European Journal of Oncology Nursing 26 (2017) 36–41

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Symptoms and self-care following pancreaticoduodenectomy: Perspectives from patients and healthcare professionals - Foundation for an interactive ICT application

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ARTICLE INFO

Article history:
Received 17 February 2016
Received in revised form
25 November 2016
Accepted 4 December 2016

Keywords:
Pancreatic neoplasms
Pancreatic surgery
Pancreaticoduodenectomy
Symptoms
Self-care
advice
ICT
Smartphone application

ABSTRACT

Purpose: Poor prognosis and a problematic recovery period after pancreaticoduodenectomy means that patients may benefit from early detection of symptoms and support for self-management. Interactive Information and Communication Technology tools can be used for this purpose, but the content needs to be relevant to patients as well as healthcare professionals. To facilitate development of the content of an application for this purpose, the aim of this study was to explore common symptoms and self-care in the first six months after pancreaticoduodenectomy, as identified by patients and healthcare professionals.
Method: Data were collected through individual interviews with patients (n = 14), along with two focus group interviews and one individual interview with healthcare professionals (n = 10). Data were analysed using qualitative content analysis.
Results: Common symptoms after surgery were those related to eating, bowel function and emotional wellbeing, along with fatigue and pain. Some self-care activities and advice were mentioned in the interviews. The patients often experienced a lack of advice on self-care at discharge.
Conclusions: The results render knowledge of the symptoms it is important to be aware of and to assess regularly after pancreaticoduodenectomy. The results also contribute to knowledge about specific self-care related to these symptoms, even though it was not extensively described, and further research is needed to define evidence-based self-care advice.

1. Introduction

Pancreatic cancer is rare but has a high mortality rate (Ferlay et al., 2013). Even after intentional curative surgery and adjuvant chemotherapy the prognosis is poor, with a median survival time of about 2 years (Neoptolemos et al., 2010). Most resectable tumours are located at the head of the pancreas or periampullary region and for these the standard treatment is pancreaticoduodenectomy. The surgery includes removal of the pancreatic head, duodenum, distal common bile duct and gall bladder, with or without preserving the gastric antrum and pylorus (Pappas et al., 2010). The recovery period can be long and problematic, since half of patients will suffer from postoperative complications such as delayed gastric emptying, pancreatic fistula, abdominal abscess, wound infection and cardiopulmonary problems (Winter et al., 2006). When reviewing the literature, common postoperative symptoms as experienced by patients include fatigue, appetite loss, nausea/vomiting, taste alterations, diarrhoea, sadness, worry and pain, but most symptoms decrease during the first six months (Andersson et al., 2012; Chan et al., 2012; Farnell et al., 2005; Gerstenhaber et al., 2013; Kostro and Sledzinski, 2008; Morak et al., 2010; Nieveen van Dijkum et al., 2005; Nimura et al., 2012; Pezzilli et al., 2011; Schniewind et al., 2006).

It is emphasised that care and support for patients with cancer

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http://dx.doi.org/10.1016/j.ejon.2016.12.002

should focus on recovery, support for self-management, early recognition of signs and symptoms, and routine use of patient-reported outcome measures (Maher, 2013). Self-management has recently been interpreted as actions patients take to manage their health condition, and important preconditions for self-management is the interactions between patients and healthcare professionals (McCorkle et al., 2011). Self-management interventions strive to help patients to take an active role in preventing and managing symptoms, during and after treatment (McCorkle et al., 2011). Swedish law stipulates that patients should be given the opportunity to take an active role in their own care (The Swedish Riksdag, 2014). The Swedish National Care Programme for patients with pancreatic- or periampullary cancer involves patients learning about common complications and receiving regular self-care advice (Confederation of Regional Cancer Centres in Sweden, 2014). Patients also emphasise the importance of support from healthcare professionals in terms of discussing self-care needs after discharge (Andersson et al., 2012). However, the evidence around self-care strategies are scarce, and focus mainly on enzyme supplements and managing medication for pain, as well as how to manage eating-related problems (Andersson et al., 2012; Cooper et al., 2015).

Given the poor prognosis and problematic recovery period, challenges arise in supporting these patients after discharge, and encouraging them to take an active role in their own recovery. Collecting patient-reported symptoms through interactive Information- and Communication Technology (ICT) tools may improve patients' symptom management (McCann et al., 2009; Ruland et al., 2010) and self-care ability (Seto et al., 2012). Patients with cancer have reported a positive attitude to using ICT applications to enhance self-management (Jansen et al., 2015), and noted that it improves symptom management (McCann et al., 2009; Ruland et al., 2010).

Based on this, we intend to develop an ICT application for smartphones and tablets, where patients report symptoms to their healthcare professionals and receive support for self-management by having continuous access to their healthcare professionals and written self-care advice in real time. The content of this application must be evidence-based and relevant to both patients and healthcare professionals (Rose and Bezjak, 2009). Therefore, with the goal of developing the content of the interactive ICT application, the aim of this study was to explore common symptoms and self-care in the first six months after pancreaticoduodenectomy, as identified by patients who have undergone this surgery and by healthcare professionals caring for these patients.

2. Methods

2.1. Design

The study design is underpinned by the Medical Research Council's complex intervention evaluation framework (Craig et al., 2008). The framework includes three phases: developing the intervention, assessing feasibility and evaluating the intervention. The present study represents the initial phase i.e. developing the content for the ICT application.

2.2. Setting

The Gastrocentrum at Karolinska University Hospital is a specialised clinic with the highest volumes of pancreatic surgery in Sweden. Following pancreaticoduodenectomy, the patients are cared for on a surgical ward for 1–2 weeks, and thereafter at a rehabilitation unit for one week. At discharge they are informed they should contact the clinic's outpatient unit if they feel the need to. One month after discharge, the patient has an appointment with a registered nurse and a surgeon at the outpatient unit.

2.3. Interviews with patients

2.3.1. Sample

Over a period of six months, all patients who had undergone a pancreaticoduodenectomy at the setting due to suspected cancer were screened for eligibility. Inclusion criteria involved having been discharged from surgery within the last 6 months, being Swedish-speaking, having no cognitive impairment and living in the Stockholm area. After stratification for equal sex distribution, 14 patients were invited and all consented to participate in the study. Demographic data are shown in Table 1.

2.3.2. Data collection

The interviews followed an interview guide with the following questions: Which symptoms have you experienced at home after surgery? How do you deal with these symptoms? What advice have you received from healthcare professionals? Do you wish to receive advice about self-care or do you prefer to receive help from someone else? Probing questions were used where required. The interviews lasted on average 40 min (range 19–60 min), and were audio recorded and transcribed verbatim. Seven patients were interviewed in connection with a follow-up appointment at the outpatient unit, six at home, and one over the phone.

2.3.3. Data analysis

During the interviews, notes were also made about the main issues raised according to the interview guide. In the final few interviews, no new major findings were identified from the notes. Data were analysed using inductive qualitative content analysis (Elo and Kyngäs, 2008). Initially, the interview transcripts were read through several times to make sense of the data and the whole. The text was then coded by symptoms or self-care, using open coding where notes and headings were written in the text while reading it. The codes were then transferred to a coding sheet where similar codes were grouped together to create categories. The codes and categories were discussed by the researchers and revised until agreement was reached.

2.4. Interviews with healthcare professionals

2.4.1. Sample

A purposeful sample of 12 healthcare professionals was invited to participate in two focus groups. The inclusion criterion was that they should represent all professions in contact with the current patient group throughout the care chain. For all professions, the persons at the site with the longest experience in caring for the patient group were invited. At the time of the focus group interviews, three of the participants who had been invited were unavailable, and one of them agreed to be interviewed individually instead, which resulted in a final sample of ten; registered nurse ($n = 4$), enrolled nurse ($n = 2$), physiotherapist ($n = 2$), surgeon ($n = 1$) and dietician ($n = 1$). Their experience of caring for the patient group ranged 2–20 years.

2.4.2. Data collection

Focus group interviews were chosen as they take advantage of group dynamics in order to access rich information in an efficient manner (Kitzinger, 1994). The individual interview was conducted by telephone with the surgeon who could not participate in either focus group. A moderator and an observer not known to the healthcare professionals facilitated both focus groups. The interviews followed an interview guide which contained the