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# Pancreatic Enzyme Replacement Therapy Following Surgery for Pancreatic Cancer: An Exploration of Patient Self-Management

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## Abstract

**Background:** Challenges For those diagnosed with pancreatic cancer, ill-addressed pancreatic exocrine insufficiency (PEI) following surgery can result in malnutrition related complications that may impact on predict mortality and morbidity. The use of pancreatic enzyme replacement therapy (PERT) is recommended and often demands a degree of patient self-management. Understanding more about how this treatment is managed is fundamental to optimising care.

**Objective:** This study aimed to explore patient self-management of PERT following surgery for pancreatic cancer.

**Methods:** Semi-structured interviews were conducted with nine participants. Eligible participants included adult patients who had undergone surgery for a malignancy in the pancreatic region and were prescribed PERT post-operatively. Inductive thematic analysis was used to analyse our findings.

**Results:** Data analysis revealed three overarching themes; the role of professional support, factors influencing decisions to use PERT in symptom management and the challenges of socializing. The difficulties negotiated by participants were considerable as they struggled with the complexities of PERT. Symptom management and subsequently reported physical repercussions and undesirable social implications were problematic. Professional support was largely inconsistent and relinquished prematurely following discharge. Consequently, this impacted on how PERT was self-managed.

**Conclusion:** Enabling patients to appropriately self-manage PERT may lessen the post-treatment burden. Our findings suggest that support should continue throughout the recovery phase and should address the patient's 'self-management journey'. Intervention by healthcare professionals, such as a specialist dietitian is likely to be beneficial. Furthermore there are

focal issues, primarily explicit education and appropriately timed information that require consideration by those developing and delivering services.

## Introduction

As cancer increasingly emerges as a chronic condition, governmental agendas set out the provision of supportive care for survivors [1,2-4] with a focus on how patient self-management can optimize ‘living with the illness and its effects’.[5] For patients with pancreatic cancer, existing evidence suggests that post-operatively, patients receive insufficient information from their health care providers to self-manage their condition at home. [6]

For this group of patients, surgery remains the only established curative treatment. A common surgical procedure for tumour resection is the pylorus-preserving pancreaticoduodenectomy (PPPD). Anatomical alterations following PPPD and ill-addressed associated pancreatic exocrine insufficiency (PEI) can result in malabsorption of nutrients [7-9] and malnutrition related complications that impact on morbidity and mortality. [10,11] By focusing on treatment of underlying disease and longevity, PEI can be overlooked with qualitative evidence suggesting that more support could be provided to patients.[1,6,12,13] For this cohort, who are particularly vulnerable to deterioration in nutritional status and QoL, arguably, supportive management of gastrointestinal problems could be improved.[13]

Pancreatic enzyme replacement therapy (PERT) is commonly prescribed to patients with PEI to facilitate nutritional improvement.[14,15] Dosage of PERT requires tailoring to dietary fat intake and drug efficacy improves when flexibly self-dosed by patients.[16] Therefore following initial guidance by a specialist dietitian, PERT may demand a degree of self-management with efficacy pivoting around patient compliance.[11,17] Whilst recommendations in the UK include post-operative dietetic referral for nutritional counselling, [11,18] including PERT education, international guidelines fail to impart clear guidance on PERT with ambiguous direction on patient education and follow-up procedures. [17]

Studies focusing on the use of pancreatic enzyme replacement therapy (PERT) indicate that patients are often under-treated following surgery, with the intricacies of therapy being cited as a barrier.[1] Whilst research by Carey and colleagues suggests that inappropriate PERT usage after surgery is predominant, [19] patient perception of PERT was not a focal point of their investigation, therefore our understanding of how survivors actually manage PEI is limited. Moreover, a dearth of patient perspective based evidence more generally means that the nature of the issues around self-management of PERT remain unclear.

It is well documented that patients with cancer wish to manage their own care [5, 20] Furthermore, in the UK, the Expert Patient Programme suggests that having an active role in managing one’s own condition enhances QoL. [21] To facilitate this, a better understanding of how survivors of cancer manage the changes precipitated by treatment is required. To gain insight into how patients are supported to manage such changes, we explored the self-management of PERT following surgery for pancreatic cancer with the aim of understanding the experience of cancer survivors.

## Methods

### Setting

Participants were recruited from outpatient clinics, located at two hospital sites within one National Health Service (NHS) trust in the north of England. The study was approved by the Yorkshire and the Humber National Research Ethics Service committee (study number

15/YH/0031) and conducted in accordance with the ethical principles that have their origin in the 1964 Declaration of Helsinki and its later amendments.

## Study Design

A paucity of relevant literature warranted a qualitative methodological approach to explore and map out this little known area and to facilitate an in-depth ‘inductive exploration’.[22, 23] Furthermore, the innately intricate nature of the phenomenon lent itself to qualitative methods as these methods subscribe to capturing the interpretations of people’s perception of different events[24] and highlight issues that are not apparent when using more structured, quantitative methods.

Using semi-structured interviews, data was gathered in accordance with an interpretivist perspective to ascertain an inside perspective from participants.[22] Data analysis was performed using qualitative inductive thematic analysis to permit the data set to be expressed in rich detail which is compatible with Braun & Clarke’s vision.[25] Adopting an inductive approach was justified as it eliminated any potential influence arising from the researcher’s analytic preconceptions. The desire to determine underlying conceptualisations held by participants lent itself to thematic analysis as the participants’ interpretations yielded the most appropriate explanations for their behaviours, actions and thoughts.[26] However, the researchers wished to also consider how the wider social context may influence these interpretations.

## Recruitment

Individuals attending three pancreatic surgeons’ clinic were invited to participate. Recruitment was conducted via a maximum variation sampling approach. Participants were purposefully sampled by age, sex, marital status and the surgeon overseeing their care. In contrast to analysis by grounded theory which relies on theoretical sampling, thematic analysis approaches are appropriate when samples are defined before proceeding with the study.[27] Eligible participants included adult patients who had undergone a PPPD greater than six months ago for a malignancy in the pancreatic region and were prescribed PERT post-operatively. Individuals who were ineligible for surgery, not prescribed PERT post-operatively or unable to consent were excluded from the study. Participants were identified by the overseeing clinicians during scheduled follow-up visits. Upon expression of interest, an information leaflet was offered. Potential participants were telephoned by a research dietitian three to five days later to further discuss participation. Recruitment continued until it was considered that no new information that challenged existing themes was identified.

## Data Collection

Semi-structured interviews were conducted in a quiet room in the participant's home. Informed written consent was obtained prior to each interview. A semi-structured interview provided an undiluted focus on the individual and addressed assumptions by asking open questions to encourage extended replies.[24]As the interview was of an exploratory nature, an open-ended schedule was drafted using non-directive, open-ended questions. Every interview began with an open introductory question: 'How have you been since surgery?' This was then followed by 'Can you tell me about your experience of using PERT?' or 'What does PERT mean to you?' Probing questions were employed only when appropriate to accommodate emerging ideas throughout the interview. Interviews were digitally recorded with participants' permission, ensuring respect and protection for their rights of confidentiality and dignity.

## Data Analysis

Audiotapes were transcribed verbatim by the principal investigator (LD) and recordings were repeatedly listened to, to ensure accuracy of the transcription. This preceded data 'immersion'[25] whereby the researcher ascertained repeated patterns of meaning, reading and re-reading the data several times. This ''repeated reading'' refers to the researcher's closeness with the data[25]. The software program, NVivo10[28] was used to sort and manage codes that represented relevant data. Codes identified features of the data that were considered pertinent to the research question. The accompanying field notes were simultaneously scrutinized. As is inherent to thematic analysis, the whole data set was given equal attention to allow full consideration be given to repeated patterns within the data. Following coding completion, sub-themes illustrating larger sections of data were sought. One important step in thematic analysis is that the 'themes' need to be evaluated to ensure they represent the whole of the text.[29] Therefore sub-themes were re-examined and refined to yield a thematic "map" of the analysis. Braun and Clarke suggest thematic maps assist the researcher in visualising and considering the links and relationships between themes.[25] At this stage, themes with insufficient data to support them were discarded. The analysis process was iterative; each stage was revisited before determining the overarching themes. Finally, the process of defining the themes ensued with considerable reflection on how the story told within each theme corresponded to the overall story that emerged from the data.

## Rigour of Study

During each interview, the researcher was attentive to building participant rapport, remained sensitive to the language used and attempted to check the understanding of a participant's response as opposed to relying on their own interpretation at a later point in time. Data collection was enhanced by recording detailed field notes and using a reflexive journal which aided the provision of 'thick description'.[24] This 'thick description' permits the reader to verify if the conclusions drawn hold 'validity' and subsequently to decide for themselves if 'transferability' to other settings is plausible. Equally, authors were committed to leaving an audit trail so as to provide 'transparency of method'. Data analyses should be conducted by more than one researcher to optimise dependability.[29] Data was constantly discussed and checked by 2 independent persons (LD and VH). This was used as a constant peer-review process to ensure that the analysed data were true findings and to recognize that bias could occur when describing participants' experiences. To strengthen the analysis process, reflexivity was achieved by detachment of the researcher from their role as a clinical dietitian in order to minimise aspects of the process being shaped by the researcher's expectations.[30] Whilst it is acknowledged that complete detachment is unattainable, the credibility of the results was sustained by withholding the researchers own agenda from the interview structure and transcribing all interviews in the participants' own words.

## Results

### Participants

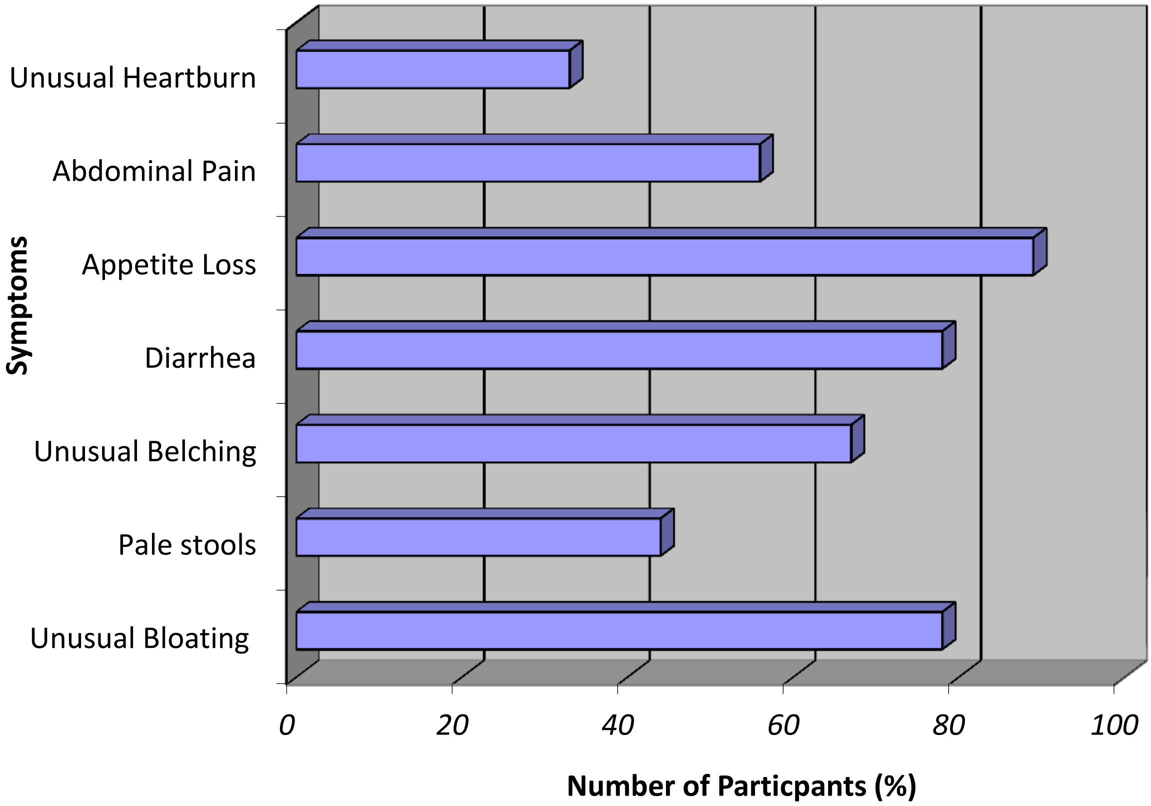
Ten patients were approached, nine consented to interview and one declined due to feeling unwell. Median participant age was 68 years and all described their ethnicity as White British. The average post-operative length was 16 months and all had been prescribed Creon® as the PERT drug of choice. Participants were assigned a pseudonym during transcription to protect their anonymity. Table 1 presents basic demographic data.

**Table 1: Characteristics of Study Patient Participants (n=9)**

| Characteristic | Value |
|---|---|
| Gender (n) | |
| Male | 4 |
| Female | 5 |
| Age, median (range), y | 68 (43-73) |
| Months since surgery, mean (range) | 16 (6-26) |
| Marital status (n) | |
| Married | 6 |
| Single | 3 |

| | |
|---|---|
| Employment status (n)<br>Retired<br>Employed | 7<br>2 |
| Ethnicity (n)<br>Caucasian British | 9 |
| Weight loss, mean (range), % | 16 (8-24) |
| Prescription (name, n) | Creon® (9) |
| Starting dosage (PhEur units lipase activity, n) | 50,000 with meal (9)<br>25,000 with snack (9) |

***Figure 1: Post-Operative Symptoms Reported by Participants***



## Themes

The thematic analysis of transcripts elicited key concepts that were evident in the data. Three overarching themes emerged: the role of professional support; factors influencing decisions to use PERT in symptom management and the challenges of socializing.

### The Role of Professional Support

The concept of professional support arose as a primary theme as a key point of discussion was the support provided whilst an inpatient and following discharge from hospital. Family and carers appeared to have a central supportive role however professional support was deemed inconsistent throughout the recovery trajectory. The focal points of discussion included the sources of education used by participants to acquire information on PERT and the significance of the timing of the advice received.

#### *Sources of Initial Education*

When initially commencing PERT, conflicting viewpoints emerged regarding the quality of advice received. Participants used a range of sources to access information: professional sources included the dietitian, ward nursing staff, hospital physicians, specialist nurses and GPs. Family and friends also assisted in the acquisition of knowledge. Despite recommendations not all participants received an education session with the dietitian. In the absence of this, many sought information from nursing staff on the ward immediately after surgery though it was felt that the level of detail offered was minimal. Some participants reported initially being completely unaware of the need for PERT due to the ambiguity of information provided in hospital:

*'I didn't know what it [PERT] was for- I really wasn't sure, they just said take it with your food, no explanation offered whatsoever. I hadn't realized what it was for at first.'* ***P8***

*'They don't explain it [PERT] to you in hospital, you know..... They just give it to you and because you don't know any better, you just do what they say.'* ***P5***

A minority conveyed a positive experience with the education received. Notably, those that had undergone an individualised educational session with the dietitian prior to discharge:

*'She* [the dietitian] *did explain it all before I left hospital though to be sure that I knew what I was doing with it....[PERT] which was good of her because you do need to know. It is a new drug to me. I had never known about it before'* ***P6***

However other participants largely misinterpreted the role of the dietitian, unaware that the dietitian could assist in symptom management by guiding dose adjustment. These individuals struggled with dose confusion following discharge and hesitated to contact the dietitian.

*'I told him [doctor] about the wind and the discomfort .... I never thought about the dietitian.... I thought he [doctor] might have some opinion about this reflux and sickness thing.'* ***P8***

The support received from other health professionals after discharge was not regarded positively. A perceived lack of information from hospital based physicians, specialist nurses and GPs meant that participants grappled with unanswered questions regarding symptom management. This was a predominant point of criticism. Participants relayed episodes whereby they felt an insufficient approach was taken:

*'The GP that I have got now... I told her about getting all this wind in my stomach and she said to me 'Oh there is nothing that we can do about that'. So I just figured that I had to get on with it ...'* **P5**

*'I explained it to the doctor* [consultant] *....I said I was feeling sick - I asked him what do you think it is....is it the Creon? He said 'probably'....just probably! Nothing more.'* ***P7***

Individualised advice regarding PERT was deemed necessary:

*'....perhaps more information on how to adjust your dose, I suppose not standardizing the dose for different meals really. Whereas, I have adjusted this myself but I still feel confused.'* ***P4***

All participants highlighted a central role for family and carers with regards to accessing information on PERT and in adapting to using it in their daily lives. For some, family and friends were pivotal in reminding them to take PERT and participants spoke graciously of their helpful prompts. Equally, their presence during initial consultations proved beneficial:

*'....the dietitian coming round to speak to me all about Creon dosing and what to expect when I got home was really just very hard to take in. It is a lot of information. My husband or my dad was there thankfully because I found that I just couldn't take it all in.'* ***P4***

There was a unanimous desire for improved peer support and participants frequently queried if their own experience equated to that of others. Access to peer support was limited and considered instrumental towards gaining knowledge on PERT.

### *Timing of Advice*

Those who received dietetic input felt the timing of advice was important and that pre-operative PERT education would have been beneficial due to feeling disorientated following surgery. They emphasised the importance of information being reiterated in the clinic setting post-operatively*:*

*'Getting the information at that time - you just can't register...after surgery and drugs, you are not thinking straight. You might listen at the time but when they have gone you think - what did they say?!'* ***P7***

Only one participant felt pleased with the timing of advice issued:

*'Thankfully she* [dietitian] *gave me the information before I came out of hospital, obviously I am on Creon so I needed the info. I got the right information at the right time. When I came out, I knew exactly where I stood, what was happening with them, what I needed to do with them...'* ***P6***

As the timing of advice impacted on information retention, a few participants expressed appreciation to have the option to phone the dietitian if needed and this was perceived as an important source of support post-discharge.

## Factors Influencing Decisions to use PERT in Symptom Management

Although the burden of PEI associated symptoms varied, the decisions used by participants to determine PERT usage was mainly influenced by insufficient knowledge and uncertainty regarding the medication. Participants inappropriately omitted PERT on a frequent basis and subsequently employed alternative strategies to overcome their symptoms. Equally, some expressed concern regarding excessive use of PERT due to the fear of potential side effects and anxiety with dosing.

### *Missed Opportunities to take PERT*

Few participants were symptom free, several described bloating, belching, flatulence, pain and discomfort after eating alongside urgency and frequency with bowel motions. There appeared to be a lack of information with respect to treating symptoms. Simple strategies such as increasing PERT dose were frequently overlooked:

*'Sometimes it [stools] is a little bit loose.... and I do wonder if it is because I eat the wrong things or don't have enough to drink.'* ***P3***

Alternative strategies to increasing PERT were frequently used in an effort to alleviate symptoms. Some participants resorted to anti-diarrhoeal or anti-sickness medications; others opted for food avoidance or cautious 'trial and error' strategies to observe the limits of what they could eat prior to experiencing unpleasant symptoms. One participant described reducing their overall dietary intake in an effort to decrease the amount of PERT required. It was felt that reducing PERT in this manner would then eliminate unwanted symptoms:

*'If I am eating out anywhere or on holidays, whereby I am generally eating more ... I'm having to increase the Creon and take the big one with meals because I'm eating more ...so I think it must be them that is causing it* [pain]. *Because when I am at home, I'm fine. I tend to cut back so that I just take the little one with most meals and no pain!'* ***P9***

***Concerns Regarding PERT Usage***

A lack of knowledge about the effects of pancreatic resection was evident. Many attributed the characteristic symptoms of malabsorption to PERT itself:

*'I am just putting it all down to Creon myself now because it has got to be that! I wasn't like this before I started taking the Creon. It has to be causing the wind and the sickness.'* ***P9***

Early satiety and debilitating pain were considered repercussions of PERT. Nevertheless, irrespective of these knowledge inconsistencies, there was an overall acceptance of the need for PERT:

*'I mean it is the Creon that is making me feel bloated. But then I know that if I haven't had it, I do get the runs so I know it is helping on some level.'* ***P3***

Symptoms were deemed an outcome rather than potentially treatable. A small minority grasped the concept of adjusting PERT appropriately but there was inconsistent knowledge around the timing of the medication.

Few participants demonstrated comprehension around increasing PERT if consuming high fat foods and anxiety with dosing prevailed generally across the group. Participants expressed fear of ‘over-dosing’ and deliberated over the potential long-term effects of the medication. One participant rendered the anxiety associated with dosing to be one of the most significant post-operative obstacles faced:

*‘I seem to be just constantly thinking, how much Creon do I need to take with this....the Creon and dosing of it has been one of the hardest things to cope with after the surgery’* ***P4***

This uncertainty generated a desire for more individualised advice regarding PERT, preferably tailored to the participants own dietary habits:

*‘It might have helped to provide a more rough guide on how to adjust your dose. I don't know if this is something they do with other patients, you know adjusting it according to what you eat.’* ***P1***

## The Challenges of Socializing

All participants discussed PERT in the context of socializing. Many felt that PERT impacted upon activities such as eating out, holidays and even routine day-to-day activities such as cooking. The predominant issues that arose were the perceived restriction of activities and a social discomfort.

### *Restriction of Activities*

The difficulty with remembering to take PERT was noted. This was particularly challenging in social settings where participants felt distracted and became susceptible to forgetting PERT. Occasionally, this had unpleasant consequences:

*'The problem for me is remembering to take them, particularly when you are out in company. You are talking away, your meal comes...knife and fork in hand and sometimes I can be a mouthful into it, I can be half way through it - well if I am half way through it, then I have got a problem. I will then get gripping pains and then it will be diarrhoea.'* ***P8***

Participants aspired to once again enjoying routine social activities including eating out. However, PERT hindered spontaneity when eating out, notably when participants did not have ready access to it; frequently forgetting the medication when leaving home was especially an issue during the earlier post-operative period. It often impacted negatively on social occasions:

*'Knowing that you can't go anywhere without taking it is a pain though. .... it does have an impact on my life in more ways than one'* ***P7***

The majority gradually adapted to remembering PERT. However, some participants continually struggled to integrate the medication into their social lives, even several months post-operatively and this was particularly prominent amongst male participants. One gentleman described uncertainty whilst trying to manage PERT when eating out:

*'Going out for a meal, when you have a starter, it is hard to work out the amount of fat in things and what dose you should take. I have 25,000s as well. So it gets quite confusing.'* ***P4***

Contrastingly, one participant comfortably adjusted PERT when eating out:

*'I have not found it to be a problem; I take my Creon with me. Pick what I want off the menu, take my Creon and away we go'* ***P6***

PERT impacted on routine lifestyle activities. One participant found cooking had become burdensome as tasting food during meal preparation was hampered by the uncertainty of needing PERT with each mouthful. Holidaying also invoked apprehension as participants contemplated how they would cope in a different environment.

### *Social Discomfort*

As our socialisation tends to be largely centred on eating, participants frequently referred to dealing with the social embarrassment of symptoms including wind and steatorrhea on these occasions. The extent of symptoms suffered and the impact they exerted varied and for some participants it caused significant distress:

*'I didn't think to take the extra dose with the fish and chips. I forgot all about it and then I could feel this sensation starting, so I went to the toilet and I thought 'oh god' ....because you don't just go once! .... I didn't even have time to pull my trousers up before I had to go again'* ***P8***

*'....It does affect your life. You know...usually I am getting this incredible urge to belch and burp and you simply cannot be doing it in front of other people.'* ***P5***

Participants even altered their diet to minimise the risk of embarrassing symptoms. One participant substituted main meals for light salads prior to socializing, adjusting PERT was overlooked. Moreover, PERT presented a perceived social stigma. When in the company of less familiar acquaintances, participants conveyed discomfort:

*'At social events you are taking your pills out - you know, you start to feel self-conscious. You think 'Oh everybody is looking at me and wondering what I am taking'* ***P4***

## Discussion

Following acute pancreatic cancer treatment, survivors face the difficulty of adjusting to physical, emotional and social challenges in order to achieve an optimal QoL. Given the poor prognosis of this group it is imperative to initiate a proactive approach towards recognising and solving problems. This study aimed to understand patient self-management of PERT following surgery for pancreatic cancer.

Optimum post-operative patient care demands careful coordination between multiple providers, appropriate information exchange and a coherent communication flow between all involved in patient treatment.[31] In this study, the support offered by health care professionals was reported to be inconsistent, varied and often viewed negatively by participants. Our findings suggest that there is scope for improving the model of care to facilitate self-management post-operatively in this group of patients. Gooden and White [13] propose a clinical gap in the management of PEI; our data enhances this understanding by specifically identifying a lack of support with how patients use PERT.

As our findings are limited to patient perspective, it is not possible to say what factors led to the perceived lack of support from healthcare professionals. Clinical pressures and time-restricted appointments often challenge the physician [31] and they may subsequently struggle to adequately address PERT management. In addition, the PEI investigatory process may be complex, emphasizing the need for individualised specialist input. Furthermore, the realisation that there are chronic changes following surgery presents numerous new challenges for the patient and their healthcare team. Previous work suggests that patients with chronic illness often feel left to “just-get on” with self-management, causing apprehension and uncertainty. [32] This is reflected in our findings where ambiguity resided regarding PERT dose, administration and potential adverse effects; concerns that persisted long after the initial post-operative period. Managing altered bodily functions challenged participants in their daily lives, even up to two years following surgery. Corresponding to patients with other cancers, long term management of the illness appears to follow a learning curve that may span several years [33]. Essentially, congruency between patient perceived outcomes of surgery and manageable symptoms is needed.

Cooper et al [6] acknowledge a long process of "remapping the body" as patients diagnosed with pancreatic cancer adapt their eating habits to cope with the effects of surgery. We note participants adopted dietary adjustments akin to this whilst also using various alternative medications to minimise symptoms. However, misconceptions of PERT caused participants to overlook potential dose increases that may alleviate symptoms. Hence "remapping the body" became even more challenging. Ultimately, it is possible that enabling patients to appropriately self-manage PERT may lessen the post-treatment burden.

We confirm earlier findings whereby several patients did not receive dietetic counselling despite the advocated need.[6,13, 34] Interestingly, some individuals that were counselled by the dietitian were unaware of the opportunity for dietetic support with PERT following discharge. This could be due to inappropriately timed advice as patients may struggle to comprehend advice issued on discharge following a PPPD. [35]

Surgery may have profound consequences on a patient's sense of self and social identity and similar to earlier findings, our participants wished to be part of the social context. [12, 36] Subsequently their actions were aimed at reducing the gap between their pre and post-operative self. The external environment is of great importance to pancreatic cancer survivors [12] and from this respect, family and relatives made a key contribution to self-management. Their supportive role helped patients adapt to the logistics of PERT. Given the impact others may have on meal choices and social outings, those closest to the patient could benefit from attending PERT counselling sessions to optimise self-management. Equally, our findings illuminate dissatisfaction with the level of peer support offered; this was threaded across all participant narratives. Contact with other survivors who have a “lived experience” following surgery may prove beneficial.[37] Interaction with other survivors may foster positive adaptation to PERT self-management, reduce knowledge inconsistencies and therefore improve QoL through cancer survivorship.

## Limitations

This study depicts patients’ accounts; there are no observations of the clinical encounters, nor the perspectives of the healthcare professionals involved. Recruitment was from one NHS trust in the north of England and, as is the nature of qualitative research, it is not intended that the findings are generalizable across all patients using PERT. Equally, only patients who felt well agreed to participate. Findings may be limited by conducting interviews at solely one time point and as the post-operative period ranged up to 26 months, recall bias is possible. However to the author’s knowledge, no research has previously focused on the phenomenon of PERT amongst this population and the findings provide some indication of the problems patients face. The quality of data in terms of richness, experiences and relatedness to the research question was priority and subsequently the depth to analysis was sufficient to develop the findings from the sample size obtained. The richness of data was also enhanced by the in-depth nature of the interviews conducted.

## Implications for Research

It is clear from our findings that some areas require further exploration. The existing lack of good quality evidence pertaining to PEI management [11] indicates a potential line of inquiry towards examining the daily use of PERT amongst this cohort. The themes identified in this study provide a context for further research and the patients perspectives could be used to inform the development of services. Ensuring that patients have a good understanding of existing services could be beneficial to allow symptom burden to be addressed. Future investigation should explore the processes by which patients decide and select what sources they seek information from as they journey through the trajectory of recovery.

## Conclusion

When using PERT, patients negotiated considerable challenges. The identified lack of support extended across primary and secondary healthcare settings emphasising the need for a more collaborative MDT approach. Our findings suggest that intervention by a specialist dietitian is likely to be beneficial [9] although the timing of advice should be considered. Whereas there may be added benefit to imparting education around PERT pre-operatively in the outpatient clinics, we also noted opportunity for improved patient-centred medication management in the acute setting, namely in the form of open dialogue between patients and staff on the ward. Above all, emphasis should be placed on ensuring that patients are given opportunities to voice their concerns around self-managing PERT. The biographical disruption caused by both the disease and surgery generated challenges for the pancreatic cancer patient yet professional support was inconsistent and relinquished prematurely following discharge. To promote survival, health and well-being, a one size fits all approach is imprudent and optimum patient care should address the patient ‘self-management journey’. [38] Those planning the delivery of patient care should consider how this is best managed by the MDT service to ensure patients are supported with self-managing PERT throughout the recovery phase and beyond.

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