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General

Cancer caregivers are primarily motivated by love and sense of duty

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Cancer is a debilitating disease for which patients often need caretakers to help them live their lives and complete basic activities. This study aims to characterize the burden of the caretaker. A 14-question survey was sent out to randomly selected United States cancer caretakers to analyze the social, emotional, and physical burden of their caretaking. The results show that a majority of caretakers are direct family to the patient (69.5%). The patients' cancers are often in early stages with about 54.5% having stage 1 cancer and 22.5% having stage 2 cancer while only 8.5% had stage 3 cancer and 17.8% had stage 4 cancer. When asked about their motivation, caretakers most often do it because of love (58.82%) with family responsibilities/duty being the second highest reason (35.56%). When asked about their biggest burden, many caretakers said that grief was the biggest issue (30.50%) with mental health issues also being troublesome (28%). 75.6% of respondents said that being a cancer caretaker has negatively impacted their mental health from either anxiety (37.29%), depression (33.9%), or other conditions (4.41%). When asked about the negative impacts of being a caregiver, 43.5% stated they faced high financial costs to give care, and 35% stated they met a lack of social support or lost friends. In comparison, 33% stated they had negative physical impacts. The number of participants who face overwhelming or high stress nearly quintupled from baseline, from 13% to 59.5%. This cross-sectional survey of US adults demonstrates that there are clear negative impacts on cancer caregivers on their physical, financial, social, and mental health. These data underscore the importance of taking care of patients' caregivers.

INTRODUCTION

Cancer develops when there is uncontrolled and rapid growth in cells due to a genetic mutation, forming a tumor. Cancer was first documented in Ancient Egypt in nearly 3000 BCE. Since then, our understanding of the disease has grown significantly.

Cancer has 4 major stages corresponding to increasing severity. During stage 1 of cancer development, the cancer is still localized, meaning it has not yet spread to other parts of the body or deeper into the tissues in the area. Stage 2 cancer is when the tumor has grown significantly in size and has started to deeply occupy the surrounding tissues, but has not yet spread to other parts of the body. In stage 3, the cancer is larger and has begun to spread to other organs, tissues, and/or lymph nodes. It is also mildly malignant in this stage and has deeply spread in local tissues. Stage 4 cancer is when the cancer is widespread in the body; at this point, the cancer is considered metastatic and can be life-threatening. Cancer in all stages poses a risk to patients as it consumes resources from the body. However, as the stages progress, cancers become more deadly.

Due to the debilitating properties of the disease, many cancer patients need caretakers to live normal healthy lives.[1] However, being a cancer caretaker can be taxing to the caretaker's mental, social, and physical health.[2]

METHODS

Two hundred cancer patient caregivers (N=200) residing in the United States were surveyed through an online survey research platform to provide a random spread of sampling. Participants were not limited by the survey platform to any device or environment. The surveying platform has over 700 million users globally and thus can stimulate randomization and eligibility for the survey participants. The software uses advanced tools to avoid fraudulent results as well as to provide a representative and weighted proportion of the population.

The survey was formatted with the first question used to screen the participant for eligibility in the study. The screening question used in this study was whether or not the respondent would be willing to take part in a survey regarding cancer patients. Following the first screening question, 11 questions were asked to the respondents about their respective cancer patient's status as well as the burden(s) that they as the caretakers face. The final question was open-ended and designed to capture the participants' feelings not discussed in the survey [Figure 1].

Data were analyzed using JMP 17 for Windows.

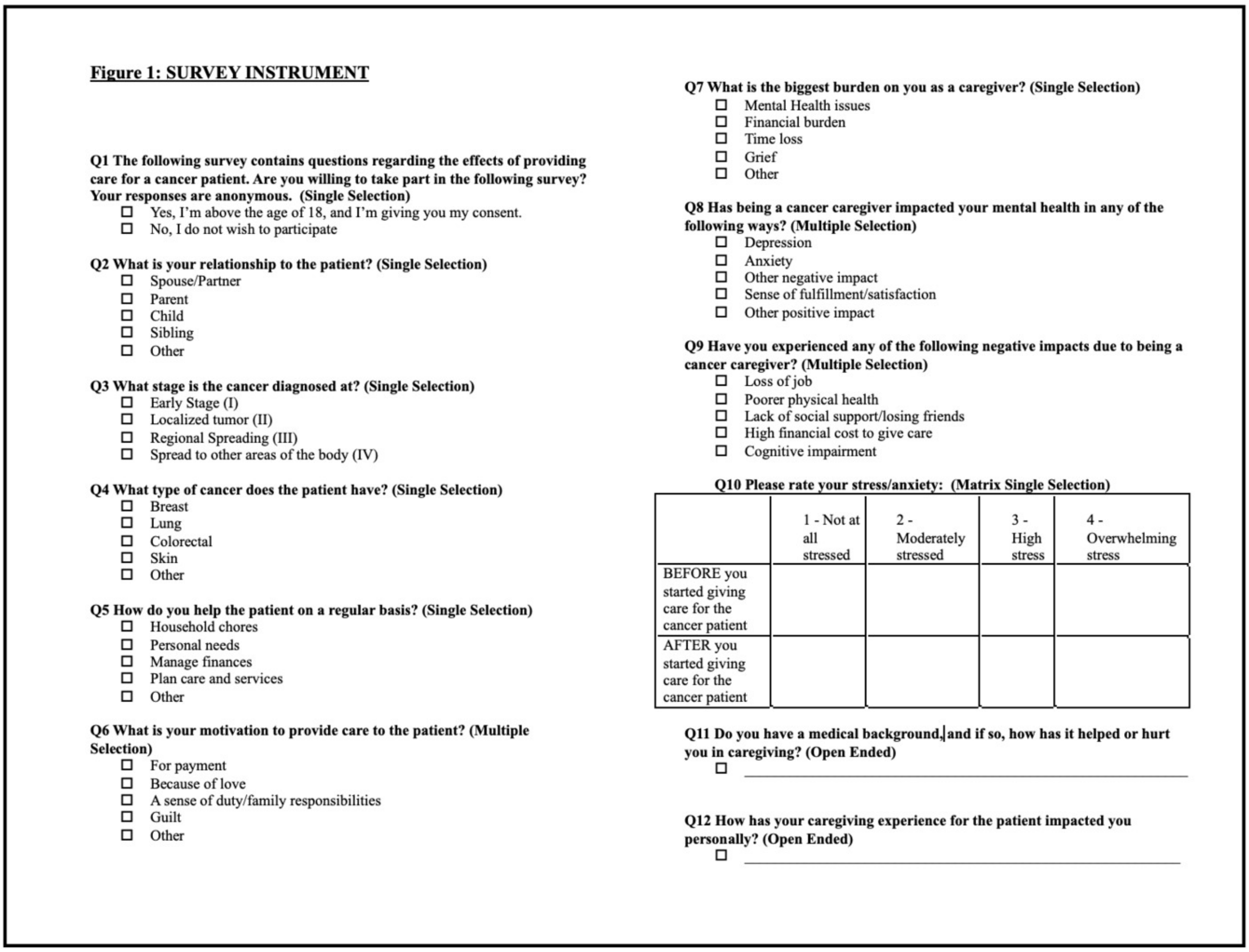

Figure 1: SURVEY INSTRUMENT

Q1 The following survey contains questions regarding the effects of providing care for a cancer patient. Are you willing to take part in the following survey? Your responses are anonymous. (Single Selection)
- ☐ Yes, I'm above the age of 18, and I'm giving you my consent.
- ☐ No, I do not wish to participate

Q2 What is your relationship to the patient? (Single Selection)
- ☐ Spouse/Partner
- ☐ Parent
- ☐ Child
- ☐ Sibling
- ☐ Other

Q3 What stage is the cancer diagnosed at? (Single Selection)
- ☐ Early Stage (I)
- ☐ Localized tumor (II)
- ☐ Regional Spreading (III)
- ☐ Spread to other areas of the body (IV)

Q4 What type of cancer does the patient have? (Single Selection)
- ☐ Breast
- ☐ Lung
- ☐ Colorectal
- ☐ Skin
- ☐ Other

Q5 How do you help the patient on a regular basis? (Single Selection)
- ☐ Household chores
- ☐ Personal needs
- ☐ Manage finances
- ☐ Plan care and services
- ☐ Other

Q6 What is your motivation to provide care to the patient? (Multiple Selection)
- ☐ For payment
- ☐ Because of love
- ☐ A sense of duty/family responsibilities
- ☐ Guilt
- ☐ Other

Q7 What is the biggest burden on you as a caregiver? (Single Selection)
- ☐ Mental Health issues
- ☐ Financial burden
- ☐ Time loss
- ☐ Grief
- ☐ Other

Q8 Has being a cancer caregiver impacted your mental health in any of the following ways? (Multiple Selection)
- ☐ Depression
- ☐ Anxiety
- ☐ Other negative impact
- ☐ Sense of fulfillment/satisfaction
- ☐ Other positive impact

Q9 Have you experienced any of the following negative impacts due to being a cancer caregiver? (Multiple Selection)
- ☐ Loss of job
- ☐ Poorer physical health
- ☐ Lack of social support/losing friends
- ☐ High financial cost to give care
- ☐ Cognitive impairment

Q10 Please rate your stress/anxiety: (Matrix Single Selection)

	1 - Not at all stressed	2 - Moderately stressed	3 - High stress	4 - Overwhelming stress
BEFORE you started giving care for the cancer patient				
AFTER you started giving care for the cancer patient				

Q11 Do you have a medical background, and if so, how has it helped or hurt you in caregiving? (Open Ended)
☐ ____________________

Q12 How has your caregiving experience for the patient impacted you personally? (Open Ended)
☐ ____________________

Figure 1. Survey instrument

RESULTS

Out of all the caregivers, 29.5% of them were related to the cancer patient as either spouse/partner. 16% were parents/legal guardians. 14% were children of the patient. 9.5% were siblings to the patient, while 26% were other relations either a friend, themselves, or another third party.

For over half of the cancer patients (54.5%) their condition was in stage 1 cancer. 22.5% had localized stage 2 cancer. 8.5% had regional stage 3 cancer. With 14.5% having malignant stage 4 cancers. For all of these cancers, the most common type was breast cancer at 31% followed by Lung cancer at 21.5% and Skin cancer at 15%. Only 8.5% suffered from colorectal cancer while the remaining 24% suffered from other cancers.

The majority of responsibilities for the caregivers were Personal needs for the patient at 46.5%. 21.5% helped mostly with household tasks. 16.5% helped to plan care and services for the patient. 7.5% of caregivers had the main responsibility of financial services with 8% doing other tasks.

When asked for their main motivations, 75% of respondents said that love was one factor motivating them, while 50.5% of respondents said that a sense of duty also played a role. 8% of respondents said that payment was their motivation while 3.5% said that guilt motivated them. An additional 5% stated other reasons motivating them as well.

The biggest burden for caregivers was often grief at 30.5%, mental health at 28%, and financial burdens at 15.5%. 13.5% said that time loss was the biggest problem with 12.5% stating other factors burdened them the most.

When asked to expand on mental health issues due to their caregiving, a large number stated negative consequences: 55% said that they faced anxiety, 50% said they faced depression, and 6.5% said they faced other negative effects. However, some also stated positive effects they faced including 24.5% stating they feel a sense of fulfillment and satisfaction due to their service and 11.5% stating other positive effects.

When asked specifically about their stress/anxiety before and after they started being a caregiver, there was a significant increase in stress levels after caregiving began. Before caregiving, 22.5% stated they had no stress at all, 64.5% stated moderate stress, 10.5% stated High stress and only 2.5% stated unmanageable levels of stress. In contrast, after beginning caregiving, only 7.5% stated no stress at all, 33% stated moderate stress, 47.5% stated high stress and 12% stated unmanageable stress. This shows a 46.5% decrease in participants feeling no or moderate stress and that same increase in participants feeling high or unmanageable stress.

Other non-mental health-related impacts include loss of job (13%), Poorer physical health (33%), Lack of social interaction (35%), High financial burden (43.5%), and Cognitive impairment (8.5%).

When asked if they had a medical background and how it impacted them, the majority of caregivers reported not having a medical background. Those who did have a medical background reported that it only helped in understanding the condition, but did not improve the quality of the care itself.

When asked an open-ended question about their experiences with caregiving, most stated mental and physical health issues, tiredness, and grief. Some accounts include “emotionally drained”, “sad and strong at the same time”, “makes you appreciate life”, “extreme patience”, and “very very tired”.

DISCUSSION

The caregivers of cancer patients are uniquely-vulnerable to physical, financial, social, and mental health-related obstacles. In order to serve the patient, it is imperative that that the caretaker is adequately supported; in fact, previous studies suggest that caregivers’ psychological and physical condition is directly correlated with patients’ self-perceived burden (SPB), which can in turn impact patient outcomes.[3] Previous studies also suggest that caretakers with the highest perceived burden often share certain characteristics, such as being a woman, providing care for many hours, and losing sleep.[4] Through characterizing the caregiver burden, this study aims to identify the specific struggles and areas of support for caretakers.

The survey results indicate that caregivers are primarily family or close friends, with almost a third of those surveyed identifying as the spouse. This data is consistent with previous research.[5] These strong, pre-existing relationships also provide context for some of the emotional burdens reported by the caregivers, such as grief and depressive symptoms. This conclusion parallels previous findings, which link familial caregiving to existential distress and helplessness derived from uncertainty in patient outcomes.[6] Additionally, family dynamics serve as a moderating factor in perceived cancer caregiver burden.[7] Bensen et. al highlighted four main themes of familial distress in the families of a caregiver: failed support, relational tensions, denial, and additional care work.[8] As such, dysfunctional family dynamics potentially explain why stress and subsequent mental health issues increased in our sample of caregivers.

The surveyed caregivers also reported love and duty to their loved one as primary motivators for their caregiving responsibilities. This explanation potentially fills a present gap in the literature; previous studies primarily focus on how other factors impact the cancer caretaker burden, without taking into account the potential motivations of the caretaker. However, understanding motivation may aid in developing necessary support for caretakers. Previous analyses parallel this hypothesis: understanding the intersectionality of different factors contributing to burden, including motivational factors, may inform caretaker support strategies such as interventions and assessment tools.[9] Overall, these relationships add to the complexity of the caregivers’ burden.

The following caregiver burdens were reported as most significant: grief, mental health, physical health, social health, and finances. The deterioration in social health is consistent with other studies; when caregivers are busy caring for their loved one, they often report less social interaction with others.[10] Decreasing these interactions may also decrease perceived social support, which can further impact mental health and perceived caregiver burden. A similar relationship was found between physical health and caregiver burden; specifically, too many caretaker tasks and/or pre-existing caretaker health conditions can exacerbate the perceived caretaker burden.[10] The financial implications on a caretaker are also consistent with previous research. For instance, transportation alone can be a source of stress for cancer patient caretakers. Previous analyses revealed that biweekly transportation costs can be as high as $43.60, and almost 60% of those surveyed reported a need for transportation accommodations on the “institutional level”.[11]

The results of this study emphasize a need for caretaker support and interventions. Previous research indicates promising results with regard to intervention efficacy; for instance, interventions that involve both caretakers and the patient-caretaker dyads yielded statistically significant improvements in the same core characteristics described in the present study: mental well-being, anxiety, and depression.[12] Another promising direction involves meaning-making interventions, which have shown to the combat negative effects of caregiver burdens related to depressive and grief symptoms, namely existential distress.[6] While these interventions are promising, many are still in their early phases of development, and indicating a need for future efforts that focus on efficacy and real-world effectiveness.[13] Through mitigating these negative effects, we may ease the burden of cancer patient caretakers.

CONCLUSION

The results of this study depict caregivers, namely family members and friends, motivated by love and a sense of duty when providing care. The present research also highlights the unique challenges faced by caregivers and informs future initiatives to mitigate these challenges, thereby improving outcomes for both cancer patients and their caregivers. Ultimately, these efforts may translate to a more sustainable caregiving experience.

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