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Original article

Patients' experiences with home parenteral nutrition: A grounded theory study

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SUMMARY

Background & aims: Parenteral nutrition (PN) provides nourishment and hydration as an intravenous infusion to patients with intestinal failure (IF). The aim of the study is to generate theory that explains the experiences of adult patients living with home parenteral nutrition (HPN) and complex medication regimens.

Methods: A grounded theory methodology was used to explore the experiences of twelve patients receiving HPN. A semi-structured interview was conducted and recorded in each participant's home setting. Each interview was transcribed verbatim. The simultaneous process of data collection and analysis was followed reflecting the principles of the constant comparative approach.

Results: A total of 15 patients gave written consent, with 12 of them agreeing to be interviewed. All the participants had previously undergone surgery as a result of chronic ill health or sudden illness. Analysis revealed two core categories: stoma and HPN, and these were supported by the subcategories: maintaining stoma output, access to toilets, managing dietary changes, maintaining the HPN infusion routine, access to technical help to set up an HPN infusion, mobility with HPN equipment and general health changes. The strategy of living with loss was demonstrated by all the participants, and this was supported by the action strategies of maintaining daily activities and social interactions.

Conclusions: This study generates new understanding and insight into the views and experiences of patients receiving HPN in the UK. The findings from these participants have been shown to resonate with the Kubler-Ross Model [1] of the five stages of grief. The theory of living with loss was generated by the use of a grounded theory methodology. This small scale exploratory study reveals opportunities for improvements in practice to be considered by the nutrition support team (NST) and other healthcare professionals involved in the patient's hospital stay prior to discharge on HPN.

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1. Introduction

Intestinal failure (IF) is a condition that can lead to a range of health problems associated with extensive loss of absorptive function and capacity of the small intestines [2]. The causes for IF include congenital defects, obstruction, abnormal motility, major surgical resection and severe inflammatory bowel disease. The term short bowel syndrome (SBS) is used to describe the clinical consequences caused by IF [3], whereby the body is unable to

absorb nutrients (fat, protein and carbohydrate), water, minerals and vitamins from the diet to maintain health or sustain life. Wanten et al. [4] defined short bowel syndrome when less than 200 cm of small intestines remain (or 75% is lost) as the result of surgery, bowel disease, or a congenital defect. Parenteral nutrition (PN) provides optimally balanced macronutrients, micronutrients and electrolytes by intravenous infusion. PN is a life-saving therapy for patients with severe IF [5]. In some cases patients with chronic IF become reliant on PN long term in order to meet nutritional and fluid requirements.

Since the 1970s adults in the USA with chronic IF caused by non-malignant diseases were offered home parenteral nutrition (HPN) [6]. Patients or their main carers learnt how to set up the infusion,

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and to connect it to the central venous catheter aseptically at home. Patients with chronic IF from SBS continued with oral diet and fluids, and took oral medications to reduce losses from ileostomies or chronic severe diarrhoea [7]. From the mid-1970s the use of HPN became available in some European countries. In 1977 St Mark's Hospital, London discharged the first UK patient on HPN [8]. Between January 1977 and March 1986, 200 adult patients were registered as receiving HPN in the UK [9]. They were managed by home parenteral nutrition teams in 28 centres, with 7 centres being responsible for 75% of these patients.

In 1994 the HPN cost in the UK was estimated to be around £55,000 per patient year in the community [10]. HPN involves a range of non-drug related expenditures, making the total cost of this treatment modality much higher than those for other chronic health conditions such as hypertension or diabetes. In 2008 the UK National Commissioning Group published a report on the 'Strategic framework for intestinal failure and home parenteral nutrition services for adults in England' [11]. It reported that 18 adult patients per million populations require prolonged management of IF in hospitals, and 14.6 adult patients per million population need HPN on discharge from hospital. They live in local communities and continue to be monitored by HPN teams at regular out-patient clinics.

Since the 1980s there has been increased international research interest to explore the quality of life (QoL) of patients receiving HPN [12]. In 2005 Winkler [13] reported poor QoL in patients with HPN dependency compared with healthy populations or patients with other intestinal diseases not requiring HPN. In 2010 Baxter et al. [14] published a validated questionnaire to measure the QoL of patients treated with HPN. A Swiss multicentre, nationwide, observational study of 33 adult patients receiving HPN found improvement in anthropometric parameters and QoL at baseline and after a follow-up of 3 months [15]. Schliefert et al [16] conducted a quantitative, cross-sectional cohort study of 8 Australian adult patients receiving HPN. These researchers found that the HPN patients' QoL was low compared with Australian norm values. Dreesen et al. [17] developed a set of quality of care interventions for adult patients on HPN which could be incorporated in quality improvement programmes. A narrative review [18] from 1970 to 2013 did not identify any published qualitative studies on the experiences of patients receiving HPN in the UK. The aim of this study was to generate theory that explains the experiences of adult patients living with HPN and complex medication regimens.

2. Materials and methods

2.1. Interviews

The Sheffield HPN team at Royal Hallamshire Hospital (RHH) has been looking after patients treated with HPN since the early 1990s. Over the years, patients with severe IF from nearby cities in South Yorkshire (Barnsley, Rotherham, Doncaster and Bassetlaw) and as far afield as Boston and Mansfield have been referred for HPN. By 2012 the Sheffield HPN team was looking after twenty-five adult patients receiving HPN. This study used a qualitative grounded theory approach that involved simultaneous data collection and analysis, theoretical sampling and the use of theoretical memos [19]. Ethical approval was obtained from the UK Integrated Research Application System (IRAS), reference number 12/NW/0554; and from the Research Department at Sheffield Teaching Hospitals NHS Foundation Trust. Patients who were receiving HPN feeds alone, home intravenous fluids alone, or a combination of HPN feeds and intravenous fluids, were included in the study. Patients treated with HPN, but who were too ill with impaired consciousness, were excluded as their underlying life-limiting condition imposed different constraints on their experiences with HPN. The author (CW) was not a

member of the Sheffield HPN team so participants eligible to take part in the study did not know the researcher.

An invitation letter, information pack and informed consent form were sent to patients before their next HPN out-patient clinic appointment between October 2012 and September 2013. In addition, a recruitment poster was used to advertise the study at the hospital's out-patients clinic. Patients who met the inclusion criteria were purposefully sampled. 15 out of the 25 patients of diverse social and clinical background gave written consent, of whom 12 agreed to be interviewed. As such this is a representative sample of patients meeting the inclusion criteria. In qualitative research the aim is often not to generalise from a sample, rather ensure the sample is representative, (ensuring the range of views held) and this includes theoretical sampling as acceptable [20]. Table 1 provides information on the participant's underlying disease. All study participants continued with stoma care and HPN treatment at home when they were discharged from hospital.

A 60-min audio recorded semi-structured interview was conducted by the author (CW) at each participant's home. Participants were encouraged to describe their experiences living with HPN and taking a complex medication regimen. An interview guide containing questions and probes was used to guide the conversation, ensuring that the conversation stayed focused. The researcher (CW) did not use all the questions, and they were not asked in a specific order when exploring the lived world of the participants in context of their experiences with HPN. Throughout all the interviews the researcher maintained a value-neutral approach, making no attempts to ask leading questions which might favour a particular outcome. The initial interview guide was developed (a requirement of the ethics application) using published guidance and information used by other researchers in this field [21]. This guide contained open-ended questions and probes; however, these were not treated as structured or prescriptive in their utilisation. Each interview commenced with the same opening question; 'Tell me about how you came to receive home parenteral nutrition?' Each interview was fully transcribed verbatim by the author (CW) with all identifiable names removed.

2.2. Data analysis

This study followed analytic processes and techniques developed by leading grounded theorists: Glaser and Strauss [19], Strauss and Corbin [22], Charmaz [23]. A combination of approaches were used which included open, focused and selective analytic techniques for refining category, linkage and connections. Table 2a provides the basic methodological information on the grounded theory approach [19,22,23].

This initial data analysis of the first interview transcript was used to direct data collection or purposeful sampling [23]. Each interview transcript and the open codes generated by (CW) were reviewed by co-authors (BL and DW independently). Theoretical memos were maintained throughout in order to support the generation of themes, phenomena, early categories and subcategories

Table 1
Underlying disease of the participants.

Participants with 'Chronic ill health' (n = 4)	
Crohn's disease (short bowel & stoma from surgery)	3
Gastrostomies (short bowel & stoma from surgery)	1
Participants with 'Sudden illness' (n = 8)	
Mesenteric venous thrombosis (short bowel & stoma from surgery)	5
Bowel fistula (from surgical complication)	1
Rectal cancer (known Crohn's disease with short bowel & stoma from surgery)	1
Encapsulating peritoneal sclerosis (end stage kidney disease with short bowel & stoma from surgery)	1

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