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ORIGINAL ARTICLE

Using photography to explore psychological distress in patients with pancreatic cancer and their caregivers: a qualitative study

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Abstract

Purpose The quality of life (QOL) experiences of patients with pancreatic cancer and their caregivers is poorly understood. Psychological distress is high, but few studies examine the factors associated with psychological distress. The purpose of this study is to gain a richer understanding of the factors associated with psychological distress from patient and caregiver perspectives.

Methods Twenty participants (13 patients, 7 caregivers) completed group discussions on the experiences of living with pancreatic cancer. Using photovoice methods, participants took photographs and provided narratives depicting the distress they experienced. Participant-produced photographs and group discussion transcripts were analyzed to identify key themes using thematic analysis.

Results Commonalities between patient and caregiver sources of distress emerged despite their distinct roles. Findings revealed four major areas of distress: diagnosis of an unexpected advanced cancer, changes in roles and identity, management of weight loss and gastrointestinal problems, and fear of the future. Participants also discussed unique perspectives such as the stigma of pancreatic cancer and caregiver guilt.

Conclusions Photovoice provides a unique insight into the lives of patients with pancreatic cancer and their caregivers. Our findings contribute to the gap in the current literature by providing a better understanding of the factors surrounding pancreatic cancer distress. We also identify several clinical recommendations to improve cancer care delivery and areas for future research.

Keywords Pancreatic cancer · Photovoice · Quality of life · Distress · Caregivers · Qualitative

Abbreviations

QOL	Quality of life
GI	Gastrointestinal

Introduction

Pancreatic cancer is the third leading cause of cancer death in the USA with the lowest 5-year survival rate at 8% [1]. In contrast to many other cancers, there are no screening tests for pancreatic cancer, and symptoms do not usually manifest until the cancer has progressed [2]. Surgery is the only realistic chance for a cure, which provides a median survival time of 20.1 to 28.0 months [3]. However, with more than half of patients (52%) presenting with an advanced stage, less than 20% will be eligible for a resection [2]. Those with resectable tumors undergo a complicated surgical procedure, which is often accompanied by adjuvant chemotherapy to a lower risk of recurrence [2]. Those with non-resectable tumors may opt for palliative systemic therapy for relief of symptoms [3].

The quality of life (QOL) experiences of patients and their caregivers is poorly understood [4, 5]. Existing quantitative research focuses on the prevalence and severity of impaired QOL domains. QOL is significantly lower across all domains

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of physical, emotional, social, cognitive, and role functioning compared to other gastrointestinal (GI) cancers [6], particularly for caregivers as the cancer progresses [7]. Rates of subclinical or clinical depression and/or anxiety range from 12 to 78% [4, 6, 8, 9] with unmet physical and psychological needs at moderate to high intensity [10]. Existing qualitative research focuses on the management of pancreatic enzyme insufficiency [11], family communication [12], and stressors related to family caregiving [7], with findings restricted to the experiences of participants from Australia [11], patients with unresectable tumors [7], first-degree relatives [12], and use of investigator-driven questions [7, 11, 12], which may inadequately reflect the full experiences of pancreatic cancer participants within the framework presented by researchers [13]. Thus, a recent 2018 integrative review on the symptom experience of pancreatic cancer concluded the need for more qualitative studies to better understand psychological distress from participant perspectives [5].

Participatory action research methods such as photovoice are highly effective in studying distressed and understudied populations from participant perspectives [14]. Developed by Wang and Burris in the 1990s [15, 16], photovoice is a technique that empowers participants to document meaningful aspects of their lives through photographs and share them with others. Because the photographs and discussion topics are generated by the participants themselves, the process allows participants to be the experts on their issues, resulting in a more comprehensive exploration and discussion of the experiences that are most salient to participants [16]. The end products of the story and images provide a glimpse to the realities of the lives of participants that researchers previously may not have had access to. In the psycho-oncology literature, photovoice has successfully explored the QOL experiences of cancer survivors and their caregivers [13, 17–19], including identifying unmet needs and areas for clinical interventions [20, 21].

Therefore, photovoice may provide a more comprehensive understanding on the impact of pancreatic cancer and offer new insight into the lives of participants. This study is part of a larger study that is the first to use photovoice to investigate the lived experiences of patients with pancreatic cancer and their caregivers [22]. Two main topics that emerged from our main study include psychological distress and coping. This manuscript focuses on the findings related to psychological distress.

Methods

Inclusion criteria

Inclusion criteria encompassed male and female patients diagnosed with primary pancreatic ductal adenocarcinoma in the past 5 years and their self-identified primary caregiver. Patient refusal did not exclude caregiver participation, and caregiver refusal did not exclude patient participation. Exclusion criteria encompassed age less than 18 years, insufficient English, and poor performance on the Mini-Mental State Examination (score $\leq$ 23) [23].

Study procedures

This study was approved by the institutional review board as part of a larger study examining the lived experiences of individuals affected by pancreatic cancer [22]. Study procedures were conducted at an academic teaching hospital. Medical records were screened between August 2014 and June 2016 for eligibility. Eligible participants interested in research opportunities were approached at their medical appointment. Informed consent was obtained from all participants in the study.

Information on tumor resection (resectable/non-resectable tumor) and treatment status (in active treatment/surveillance) was extracted from patient medical records. Participants completed a brief demographic survey and were contacted to begin the study when a group was identified. Group members were selected based on participant type (patient/caregiver) and availability to meet at a mutual time. To reduce travel burden, sessions were offered in-person or by phone through organized phone conferences. Study materials were distributed electronically to those selecting attendance by phone. All participants received a training orientation to photovoice methods, tips on digital camera use, and ethics of photography. A consent form was completed when an identifiable third party was included in a photograph. Digital cameras were distributed to participants without access to a camera.

Two biweekly 90-min group discussions were held for each participant on the focus question: *What do you want others to know about what it is like living with pancreatic cancer or caregiving for someone with pancreatic cancer*? Topics were self-generated by participants to ensure the participatory nature of the study. Discussions were held in small groups of two to three people to allow sufficient time to discuss each participant's experience. Participants were instructed to bring three photographs corresponding to their selected topic, including a title and brief narrative about the photograph, which were all shared with the group. At the first group discussion, we asked two main questions:

1. Why did you take this picture and how does it relate to the topic?
2. Are the other group members' experience similar or different?

The SHOWED technique [15] was also used to further contextualize the photographs. These questions include the following: What do you see?, What is happening?, How does this relate to our lives?, Why does this situation exist?, and What can we do about it? At the end of the first group discussion, we asked participants to identify a second topic for their next photo assignment and repeated the same procedures listed above for the second group discussion. All sessions were audio-recorded for analyses.

Data analysis

Group discussions were transcribed verbatim by research assistants and subsequently checked and corrected by the lead group facilitator (SSW). Files were uploaded to the qualitative software package NVivo 11 Pro. Data was analyzed using thematic analysis [24]. Key phrases were highlighted and coded into nodes representing similar ideas; text that reflected multiple ideas was coded to more than one node. Related nodes were grouped together to create preliminary themes, which were then reviewed with the participants to ensure accuracy of findings grounded in the participants' experience. Ongoing data analysis and enrollment of participants continued until theme saturation was reached for patient and caregiver groups. Theme saturation was determined by SSW and her supervisor (DBP) when no new information emerged from the patient and caregiver transcripts [25]. Analysis team meetings from multiple disciplines (psychology, oncology, sociology) were then held to review and refine categorization of themes. Pseudonyms were assigned to conceal identity of the participants.

Results

A total of 71 individuals (46 patients, 25 caregivers) consented to participate. Five patients (7.04% of total participants; 10.9% of patient participants) died, and 29 participants (40.8%) withdrew prior to the start of the study due to health decline and desires to focus on medical treatment. Thirty-seven participants attended the training orientation; 17 of these 37 withdrew due to decline in interest, resulting in a total of 20 participants that completed the study. Six patient groups and four caregiver groups were held. Each group completed two photovoice discussions. No new themes emerged in 20 consecutive transcripts, and as such, we determined that theme saturation was achieved with 13 patients and 7 caregivers. Table 1 presents the demographic and clinical characteristics of the participants who completed the study. Patient tumor resection and treatment status were coded the same for their identified caregivers. The majority of participants attended the study in-person (75%). Participants were primarily age 60–69 (55%), Caucasian (95%), female (55%), and partnered (70%). Patients were primarily in active treatment (69.2%) with resectable tumors (61.5%); patient-identified caregivers were primarily spouse/partner caregivers (85.7%). Qualitative findings are presented below and summarized in Table 2.

Diagnosis of an unexpected advanced cancer

At diagnosis, patients reported that poor survivorship statistics, minimal treatment options, and few clinical trials contributed to initial waves of depression. However, anger was the more predominant emotion as they searched for answers to why they had pancreatic cancer:

> The 'why me' came on really strong…I couldn't shake that. This has been thrown at me. I did nothing to deserve it…I never smoked, I don't drink, I was health conscious, I'm not diabetic. I went through all of the risk factors and had none of them (Brittany).

Anger was further fueled by interactions with healthcare professionals who focused on areas of health decline, living wills, and power of attorney. These interactions sent mixed messages to patients that their doctors were giving up on them and reinforced the perception that pancreatic cancer was a death sentence, even among patients with resectable tumors. Edward presented a photograph of a cemetery (Fig. 1) to illustrate his disappointment with the healthcare system: "The attitude of the industry is that when you have pancreatic cancer, they can't do anything for you…they told me basically to go home and get ready to die."

There was also significant distress about prognosis and treatment outcomes. Patients worried whether they would survive the surgery—"Stepping foot into the hospital the day you have surgery, you don't know whether or not you're ever going to step foot outside again. That's a daunting step" (Fiona)—or develop complications of having diabetes and other side effects. They wondered about their recovery time and whether they would ever resume previous functioning again. The uncertainty of "when our time is coming" (Brittany) was even more distressing as patients tearfully asked for more time with family and grandchildren. Caregivers feared losing their loved ones:

> The fear of the unknown, the fear of not being sure of how it's going to happen and how I'm going to react… I'm afraid of losing him…I'm worried about how I'm going to feel…What the hell is gonna happen to me? I have to stay here (Jacklyn).

Management of weight loss and GI symptoms

As patients moved towards treatment, GI-related issues were a major source of distress. Although symptoms of nausea, vomiting, indigestion, diarrhea, and taste disturbance made it

Table 1 Participant demographic and clinical characteristics

Variable	Patients ($n = 13$) Number (%)	Caregivers ($n = 7$) Number (%)	Total sample ($N = 20$) Number (%)
Age bracket			
40–49	1 (7.7)	0 (0)	1 (5)
50–59	4 (30.8)	2 (28.6)	6 (30)
60–69	6 (46.2)	5 (71.4)	11 (55)
70–79	2 (15.4)	0 (0)	2 (10)
Sex			
Male	6 (46.2)	3 (42.9)	9 (45)
Female	7 (53.8)	4 (57.1)	11 (55)
Race			
Caucasian	12 (92.3)	7 (100)	19 (95)
Other	1 (7.7)	0 (0)	1 (5)
Relationship status			
Partnered	7 (53.8)	7 (100)	14 (70)
Unpartnered	6 (46.2)	0 (0)	6 (30)
Tumor resection[a]			
Resectable	8 (61.5)	5 (71.4)	13 (65)
Non-resectable	5 (38.5)	2 (28.6)	7 (35)
Treatment status[a]			
In active treatment	9 (69.2)	6 (85.7)	15 (75)
Surveillance	4 (30.8)	1 (14.3)	5 (25)

[a] Patient tumor resection and treatment status were coded the same for their respective caregivers

challenging to eat, patients did whatever they could to improve survival. They fought images of emaciation and feared their families would "see me waste away" (Greg). Brandon stated,

> I would take whatever meal I wanted to eat and I would put it in a blender. I would add water or chicken broth or beef broth and I would drink it. And you know, if that's the way I have to survive, then so be it.

Patients were frustrated that they were no longer in control of their illness, and endless questions about their diet and weight added to the frustration. Caregivers watched from the sidelines as they too felt helpless in their inability to control treatment or disease side effects:

> Well, I am helpless. I can give her emotional support but I can't cure the cancer, I can't make her not nauseous, I can't make her go to the bathroom, I can't make her eat normally…so it's very frustrating because there's so many things out of my control (Jason).

Changes in roles and identity

Pancreatic cancer now consumed the lives and activities of the participants. Social gatherings and travel plans were canceled as packing and traveling to medical appointments became the new reality. Patients struggled to maintain their identity; for some, the ability to work, complete household chores, and resume the caretaker role was no longer possible as fatigue and treatment side effects limited physical functioning and independence:

> After being so incapacitated from surgery and having to be bathed by my husband, helped in and out of bed, not being allowed to go up and down the stairs for three to four weeks, having my meals brought to me for a good month, you lose that sense of self (Fiona).

The constant attention from family and friends reinforced the feeling of being a patient. Brittany presented a photograph of herself buried behind medication bottles to illustrate this point (Fig. 2): "Since my diagnosis, people have paid too much attention to the 'cancer patient me.' I've asked my friends and family to treat me as just me, and leave the 'patient me' to my oncologist." Other patients found themselves

Table 2 Overview of findings

Finding	Brief description
Diagnosis of an unexpected advanced cancer	Patients were angry with the unexpected diagnosis of an advanced cancer and felt like pancreatic cancer was stigmatized as a death sentence. Caregivers had less time to process their emotions but were extremely distressed with how they would cope with bereavement
Changes in roles and identity	Patients felt like they were losing who they were and becoming more entrenched as "the patient." They did not want to be viewed as a role model because they were just trying to survive. Caregivers struggled with balancing multiple roles and the need for self-care
Management of weight loss and GI symptoms	Weight loss and GI problems were the most distressing side effect. Patients fought hard to eat to survive, and caregivers felt helpless in their ability to manage treatment side effects
Fear of the future	Patients were unsure about how they would do following treatment completion and caregivers became hypervigilant of symptoms and skeptical of good prognosis

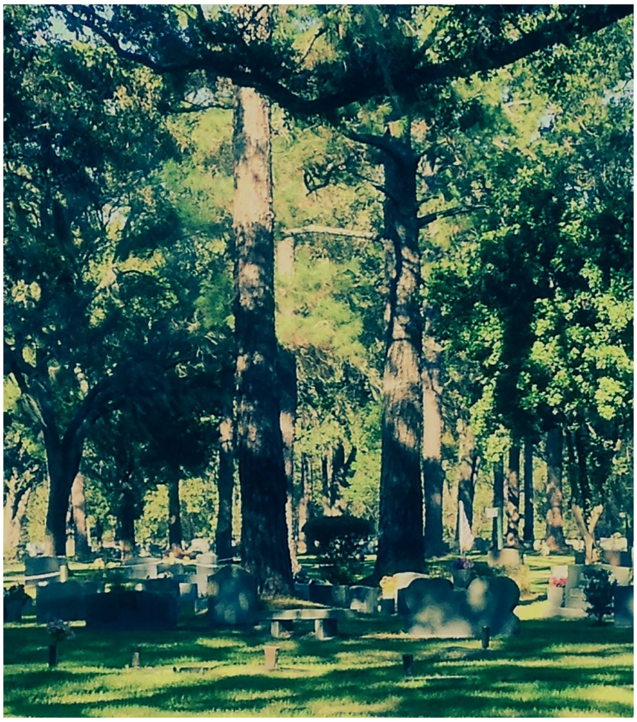

Fig. 1 Make ready for the end. *Source*: contributed by a patient participant. Used with permission. *Note*: this photograph of a cemetery depicts the stigma of pancreatic cancer as a death sentence

becoming a role model for others, but many patients wanted others to know they were not doing anything out of the ordinary: "I'm nobody's hero, I'm nobody's idol. I'm not anyone to be looked up to. I'm just a guy trying to survive" (Brandon).

Caregivers struggled with their new caregiver role. The fixed schedule and inability to travel produced a sense of confinement as they highlighted needs to escape from current reality. Balancing relationships was difficult as caregivers tried to maintain their "husband-wife relationship" without it becoming too much of a "patient-nurse relationship" (Gretchen). The sudden adjustment to learning new medical information, maintaining appointment records, medications, diet and nutrition, alternative treatments, clinical trials, home health care, emergency preparedness, and living will compliance was "mentally draining and extremely frustrating" (Jason); caregivers felt like they were one person trying to assume five different roles of a nurse, secretary, and pharmacist, all while maintaining who they were and picking up the patient's previous tasks. Ian presented a photograph of a deconstructed motor to illustrate caregiver burnout (Fig. 3): "Where do we begin? We need help!" Although caregivers recognized the need for self-care, they tended to "put ourselves on the back-burner" (Helen); taking time out of the day for oneself meant taking time away from the patient, which produced feelings of selfishness and guilt. The perceived unimportance was further fueled by lack of interactions with medical providers: "Even when you go in and see Dr. X or any of the other providers, it's about them [the patients]. Nobody says how are *you* doing?" (Gretchen). Although caregivers reported having good social support from family and friends, they appreciated being in a caregiver group because they did not want to burden their family and felt like others would not understand.

Fig. 2 Can't I just be me? *Source*: contributed by a patient participant. Used with permission. *Note*: this photograph of a patient hidden behind medication bottles depicts the need to maintain sense of self and identity

Fear of the future

For those with resectable tumors, fear of recurrence was prominent, especially as patients moved towards treatment completion. The thought of going through the cancer again was highly distressing. Treatment decision making on port removal was described as "cutting your umbilical cord" (Eileen). Although some thought of it as freeing, others feared how they would do without weekly checkups from their medical team. Caregivers reported becoming more vigilant of new symptoms, aches, or pain as treatment progressed. Although they were excited that the patient was doing well, they were also skeptical of the situation, even when presented with good news from the medical team. They continued to question whether the cancer was really gone, in remission, or in hiding throughout the cancer trajectory. Jacklyn presented a photograph of a dark cloud (Fig. 4) to signify the constant overshadow of doubt and worry:

> No matter what kind of wonderful day you're having, you know that these black clouds are there and on any day, life could change again in a minute. So you never ever really are without feeling that.

Fig. 3 Where do we begin? We need help! *Source*: contributed by a caregiver participant. Used with permission. *Note*: this photograph of a deconstructed motor depicts the feeling of being overwhelmed with the cancer and caregiving experience

Fig. 4 Go away. *Source*: contributed by a caregiver participant. Used with permission. *Note*: this photograph of dark clouds depicts the lingering fear of losing the patient that is always in the back of the mind of caregivers

Discussion

Pancreatic cancer represents a unique group that is distinct from other cancers due to its high mortality, lack of early detection, and limited treatment options. Psychological distress is high, but few studies examine the factors associated with distress. This study is the first to explore the lived experiences of patients with pancreatic cancer and their caregivers using the photovoice methodology. Our findings offer new insight into the lives of pancreatic cancer participants and contribute to the gap in the literature by providing a better understanding of the psychological distress surrounding pancreatic cancer.

Consistent with the literature, patients with pancreatic cancer and their caregivers reported similar sources of distress despite having distinct roles, supporting the notion of parallel experiences between patients and caregivers [9]. Psychological distress was high at initial diagnosis, particularly with the shock of being diagnosed with an unexpected advanced cancer [26]. As patients moved towards treatment, GI-related issues was a major source of distress [11], particularly related to nausea, taste disturbance, and weight loss. The inability to control treatment-related side effects led to feelings of loss of control, which consequently affected sense of self and identity. As patients struggled to reconcile with the loss of previous roles, caregivers struggled with managing multiple roles, which consequently led to caregiver burnout [27] and lack of self-care [7]. Thus, management of role changes was another major source of distress. Fear of the future was also a prominent factor associated with distress, particularly fear of recurrence among those with curative resection [28].

However, our study also revealed several new findings that offer direction for future research. First, the stigma of pancreatic cancer as a death sentence is an area that has not been explored in the pancreatic cancer literature. Although physicians were following cancer care delivery guidelines by discussing end-of-life care with patients, it is also important to be mindful of the unintended effects these interactions may have, such as the perception that providers are giving up on them. Second, although most studies focus on the prevalence of depression among patients with pancreatic cancer [8, 29–31], our findings suggest that anger may be the more prominent emotion to explore at diagnosis. Third, in contrast to previous findings [11], patients in our study reported having a strong appetite, which may reflect advances in pancreatic cancer treatment in symptom management. However, patients continued to complain about fatigue, taste disturbance, and weight loss, which may suggest targeted areas for improvement. Fourth, caregivers in our study recognized the importance and need for self-care but *actively* chose not do so due to feelings of guilt and selfishness for taking time away from the patient. This feeling was especially prominent among our female caregivers, which may suggest gender-related differences. There were also reports of difficulty with balancing spouse/partner roles as a caregiver, which suggests another area to explore. Lastly, it is interesting to note that although the majority of our sample (65%) had resectable tumors with curative intent, much of the discussions were similar to those with advanced cancers. Fear of recurrence appeared to be the only additional source of distress, which may represent an unmet need among those with resectable tumors.

There are some limitations to our findings. For example, our recruitment site offers several pancreatic cancer clinical trials and routinely performs surgery for resectable tumors. Thus, our recruitment site and study retention rates may have reflected a subset of experiences among participants that were provided with a better prognosis compared to the general pancreatic cancer population. Our sample also comprised primarily of

Caucasians; additional themes may have emerged from participants of other regions or cultures. Lastly, although theme saturation was achieved for patient and caregiver groups, the almost 2:1 ratio of patient to caregiver enrollment reflected the fact that caregivers were difficult to enroll unless they presented to the clinic. Therefore, additional themes may have been missed for caregivers who were unable to attend clinic visits.

Clinical recommendations

Our findings present several clinical implications. Specifically, healthcare professionals may consider assessing the readiness of patients to discuss end-of-life care at a separate visit from the initial diagnosis to improve reassurance of care and avoid stigmatizing pancreatic cancer as a death sentence. Acknowledgment of caregivers during clinic visits is also needed to increase caregivers' sense of importance and role in patient-provider interactions. The development of clear pancreatic cancer survivorship care plans is needed [32], especially for patients with resectable tumors to address fears of recurrence. Given the similarities between patient and caregiver experiences, group-based psychosocial interventions using a dyad framework and coping strategies targeting sense of control, guilt, anger, self-care, and fear of recurrence may be beneficial. Future research is encouraged to identify when these interventions may be best implemented. Based on our previous research [33], we suggest that offering resources after a few weeks of active treatment may be the best timeframe to give participants some time to adjust to their diagnosis.

Conclusions

Overall, the participatory-based nature of this study provides unique insight into the QOL experiences that are most salient to pancreatic cancer patients and their caregivers. Specifically, photovoice provided an engaging way for participants to describe their lived experiences and collaborate with researchers in generating content (e.g., photos, discussions, themes) that accurately represent their lives. As a result, we contributed to the gap in the literature by providing a better understanding of the psychological distress surrounding pancreatic cancer and provided a voice to a cancer group that is often understudied in the psycho-oncology literature. Consequently, several clinical recommendations and directions for future research emerge that may contribute to enhanced supportive care for patients with pancreatic cancer and their caregivers.

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Compliance with ethical standards

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

Conflict of interest The authors declare that they have no conflicts of interest.

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