A qualitative study of physiotherapy education for parents of toddlers with cystic fibrosis

Claire J. Tipping\textsuperscript{a,b,*}, Rebecca L. Scholes\textsuperscript{b}, Narelle S. Cox\textsuperscript{b,c}

\textsuperscript{a} Department of Physiotherapy, Alfred Hospital, Commercial Road, Prahran, VIC 3181, Australia
\textsuperscript{b} School of Physiotherapy, Monash University Peninsula Campus, Physiotherapy Building B, PO Box 527, Frankston, VIC 3199, Australia
\textsuperscript{c} Department of Physiotherapy, Monash Medical Centre, 246 Clayton Road, Clayton VIC Australia 3168

Received 27 September 2009; received in revised form 21 January 2010; accepted 14 February 2010
Available online 31 March 2010

Abstract

Background: Education and daily physiotherapy are often highlighted as difficult and stressful tasks for parents of young children with cystic fibrosis. This study aimed to identify factors that impair the delivery and retention of physiotherapy education for parents of these children and factors that impair effective physiotherapy treatment in the home environment.

Methods: A focus group of physiotherapists and six semi-structured interviews of parents with children with cystic fibrosis were conducted. The qualitative method of Grounded Theory was used to analyse the information and develop key themes.

Results: Major emergent themes were 'transitions', 'psychological distress' and 'connectedness'. Factors influencing the effectiveness of parental physiotherapy education include the large volumes of information, appropriateness of educational resources and timing of education. Factors influencing home physiotherapy management for toddlers include mastering techniques, the transition from infant to toddler and time management.

Conclusion: Physiotherapy education and management were key causes of psychological distress for parents. This research suggests that significant targeted development of educational resources is warranted, in conjunction with dedicated and ongoing formal psychosocial support for parents.

© 2010 European Cystic Fibrosis Society. Published by Elsevier B.V. All rights reserved.

Keywords: Cystic fibrosis; Education; Physiotherapy; Physical therapy; Paediatrics

1. Introduction

Cystic fibrosis (CF) is a lifelong genetic condition requiring complex daily physiotherapy regimes. To ensure patients and families are independent in the day to day management of CF they require effective ongoing education (1–4). The educational process is a major cause of stress to parents of children with CF (5) and parents are often identified as having a substantial gap in their disease knowledge (6). During infancy and childhood, parents are responsible for completing the daily physiotherapy routine. Home treatment during the toddler phase has been found to be particularly stressful (7). The vital nature of education in CF management highlights the need for a thorough understanding of parental education requirements and the difficulties faced by parents during this stage.

The aims were to identify from parents and physiotherapists what factors

- impair delivery and retention of physiotherapy education of parents of infants and young children with CF and,
- impact effective physiotherapy treatment in the home for toddlers with CF.

2. Methodology

2.1. Design

Qualitative research using Grounded Theory methods as described by Strauss and Corbin (8) were used to address the
aims of this study. Qualitative research seeks to understand human experiences, perceptions and behaviours using a naturalistic interpretative approach to the subjects and their setting (9). Participants were identified and recruited using purposeful sampling by the clinical co-researcher (NC) from the CF clinic at Monash Medical Centre (MMC). Purposeful sampling is the process of recruiting participants who appear to be valuable sources of information, as opposed to a random sample (9). We opted to recruit participants who fitted the study criteria, mentioned below, but who also appeared to the clinical co-researcher (NC) to be appropriate to interview as they would be willing to discuss the difficulties and challenges of having a child with CF. A variety of participants (by child age and gender) were utilised to gain a broader understanding of people experiences (9).

One focus group of paediatric physiotherapists (1 h duration) and 6 semi-structured interviews of parents (25–55 min duration) were conducted guided by interview maps.

Focus groups are a qualitative research method, which helps to gain understanding into the experience, perceptions and understanding of the group being examined (9). They consist of small groups of people from similar backgrounds who gather together to discuss a particular topic whilst guided by a mediator and focus group map. Focus groups are commonly used so that the discussions and anecdotal story telling may spark ideas and comments from other members of the group (10).

Focus group sample size was determined by the current literature that suggests 6–12 participants per group (10,11). These numbers are recognised as being appropriate to facilitate adequate discussion (10,11).

Semi-structured interviews are a method of data collection which is closely associated with Grounded Theory (11). They involve one on one interviews which are guided by an interview map. Questions are generally open ended and the interviewer can ask follow up questions to clarify details or explore new avenues which emerge during the interviews. Interview guides are dynamic and altered according to the results of the previous interview (11).

Sample size for the interviews was determined by completing interviews until theoretical saturation of data was reached i.e. the point at which no new theories were identified (8).

Ethics approval was obtained from the Southern Health and Monash University Ethics committees. All participants were required to give written informed consent.

2.2. Characteristics of participants and facilitator

Two groups of participants were consulted during this study, paediatric physiotherapists and parents of children with CF. Physiotherapists were included if they were involved in CF care and education at MMC. Parents were included if they had a child with CF between 2–16 years of age and were involved with the CF clinic at MMC. Participants were excluded if they did not speak English or were under 18 years of age.

The focus group and the first interview were conducted by an experienced facilitator (RS), whilst the subsequent interviews were conducted by the principal researcher (CT) under the guidance of the experienced facilitator (RS).

2.3. Data analysis

Grounded Theory principles (8) were applied in the analysis. Grounded Theory is based on identification of themes within the data and developing relationships between the themes. Themes which emerge from the data are then tested in subsequent data collection and analysis. Grounded Theory is an iterative process, through which data collection, analysis and theory development are ongoing. This ensures the theories generated are connected to or ground into the collected data (8).

Focus group and semi-structured interviews were conducted, digitally recorded and transcribed. Each participant was assigned a code number and pseudonym for transcription and quotation. The data analysis involved the audio and transcribed versions of data being reviewed numerous times to capture the full impression of the data. Line by line analysis was then completed to identify categories. The relationships between the categories were explored to develop sub categories and themes. Key quotations were identified and reviewed with the audio data for accuracy. The researchers met to discuss the emerging themes and were found to be in agreement with themes and categories.

2.4. Validity and trustworthiness

Trustworthiness of results are discussed in four components; credibility, transferability, dependability and confirmability (12). To enhance the credibility of the results data analysis was completed independently by two researchers (CT and RS). The coding process was completed numerous times by each researcher to ensure clear development of themes. Transferability is addressed by clearly outlining data collection and analysis to allow completion of a similar study in other population groups. Dependability of results was improved through the use of quotations to validate and reinforce key themes. Confirmability was enhanced through two researchers independently analysing the data, saturation of data and member checking, whereby participant members were asked to review the emerging themes and comment on their accuracy. This showed that participants were in agreement with the emerging themes and relationships. Recall bias of parents was addressed by having children of participants spread across a wide age range.

3. Results

One focus group of physiotherapists (n=5) and six semi-structured interviews of parents (n=6) were conducted. During each data collection session open ended questions were asked regarding the initial physiotherapy education process and physiotherapy treatment for toddlers in the home environment. Participants were encouraged to discuss the challenges within these areas, whilst also highlighting the successful aspects. Each group of participants showed variability amongst the
participants: the physiotherapists had differing levels of academic and clinical experiences, while the parents had children who exhibited varying illness severity and a wide spread of ages (Table 1).

The data from the focus group and interviews were analysed and three key themes emerged: transitions, psychological distress and connectedness. The themes identified highlight important underlying aspects of CF education and management. The relationships between the themes and their sub categories are detailed with reference to relevant quotes in Fig. 1.

3.1. Theme 1: transition

Transition is the passage of change from one state, form or place to another (13).

3.1.1. Physiotherapy treatments

As infants become toddlers physiotherapy treatments may progress from passive treatment techniques (percussion and vibrations) through to active treatments (positive expiratory pressure, flutter, forced expiratory techniques, direct coughing and exercise). The active techniques commonly begin as unstructured activities or games and progress through to structured treatments as the child improves their ability to complete the required skills (Quote 1, Table 2). The timing of this transition takes into consideration the child’s age and the ability to achieve the current treatment regime (Quote 2, Table 2).

Research further identified that a particular challenge to parents was physiotherapy management through the transition from infant to toddler (Quote 3, Table 2) and during the toddler years. This was highlighted by both the physiotherapists and the parents (Quote 4, Table 2). Parents commonly reported daily challenges they face with their toddlers during passive and active physiotherapy treatments (Quote 5, Table 2).

Parents emphasised the difficulties associated with fitting physiotherapy in around the other family commitments (Quote 6, Table 2). Guilt proved to be commonly associated with the responsibility for physiotherapy, particularly if treatment sessions were incomplete (Quote 7, Table 2). This emphasises the burden of daily physiotherapy and demonstrates a key source of psychological distress.

3.2. Theme 2: Psychological distress

Psychological distress emerged as a significant theme described by all parents and physiotherapists. Psychological distress encompasses the emotional feelings and concerns of parents, combined with the coping strategies they implement.

3.2.1. CF diagnosis

The diagnosis of CF was a significant cause of psychological distress to all parents and was well recognised by the physiotherapists. Feelings of shock and being overwhelmed were common experiences of parents during this time (Quotes 8 and 9, Table 2).

3.2.2. Physiotherapy education

The emotional responses associated with the CF diagnosis are coupled with the challenge of the intense education parents receive addressing the care of their child with CF. Parents in this study underwent an intensive 2–5 days of education immediately following the initial diagnosis of CF (generally made between 0–8 weeks after birth) (Quote 10, Table 2). During this time, parent’s knowledge of CF increased dramatically. Due to the multidisciplinary nature of CF management, parents received education from a range of health care professionals, this proved to lead to an overload of information for most parents. Parents’ level of knowledge continued to increase in surges throughout the child’s life, generally increasing significantly when new treatments were introduced, during hospital admissions and as parents completed independent research or attended CF Victoria seminars.

The transition of knowledge for children varied to that of their parents. Children were generally educated progressively over a long period of time. Education was suited to the child’s age and their clinical needs (Quote 11, Table 2). The types of educational resources used and the layout of the resources impacted on the effectiveness of education. All parents viewed written and video material as being an important adjunct to verbal and practical education, however the trustworthiness of the resources was occasionally questioned (Quote 12, Table 2).

Parents reported feeling “overwhelmed” and “mindboggled” from the education process. The stress associated with the importance of the education also affected parents (Quote 13, Table 2). Some parents found the mastering of new physiotherapy skills particularly difficult and highly stressful (Quote 14, Table 2).

---

Table 1
Demographic details of physiotherapists and parents.

<table>
<thead>
<tr>
<th>Participant (code number)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapists</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grade</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>(level of seniority/4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CF experience (years)</td>
<td>8</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Post graduate qualifications</td>
<td>Masters, Nil, Nil, Nil, Nil</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant (code number)</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9*</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents of children with CF</td>
<td>Age of child (years)</td>
<td>8</td>
<td>5</td>
<td>16</td>
<td>8/2 b</td>
<td>2.5</td>
</tr>
<tr>
<td>Gender (child)</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td>F/M</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Gender (parent)</td>
<td>F</td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Number of CF related overnight hospital admissions</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>8/0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>First child</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes/No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Number of siblings</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>3/3</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

* This parent represented two of her children, both with CF.

b This child is a fraternal twin, whose sibling is unaffected by CF. The twins are the 3rd and 4th children in the family.
3.3. Theme 3: connectedness

Connectedness emerged as being highly influential in the care of a child with CF. Social connectedness is the concept of having someone to talk to, someone to trust, someone to rely on and someone who knows you well (14). Connectedness also encompasses the need for social supports.

3.3.1. Connectedness with health care professionals

The importance of regular contact between the families and the CF team was recognised by both the physiotherapists and parents.

Feedback was shown to form an important part of education, particularly with treatment techniques, as it provides the therapists with an opportunity to assess the parent’s performance of prescribed treatments. Physiotherapists describe feedback as being challenging as often parents find feedback intimidating and an additional source of stress. The physiotherapists have to weigh up the benefits of feedback against the stress that it may cause the parents (Quote 15, Table 2). Parents however tended to be very accepting of feedback and viewed it as being a positive and valuable experience (Quote 16, Table 2). Feedback, however, tended to be more effective when a good relationship was formed between the parents and physiotherapists.

3.3.2. Social supports

Social supports arose as a major coping strategy for parents. This involved a mixture of formal supports (counsellors, physiotherapist, CF team and CF Victoria) (Quote 17, Table 2) and informal supports (family, friends and spouse) (Quote 18, Table 2). Parents identified the importance of having strong social supports, particularly through the initial diagnosis of CF and the initial education process. Parents tended to have a relatively thorough understanding of the social supports available and the most suitable supports for them.

Family functioning was a significant aspect to CF care. This particularly concerned fitting physiotherapy treatments in around other commitments and the differing parental roles. Mothers tended to be primary care givers; therefore were primarily responsible for completing daily treatments (Quote 19, Table 2). This often resulted in family difficulties as it increased the responsibility and stress associated for the mother, whilst increasing the guilt associated with missed treatments (Quote 6 and 7, Table 2).

4. Discussion

The three themes: transition, psychological distress and connectedness, are major components of CF management and are interrelated (Fig. 1). The key findings across these relationships are that many factors related to CF physiotherapy education and management cause an increase in psychological distress. These are particularly evident post initial diagnosis and during the transition from infant to toddler. Connectedness with others and social supports appeared to be effective in decreasing the experience of psychological distress.

Various models have been developed in the past to demonstrate the relationship between coping strategies and psychological distress in families with children with chronic illnesses (15–17). These models take into consideration demographics of the patient and illness parameters, family functioning, relationship between parent and child, methods of coping, stressors and social–ecological factors. These models demonstrate similarities with the conclusions of this study in regard to the importance of social–ecological factors (social support and family environment) and
family functioning on assisting parents to cope with the levels of psychological distress experienced. The models also acknowledge the impact disease characteristics can have on parental coping, in keeping with this study in relation to the impact of transitions and treatment routines (15–17).

The similarities between the conclusions of the above mentioned studies, indicates that it may be possible to generalise the results of the present study to other chronic childhood illness. This study also gathered information from mothers and fathers as well as physiotherapists which decreases the bias associated with the resulting conclusions. The age range of children represented in this study also allows for greater representation of the population and further decreases bias.

4.1. Physiotherapy education for parents

Education proved to be a significant source of stress for parents of children with CF and many factors were identified which impair its effectiveness. Overload of information is a common problem. Hummelink (6) found that parents can feel overwhelmed and intimidated by the initial education process provided by the CF team. This is consistent with the findings of this study.

The parents involved in this study clearly described the feelings of psychological distress when discussing education, using a variety of adjectives as highlighted in the quotes referred to above. Bernard (1) reported a similar set of adjectives used by parents of children with CF. This demonstrates consistency between the studies, and verifies the findings of this study. Timely delivery of education can be a challenge to parents whom often struggle to absorb information immediately after initial diagnosis (6,18). Despite this, Sawyer (19) found that all parents of children with CF endorsed the timing of their educational program and would encourage other parents to complete education immediately following diagnosis (19).

Educational resources have the ability to assist or hinder the education process. Parents reported the effectiveness of written and video material in complementing verbal and practical education. However trustworthiness of an educational resource may be doubted by parents if the resource is outdated. Regular improvements need to be made to educational resources to ensure the information provided to parents is current and of high quality. Mitchell (18) also highlighted this as a need expressed by parents of children with chronic illness and disabilities (18).

This study in conjunction with past research suggests that a physiotherapy specific educational package consisting of a

<table>
<thead>
<tr>
<th>Table 2 (participant)</th>
<th>Quote</th>
<th>Table 2 (participant)</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 (6)</td>
<td>“At the time we also had a bit of support unit with my mum and sister in law there and they were taught [physiotherapy techniques] as well for back up and a bit of emotional and moral support for me.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19 (6)</td>
<td>“My husband who is an angel, he is fantastic, he also wasn’t 100% support[ive] in that manner, he left most of it (physiotherapy) for me.”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
variety of educational mediums could be beneficial for parents (18). Such a package could include hints and strategies to overcome common problems associated with daily physiotherapy. The effectiveness of an educational package needs to be further examined within this population.

Mastering physiotherapy techniques by parents emerged as a difficult aspect of education. Physiotherapists viewed feedback during education sessions as imperative, however stated that it may be intimidating for parents. Previous research identified that it is important that parents have the opportunity to complete physiotherapy supervised skill development sessions to empower parents to be confident with the techniques they are performing (19), which is consistent with the results of this research.

4.2. Physiotherapy in toddlers

Completing daily physiotherapy with toddlers proved to be a challenging task. Parents described a range of factors that impacted on the ability to complete physiotherapy and highlighted the stress caused by the burden of physiotherapy.

Parents acknowledged the toddler phase as being a difficult time for any parent, particularly when compounded by the added challenges associated with managing CF. Completing daily physiotherapy treatments is particularly difficult as toddlers have short attention spans, become increasingly active and do not understand the importance of physiotherapy (7,20). In contrast, Eiser (21) found that CF physiotherapy was an equal concern for parents throughout childhood with no age groups being particularly difficult. The difference in findings between this study and the findings of Eiser (21) could be due to the differences in data collection methods, specifically the use of interviews compared to surveys.

Time management is often a challenge for parents and physiotherapy is reported as being difficult to fit in amongst family commitments and the needs of other children. Therapy compliance levels have been demonstrated to be lower where treatments have a negative impact on family life and cause a high level of stress (1,22,23). As such it is important for all parties to have an understanding of the time pressures associated with physiotherapy performance in an effort to maintain or improve compliance and adherence. Furthermore, parents describe significant feelings of guilt and stress associated with non-compliance with physiotherapy treatment, such feelings may serve to positively reinforce the non-compliance-stress cycle.

4.3. Psychological distress and connectedness

Parents in this study demonstrated high levels of psychological distress caused by a variety of factors related to CF education and physiotherapy treatment. Connectedness and social networks provide emotional support and meaningful social engagement (14). This can impact on particular aspects of psychological distress including perceived levels of coping, depression, distress and sense of wellbeing (14). The beneficial aspects of social networks on health include stress reduction and physiological wellbeing, decreasing symptoms of psychological distress (24). The participants in this study emphasised the individual importance of connectedness.

Strong connectedness with health care professionals emerged as being beneficial when managing CF. Strong patient–therapist rapport can result in higher levels of compliance due to an increased understanding of the treatment regime and the use of patient centred programs (1,25,26). Strong relationships with health care professionals can also provide a great source of support to the patient and their families. Physiotherapists did not emphasise the importance of their role as a support for parents, nor appear to comprehend how greatly parents depended on them for support. This could be due to physiotherapists concentrating on the primary aims of physiotherapy sessions, related to education and management and not acknowledge the additional emotional support that they provide parents during these sessions.

Research suggests that parents require ongoing formal psychosocial support to help to decrease and cope with the high levels of psychological distress experienced during early diagnosis and the toddler years. Formal psychosocial support could be beneficial in building strong rapport with additional member of the health care team and provided ongoing invaluable support to parents on an ongoing basis.

4.4. Bias and limitations

Due to the homogenous nature of the participants represented, the results obtained in this study may not be able to be generalised to different CF population groups, for example families who are managed through different health care networks, thus limiting external validity.

5. Conclusion

In conclusion parents of children with CF experience varying levels of psychological distress. This is influenced by the difficulties associated with transitions in physiotherapy treatment and education, the diagnosis of CF and juggling family commitments with the importance of physiotherapy treatment. Connectedness encompassing social supports and family functioning and enable parents to effectively cope with the varying levels of psychological distress they experience.

The high levels of psychological distress experienced by these parents and the number of compounding factors influencing this distress indicates that formal psychosocial and educational support is warranted. Formal psychosocial support is particularly important during the initial phase post diagnosis but should be maintained for parents through individual challenges and difficulties. To maximise the effectiveness of the education process, dedicated and ongoing physiotherapy education for parents is required. A physiotherapy specific educational package consisting of a variety of educational mediums could be beneficial for parents, however further research needs to be conducted to determine its effectiveness.
References