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# Supplemental tube feeding: qualitative study of patient perspectives in advanced pancreatic cancer

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## ABSTRACT

**Objectives** Malnutrition is associated with poor quality of life and survival outcomes for patients with cancer, but is challenging to prevent or treat in pancreatic cancer due to the multifactorial drivers of nutritional decline. A novel application of percutaneous endoscopic gastrostomy with a jejunal extension tube to deliver supplementary nutrition may improve outcomes, and will be tested in a randomised controlled trial. This study explored the perspectives of people living with pancreatic cancer regarding the acceptability of this proposed intensive nutrition intervention, to elucidate appropriateness and anticipated barriers, and facilitate informed design of the planned trial.

**Methods** Participants were patients with pancreatic cancer previously enrolled in a Pancreaticobiliary Cancer Biobank. Qualitative semi-structured interviews were conducted by telephone and transcribed verbatim for deductive thematic analysis. The Framework Model was used, with the Theoretical Framework of Acceptability as the analytical framework.

**Results** 10 participants were recruited. Four overarching themes were developed from interviews: (1) deterioration in physical and mental well-being are consequences of debilitating nutrition impact symptoms; (2) willingness to participate depends on an individual threshold for nutritional deterioration; (3) predicted perceived effectiveness outweighed anticipated burdens and (4) adequate dietetic support is needed for maintaining a percutaneous endoscopic gastrostomy with jejunal extension feeding tube at home with confidence.

## WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Malnutrition is prevalent in advanced pancreatic cancer and is associated with worse quality of life.
- ⇒ Patients with pancreatic cancer experience multiple nutrition-impact symptoms affecting the intake, digestion and absorption of nutrients.
- ⇒ Maintenance of nutrition status is therefore difficult with traditional nutrition support.
- ⇒ Enteral tube feeding is not routinely offered to patients with advanced pancreatic cancer.

## WHAT THIS STUDY ADDS

- ⇒ Perspectives of patients currently living with pancreatic cancer regarding the acceptability of a proposed intensive nutrition intervention which comprises supplemental tube feeding via percutaneous endoscopic gastrostomy with jejunal extension, along with frequent telehealth dietetic support and multidisciplinary symptom management, for the duration of chemotherapy treatment.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ The results of this qualitative study will inform the design of a randomised controlled trial which has the potential to significantly change the current nutrition management of patients with advanced pancreatic cancer.

**Conclusions** Most participants believed that the intervention would benefit people with advanced pancreatic cancer to maintain their nutrition throughout chemotherapy. Regular and ad hoc support was considered essential,

and the degree of individual nutritional deterioration was identified as an important indicator for trial participation.

## BACKGROUND

Pancreatic cancer is the 12th most common cancer, and the 6th leading cause of cancer-related mortality, worldwide.<sup>1</sup> Clinically significant weight loss, defined as >10% of body weight, is common in patients with pancreatic cancer, with 42–85% of the patients presenting with significant weight loss at diagnosis.<sup>2,3</sup> The aetiology of weight loss and resultant malnutrition in patients with pancreatic cancer is multifactorial; disease-related and treatment-related symptoms such as loss of appetite, nausea, epigastric pain and steatorrhoea cause anorexia and insufficient oral intake,<sup>2</sup> with over 50% of the patients experiencing at least one of these nutrition impact symptoms.<sup>3</sup> Nutrient malabsorption is also common due to pancreatic exocrine insufficiency and cancer-related systemic inflammation mediated by tumour-derived cytokines.<sup>4</sup> Malnutrition as a consequence of both reduced nutrient intake and absorption is associated with suboptimal treatment outcomes and complications, including reduced tolerance to chemotherapy and shorter survival.<sup>4</sup> Nutrition impact symptoms and poor nutrition status are also associated with increased patient distress and reduced quality of life in pancreatic cancer.<sup>5</sup> As the global burden of pancreatic cancer is projected to significantly increase over the next 40 years,<sup>6</sup> and malnutrition is a widely accepted predictor of poor outcomes in patients with cancer,<sup>7,8</sup> optimisation of nutrition status and relieving nutrition impact symptoms are critical to improving quality of life and survival for patients with pancreatic cancer.

Dietary counselling-based interventions and oral nutrition supplementation are current first-line strategies to manage malnutrition and nutrition-impact symptoms in patients with pancreatic cancer. However, these interventions have been shown to have limited benefit for improving nutrition status, quality of life and survival,<sup>9,10</sup> highlighting the challenging nature of achieving weight maintenance in patients with advanced pancreatic cancer where the multitude of nutrition impact symptoms complicates the provision of nutrition support.<sup>2</sup> Supplemental enteral tube feeding may be a solution to optimise nutrition intake, however, is not common practice currently in the palliative setting.<sup>11</sup> For patients with pancreatic cancer, a percutaneous endoscopic gastrostomy with a jejunal extension (PEG-J) could be used to provide nutrition directly into the small bowel in view of tumour-related delayed gastric emptying or gastric outlet obstruction, and can remain in situ for 6 months or longer.<sup>12</sup> In a small feasibility study exploring jejunal feeding in advanced pancreatic cancer, improvements in weight stability, symptom severity and quality of life were demonstrated, however, larger sample sizes and

randomised controlled trials (RCTs) are required to validate these findings.<sup>13</sup>

In planning for future trials to investigate the impact of PEG-J feeding in advanced pancreatic cancer, determination of the acceptability of this intervention to patients is vitally important to maximise engagement with proposed health interventions and associated research trials.<sup>14</sup> ‘Acceptability’ has been defined as a ‘multi-faceted construct that reflects the extent to which people delivering or receiving a health care intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention’ in a theory by Sekhon *et al.*<sup>14</sup> This study aims to explore the appropriateness and acceptability of supplementary enteral feeding via a PEG-J from the viewpoint of patients currently living with pancreatic cancer. Emerging themes from this study will directly influence protocol development of an RCT assessing the effects of enteral nutrition on health outcomes and quality of life.<sup>15</sup> Consideration of patient perspectives on receiving supplementary enteral nutrition via a PEG-J tube aims to minimise anticipated barriers to recruitment and ensure ongoing representation of the target patient cohort throughout the study.

## METHODS

### Participants and setting

Participants were recruited from a single tertiary hospital in metropolitan Victoria, Australia, between August 2022 and June 2023. Potential participants were identified through the Pancreaticobiliary Cancer Biobank, approved by the Monash Health Human Research Ethics Committee (HREC) (Ref 15450A). Participants were adults (18 years or older) with a diagnosis of pancreatic cancer who had previously provided written consent to participate in the Pancreaticobiliary Cancer Biobank, including a written indication of consent to be contacted for future research. Patients in the terminal end-stage of life, who did not have adequate cognition or language skills to provide consent or complete the interview in the English language, or without a corresponding email were not eligible to participate.

### Recruitment

Participants were selected using a purposive sampling technique. Every fifth patient on the Pancreaticobiliary Cancer Biobank list was screened and eligible patients were contacted to enquire about preliminary consent regarding participation in this study (DC). Consenting participants were contacted by phone to explain the purpose of the study and ensure participants understood the voluntariness of participation. Participants were provided with a patient information and consent form via email outlining the planned nutrition intervention and purpose of this research. Once verbal consent was obtained, baseline demographic data including

**Table 1** Semi-structured acceptability interview questions and corresponding constructs of the Theoretical Framework of Acceptability<sup>14</sup>

Interview questions	Logic
Based on the information I have just provided; how well do you feel like you understand this trial? ▶ Do you think it would work?	Perceived effectiveness
If you were approached to enrol in this trial now, would you participate? ▶ Why/why not?	Affective attitude Ethicality
Would you have participated if you were approached just after your diagnosis? ▶ Why/why not?	Affective attitude Ethicality
How would you feel about learning to manage a PEG-J for top-up nutrition at home?	Affective attitude Ethicality
Based on what you have been told, how would you feel about the effort required to manage a PEG-J tube, so you are able to meet your nutrition needs as part of your treatment?	Affective attitude Self-efficacy
How important do you think using a PEG-J to support nutrition through treatment is?	Affective attitude Ethicality
Can you think of any potential negative aspects of having a PEG-J during treatment? ▶ Would this affect your decision to participate in a trial like this?	Burden Opportunity costs
The cost of the formula for the PEG-J tube would be around \$A157 per week, if you were not having any other food or drink. How important is it to you that the nutritional formula is supplied to future participants for free?	Burden Opportunity costs
From your own experience during cancer treatment, can you describe how additional nutrition would have impacted you?	Perceived effectiveness
What impact do you think PEG-J feeding will have on the quality of life for people undergoing similar treatment to you?	Perceived effectiveness
If you were participating in this trial, would you be able to complete a quality of life questionnaire at 3 and 6 months?	Burden Opportunity costs
PEG-J, percutaneous endoscopic gastrostomy with jejunal extension.	

age, gender, details of cancer diagnosis and treatment were collected (TD, KG). The clinical stage of the disease was reported according to the 2017 National Comprehensive Cancer Network guidelines.<sup>16</sup> Participants were informed that they could withdraw consent at any time during the interview.

### Study design and procedures

One-on-one recorded semi-structured telephone interviews were conducted by research assistants (TD, KG), to explore the acceptability of a prospective intensive nutrition intervention using PEG-J feeding tubes to patients with pancreatic cancer according to the Standards of Reporting Qualitative Research.<sup>17</sup> The telephone questionnaire was designed to be conducted within 20 minutes to minimise participant burden. At the commencement of the questionnaire, the research interviewer described the proposed nutrition intervention to participants using a standardised script provided by the research team, written with neutral lay-person language, to ensure understanding.

### Measurements

An interview guide (table 1) was developed by the researchers (KF, LH and TH), informed by the Theoretical Framework of Acceptability (TFA).<sup>14</sup> The analytical framework to explore patient acceptability was based on six of the seven constructs of the TFA: affective attitude, burden, ethicality, opportunity costs,

perceived effectiveness and self-efficacy<sup>14</sup>; intervention coherence was not measured because this is a theoretical intervention that has not been delivered to participants.

### Data preparation

The recordings of the interviews were de-identified and transcribed verbatim (GN). Audio files and transcription documents were stored in a secure password-protected cloud-based repository.

### Research positioning and reflexivity

The researcher GN is a third-year medical student currently completing clinical placement in metropolitan Victoria, Australia. As an outsider in this research field, GN sought to understand the interplay of biopsychosocial factors influencing health outcomes for patients with pancreatic cancer.<sup>18</sup> GN carefully assessed and evaluated her subjective responses during the analytical deductive process and reflected on how this evolved and influenced the interpretation and analysis of data throughout the research process.<sup>19</sup>

### Rigour

The interview questions were developed to ensure each question aligned with a construct in the TFA, to promote rigour in data collection. Purposive sampling was used to recruit a small but diverse cohort of participants to represent different cultural, social

**Table 2** Characteristics of the interview sample (n=10)

Participant characteristics	N, (%)
Sex	
Man	5 (50)
Woman	5 (50)
Other	0 (0)
Age (years)	
40–49	1 (10)
50–59	0 (0)
60–69	3 (30)
70–79	4 (40)
80–89	1 (10)
90–99	1 (10)
Clinical stage of pancreatic cancer at diagnosis (NCCN)	
Resectable	2 (20)
Borderline resectable	3 (30)
Locally advanced	3 (30)
Metastatic	2 (20)
Chemotherapy treatment prior to interview	
Yes	7 (70)
No	3 (30)

NCCN, National Comprehensive Cancer Network.

and physical backgrounds and reduce the impact of confounding factors such as age, socioeconomic status and gender, therefore increasing the dependability of data collection.

### Analysis

Descriptive statistics were used to summarise participants' sociodemographic data. Data from semi-structured interviews were analysed using the deductive approach from the Framework Method as described by Gale *et al.*<sup>20</sup> To assist with determining sample size, Malterud's idea of information power was used,<sup>21</sup> whereby a lower number of participants is required when there is more information held by the sample. Deductive coding of TFA constructs began with hand coding of all interviews and NVivo software was used to organise, manage, visualise and analyse data (GN). Two researchers (KF, LH) independently hand-coded two transcripts each. Researchers (GN, KF and LH) met to discuss the coding accuracy of interviews and to develop themes until a consensus was reached.

## RESULTS

### Participant sample

10 participants consented to be interviewed, and 10 telephone interviews were conducted, providing a total response rate of 100%. Demographics of the interview sample are shown in table 2.

Nine participants (90%) thought that supplementary enteral nutrition delivered via a PEG-J tube would be effective. Six participants (60%) indicated they would be likely to participate in a trial involving this nutrition intervention if asked when they were first diagnosed,

three (30%) indicated they would not, and one (10%) was uncertain. When asked if they would be likely to participate if approached at present, seven participants (70%) indicated they would, one participant (10%) indicated they would not and two (20%) were uncertain.

### Themes

Four key themes emerged from analysis of the data using the Theoretical Framework of Acceptability constructs, with exemplary quotes shown in table 3.

#### Deterioration in physical and mental well-being are consequences of debilitating nutrition-impact symptoms

Maintenance of nutrition was important to patients with pancreatic cancer, with all participants acknowledging the difficulty of maintaining optimal oral intake. Participants reported that disease-related gastrointestinal symptoms including nausea and anorexia affected weight maintenance even prior to diagnosis, and were exacerbated by treatment side effects. This was identified by all participants to affect physical health and mental well-being in some way.

I couldn't eat, I couldn't even look at food. And I felt very weak and no strength. (Participant 1, woman, late 70s)

Declining physical health, reduced tolerance and response to chemotherapy with consequences on prognosis were raised by all participants to be outcomes of poor nutrition contributing to decreased quality of life. One participant identified that earlier nutrition intervention could have a preventative effect, mitigating risk of adverse complications and hospitalisations related to poor nutritional status.

It would've saved me a month in hospital and all the stress that goes with that. (Participant 2, woman, late 70s)

Most participants reported significant emotional and psychological burdens associated with trying to meet nutritional requirements through oral intake alone. They described having intrusive preoccupations, with thoughts of food and strategies to improve intake disrupting daily life and affecting mental health. One participant shared that these anxieties and negative sentiments towards food also negatively impacted family members and/or caregivers who accompanied and supported them during their journey with cancer.

I mean, it would benefit me, it would benefit my partner as well, or your friends and your family. Because I know everyone was worried about me because I couldn't eat, and then I wouldn't eat – I should say it's a win-win for everyone. (Participant 2, woman, late 70s)

**Table 3** Qualitative analysis of participant responses using the Theoretical Framework of Acceptability<sup>14</sup> constructs\*

Theoretical Framework of Acceptability construct	Definition	Defining quote: for	Defining quote: against
Affective attitude	How an individual feels about the intervention	'I can't speak more highly of it. I think it's a marvellous idea... If I had the opportunity, I maybe wouldn't have spent the month in hospital – by having, the tube put down my throat in the first place.' (Participant 2, woman, late 70s)	'For me, it's something that I wouldn't have any interest in at all.' (Participant 7, man, early 40s)
Burden	The perceived amount of effort that is required to participate in the intervention	'I think everyone that goes through chemo, you – well, you know about symptoms like the mouth ulcers and things like that. And if you know how painful it's going to be, having a feeding tube is much easier, even though it might be a little uncomfortable – but after a few days, you get used to it anyways.' (Participant 2, woman, late 70s)	'For me, it would actually be really, kind of, negative. Like I said – quality of life and movement, and not having a line coming in and out of me, is really important, I'm still quite active (Participant 7, man, early 40s) I'm not really sure, it does seem like a little bit of effort. (Laughs) Yeah, no it's sort of the diagnosis is all fairly new and it's all a bit overwhelming.' (Participant 9, woman, early 60s)
Ethicality	The extent to which the intervention has a good fit with an individual's value system	'I just feel – I'm very conscious of my nutrition and I just don't know whether I'm getting enough when I'm feeding myself. By doing this, I know a qualified person has done it and I know I'm getting the right nutrition.' (Participant 4, woman, early 60s)	'Mobility, kind of, body image, uh, yeah, absence of, you know, actual whole foods going down my mouth, as opposed to being inserted within you.' (Participant 7, man, early 40s)
Opportunity costs	The extent to which benefits, profits or values must be given up to engage in the intervention	'But I think that amount of money, I'd be willing to pay it myself, even if it wasn't free – for that amount of money, because you wouldn't be eating anything else, and everyday food costs you something.' (Participant 2, woman, late 70s)	'I can only speak on my behalf – but extremely important, as I have no income, no government supports or benefits.' (Participant 3, man, mid 70s)
Perceived effectiveness	The extent to which the intervention is likely to achieve its purpose	'I think it would be a big help. Cause I'm not quite sure how much is getting through at the moment. You know, I'm taking enzymes and stuff, but I'm not gaining any weight at this stage. So I think it would be quite important.' (Participant 8, man, early 90s)	'For me, it would actually be really, kind of, negative... quality of life and movement, and not having a line coming in and out of me, is really important.' (Participant 7, man, early 40s)
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention	'I'm sure given the right guidance it would be good.' (Participant 10, man, late 70s) 'I don't see that as an issue. I think it would be, um, I believe, easy to manage.' (Participant 3, man, mid 70s)	'I should imagine I'd be quite concerned about doing it at home. Um, even though you've got video and things like that – because I'm not very good at doing things like that either.' (Participant 2, man, late 70s)

\*Intervention coherence cannot be measured because this is a theoretical intervention that has not been delivered to the participants.

### Willingness to participate depends on on individual threshold for nutrition deterioration

Patients reported they would be accepting of nutrition interventions when they recognise their current nutrition status was declining beyond an unacceptable threshold and was impacting their quality of life. Seven participants (70%) reported that their prior efforts to improve nutrition were inadequate, and identified the need for additional support. The majority of participants (70%) had commenced chemotherapy treatment at the time of this study and most reported considerable side effects which hindered their ability to

maintain adequate oral intake. Furthermore, all individuals with locally advanced or metastatic pancreatic cancer reported considerable symptom burden and were particularly amenable to receiving the nutrition intervention.

Because I have – even before my diagnosis, I had trouble eating, so I would definitely - and I love eating. (Participant 4, woman, early 60s)

However, some participants reported feeling overwhelmed with recently receiving a diagnosis of cancer and commencing treatment which resulted

in significant changes to their daily lives. For these participants, continuing life as normal and maintaining autonomy were paramount, and receiving a PEG-J tube for supplementary enteral feeding was perceived to be an invasive intervention that may impact their control of food and fluid. Three participants (30%) expressed that their current level of disease burden was manageable, and shared that they would only consider receiving nutrition intervention when they felt they were no longer able to maintain their oral intake, disease/treatment symptoms became intolerable with clear impacts on physical health or they were experiencing significant side effects of chemotherapy treatment. All of these participants had resectable or borderline resectable pancreatic cancer. Despite not being willing to be recruited to a study of this nature at present, these participants acknowledged the role of the intervention in improving nutrition.

It's a little hard to say, because at the moment I'm still sort of eating ok and everything's been all right and I'm still, you know, managing to eat quite normally ... but, you know, sort of getting further along ... it could be very important. (Participant 9, woman, early 60s)

#### **Perceived effectiveness outweighs anticipated burdens associated with supplementary enteral feeding**

Most participants acknowledged that supplementary enteral feeding would be an effective intervention to maintain nutrition status and have beneficial impacts on multiple domains of health, including physical and emotional, which outweighed anticipated burdens. Improved tolerance of chemotherapy, increased energy levels and reduced risk of complications were regarded by most participants as notable expected beneficial impacts of the intervention. Furthermore, some participants expressed that professional involvement in managing their nutrition, such as that provided through participation in the intervention, would alleviate their worries regarding maintaining adequate nutrition status.

I just think it would improve their quality of life – because, it's just that I don't (sighs) I feel that, you know, it's all been taken care of – and you'd be able to have more energy, you just wouldn't have to worry about your food everyday. (Participant 4, woman, early 60s)

All participants acknowledged the potential financial cost associated with supplementary enteral feeding could be a significant burden that for some would be unsustainable if not met by an external payer, for example, the public hospital system. Most participants concluded that the benefits of symptom severity, quality of life and prognosis, would outweigh the financial burden.

I would say that would be very important, because the cost, yeah, you know, I mean... obviously you're

having treatment and you're not working and you know, but you've still got bills coming in and everything, so money, you know obviously... is a bit tight at these times. So, it would be incredibly helpful if it was provided for free. (Participant 9, woman, early 60s)

Many participants thought holistically regarding the participation in the intervention and expressed that the expected outcome, namely benefits on physical and mental well-being, would justify the transient burden associated with using a PEG-J tube. When comparing previous and current symptom burden, accounting also for chemotherapy-related side effects, participants generally thought additional burdens associated with supplementary enteral feeding and managing a home-based intervention were acceptable.

You know about symptoms like the mouth ulcers and things like that... if you know how painful it's going to be, having a feeding tube is much easier, even though it might be a little uncomfortable. (Participant 2, woman, late 70s)

For two participants (20%), restriction on mobility, discomfort and negative body image related to PEG-J tube insertion were additional anticipated burdens that were considerable and contributed to their hesitancy in accepting the intervention.

Like I said... quality of life and movement, and not having a line coming in and out of me, is really important, I'm still quite active. (Participant 7, man, early 40s)

#### **Adequate supports are crucial for success of maintaining PEG-J tube at home**

Some participants expressed that easily accessible supports, such as visits from or phone consults with a nurse or dietitian, would be vital to ensure confident and safe management of a PEG-J tube at home. Three participants (30%) stated that detailed explanation and instructions regarding the management of the PEG-J tube and use of medical equipment would be required for the successful delivery of the intervention. Two participants (20%) noted that their age and familiarity with technology might hinder their ability to self-manage a PEG-J tube, and were concerned about this affecting their participation in the intervention and its effectiveness. They identified that prior and continuing education and safety-netting were essential to allay their apprehension and empower them to manage a PEG-J tube. Overall, caring for a PEG-J tube at home was seen to be feasible, with acceptable levels of participant burden if adequate and accessible supports are in place.

I'm very conscious of my nutrition and I just don't know whether I'm getting enough when I'm feeding myself. By doing this, I know a qualified person has

done it and I know I'm getting the right nutrition.  
(Participant 4, woman, early 60s)

## DISCUSSION

A proposed intervention consisting of home enteral nutrition delivered via PEG-J tube was found to be largely acceptable to participants with pancreatic cancer. Overall, participants appreciated the detrimental consequences of malnutrition, and the proposed intervention was perceived to have the potential to improve physical health and reduce psycho-emotional burdens associated with disease-related symptoms and consuming adequate nutrition. Maintenance of nutrition is widely accepted to be vitally important for patients with cancer, due to the significant sequelae of malnutrition.<sup>4</sup> Prior studies have shown that enteral nutrition has beneficial impacts on health outcomes and quality of life for patients with advanced cancer, if oral intake is inadequate.<sup>11 22</sup> However, the provision of enteral nutrition for patients with advanced cancer has not been extensively studied, hindering current understanding of the impacts on health outcomes and quality of life. In addition to assessing the clinical utility of enteral nutrition in this patient group, it is equally important to explore patient perspectives regarding the feasibility and effectiveness of such interventions.

Research co-design aims to ensure that meaningful research is conducted to improve the standard of care for patients and is increasingly recognised to significantly improve research quality.<sup>23</sup> 'Acceptability', as defined by Sekhon *et al*,<sup>14</sup> is a complex concept influenced by individual belief systems, and anticipated and lived experiences, which is fundamental to the successful implementation of a healthcare intervention. Understanding factors that improve acceptability and anticipated barriers to participation enables greater adherence and effectiveness of proposed healthcare interventions. The present study showed that willingness to participate in a trial involving supplementary feeding via a PEG-J tube requires the intervention to align with participants' ethical beliefs and meet current perceived nutrition needs. However, nutrition status and needs as perceived by patients may not align with dietitian or health professional perspectives, and effective rapport and communication are vital to ensure concordance of understanding. This is important as deteriorations in health due to malnutrition may be preventable with prophylactic and prompt management by dietitians and other health professionals, and nutritional rescue might not be achievable when patients themselves recognise the necessity of additional nutrition supports. This study has also demonstrated that patients with advanced pancreatic cancer perceived home enteral nutrition to have potential benefits not only to their personal quality of life, but also to carer burden.

At present, home enteral nutrition is not standard practice for patients with advanced pancreatic cancer globally,<sup>11</sup> however, previous systematic reviews have shown that ensuring adequate nutrition and prevention of malnutrition may improve the quality of life.<sup>22 24</sup> Current guidelines state that enteral nutrition can be considered for nutritional support when intake is insufficient, despite oral nutritional interventions.<sup>12</sup> In palliative care, where patients have a life-limiting illness, the goal of treatment is to relieve symptom burden and improve quality of life for both the patient and their family or carers.<sup>25</sup> In this setting, the utility of enteral nutrition remains controversial<sup>25</sup>; despite the theoretical potential benefits of supplementary enteral nutrition to support patients during cancer treatment, it is rarely offered by clinicians as an option for patients. Moreover, there are complex social and cultural factors that contribute to varying beliefs and perceptions towards nutrition interventions at different stages in the continuum of palliative care.<sup>11</sup> Maintaining adequate energy requirements with enteral nutrition may confer direct benefits to the quality of life (which aligns with the goals of palliative care) and improvements to psychological well-being, as well as indirect influences by mitigating the consequences of malnutrition.<sup>22</sup> This study has demonstrated that patients with advanced pancreatic cancer perceived home enteral nutrition to have potential benefits not only to their personal quality of life, but also to carer burden, and further studies are needed to test the feasibility of such interventions and consequential effects on quality of life and health outcomes.

The practicalities of the proposed intervention are important to consider. Mitigation of anticipated burdens associated with the management of home enteral nutrition, including financial burden and self-efficacy, was highlighted by participants to be important for acceptability. To enable home enteral nutrition provision for patients with advanced pancreatic cancer, health service budgets would likely need to expand to support this cohort of patients. Furthermore, telehealth is an easily accessible and convenient means of communication and support for patients receiving home enteral nutrition and also enables the provision of clinical support to regional and rural areas.<sup>26</sup> Given the demographics of the patient cohort with pancreatic cancer being generally older, with the median age of diagnosis being 72.8 years,<sup>27</sup> consideration of access and technology literacy is important. A previous study, in a similar cohort, found that telehealth was a largely acceptable mode of delivery for nutrition interventions, provided there is a low user burden and adequate support systems, such as nurse/dietitian home visits to support the implementation of home enteral nutrition.<sup>26</sup>

A strength of this study is the novel enquiry into patients' perspectives regarding supplementary enteral nutrition in advanced pancreatic cancer. Additionally,

this study will inform the co-design of a planned RCT, enabling future research to be conducted with consideration of patient perspectives.<sup>15</sup> This study has several limitations. While acknowledging the benefits of co-design, the acceptability of supplemental PEG-J feeding may be different for participants of the future RCT, who have lived experience of the intervention. Selection bias is a potential study limitation, as a higher proportion of patients registered in the Pancreaticobiliary Cancer Biobank have inoperable disease and are more likely to have more advanced disease and experienced significant disease-related symptoms or side effects of chemotherapy treatment. Due to their current level of symptom burden, participants in this study may have been more likely to be amenable to receiving the nutrition intervention. Furthermore, despite best efforts to ensure an adequate understanding of the nutrition intervention, it was not possible to provide comprehensive descriptions of potential adverse effects and complications to participants. As this was a study exploring acceptability, the brief explanation was considered appropriate. The use of telephone to conduct the interviews may have allowed some participants to express themselves more freely than a face-to-face interview, but may also have been a barrier to engagement for those whose preference is for face-to-face communication.<sup>28</sup> The requirement for potential participants to have access to email in order to be eligible for this study was a potential source of bias, however did not affect recruitment in this study.

There remains scope for future research to focus on investigating the feasibility and utility of home enteral nutrition for patients with advanced pancreatic cancer in the palliative setting and evaluation of the impacts of such interventions on health outcomes and quality of life. The findings from this study will inform the design of an RCT exploring the effect of an intensive nutrition intervention delivered via PEG-J tube, on health outcomes and quality of life for Australian patients with advanced pancreatic cancer.<sup>15</sup> Participants' perceptions of factors that would increase the acceptability of the intervention and barriers to engagement will directly inform recruitment processes of the RCT protocol and ensure consumer representation throughout the study as it progresses.

## CONCLUSION

This study has shown that a proposed intensive nutrition intervention involving supplementary enteral feeding delivered via PEG-J tube is acceptable to patients with pancreatic cancer when the intervention is perceived to align with their values and individual nutritional requirements, including adequate perceived effectiveness and low levels of burden. Improvements in disease-related symptom severity, nutrition status and quality of life were key drivers for participants to regard the intervention with a positive effect. Future

studies exploring the delivery of home enteral nutrition in this setting should include consideration of personal experiences with cancer and chemotherapy, appropriate timing of intervention delivery and easy-to-use accessible telehealth supports to ensure alignment with individual ethical values and increase acceptability.

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**Contributors** KF, LH, TH and DC conceived and designed the study. GN, KF, LH and DC contributed to the acquisition, analysis or interpretation of data. GN drafted the manuscript; all authors revised it critically for important intellectual content. LH is responsible for the overall content as guarantor. All authors approved the version to be published. All authors agree to be accountable for all aspects of the study's accuracy and integrity.

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**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by Monash Health Human Research Ethics Committee (Ref: RES-22-0000440A). Participants gave verbal informed consent to participate in the study before taking part.

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**Data availability statement** The ethical approval obtained to conduct this study does not extend to the sharing of data, therefore the data supporting the findings of this study are not openly available. De-identified data may be shared upon reasonable request to the corresponding author if the proposed research has undergone ethical review.

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