







# Profile of the Postoperative Care Provided for Patients With Pancreatic and Periampullary Cancers by Family and Unpaid Caregivers

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## ABSTRACT


**PURPOSE** Patients with pancreatic and periampullary cancers may experience significant reduction in their quality of life and often rely on family and unpaid caregivers for assistance after surgery. However, as caregivers are not systematically identified, little is known about the nature, difficulty, and personal demands of assistance they provide. We aim to assess the frequency and difficulty of specific assistance caregivers provide and identify potential interventions that could alleviate the caregiving demands.

**METHODS** This was a prospective, multi-institutional study of caregivers accompanying patients with periampullary and pancreatic cancer at their 1-month post-pancreatectomy office visit. An instrument that drew heavily on the National Study of Caregiving was administered to caregivers.

**RESULTS** Of 240 caregivers, more than half (58.3%) of caregivers were the patients' spouse, a quarter (25.8%) were daughters or sons, 12.9% other relatives, and 2.9% nonrelatives. Caregivers least frequently provided assistance with transportation (14.6% every day) and most frequently provided assistance with housework (65.0% every day,  $P = .003$ ) and diet (56.5% every day,  $P = .004$ ). Caregivers reported the least difficulty helping patients with exercise (1.5% somewhat difficult). Caregivers reported significantly more difficulty with assisting with housework (14.5% somewhat difficult,  $P < .001$ ) and diet (14.9% somewhat difficult,  $P < .001$ ). Caregivers identified the immediate postpancreatectomy and early discharge periods as the most stressful phases. They also reported having received very little information about available services that could have supported their efforts.

**CONCLUSION** Caregivers of patients with periampullary or pancreatic cancer provide considerable assistance in the postoperative period and many reported difficulty in assisting with housework and diet. Work is needed to better prepare and support caregivers to better enable them to adequately care for patients with pancreas and periampullary cancer.

## ACCOMPANYING CONTENT

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## INTRODUCTION

The incidence of pancreatic and periampullary cancer has been on the rise, with pancreatic cancer projected to be the fourth leading cause of cancer deaths in the United States in 2021.<sup>1</sup> Although significant advances have been made in the efficacy of chemotherapeutics for the disease, surgical resection remains the only treatment that provides patients the possibility of long-term survival.<sup>2</sup> However, surgical resection is associated with significant morbidity that can

decondition patients and often lead to significant weight loss for several months postoperatively.<sup>3,4</sup> Additionally, any pancreatic resection has a significant impact on patients' quality of life. Part of this may be caused by postoperative exocrine insufficiency, manifesting as diarrhea, indigestion, bloating, need for enzyme replacement therapy, and endocrine insufficiency, such as diabetes with the need for insulin.<sup>5-8</sup> These factors aggravate the already diminished quality of life that is present at the time of preoperative surgical evaluation.<sup>9</sup> Patients are forced to make acute

## CONTEXT

### Key Objectives

What is the nature, frequency, and difficulty associated with the care that family and other unpaid caregivers provide patients with pancreatic and periampullary cancers who have undergone a pancreatectomy?

### Knowledge Generated

Caregivers most frequently assisted with housework and diet and reported the greatest amount of difficulty with these. Caregivers identified the immediate postpancreatectomy and early discharge periods as most stressful and wanted more information on postoperative expectations and better preparation as a caregiver.

### Relevance

This study highlights room for improvement in better preparing and supporting caregivers to adequately care for patients with pancreas and periampullary cancer.

adjustments to their physical activities and diets to accommodate their postoperative gastrointestinal anatomy and function.

For these reasons, as well as the often advanced age, and frailty of patients with pancreatic and periampullary cancers, postpancreatectomy patients often rely on family and unpaid caregivers for support after hospital discharge.<sup>10</sup> However, surgical research has not focused on out-of-hospital postoperative care and logistics. Specifically, caregivers are not systematically identified or routinely assessed in most cancer care delivery settings.<sup>11</sup> Little is known about who caregivers are, as well as the nature and degree of assistance that they provide patients after pancreatectomy. The aim of this study was to identify the demographic characteristics of family and unpaid caregivers for patients with pancreatic and periampullary cancers after pancreatectomy. Additionally, this study assesses the frequency and difficulty of specific help provided by caregivers and identifies potential interventions that may alleviate the demands of caregiving.

## METHODS

This prospective, tri-institutional study was conducted from January 2019 to January 2020. The study was approved by the institutional review board (IRB) of all participating institutions. The study design and results were reported in concordance with the Checklist for Reporting of Survey Studies (Data Supplement [Table 1], online only).<sup>12</sup> The surgery clinic schedule was screened by the clinic's charge nurse for patients who had undergone surgical resection for pancreatic or periampullary cancer and were scheduled for their 1-month postoperative clinic appointment. Eligible patients met with research staff before their scheduled appointment to be introduced to the study and its procedures and were invited to participate. A caregiver was defined as a person older than 18 years who accompanied the patient to

the postoperative visit and was identified by the patient as their primary caregiver. In accordance with the IRB's protocol, informed consent was obtained first from the patient and then from the caregiver. Once patient consent was obtained, caregivers were then given an iPad to complete the survey on a REDCap platform in a private room separate from the patient.<sup>13</sup> Caregivers were also given the option to complete the survey online at a later time via an emailed link. Providers were blinded to patients' and caregivers' participation or lack thereof during the clinic visit.

### Instrument and Data Sources

An instrument was developed that included comprehensive measures of caregiver demographics, caregiving circumstances, and experiences. The instrument drew heavily on widely tested and validated measures of caregiver experiences from the National Study of Caregiving.<sup>14-16</sup> The frequency of specific types of assistance provided by caregivers was assessed on a 1 (not at all) to 4 (a lot) Likert-type scale. Caregivers assessed the difficulty of each type of assistance on a 1 (not at all difficult) to 4 (very difficult) Likert-type scale. Additional instruments included the Patient Health Questionnaire-2 (PHQ-2),<sup>17</sup> Generalized Anxiety Disorder 2-item (GAD-2),<sup>18,19</sup> and Rapid Estimate of Adult Literacy in Medicine items.<sup>20</sup> The PHQ-2 was designed as a depression screening tool and uses a 0-6 scale, where a score of 3 or greater serves as a validated cutoff for detection of depression. The GAD-2 screens for anxiety and is similarly scored on a 0-6 scale with a cutoff score of 3. Respite care was defined as paid services for patient assistance so that the caregiver could take time off. Paid help was defined as a service to perform household chores and personal care. Two open-ended questions were added for qualitative analysis: one question regarding the most stressful time for the caregiver during the patient's treatment and the second asking what information or service would have been most helpful to the caregiver. The goal of the open-ended

questions was to elicit input and experiences that were not assessed in the closed-ended, structured questions. This decision was guided by the dearth of preexisting literature on caregivers' experience caring for patients with pancreatic or periampullary cancer.

Patient-level clinical variables were abstracted from the institutions' National Surgical Quality Improvement Project databases. Variables abstracted include patient sex, age, race, body mass index, preoperative use of chemotherapy and radiation, indication for operation, and type of operation.

**Statistical Analysis**

All statistical analyses were performed using Intercooled Stata software, version 15.1 (StataCorp, College Station, TX). Categorical variables were presented in frequencies with percentages and compared across groups with the Chi-squared test. The frequency and difficulty associated with specific assistance were analyzed as ordinal variables and were compared across each other with Kendall's rank-order correlation coefficient. The specific assistance associated with the lowest frequency and least difficulty was used as the controls against the other assistance for the comparative analyses. Continuous variables were presented in medians with interquartile ranges and compared across groups with the Kruskal-Wallis test. Statistical significance was accepted at the *P* < .05 level. Open-ended questions were analyzed qualitatively using a grounded theory approach and categorized themes were identified from the responses.

**RESULTS**

**Caregiver Demographics**

A total of 240 caregivers participated in the study (response rate 90.6%). The median age of caregivers was 60.0 years (IQR, 50.0-68.0 years), 70.8% of whom were women (Table 1). The majority were White (83.8%) and married (79.2%). More than half of the caregivers had at least a college graduate level education. When assessing the relationship of caregivers to patients, 58.3% reported being a spouse, 25.8% a daughter or son, 12.9% another relative, and 2.9% a nonrelative. Most caregivers (70.8%) lived with the patient, and for those who did not, most drove (84.3%) to the patients' residence with a median one-way traveling time of 15.0 minutes (IQR, 5.0-60.0 minutes). Less than half of caregivers logged into the MyChart/Patient Gateway, and for those who did, 91.1% used the patients' log-in instead of their own.

**Patient Demographics**

There were 201 patients who participated in the study. Of all patients, 42.9% were female, with a median age of 68.2 years (IQR, 60.8-74.7 years). The majority of patients were White (87.1%), with another 6.9% and 3.7% being Black or African

**TABLE 1. Demographics of Caregiver of Patients With Pancreatic and Periampullary Cancers Who Have Undergone a Pancreatectomy**

Variables	N = 240
Age, years, median (IQR)	60.0 (50.0-68.0)
Female, No. (%)	170 (70.8)
Race, No. (%)	
White or Caucasian	201 (83.8)
African American, African descent, or Black	22 (9.2)
Hispanic or Latino	2 (0.8)
Asian or Asian American	13 (5.4)
Others	2 (0.8)
Marital status, No. (%)	
Married	190 (79.2)
Widowed	8 (3.3)
Single/never married	24 (10.0)
Divorced/separated	17 (7.1)
Refused	1 (0.4)
Education attainment, No. (%)	
Less than high school	3 (1.2)
High school graduate (grade 12 or GED)	33 (13.8)
Some college or technical/vocational school	71 (29.6)
College graduate (BS, BA)	59 (24.6)
Postgraduate or professional degree	74 (30.8)
Adults age 18 years or older in the household, median (IQR)	2.0 (1.0-2.0)
Child younger than 18 years in the household, No. (%)	53 (22.1)
No. of children younger than 18 years in the household? median (IQR)	2.0 (1.0-3.0)
Relationship to patient, No. (%)	
Spouse	140 (58.3)
Daughter or son	62 (25.8)
Other relative	31 (12.9)
Nonrelative	7 (2.9)
Live with patient, No. (%)	170 (70.8)
Mode of transportation to patients' residence, No. (%)	
Walk	3 (4.3)
Drive	59 (84.3)
Taxi/uber/lyft	1 (1.4)
Train	1 (1.4)
Airplane	6 (8.6)
Traveling time, minutes, median (IQR)	15.0 (5.0-60.0)
Log into MyChart/Patient Gateway, No. (%)	101 (42.1)
Log-in account, No. (%)	
My own log-in	8 (7.9)
The patients log-in	92 (91.1)
I do not remember	1 (1.0)
Has the patient discussed their personal values, life goals, and preferences regarding future medical needs with you? No. (%)	213 (88.8)
Would you have liked the patient to discuss their preferences regarding discussion of personal values, life goals, and preferences, No. (%)	16 (6.2)

Abbreviation: GED, general education development.

American and Asian, respectively. The median body mass index for the cohort was 25.1 kg/m<sup>2</sup> (IQR, 22.5–28.1 kg/m<sup>2</sup>). Eighty one percent of patients underwent pan-creatoduodenectomy, with the rest undergoing distal pan-createtectomies. When assessing the indication of the operation, 69.2% of patients underwent pancreatectomy for pancreatic adenocarcinoma, followed by 5.0% for intraductal papillary mucinous neoplasms and 4.2% for ampullary adenocarcinoma. Of patients with pancreatic adenocarcinoma, 36.6% had received preoperative chemotherapy and 28.2% had received preoperative radiation therapy.

### Caregiver Well-Being and Support

Caregivers reported a median general health score of 69.5 (IQR, 51.0–85.0) on a 0–100 scale. The prevalence of a positive depression screen with the PHQ-3 was 17.5%, and the prevalence of a positive anxiety screen with the GAD-3 was 23.8%. The breakdown of response to each instrument is shown in [Table 2](#). Most caregivers reported having confiding support (96.6%) and caregiving support (77.6%). However, only 11.8% of caregivers used respite care, and 11.0% used a paid helper.

### Nature and Difficulty of Assistance Provided

The least frequently provided type of assistance was transportation (18.8% most days, 14.6% every day). Caregivers most frequently provided the following assistance: shopping (32.8% most days, 17.2% every day,  $P < .001$  when compared with transportation), housework (16.9% most days, 65.0% every day,  $P = .003$  when compared with transportation), self-care (10.1% most days, 20.7% every day,  $P = .003$  when compared with transportation), and diet-related assistance (18.8% most days, 56.5% every day,  $P = .004$  when compared with transportation; [Fig 1](#)).

When assessing the difficulty associated with each type of assistance, caregivers reported the least amount of difficulty helping patients with exercise (1.5% somewhat difficult, 0.8% very difficult). Caregivers found all other assistance significantly more difficult to perform when compared with exercise ([Fig 2](#).) Notably, caregivers found significantly more difficulty associated with assisting with housework (14.5% somewhat difficult, 1.3% very difficult,  $P < .001$  when compared with exercise) and diet (14.9% somewhat difficult, 2.8% very difficult,  $P < .001$  when compared with exercise).

### Most Stressful Time Periods and Caregivers' Needs

Caregivers identified the period immediately after the operation while the patient was still in the hospital and the period on discharge as the most stressful phases ( $n = 112$ , 46.7%). Caregivers noted in free-text comments that stress was associated with the intensity of care required, especially at home, surrounding symptom management and medication management (ie, timing of insulin dosing, frequency of pancreatic enzyme replacement). The second most endorsed

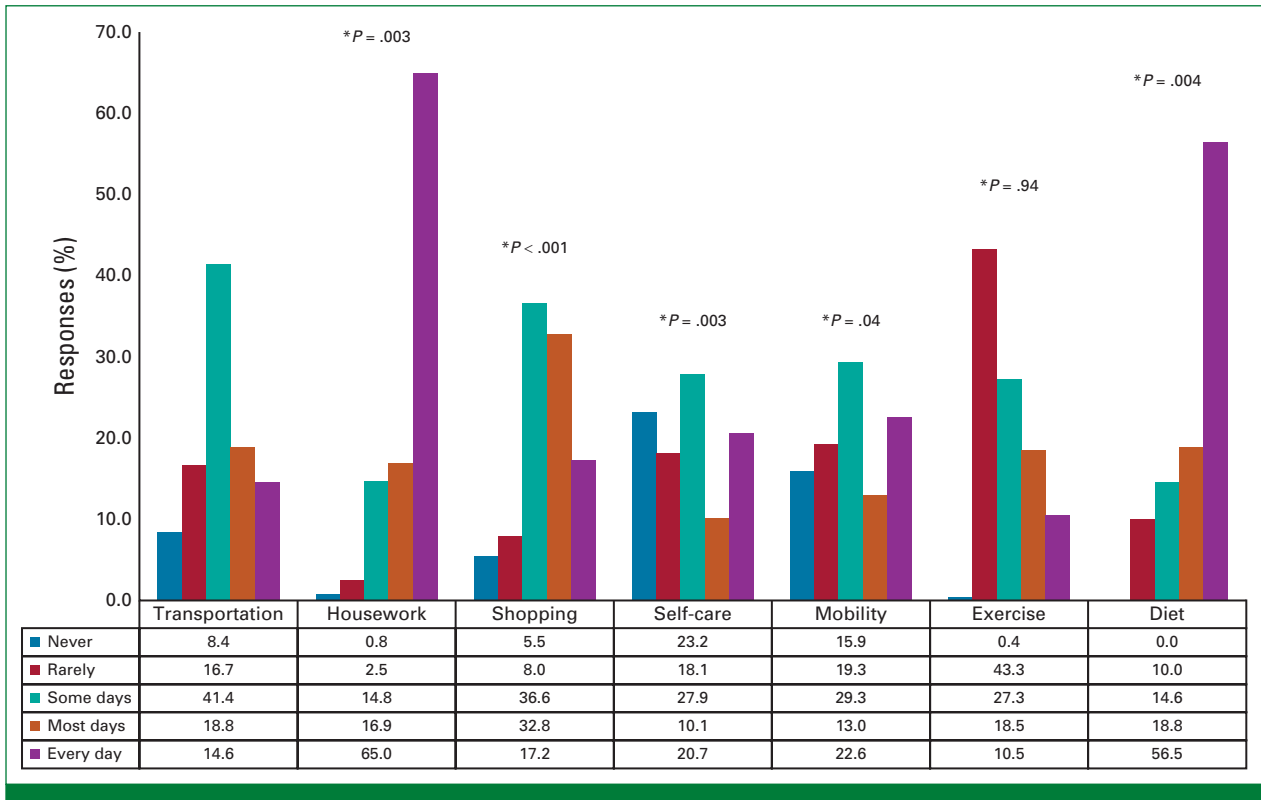
**TABLE 2.** Well-Being End Points and Support Utilization for Caregivers of Patients With Pancreatic and Periampullary Cancers Who Have Undergone a Pancreatectomy

Variables	N = 240
General health, median (IQR)	69.5 (51.0-85.0)
PHQ-2 score $\geq 3$ , No. (%)	42 (17.5)
Little interest or pleasure in doing things past 4 weeks, No. (%)	
Not at all	131 (54.6)
Several days	63 (26.2)
More than half the days	23 (9.6)
Nearly every day	23 (9.6)
Bothered by feeling down, depressed, or hopeless past 2 weeks, No. (%)	
Not at all	149 (62.1)
Several days	75 (31.2)
More than half the days	13 (5.4)
Nearly every day	3 (1.2)
GAD-2 score $\geq 3$	57 (23.8)
Feeling nervous, anxious, or on edge past 4 weeks, No. (%)	
Not at all	74 (30.8)
Several days	131 (54.6)
More than half the days	19 (7.9)
Nearly every day	16 (6.7)
Not being able to stop or control worrying past 4 weeks, No. (%)	
Not at all	119 (49.6)
Several days	77 (32.1)
More than half the days	31 (12.9)
Nearly every day	13 (5.4)
Social support, No. (%)	
Friends and family confiding support	229 (96.6)
Friends and family caregiving support	184 (77.6)
Support group participation	8 (3.4)
Service support, No. (%)	
Respite care	28 (11.8)
Paid helper	26 (11.0)

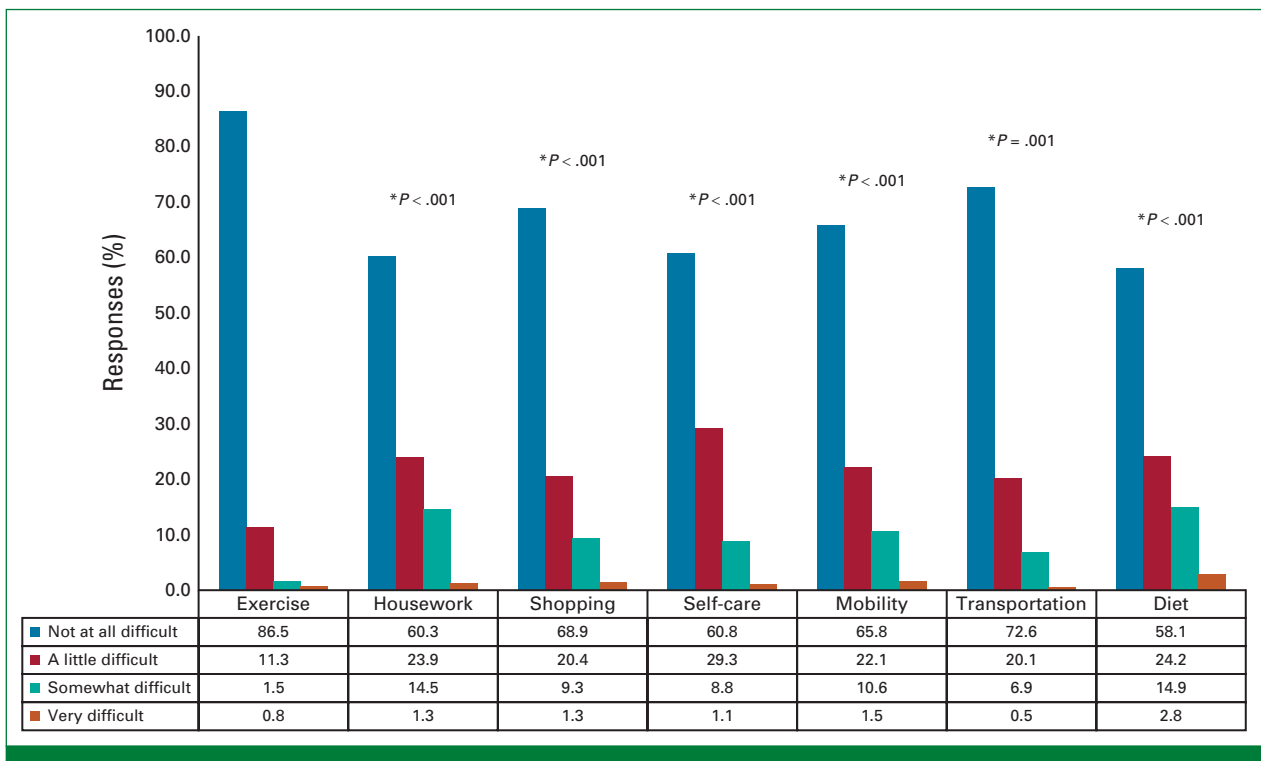
Abbreviations: GAD-2, Generalized Anxiety Disorder 2-item; PHQ-2, Patient Health Questionnaire-2.

aspect of stress involved psychosocial stress around the time of initial diagnosis ( $n = 47$ , 19.6%), followed by stress during treatment with chemotherapy ( $n = 30$ , 12.5%) and struggles with the patient's dieting needs and restrictions ( $n = 13$ , 5.4%). Other themes identified included stress because of travel and logistics ( $n = 8$ , 3.3%), finances (including pressure to remain at one's job to retain health insurance, for those who worked;  $n = 6$ , 2.5%), and challenges during treatment with radiation ( $n = 6$ , 2.5%; [Table 3](#)).

The majority of caregivers would have liked more information on expectations of postoperative care ( $n = 40$ , 16.7%). Additionally, they reported having received very



**FIG 1.** The nature of assistance provided by caregivers to patients with pancreatic and periampullary cancers after pancreatectomy. \**P* values compare the specific assistance with transportation as the control group.



**FIG 2.** The degree of difficulty of assistance provided by caregivers to patients with pancreatic and periampullary cancers after pancreatectomy. \**P* values compare the specific assistance with exercise as the control group.

**TABLE 3. Qualitative Assessment of Open-Ended Questions Surrounding the Most Stressful Period as a Caregiver and Information or Services That Would Have Been Most Helpful With Representative Caregiver Quotes**

Most Stressful Period for Caregivers
<p>Immediate period after operation and upon discharge (n = 112)</p> <p>"Immediately after surgery while pain and diet require constant attention."            "Just not knowing what was considered normal, side effects or when I should call the doctor."            "Bringing Dad home after surgery and not really being prepared for how much care he was going to be. Had I known, he would have had to go to rehab for a bit."            "On the day of discharge, I was very nervous about the tube feeds, insulin, meds, sugar readings, and getting everything done at the right time."            "When we were first discharged, keeping track of the medications was a little overwhelming."</p>
<p>Time of diagnosis (n = 47)</p> <p>"The most stressful time was the first initial diagnosis, not knowing the outcome of the future and next steps in treatment."            "The initial diagnosis of cancer and finding out what treatment plans we would have to go through: chemo, radiation, major surgery. Each step felt like a hurdle."</p>
<p>During chemotherapy (n = 30)</p> <p>"He went through a lot after his third cycle of chemotherapy."            "Driving him for chemotherapy sessions and appointments was a lot."</p>
<p>Struggles with dieting needs and restrictions (n = 13)</p> <p>"His lack of dieting and not wanting to eat."            "When he is not feeling well that is stressful and even just being able to have the food in the house he likes stresses me."</p>
<p>Traveling needs (n = 8)</p> <p>"Traveling is most stressful. I do all the driving for [patient's name] and myself. It's driving into the city that gets stressful."            "Driving to radiation every day was stressful. Going to the hospital all the time for hospitalizations, bloodwork, radiation, and chemo felt overwhelming."</p>
<p>Finances (n = 6)</p> <p>"When I needed to miss work and incur large travel costs to visit."            "Had to stay in a hotel, and could only stay for a few days as I had to go to work as I am the only one working and I hold the insurance."</p>
<p>Information or service that would have been or was helpful</p>
<p>Information about expectations of postoperative care (n = 40)</p> <p>"How do I, as a caregiver and not a medical professional, provide and maintain her care properly and within reason at home?"            "Maybe a video or list of as much information on what to expect after surgery or a type of hotline just for surgery patients' caregivers to call just to ask questions so they don't have call the office and then wait for a response."            "Maybe we didn't ask the right questions but in this situation, you wish you had asked a lot of questions that you didn't. Would be nice if the surgeons and oncologists had a list of frequently asked questions and brought those up when the patients and family are taking in so much info. at one time while feeling lots of emotion too. So, saying to a pt. 'One of our FAQs is XXXXX, are you curious about that?' would be very helpful."            "I feel that caregivers are given very little information about services available (home health aides, cleaners, or services to drive patients to appointments). More information to the caregiver about support groups or services would be greatly appreciated. Of course, the patient deserves the best care, but delivering that care involves family and friends and it can be exhausting. We need more than a brochure."</p>
<p>Education on dietary needs and restrictions (n = 17)</p> <p>"A weekly menu to follow, I used the suggested diet from [hospital] with small meals every 2 hrs"            "Meals on wheels."            "Having some easy to prepare food for her and some guidance on tracking medicine dispensing."</p>
<p>Visiting or home nursing services (n = 9)</p> <p>"The visiting nurses (nurse, physiotherapy, occupational therapy) were most helpful. They were able to help reduce anxiety about patient's health."            "The nurses that visited him and the PT that saw him at home. They reinforced increasing fluids and food. Along with exercise."</p>
<p>Support group (n = 6)</p> <p>"Support group in the hospital."            "Hearing from other patients during treatments."</p>
<p>Billing expectations and financial aid (n = 5)</p> <p>"Probably one thing that would be most helpful is to know what all of the treatments and surgeries would cost and what our share in this might be. We've been told that we have excellent insurance and when I look at the bill from the insurance and supplemental insurance there is a statement 'You might be billed for \$XXX amount.' We have no idea what this mean anymore than we know that the patient might die during the surgery. This is a bit unsettling."            "I would have appreciated if someone talked to be about my employment and how caring for my husband would affect that. This person could have helped me think ahead to see how I might put support in place that would allow me to work."</p>
<p>Better communication with care teams (n = 5)</p> <p>"I was only there at the hospital when I could find people to care for my children so I was not privy to all of the patient's medical information because I wasn't there physically. It would have been nice if I could have had a person reach out to me on a somewhat regular basis to let me know how he was doing. I felt disconnected. When he was finally able to come home I felt thrown into the caregiver role without much knowledge of what his post surgery care would be, how long his symptoms/setbacks could last, what to expect during his recovery, his current medications (patient was often stubborn in taking them regularly). It was very overwhelming."            "Any online access to her daily treatment so I didn't have to call the ward nurses x2 or 3 times per day."            "Better communications at time of release. No one talked to me when the patient was released."</p>
<p>Psychotherapy (n = 4)</p> <p>"I believe therapy would be helpful for both caregivers and the patient during the time of diagnosis thru surgery recovery."            "A support team person to learn more about why my husband may have been reacting to me the way he was and is and how best to cope."</p>
<p>Paid helper (n = 3)</p> <p>"Elder services have a nurse come in several times a week and a weekly helper who does light cleaning and grocery shopping. That has been extremely helpful."            "Maid service to get to household chores."</p>
<p>Transportation and validated parking (n = 3)</p> <p>"Rides to appointments or validated parking."</p>

little information about available services that could have supported their efforts, such as home health aides, paid helpers, or services that transport patients to appointments. The second most common deficient theme identified was the lack of knowledge on dietary needs and restrictions ( $n = 17$ , 7.1%). Caregivers struggled with knowing the types of food the patient could tolerate without causing abdominal bloating or diarrhea. Those who consulted with a nutritionist postoperative felt that such a consultation alleviated that stress. Other needs identified by caregivers included having visiting or home nursing services, participating in a support group who have gone through a similar experience, billing expectations and financial aid, better communication with care teams, and psychotherapy for both caregivers and patients (Table 3).

## DISCUSSION

This study found that almost a quarter of caregivers for patients with pancreatic and periampullary cancers after pancreatectomy screened positive for depression and anxiety. Although most caregivers had confiding and caregiving support, very few reported using respite care services or paid helpers. Caregivers most frequently provided patients assistance with shopping, housework, self-care, and diet. They reported the greatest difficulty providing assistance with housework and diet. Most caregivers identified the immediate postpancreatectomy and early discharge periods as the most stressful phases, emphasizing that more information on expectations of postoperative care and better preparation as a caregiver would have been most helpful.

The surgical and oncologic literature have historically focused on in-hospital outcomes such as length of hospital stay, morbidity, and readmission rates as quality metrics for cancer care. However, hospitals are moving to shorten length of hospital stay through enhanced recovery pathways to decrease the burgeoning health care cost.<sup>21,22</sup> In this setting, a considerable amount of patient care responsibility has been shifted onto family and unpaid caregivers who presently serve as a considerable workforce even when patients are in rehabilitation and residential care facilities.<sup>23,24</sup> A recent study demonstrated that social support was associated with decreased health care utilization and improved overall survival in patients with hematologic malignancies.<sup>25</sup> Another study demonstrated that having social support was positively associated with the odds of receiving chemotherapy in patients with advanced colorectal cancer.<sup>26</sup> The ability of family and informal caregivers to provide care and assistance has a direct impact on patient outcomes, and providers should start conceptualizing health care as a process that encompasses care beyond the walls of the hospital. This study attempts to address this gap in pancreatic and periampullary cancer, an aggressive solid organ malignancy that requires a complex operation that likely renders patients even more reliant on caregivers for care.

Given the advanced age and frailty of most patients at the time of pancreatic or periampullary cancer diagnosis, support and assistance are often provided by adult children. These caregivers are typically working, in contrast to retired spouses who do not face similar working pressure. In this study, 42% of caregivers were either the children or relatives of patients. This is almost two-fold higher than the proportion (20%-30%) of adult children or relative caregivers reported in the breast<sup>27,28</sup> and lung cancer caregiver population.<sup>29</sup> Although most caregiver studies have focused on psychosocial interventions and support,<sup>30</sup> the difference in caregiver demographics in this study has important implications for future research. There is a need to focus on assessing the impact of caregiving on financial stability and work productivity as these aspects are more relevant to a younger caregiver population looking after older patients with solid organ tumors.

Notably, up to a quarter of caregivers had positive scores on the depression and anxiety screens collected in the postoperative setting. A previous cross-sectional study of 462 patients with pancreatic and periampullary tumors demonstrated that patients experience weight loss, gastrointestinal disturbances, anxiety, and depression that all significantly impair their quality of life at the time of preoperative evaluation.<sup>9,31</sup> The prevalence of patient depression and anxiety was associated with nonreceipt of chemotherapy treatment and poorer overall survival.<sup>32</sup> It is likely that patients' caregivers also experience similar impairment to their well-being in the preoperative setting. Future studies should include caregiver assessment at the time of preoperative evaluation as another important time to provide initial support.

An important finding in this study is that caregivers reported that the most frequent type of assistance they provided—with the patient's diet—was also associated with a high degree of difficulty. This is consistent with the literature reporting that postpancreatectomy patients frequently experience postoperative digestive issues. An assessment of symptom clusters in 143 patients with pancreatic cancer found that gastrointestinal disturbances such as poor appetite, trouble digesting food, and weight loss to be the most prevalent and severe symptoms and persisted even at 9 months postoperatively.<sup>33</sup> A separate study of 248 patients who had been treated via pancreatoduodenectomy demonstrated that bloating, indigestion, and excessive flatulence persisted even at 5 years after their resections.<sup>6</sup> This is likely in part due to the changes in gastrointestinal anatomy associated with the pancreatoduodenectomy procedure that necessitates modifications in both the presentation (mechanical diet) and size of patients' meals. Along with the need for pancreatic enzyme replacement therapy, caregivers likely experience difficulty in helping patients with day-to-day dietary challenges. Conversely, we found assistance with exercise to be least often identified as being difficult among caregivers. As exercise was not objectively defined in the questionnaire, caregivers may have interpreted the question

as involving less strenuous or intensive activities—or the assisting with exercise have been overshadowed by more difficult tasks, reflecting anchoring biases.

When asked about potential support that could prove helpful for caregivers, the majority sought more information and education on postpancreatectomy expectations and patient care needs. This is consistent with the literature showing that caregivers lack access to and are poorly informed about patients' health and treatment plans.<sup>34-36</sup> An assessment of 50 available websites on pancreatic cancer treatment options demonstrated a readability score equivalent to that of a second-year university level (<39% of US population),<sup>37</sup> compounding the difficulty for caregivers to access relevant and understandable disease-specific information. The efficacy of providing this information during the preoperative clinic visit may be limited by cognitive overload, with most patients themselves being unsure of postoperative expectations.<sup>38</sup> Video- and multimedia-based interventions have been shown to be beneficial to patients and caregivers in the preoperative setting for lung cancer,<sup>39</sup> and the generalizability of such an intervention to caregivers of patients with pancreatic and periampullary cancers should be investigated.

This study was conducted at 3 very high-volume, academic, tertiary referral centers for pancreatic and periampullary cancer. As such, participating caregivers may represent a more sophisticated and able population, and the study's findings may underestimate the demands of caregiving. Additionally, 84% of the studies' participant caregivers were

White. More intentional participant recruitment to include caregivers of underrepresented racial minorities is needed so as not to exclude their perspectives and experiences. Finally, this study's timeframe focuses on 30 days after the initial operation, which is a limited time window to be assessing the caregiving experience. It is unknown if identified caregiving difficulties persist beyond the 30-day observation window or if there are other key challenges that extends beyond that timeframe and are unmeasured.

However, the majority of caregivers in this study identified the immediate postoperative phase as the most stressful time period, and the data presented are expected to represent the time during which caregiving needs are the most intense.

In conclusion, almost a quarter of caregivers for patients with pancreatic and periampullary cancers after pancreatectomy were screened positive for depression and anxiety. Caregivers most frequently provided assistance with housework, self-care, and diet, and reported most difficulties with assisting with housework and diet. Most caregivers identified the immediate postoperative period and early discharge periods as the most stressful phases and desired more information on expectations of postoperative care and better preparation as a caregiver. This study provides a profile of family and unpaid caregivers for patients with pancreatic and periampullary cancers and highlights the room for improvement in better preparing and supporting caregivers in providing care to their family members.

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## EQUAL CONTRIBUTION

Z.V.F. and J.T. contributed equally to this work.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

### Profile of the Postoperative Care Provided for Patients With Pancreatic and Periampullary Cancers by Family and Unpaid Caregivers

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