

Development and Initial Pilot Evaluation of a Psychoeducational Intervention for Individuals at High Risk for Pancreatic Cancer

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OBJECTIVES: To develop and determine the acceptability of a group-based digital health psychoeducational intervention aimed at reducing cancer worry based on acceptance and commitment therapy for individuals at high risk for pancreatic cancer.

SAMPLE & SETTING: 13 individuals at high risk for pancreatic cancer with a genetic variant or family history.

METHODS & VARIABLES: Three groups met virtually for one hour each week for four weeks. These sessions provided psychoeducational materials. Digital resources provided mindfulness and educational content. Reported measurements included qualitative responses and participant-reported acceptability.

RESULTS: All participants found the sessions to be useful and would recommend them to others. Recommendations from the first two groups included requests to access the content provided during the remote sessions, contributing to the creation of digital content for the third group.

IMPLICATIONS FOR NURSING: Individuals at high risk for pancreatic cancer can benefit from psychoeducation to reduce cancer worry, which can be accomplished through digital psychoeducational interventions.

KEYWORDS familial pancreatic cancer; acceptance and commitment therapy; psychoeducation

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Pancreatic ductal adenocarcinoma (PDAC) has the lowest survival rate of all solid tumors (Khalaf et al., 2021). Once diagnosed, only 10% of patients with PDAC will survive five years, primarily because PDAC is difficult to identify and treat (Khalaf et al., 2021). PDAC diagnosis rates are increasing, and although PDAC accounts for only 3% of all cancers, it is the third leading cause of cancer-related death (Khalaf et al., 2021) and is projected to be the second leading cause of cancer-related death by 2030 (Park et al., 2021). The low survival rate for PDAC is caused by the limited treatment options at the time of diagnosis because most patients are diagnosed at an advanced stage when curative surgical resection is no longer an option (Park et al., 2021). The average U.S. adult has about a 2% lifetime chance of developing PDAC (Klein, 2021; Park et al., 2021). For individuals who have multiple family members with PDAC or an inherited pathogenic genetic variant (PGV) associated with PDAC (*BRCA1/BRCA2*, *PALB2*, *CDKN2A*, *STK11*, *ATM*, *MLH1/MSH2/MSH6*, or *PRSS1*), the risk is 2–15 times higher than that of the average U.S. adult, depending on the PGV found (Klein, 2021; Park et al., 2021). In addition, in families with an inherited risk of PDAC, risk of other cancers might also be identified, and additional surveillance and prevention recommendations should be provided (Daly et al., 2020).

Those at highest risk because of family history and/or PGVs and no personal history of PDAC are recommended to undergo surveillance to detect early precursors or cancer before it reaches an advanced stage and is no longer curable (Daly et al., 2020; Goggins et al., 2020; Klein, 2021). PDAC surveillance consists of endoscopic ultrasound (requiring

sedation) or annual magnetic resonance imaging (MRI) (Daly et al., 2020), and offers a novel opportunity to improve health outcomes for those at highest risk through early detection, subsequently lengthening median survival. The International Cancer of the Pancreas Screening Consortium (Goggins et al., 2020) followed at-risk individuals for five years and reported on cancer surveillance outcomes. For those who had cancer detected during screening, the median survival was almost 10 years compared to a median survival of 1.5 years for those whose malignancy was detected outside of the screening protocol. These data support promoting adherence to screening protocols for individuals at high risk for PDAC (Dbouk et al., 2022).

Despite promising outcomes for select patients, PDAC surveillance is not without consequence. An MRI is typically sensitive enough to identify cystic lesions, and an endoscopic ultrasound can detect solid lesions, and both have the potential to lead to unnecessary biopsy or surgery (Harrington et al., 2021). Data suggest that as many as 46% of screened patients will have an identified abnormality, such as an intraductal papillary mucinous neoplasm, that warrants additional evaluation (Overbeek et al., 2024), and most identified lesions are cystic (Harrington et al., 2021). There are no data available regarding how abnormal results from PDAC surveillance affect patient experiences; however, literature on using an MRI for breast cancer screening indicates that abnormal results may cause short-term distress, worry, and reduced quality of life (Spiegel et al., 2011). Coupled with the deadly nature of PDAC, the psychological and emotional effects of any abnormal results from endoscopic ultrasound or MRI will be increased in this context.

Cancer Worry

Cancer worry is a cognitive and emotional process associated with physical and emotional outcomes (see Figure 1). Individuals at risk for PDAC must contend with their lived experience of having seen family members diagnosed with PDAC. Patients may fixate on the negative reminders of what a PDAC diagnosis entails while they undergo repeated medical screenings that could lead to a potential diagnosis for themselves at any point in the continuum (Underhill et al., 2015). The individual's personal and family context (e.g., family experience with cancer, knowledge of cancer, cancer risk) affects the process. The effects of worry may be even more profound in individuals who perceive the highest level of risk (Hay et al., 2005), which may be particularly salient for those who are at high risk for PDAC, one of the deadliest cancers.

Across studies reporting on the experience of individuals at high risk for PDAC, the significant experience of cancer worry is consistent (Underhill et al., 2015, 2018). This at-risk population desires to understand risk-reducing health behaviors and surveillance recommendations, as well as improve their comfort and reduce the emotional effects of living with a lifetime risk of a deadly cancer (Underhill et al., 2015; Underhill-Blazey et al., 2019). Cancer worry as a concern has been seen in international literature that characterizes experiences of those who are at risk for PDAC and engage in PDAC surveillance (Konings et al., 2017; Paiella et al., 2020). Self-reported high cancer worry is more common in those at risk for PDAC, with as many as 57% of respondents reporting worry (Underhill et al., 2018), compared to those at high risk for other types of cancer, such as breast cancer, of whom about 30% report high cancer worry (Lloyd et al., 2021). Rates of high cancer worry prevail among anyone at risk for any cancer, in stark contrast to the general population in which the majority report little to no worry about developing cancer. Because increased cancer risk is a lifelong experience for those living with it, attention should be paid to offer health and wellness education and support.

Acceptance and Commitment Therapy

There are known evidence-based interventions that can effectively reduce cancer worry. Contemporary psychology-based interventions, such as acceptance and commitment therapy (ACT), have demonstrated efficacy in reducing cancer worry in adult participants (Sharpe et al., 2019; Wells-Di Gregorio et al., 2019). ACT has a goal of teaching individuals to change how they respond to negative emotions and identify what can and cannot be changed to engage in more goal- and value-oriented action. Through experiential learning, such as mindfulness training and pursuing meaningful activities, participants are taught to be actively present and to cope with and express their emotional responses in line with their values and preferences (Hayes et al., 2013). ACT coupled with psychoeducation has been successful in a variety of settings, populations, and formats, and it has been shown to be effective at improving health behavior and quality-of-life outcomes (Hayes et al., 2006). Few interventions have been developed that address the complex and multidimensional needs of the *previvor* (Dibble et al., 2022), or the person living at high risk for cancer or engaging in cancer surveillance and prevention (Underhill-Blazey et al., 2022). There are no

interventions that exist particularly for those at high risk for PDAC.

Objective

The study team developed the Familial cancer Risk Assessment and Management Education–Pancreatic (FRAME-P) tool in response to the significant concern of cancer worry in this population and the lack of resources for psychosocial support. FRAME-P is a nurse-led, group-based digital health psychoeducational intervention informed by ACT. The purpose of this article is to describe participant-reported acceptability from an initial pilot-type user testing of the intervention in an at-risk cohort.

Methods

Study Design

The University of Rochester Institutional Review Board approved all participants' engagement and procedures. All study participants gave informed consent. The study is a single-arm pre-/postintervention pilot aimed to assess participant-reported acceptability.

Sample and Setting

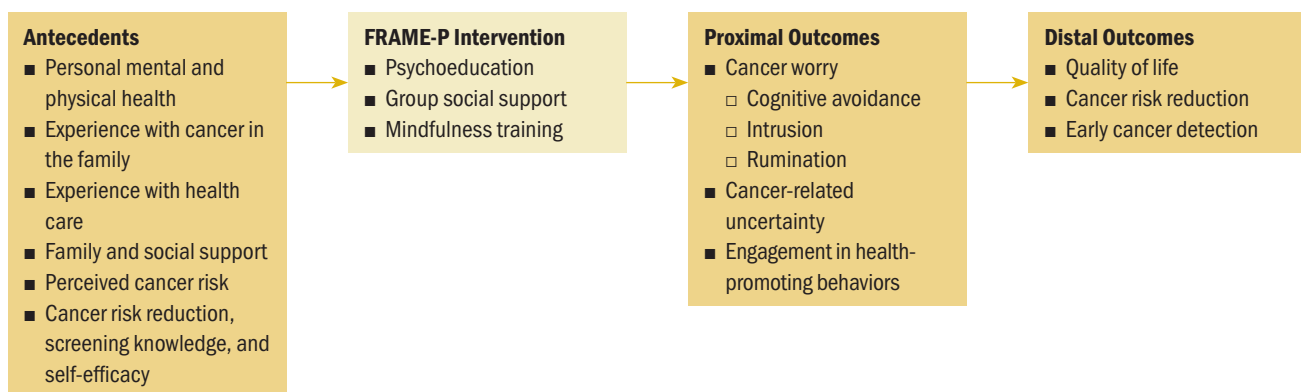
Participants were recruited remotely or in person from a single site in one clinic serving the Wilmot Cancer Institute Hereditary Cancer Screening and Risk Reduction Program at the University of Rochester in New York. Providers in the clinic identified eligible individuals who were at a high risk for PDAC, informed them of the intervention,

and asked them to participate. Eligible participants included adults who spoke English and had received care in the past year from a clinic in the Hereditary Cancer Screening and Risk Reduction Program because of PDAC risk. PDAC risk was defined by the International Cancer of the Pancreas Screening Consortium (Goggins et al., 2020), and includes individuals with the following risk factors: a known PGV associated with PDAC (e.g., *STK11*, *CDKN2A*); a PGV (e.g., *BRCA1/BRCA2*, *PALB2*, *MLH1/MSH2/MSH6*, *ATM*) and a first-degree relative with PDAC; a strong family history of two relatives on the same side of the family with PDAC; or at least one first-degree relative with PDAC, regardless of genetic testing results. Individuals without the ability to use the videoconferencing platform were excluded.

Description of Intervention

The FRAME-P intervention was designed as a nurse-led, digital, group-based intervention providing psychoeducational and ACT-based content and materials. The oncology nurse practitioner was trained in hereditary cancer care and mindfulness. Three individual groups held sessions for one hour each week for four weeks. Overall, the model demonstrates that multiple individual-, family-, and system-level factors determine whether a person experiences cancer worry or cancer-related uncertainty. The experience of worry and uncertainty can then be directly related to quality-of-life outcomes. FRAME-P's goal is to help individuals to understand and cope with personal, familial, or social experiences that lead to

FIGURE 1. Conceptual Model of Cancer Worry and the Effects of FRAME-P on Worry



FRAME-P—Familial cancer Risk Assessment and Management Education–Pancreatic

Note. *Antecedent* is defined as a circumstance, an experience, or characteristics that occur before an outcome. *Proximal outcome* is defined as a short-term outcome that occurs immediately after an experience or an intervention. *Distal outcome* is defined as a long-term outcome that can be affected by the antecedents and proximal outcomes.

FIGURE 2. FRAME-P Content Overview

Week 1

Psychoeducational content^a

- Overview of the pancreas and pancreatic cancer
- Pancreatic cancer risk assessment and group genetic testing; how is risk defined and quantified?

ACT content

- Goal setting
- Acceptance

Activities

- Get to know the group.
- Identify personal goals.
- Mindfulness practice: Be present.

Week 2

Psychoeducational content^a

- Pancreatic cancer surveillance: What is it and how do you access it?

ACT content

- Learn values.
- Identify barriers and facilitators to achieving goals.

Activities

- Group discussion
- Mindfulness practice: cognitive defusing

Week 3

Psychoeducational content^a

- Pancreatic cancer risk reduction: American Cancer Society general healthy living strategies
- Community wellness resources

ACT content

- Committed action
- Reevaluate goal setting.

Activities

- Group discussion
- Mindfulness practice

Week 4

Psychoeducational content^a

- Coping with risk and risk management
- How to access and use community resources

ACT content

- Maintaining sustained action
- Psychological flexibility

Activities

- Group discussion
- Mindfulness practice: group choice
- Wrap-up and questions

^a Provides knowledge and coping skills related to mental health needs
ACT—acceptance and commitment therapy; FRAME-P—Familial cancer Risk Assessment and Management Education—Pancreatic

cancer worry, and thereby improve the experience of worry, leading to improved long-term quality of life.

A study-specific website was created to house resources (e.g., printable handouts, Pancreatic Cancer Action Network support group information, instructions for using the discussion board), practice materials (e.g., guided breathing and mindfulness exercises), and psychoeducational videos. The FRAME-P website is not identifiable through a public search and is available only to those with access to the private link. An online Health Insurance Portability and Accountability Act–adherent group discussion board was made available to study participants. The National Comprehensive Cancer Network and American Cancer Society guidelines (Daly et al., 2020; Rock et al., 2020), ACT resources, and the study team’s preliminary research and clinical practice guided the intervention’s content. Figure 2 summarizes the content and activities provided in each week’s session.

The first two study groups received psychoeducational and ACT content and participated in mindfulness activities. Content was delivered through the live sessions as well as links on the website for these two groups. The FRAME-P website provided links to additional mindfulness practices that participants could choose to watch but were not instructed to do so. Videos of the psychoeducational content, focusing on risks for PDAC, surveillance procedures, and modifiable risk factors to prevent PDAC, were professionally created after content delivery was complete with groups 1 and 2. The videos included the psychoeducational content that had been synchronously delivered during the first two groups, only transformed to video format. The third group was provided with links to these videos to watch asynchronously prior to the group session and was requested to watch videos that corresponded to the week’s objectives prior to the group sessions. Each video was about three minutes in duration, and participants were asked to watch three to four videos prior to sessions 2, 3, and 4. The video content was then reviewed in the group session and questions were answered.

Study Procedures

Participants joined the meeting from a location of their choice using their personal device (e.g., tablet, computer). An oncology nurse practitioner (M.U.-B.) led each group session. An oncology nurse (M.B.) attended each session as a facilitator and provided all email communications about the intervention. All group sessions were audio recorded.

Data Collection

The study team tracked rates of enrollment, attrition, and completion, as well as website and discussion board usage through Google Analytics. Participants were asked to complete a REDCap survey at baseline after giving consent, prior to the first session, and about two weeks after completion of the intervention. Personal and demographic characteristics, such as marital status, family caregiver experience, experience with psychotherapy, and experience with integrative practices (e.g., breathing, meditation, mindfulness, massage, Reiki), were self-reported at baseline. Some data were extracted from the medical record during eligibility screening and retained to describe the sample (e.g., type of PGV, if any; family cancer history; personal cancer history; PDAC surveillance history; surveillance results).

A nine-item REDCap acceptability survey was sent after each session to allow participants to provide feedback about their experience with the intervention. The weekly survey asked participants to rank the content's usefulness on a four-point Likert-type scale ranging from 1 (did not seem to help) to 4 (very helpful). In addition, two open-ended items asked for feedback about participation and content. After the final session, a 10-item survey was administered asking whether participants felt the intervention was useful and accessible and whether they would do it again or recommend it to others. Participants were also asked about engagement with mindfulness activities. An open-ended question prompted participants to give additional feedback. All participants were invited to an end-of-study interview in which they were asked to share their experience with FRAME-P and any recommendations for improvements. After completing the postintervention survey or interview, participants received a \$20 gift card. Patient-reported outcome measures were administered at baseline and postintervention and are not reported at this phase.

Data Analysis

Because of the study's exploratory nature, no formal power calculation was provided. There were minimal missing data. Each missing value was substituted by the mean of the observed values for that item. The analysis was facilitated by a professional data analyst (E.P.). All enrollment, attrition, and completion data, as well as patient-reported acceptability and medical record data, are described using descriptive statistics. The enrollment rate is defined as the percentage of enrolled participants of those approached, and the

completion rate is defined as the percentage of participants who completed the four-week intervention. Transcripts from each study session as well as end-of-study interviews were thematically analyzed using MAXQDA software. Transcripts were first verified for accuracy. The principal investigator (M.U.-B.) of the project read all transcripts and formed narrative summaries. Two independent coders then reviewed all transcripts, and findings were discussed as a group until a consensus was reached.

Results

Table 1 summarizes the sample characteristics of the participants who took part in the study. During the course of the study, 65 eligible participants were approached. Of those, 14 enrolled in the study and 13 completed all study intervention procedures. Group sizes ranged from three to five individuals, and participants interacted only within their group. The most common reason for declining participation was not having time or having other priorities in the individual's family.

Between September 2021 and March 2023, the study website was available to enrolled participants. The materials page was viewed 33 times, the resources page was viewed 49 times, and the videos page (launched prior to beginning group 3) was viewed 61 times. There were 53 file downloads. Eight of 13 participants enrolled themselves in the discussion board; however, the discussion board was used only three times across all the groups. For group 3, which received digital video content, all participants were able to view and viewed the study materials prior to group sessions. No participant missed more than one session and 80% across all groups completed all sessions. All participants found the sessions useful and said they would recommend the sessions to others.

Qualitative Data

During the first session of each group, participants openly shared their experiences with family members who had PDAC and the process of finding out they were at high risk for PDAC. Sharing helped this unique population of individuals establish a sense of community. Participants also demonstrated retention of knowledge from one session to the next. After learning about the relationship between diabetes and elevated blood glucose levels in one session, several participants at the next session reported that they had reviewed their blood glucose levels in their medical records. Some individuals had surveillance completed

during the study period and engaged in the newly learned mindfulness practices from FRAME-P. One participant said that they used mindfulness practices during their MRI and that the practices “settled me and calmed [me] down. . . . I could see [myself] using [them] in other scenarios as well.” Another reported that they “have always heard that mindfulness would be good for me, now thinking it’s good because it helps you focus on specific things, rather than letting your mind wander.”

The first two groups requested that content be made available prior to the session to review ahead of time. Therefore, video content was created, and group 3 was invited to watch prior to the sessions. Feedback from group 3 indicated that the video content was acceptable and that the short and informative format was helpful. During the sessions, the participants in group 3 had questions directly related to the videos they watched, such as asking for additional details about environmental exposure as a risk factor for PDAC and the different types of surveillance screening tests. One participant said that “it’s all been new information for me. . . . I like all the information I can

get, as opposed to googling and hoping it’s factual.” When talking about a specific video, one participant said,

It’s relevant to me. As I said before, I had a cyst on my pancreas, so I’m having the endoscopic ultrasound screening sooner rather than later, and it was comforting, in a way, to read some of that stuff, that [cysts] are common. As I googled and read and researched, it’s everything from A to Z, so that nice video was kind of helpful to calm me down a bit, or calm my mind down.

Data from the qualitative feedback gathered after completion of the intervention indicated that overall, consistent with survey findings, participants found FRAME-P useful and were grateful for the resource. Participants agreed that the “session was very informative and professionally done,” as one participant stated. One participant likened the intervention to “being in a classroom.” Participants shared that they felt that the information was empowering. The discussion board was not used much, several participants did not enroll in it, and some reported difficulty with enrolling and using the feature. Peer connection was an important component of FRAME-P. Hearing stories from their peers and supporting one another was a goal of participants. Participants also asked for more opportunities for group discussion, particularly to foster conversation between peers and share their personal experiences.

Discussion

In this single-arm pilot study, the authors evaluated participant experiences with the FRAME-P intervention. Overall, enrolled participants adhered to the study protocol, completed all assessments, and found the interventions to be useful. Through engaging in this study, the authors learned about important formatting and substantive content adaptations to adjust the intervention to improve future evaluations. Although the group sessions and social connections were valued by participants, use of the discussion board was limited, indicating that there is an opportunity for future enhancement to social connection.

To date, no interventions exist for individuals at risk for PDAC to address educational, psychological, and social support needs related to living with this lifetime elevated risk. Therefore, FRAME-P is the first proposed intervention focused on providing supportive care to individuals with this specific cancer risk. Previous work to evaluate interventions

TABLE 1. Sample Characteristics (N = 13)

Variable	Median	Range
Age (years)	61	43-68
Number of family members with cancer	6	2-12
Number of family members with pancreatic cancer	2	2-3

Variable	n
Sex	
Female	11
Male	2
Reason for high risk	
Family history	12
Pathogenic genetic variant	1
Personal history of cancer (N = 4)	
Breast	2
Endometrial	1
Melanoma	1
Pancreatic ductal adenocarcinoma surveillance	
Endoscopic ultrasound	6
Magnetic resonance imaging	4

Note. Not all participants were engaged in pancreatic ductal adenocarcinoma surveillance.

to affect cancer worry has indicated that interventions have been effective; however, these have largely been completed within the domain of patients with breast cancer and individuals at risk for breast cancer (Han et al., 2019). The incorporation of ACT components into the FRAME-P psychoeducational intervention was novel and helped facilitate participants' understanding of their risk and ways to cope with the feelings and uncertainties associated with risk that may lead to worry. Broley (2013) presented a case study that applied ACT in a genetic counseling framework; however, no outcomes were reported. The current study adds important patient-reported feedback, experiences, and outcomes related to this format and type of intervention in clinical care to an at-risk cohort in the realm of PDAC.

The benefit of applying principles of ACT is the flexible and adaptable format of the approach to dealing with psychological concerns (Zhang et al., 2018). Although using ACT principles in the clinical domain of hereditary cancer risk is relatively new, there is published literature indicating that digital application of principles of ACT can affect clinical outcomes, including psychological, behavioral, and symptom outcomes (Han & Kim, 2022). Delivering ACT remotely and in a group has been found to be effective, and the current study adds supportive patient-reported experiences to this modality. In addition, FRAME-P was nurse-led and there are limited reports of nurse-led interventions that incorporate components of ACT in cancer care (Han & Kim, 2022). This nurse-led intervention was acceptable for patients. Understanding training and capacity needs for oncology nurses to intervene using this modality during standard of care will be important next steps.

Limitations

This study was conducted at one clinical site with a largely homogenous population that had access to a remote, web-based platform. The intervention was offered only in English, which limited its reach. As this program develops, future work should expand recruitment through more community-based platforms, such as social media, local nonprofit organizations, or community groups. This would facilitate a larger and more diverse participant group. In addition, the intervention was led by a trained oncology nurse. To replicate this study on a larger scale, education or resources are needed to support a nurse delivering content. Participants did not regularly engage with the discussion board platform; therefore, it was difficult to obtain user experience or feedback with that

KNOWLEDGE TRANSLATION

- Cancer worry is an important outcome experienced by individuals at high risk for pancreatic cancer.
 - Psychoeducational interventions based on acceptance and commitment therapy can be conducted via synchronous and asynchronous digital content.
 - Individuals at high risk for pancreatic cancer reported that a digital psychoeducational intervention with acceptance and commitment therapy can be beneficial for reducing cancer worry.
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method of social connection. Lastly, only a subset of individuals who were interested in the study were able to enroll; however, those who enrolled were able to complete the study. This was in large part because of time constraints and scheduling. Future work should consider a more diverse sample at multiple sites and multiple intervention modalities to aim to reach a broader population.

Implications for Nursing

Nurse-led interventions are effective at supporting patients and families in a variety of healthcare settings. In cancer care, many of these interventions have been developed to support patients actively being treated for cancer, those who have completed treatment, or caregivers for a person with cancer (Charalambous et al., 2018). It has been found that nurse-led interventions can also positively affect early detection of cancer through education, coaching, and support related to screening (Li et al., 2020). Overall, nurse-led clinical interventions can be an effective way to provide additional psychoeducational and psychological support for patients at risk for cancer.

Nurse navigators may be well poised to take on implementing a program such as FRAME-P (Byrne et al., 2020; Chan et al., 2023). Although the content of FRAME-P is specific, the model of leading patient groups through psychoeducation and mindfulness is one that an oncology nurse at any level could replicate with support, adequate access to patient-facing materials, and minimal training. The FRAME-P intervention is ideal to be led by the growing number of specialty-trained oncology nurse navigators (Chan et al., 2023).

Conclusion

FRAME-P was overall useful and filled an unmet need for social support, psychoeducation, and skills training for individuals at high risk for PDAC. Remotely

delivered group interventions are acceptable to this population. FRAME-P should be evaluated further in a larger efficacy trial. Outcomes from this work will provide the framework and structure to guide future extensions of this work to other clinical domains in inherited cancer.

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