was explained, as well as its importance to research. The caregivers were informed that they could leave the survey blank if they did not want to complete it. Once a survey was finished, it was placed in a sealed envelope, which was then placed into a manila envelope. This method was used to maintain the caregivers' privacy. Thirteen caregivers elected to complete a survey on their own terms, which made this a convenience sample.

Instrument Description

The demographic questions were formulated to identify statistics about the caregiver in addition to the age of the ill child. The Caregiver Strain Survey was obtained from a professor in the nursing field who specializes in pediatrics. This survey was used to answer the researcher's hypotheses.

The Caregiver Strain Survey was adapted from Robinson's Caregiver Strain Index (Robinson, 1983). It is an expanded version using 20 items to assess care required for activities of daily living among children with physical handicaps (Olsen, Marshall, Mandelco, Dyches, & Draper, 2002). The scale provides a 4-point measuring scale to rate

the level of strain for each activity. Caregivers rate the frequency of each occurrence stated in the survey from one to four correlating respectively to rarely, sometimes, a lot, and constantly. They also rate the level of hassle related to each occurrence from one to four correlating respectively to no hassle, little hassle, medium hassle, and big hassle. This scale has shown consistent reliability with a Cronbach's alpha of 0.86 or higher (Robinson, 1990). This modified scale has been used successfully in other studies of families of children with disabilities (Edds-McAfee, 2012; Olsen et al., 2002).

There were ten questions on the demographic questionnaire. The only fill-in the blank question was one that asked for the child's age. The rest were multiple choice. The Caregiver Strain Survey has twenty statements that could be ranked from one to four. Depending on the statement, the number one meant rarely or no hassle, two meant sometimes or a little hassle, three meant a lot or medium hassle, and four meant constantly or big hassle.

In addition to the instructions that the participants received, they were encouraged to answer the questions truthfully and to fill out the entire survey. Doing so ensured that the data collected was accurate. The instructions were explained to the caregivers in simple terms, and the surveys were easy to comprehend. This was essential because if the participants did not understand what they were doing, the information they provided could have been inaccurate.

Data Analysis and Results

While analyzing the data, the researcher used descriptive and inferential statistics. Additionally, cross tabulation tables and chi-square were used to assess the caregivers' responses.

Most of the thirteen participants (54%), were between 26 and 35 years old (see Table 1). Most of the participants (61.6%) identify as belonging to a minority, and the overwhelming majority (92%) were female (see Table 1). Each participant reported the age of the child they were caring for. The children had a mean age of 8.3 years with a standard deviation of 7.8, and 61.5% were less than ten years old (see Table 1). Only one caregiver was a grandparent, while the rest were parents (see Table 1). Annual household income for 84.6% of the caregivers was 50,000 dollars or less, and 84.6% of the caregivers had medical insurance (see Table 1).

Table 1**Demographic Variables, Response Options, Sample Size, Frequency, and Percent**

Variable	Response	Frequency (<i>n</i> = 13)	Percent %
Caregiver Age	18-25 years	1	8
	26-35 years	7	54
	36-45 years	3	23
	46-55 years	0	0
	56-65 years	2	15
Caregiver Ethnicity	Caucasian	5	38
	African American	6	46
	Hispanic	1	8
	Multi-racial	1	8
Caregiver Gender	Female	12	92
	Male	1	8
Medical Insurance	Yes	11	85
	No	2	15

Annual Household Income	Under \$30,000/year	7	54
	\$30,000-50,000	4	30
	\$50,000-99,000	1	8
	\$100,000-200,000	1	8
Caregiver provides Care to Child Aged...	1-3 years	3	23
	4-6 years	5	38
	7-9 years	0	0
	10-12 years	2	15
	13-15 years	1	8
	16-19 years	1	8
	≥ 20 years	1	8
Caregiver Role	Parent	12	92
	Grandparent	1	8
Caregiver Hours of Sleep/Night	< 6 hours	6	46
	6-7 hours	6	46
	8-9 hours	1	8
Caregiver Days of Exercise/Week	0 days	7	54
	1-2 days	3	23
	3-4 days	3	23
Caregiver # of Meals/Day	1 meal	2	15
	2 meals	5	39
	3 meals	6	46

Over half of the caregivers (54%) reported that they sometimes felt “Feelings of isolation- no one understands what I am going through caring for my child”. 23% of the participants experienced this feeling a lot or constantly (see Table 2).

Table 2 - Caregiver Feelings of Isolation Frequency and Percent

	Frequency	Percent
Rarely	3	23.1
Sometimes	7	53.8
A Lot	1	7.7
Constantly	2	15.4
Total	13	100.0

No significant findings were noted when caregiver ethnicity and caregiver insurance possession were compared to caregiver self-care or well-being. However, other significant factors were observed from this study. When comparing household income to days of exercise per week, the findings, using a chi-square test, were not significant ($p=.069$). However, the data showed that most of the caregivers who had a lower household income did not exercise as often as those with a higher household income (see Table 3).

Table 3 - Relationship of Annual Household Income to Number of Days of Exercise per Week

Annual Household Income?	Number of Days of Exercise per Week			Total
	0 days	1 to 2 days	3 to 4 days	
Under \$30,000	6	1	0	7
\$30,000-50,000	1	1	2	4
\$50,000-99,000	0	1	0	1
\$100,000-200,000	0	0	1	1
Total	7	3	3	13

When comparing caregiver age and “Feeling overwhelmed at all there is to do in caring for my child” a significant relationship was found using Chi-square because the p-value was less than .05 ($p=.011$). In general, the very young and very old caregivers felt a lot or constantly overwhelmed, while the middle-aged caregivers felt overwhelmed only rarely or sometimes (see Table 4).

Table 4 - Relationship of Caregiver Age to Feeling Overwhelmed

Caregiver Age		Feeling Overwhelmed				Total
		Rarely	Sometimes	A Lot	Constantly	
What is your age?	18-25	0	0	0	1	1
	26-35	3	4	0	0	7
	36-45	0	3	0	0	3
	56-65	0	1	1	0	2
Total		3	8	1	1	13

No significant finding ($p=.065$) was noted using chi-square when comparing “Feeling overwhelmed at all there is to do in caring for my child” to “Experiencing loss of sleep due to caring for my child.” However, on average, if the caregivers felt overwhelmed, they also experienced loss of sleep. The caregivers who did not feel as overwhelmed did not report as much loss of sleep (see Table 5).

Table 5 - Relationship of Feeling Overwhelmed to Experiencing Loss of Sleep

Feeling Overwhelmed		Experiencing Loss of Sleep				Total
		Rarely	Sometimes	A Lot	Constantly	
Rarely		2	1	0	0	3
Sometimes		2	2	4	0	8
A Lot		0	0	0	1	1
Constantly		0	0	0	1	1
Total		4	3	4	2	13

Another significant finding ($p=.010$) was discovered using chi-square when comparing “Feeling emotionally drained due to caring for my child- frazzled and worn out” and “Feeling that caring for my child creates more conflict and arguments with significant other (e.g. parents, friends, etc).” If the caregivers felt emotionally drained, they reported more conflicts with their significant others. If they did not feel as emotionally drained, this typically resulted in less conflicts (see Table 6).

Table 6 - Relationship of Feeling Emotionally Drained to Conflict with Significant Others

Feeling Emotionally Drained		Conflict with Significant Others			Total
		Rarely	Sometimes	A Lot	
	Rarely	3	0	0	3
	Sometimes	5	3	0	8
	A Lot	0	1	0	1
	Constantly	0	0	1	1
Total		8	4	1	13

When the child’s age and “Feeling that I need to change my plans in order to fulfill my child’s needs” were evaluated using chi-square, a significance of $p=.008$ was found. Caregivers who were responsible for children under the age of ten felt that they did not have to change their personal plans to care for their children. However, caregivers of children ten years or older felt that they had to change their plans for their children. This was the most significant finding of the research study (see Table 7).

Table 7 - Relationship between Age of Child and the Need to Change Plans

Age of Child	Need to Change Plans			Total
	Rarely	Sometimes	A Lot	
Less than 10 years old	4	4	0	8
10 years old or older	0	1	4	5
Total	4	5	4	13

Using chi-square, significance ($p=.017$) was found when comparing the child’s age to “Feeling that I don’t have time to maintain my physical health due to caring for my child (e.g., exercise, eating right).” The data shows that caring for a child ten years or older led to less time for the caregiver to maintain his or her physical health when compared to caregivers of children who were under ten years old (see Table 8).

Table 8 - Relationship between Age of Child and Ability to Maintain Physical Health

Age of Child	Maintain Physical Health				Total
	Rarely	Sometimes	A Lot	Constantly	
Less than 10 years old	7	1	0	0	8
10 years old or older	0	2	2	1	5
Total	7	3	2	1	13

Discussion and Implications

As revealed by the data, many caregivers are not properly taking care of themselves physically or mentally. For example, some feel isolated and overwhelmed. These individuals reported a lack of exercise, not enough sleep, and conflict with significant others. Additionally, they are not eating an appropriate amount of meals, must alter their plans for their children, and do not maintain their physical health. Regardless

of these negative aspects of their lives, every caregiver stated that their child is not an inconvenience to them and that their child brings them joy. Even though caregiving can be challenging, it is important that the caregiver loves the one he or she is caring for.

By assessing the data, the researcher could evaluate the hypotheses that were made. As previously mentioned, there were no significant findings when ethnicity and medical insurance possession were compared to caregiver well-being. Nevertheless, the researcher did discover significant findings when relating the age of the child and annual household income to self-care and well-being. It was hypothesized that caring for younger children would lead to decreased well-being. However, this was proven false. The caregivers of children age ten and above reported changing their personal plans more frequently due to caring for their children. They also reported less time to maintain their own physical health. Caregivers of children less than ten were found to alter their plans less often and were also found to have more time to maintain their physical health. An explanation for these results could be that those raising younger children already expect to have less time on their hands, regardless if the child is sick or not.

When looking at annual household income, it was hypothesized that individuals with a higher income would have more time to care for themselves. This was proven true when looking at the amount of time that caregivers exercised per week. Most caregivers with a higher income reported that they exercised numerous times a week, while most caregivers with a lower income did not exercise at all during the week. A caregiver with a lower income may not be able to afford a membership to the gym on top of the child's medical expenses. Also, those with a higher income might not have to work or work as often, which would give them time to exercise more during the week.

The caregivers who reported stress and lack of self-care should be educated on caregiver burnout and ways to promote well-being. A convenient time for this to happen is when they take their children to health appointments. The nurse could ask these caregivers some questions to assess how they are doing, instead of solely focusing on the child. A huge part of a nurse's job is patient education, but that does not have to only apply to the patient. The caregivers must stay healthy if they want to provide their ill children with the best care possible.

Strengths and Limitations

The strengths of this study included a thorough caregiver strain survey that was specific. This allowed the researcher to obtain data that was necessary to explore the research topic as well as draw conclusions. The limitations of this study included a small sample size of thirteen participants. Many of the same patients came to the hematology-oncology clinic on the days the researcher collected data, decreasing the number of potential participants. Another limitation was that only one participant was of the male gender. A small sample size can make it difficult to obtain numerous significant findings. The significant correlations should be approached with caution due to the small sample size.

Conclusions and Recommendations

This research project made it known that the age of the child and the caregivers' socioeconomic status (annual household income) can affect caregiver self-care. Since some caregivers reported a lack of well-being and possible signs of burnout, it is important that the participants, as well as other individuals at risk, receive proper teaching and information on these topics. Clinics or hospitals could provide flyers and

booklets to caregivers in addition to verbal teaching. Facilities could even host support programs where caregivers would have the opportunity to talk with other caregivers about their hassles and problems that other individuals do not fully understand.

The researcher recommends that this topic continues to be researched. In future studies, the data collection period could last longer. Surveys could also be distributed at multiple pediatric oncology facilities to get more participants, as well as a more diverse sample of individuals. Also, it would have been beneficial to include a few open-ended response questions to get a better insight of the caregivers' experiences. The topics of caregiver burden and burnout are of great concern, and they will continue to be a concern unless they are further researched.

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Appendix A

1. What is your age?
 - 18-25
 - 26-35
 - 36-45
 - 46-55
 - 56-65
 - 66 or older: _____

2. What is your ethnicity?
 - Caucasian
 - African American
 - Latino
 - Hispanic
 - Native American
 - Asian
 - Pacific Islander
 - Other: _____

3. What is your gender?
 - Male
 - Female
 - Other: _____
 - Would not like to respond

4. Do you have medical insurance?
 - Yes
 - No

5. What is your annual household income?
 - Under \$30,000
 - \$30,000-\$50,000
 - \$50,000-\$99,000
 - \$100,000-\$200,000
 - Over \$200,000

6. How old is the child that you care caring for?

7. What is your relation to the child you are caring for?
 - Grandfather/grandmother
 - Father/mother
 - Uncle/aunt
 - Brother/sister
 - Cousin
 - Other: _____

8. On average, how many hours of sleep do you get per night?
 - Under 6 hours
 - 6-7 hours
 - 8-9 hours
 - 10-11 hours
 - 12 hours or more

9. On average, how many days do you exercise per week?
 - 0 days
 - 1-2 days
 - 3-4 days
 - 5-6 days
 - 7 days

10. How many meals do you normally eat per day?
 - 1 meal per day
 - 2 meals per day
 - 3 meals per day

Appendix B

CAREGIVER STRAIN SURVEY

Below is a list of typical everyday events that parents may encounter. Thinking of what it takes to care for your child with special health care needs, circle how frequently this generally occurs for each item and how much of a hassle it seems to be for you.

	How Frequently:				How Much of a Hassle:			
	1- Rarely	2- Sometimes	3- A Lot	4- Constantly	1- No hassle	2- A little hassle	3- Medium hassle	4- Big hassle
Feeling that my time is not my own. Care of my child interferes with housework, employment, family life, hobbies or other outside interests, etc.	1	2	3	4	1	2	3	4
Feeling overwhelmed at all there is to do in caring for my child.	1	2	3	4	1	2	3	4
Feeling financial strain involved in caring for my child.	1	2	3	4	1	2	3	4
Feeling that I need to change my plans in order to fulfill my child's needs.	1	2	3	4	1	2	3	4
Feeling that my child is a joy to me.	1	2	3	4	1	2	3	4
Feeling that I don't have time to maintain my physical health due to caring for my child (e.g. exercise, eating right)	1	2	3	4	1	2	3	4
Feeling that raising my child brings me closer to my spouse (or ex-spouse where applicable)	1	2	3	4	1	2	3	4
Feeling that my child provides stimulation and learning for me.	1	2	3	4	1	2	3	4
Feeling emotionally drained due to caring for my child- frazzled and worn out.	1	2	3	4	1	2	3	4
Feeling that caring for my child creates more conflict and arguments with significant other (e.g. parents, friends, etc)	1	2	3	4	1	2	3	4
Feelings of isolation- no one understands what I am going through caring for my child.	1	2	3	4	1	2	3	4

Feeling that my child teaches me wonderful and worthwhile things.	1	2	3	4	1	2	3	4
Feeling that my child gets along well with others (e.g. siblings, other children).	1	2	3	4	1	2	3	4
Experiencing loss of sleep due to caring for my child.	1	2	3	4	1	2	3	4
Feeling physically drained by caring for my child (e.g. bathing, feeding, cleaning, etc).	1	2	3	4	1	2	3	4
Feeling that caring for my child is an inconvenience.	1	2	3	4	1	2	3	4
Feeling that my personal growth is enhanced because of caring for my child.	1	2	3	4	1	2	3	4
Feeling that caring for my child creates more conflicts with my spouse (or ex-spouse where applicable)	1	2	3	4	1	2	3	4
Feeling that caring for my child brings me closer to significant others (e.g. parents, friends, etc).	1	2	3	4	1	2	3	4
Feeling that my child doesn't get along well with others (e.g. siblings, other children).	1	2	3	4	1	2	3	4