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A Qualitative Analysis of the Information Needs of Parents of Children with Cystic Fibrosis prior to First Admission

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ABSTRACT

Purpose: Hospitalization can be stressful for patients and their families. Pre-hospitalization information is crucial in establishing a good basis for patient satisfaction. In order to develop better preparatory material for parents, this qualitative study explored whether parents of children with cystic fibrosis, admitted to a UK Children's Hospital, felt adequately prepared for their child's admission.
Design and Methods: Data were collected from twelve parents whose children had been admitted within the last two years for routine intravenous antibiotics. Semi-structured interviews were analyzed using thematic analysis.
Results: Four themes emerged from the analysis: (1) preparing for admission, (2) the ward as a challenging environment, (3) changes in the parent-professional relationship and (4) the parental role in medical care.
Conclusion: Provision of adequate preparatory information is essential in reducing parental stress, influencing how future experiences are appraised and managed. Effective parent-professional communication and opportunities to participate in care are likely to improve parental satisfaction.
Practice Implications: Preparatory information prior to hospital admission greatly assists parents in making informed decisions and working as joint advocates in their child's inpatient care.

Introduction

Cystic fibrosis (CF) is a chronic, life-limiting, multisystem disease, affecting more than 10,800 people in the UK (UK Cystic Fibrosis Registry, 2015). Patients with CF are required to complete rigorous treatment regimens comprising of daily physiotherapy, medication and nutritional monitoring (Cystic Fibrosis Trust, 2011; Bishay & Sawicki, 2016). During childhood and early adolescence, parents play an integral role in delivering care and facilitating treatment adherence within the home environment (Butcher & Nasr, 2015; Goodfellow et al., 2015; Modi, Marciel, Slater, Drotar, & Quittner, 2008). In some instances, hospitalization for more intensive treatment is required. Many children with CF are admitted to the hospital for a course of intravenous (IV) antibiotics (lasting 2–3 weeks), to manage pulmonary exacerbations (Bhatt, 2013; Cystic Fibrosis Trust, 2009; Flume et al., 2009).

It is well recognized that hospitalization is a highly stressful experience both for children and their families (Commodari, 2010; Franck, Mcquillan, Wray, Grocott, & Goldman, 2010; Franck et al., 2015; Nabors et al., 2013). Parents are required to familiarize themselves with new settings, routines, negotiate new roles in care and manage anxieties regarding their child's treatment (Verwey, 2008). For parents of children with CF, these uncertainties are likely to be especially challenging, given their central role in the day-to-day management of their child's condition. There may be added stress due to in-hospital isolation measures, in place to reduce the possibility of cross-infection (Saiman et al., 2014; Festini et al., 2006; Griffiths, Carzino, Armstrong, & Robinson, 2004). Evidence indicates that in-hospital isolation is associated with adverse psychosocial outcomes, including feelings of isolation and perceived lack of social support (Duff, 2001; Griffiths, Carzino, Armstrong and Robinson, 2004; Russo, Donnelly, & Reid, 2006; Visse, Abma, van den Oever, Prins, & Gulmans, 2013).

High parental distress has been identified as a barrier to effective participation in child care and can adversely affect the hospitalized child both during (Power & Franck, 2008) and after admission (Dunn et al., 2012; Kassam-Adams, Fleisher, & Winston, 2009; Nugent, Ostrowski, Christopher, & Delahanty, 2007). It is becoming increasingly recognized that informing and preparing parents of what to expect during their child's hospitalization is crucial in reducing distress and enabling parents to maintain a key role in care (Commodari, 2010).

In the UK, the National Service Framework for Children, Young People and Maternity Services (NSF CYPMS; Department of Health, 2003) identified this need and set out standards of care highlighting the importance of providing "accurate information [regarding hospitalization] that is valid, relevant, up-to-date [and] timely" and doing so "utilizing a range of communication methods so that information may be made

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available regarding specific conditions, medicines and procedures" (Department of Health, 2003, p. 16).

Research has shown that preparatory programs such as the conveyance of detailed information in person, via leaflet or DVD, have the potential to improve the hospitalization experience for both patients and their families (e.g., Buckley & Savage, 2010; Claar, Walker, & Barnard, 2002; Gordon et al., 2011; Margolis et al., 1998; Schmidt, 1990; Smith & Callery, 2005).

Aims

This study aimed to investigate the information needs of parents of children with CF, admitted to a UK pediatric CF service for routine IV antibiotic treatment. No research to date has qualitatively explored the preparatory needs of parents of children with CF prior to first admission. This study was designed to address this gap in the literature with specific focus placed on the following questions:

- What do parents need in order to feel adequately prepared for their child's initial inpatient hospital admission?
- How can the CF pediatric service better meet the needs of these parents, addressing the requirements set out by the NSF CYPMS (Department of Health, 2003)?

Methodology

Design

A qualitative design was employed, through which data generated from semi-structured interviews were analyzed using inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis was chosen as it provides a reflective approach that allows researchers to capture the richness and in-depth nature of participants' experiences and allows for the generation of general themes across the data set.

Participants and Recruitment

Twelve parent couples were contacted for interview. Parents had been identified by the team's Senior Nurse and Physiotherapist. Parents were eligible for participation if (i) they had a child who had experienced their first planned inpatient hospital admission (or first inpatient hospital admission since infanthood) within the last two years and (ii) the admission had been related to the delivery of IV antibiotic treatment.

Ten parent couples agreed to take part. Eight mothers were interviewed alone, and two couples were interviewed together. Parents ranged in age from 35 to 70 years (M = 45.2, SD = 9.8), self-identified ethnicity was as follows: 11 White British and one Asian British. Children ranged in age from 2 to 14 years (M = 8.1, SD = 4.1).

Ethics

Ethical approval was obtained from the University of Bath Psychology Ethics Committee and the Research and Development Department of the local NHS Trust.

Semi-Structured Interviews

Semi-structured interviews took place with each parent (or parent couple) who consented. The questions that formed the interview guide (Table 1) were developed through discussion with the CF staff team and informed by the current literature and the study objectives. The input of local (CF team) and international (literature) in the field in informing the questions, the interview schedule can be stated as having face validity. The purpose of the semi-structured interview was to systematically collect information from parents by asking uniform questions, while offering the flexibility for parents to provide additional relevant information and allow the interviewer to ask clarifying questions.

Table 1
Interview guide.

- Tell me about your child (age, health)
- Tell me about your child's first hospital admission for IV antibiotics
- What preparatory information/advice did you receive?
- How and when was this information given?
- Do you feel it was provided in a timely fashion?
- What information/advice did you find most helpful and why?
- What information and/or support did you not receive that could have been helpful?
- When would you like to have received this information?
- What effect did this preparation/lack of preparation have on the admission experience?
- How could staff best prepare parents for their child's first admission?

Interviews were conducted by the first author and took place within the parents' homes. Interviews were audio-recorded and each lasted between 45 and 75 min.

Data Analysis

The interviews were transcribed verbatim and analyzed using Braun and Clarke's (2006) six-phase guide to thematic analysis. A deductive and inductive analysis was conducted. The deductive analysis specifically drew out quotes relating to the first research question (Theme 1), whereas the inductive analysis developed the rest of the transcripts into themes, thus it was data-driven rather than research question-driven (Themes 2, 3, 4). In this way, it was ensured that the first research question was answered, while allowing an open analysis to answer the second research question.

The first author read the transcripts repeatedly to ensure familiarisation with the data. Initial ideas were noted down and the data were then coded. Data with the same codes were collated and sorted into identifiable themes and subthemes. Themes were then refined by comparing the generated themes to the original text and their appropriateness and resonance in relation to the research question were reviewed. To ensure rigor, as suggested by Yardley (2008), a 'paper trail' was kept to identify how themes had developed over time. The above process was completed by the first author alone.

To promote reliability of the analysis, the themes were verified by the third author (JD), an experienced clinical psychologist and researcher within the area of clinical health psychology. The third author independently analyzed four transcripts and then met with the first author to compare findings and reach a consensus regarding the thematic structure. Finally, the fourth author (SP), who had expertise within the area of CF, was asked to review the thematic map and codes as a final credibility check.

Results

Four main themes emerged from the analysis: (1) preparation for admission, (2) the ward as a challenging environment, (3) changes in the parent-professional relationship and (4) the parental role in medical care. Sub-themes were identified for the first theme only. Themes describe the parents' 'journey' from the clinic to the hospital ward and the associated challenges that shaped their perceptions of the hospital experience. Pseudonyms have been used to preserve parent anonymity.

Theme 1: Preparation for Admission

In all cases, admissions took place within the context of routine symptom monitoring. This meant that the consulting CF physician made a decision, following necessary tests and observations, that a hospital admission for IV antibiotics was required.

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