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Original article

Pancreatic enzyme replacement therapy following surgery for pancreatic cancer: An exploration of patient self-management

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SUMMARY

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.

1. Introduction

As cancer increasingly emerges as a chronic condition, governmental agendas set out the provision of supportive care for survivors [1–4] 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 focussing 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].

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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 focussing 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.

2. Methods

2.1. 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.

2.2. 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.

2.3. 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.

2.4. 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.

2.5. 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

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