Protocol For Study Of Information Needs Of Parents Of Infants Newly Diagnosed With Cystic Fibrosis

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Abstract

Background: Cystic Fibrosis (CF) is an inherited disorder with currently no known cure, and treatment requires significant lifestyle changes. For most parents, the diagnosis of CF in their newborn infant is unexpected and requires intensive daily treatment and monitoring. Parents have a variety of information needs and priorities. Research is needed to identify and address these needs.

Aims: To investigate the information needs, priorities, and information-seeking behaviours of parents of infants newly diagnosed with CF using a validated questionnaire in a prospective study within Queensland.
Significance: Results will assist health care professionals in communicating with parents of infants recently diagnosed with CF, and contribute to the development of adequate, appropriate and timely information packages tailored to individuals and families.

Methods: A convenience sample of 20 parents will be recruited through the Brisbane CF centre, and will be asked to participate by completing the validated questionnaire. Responses will be analysed using descriptive statistics, and open-ended questions will be grouped into themes and described.

Conclusion: This protocol describes the background, significance, aims and methods of the study.

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Introduction

Cystic fibrosis (CF) is an inherited disorder resulting from a Mendelian recessive trait from both parents (Hodgkinson & Lester, 2002; Tluczek, et al., 2011). It affects both genders equally and occurs in approximately 1:2,500 live births, with roughly 1:25 Australians a carrier of the CF gene (Cystic Fibrosis Australia [CFA], 2014; Glasscoe, et al., 2007). There is currently no known cure for CF, and treatment requires significant lifestyle changes (CFA, 2014). In Australia, initial diagnosis occurs soon after birth, with the "heel prick" newborn screening programme, and is confirmed shortly after that through sweat chloride testing (Thompson, et al., 2008). For most parents, the diagnosis of CF in their newborn infant is unexpected (Massie, et al., 2007) and the disease has been noted to cause remarkable burden on the family due to the intensive daily treatment and monitoring required, and the physical restrictions the condition entails (Canam, 1986). Parents of chronically ill children have a variety of ever-changing information needs and priorities, which are not always recognised or appreciated by health professionals, and this is certainly the case with CF. Research is therefore needed to identify and address these needs.

This paper describes a protocol for a study aiming to identify the information needs and priorities of parents of infants recently diagnosed with CF. It outlines the components of the study including a brief review of existing literature on the topic, the research problem, significance, methods, aims, research hypotheses and questions, data management and analysis, and proposed dissemination of findings.

The study is being undertaken under the auspices of the Psychosocial Research Group of the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST-CF) (www.arestcf.org)

Background

Cystic fibrosis is the most common genetic disease in Caucasians (Dillard, et al., 2008). The diagnosis of chronic illnesses such as CF has significant disruptive impacts on the family, and challenges parents both emotionally and cognitively (Jedlicka-Köhler, et al., 1996; Manning, 2012). Families require medical, educational and psychosocial support (Lomas & Fowler, 2010) and parents of sick infants have specific and individual information needs and priorities that are not being met with current clinical approaches (Sawyer & Glazner, 2004; Hummelinck & Pollock, 2006; Jessup, et al., 2013). Parents require information surrounding their child's illness in order to process the emotional impact of hospital admissions and to engage in their child's care (De Rouck & Leys, 2009). Information is crucial for parents to make informed decisions and to minimize the potential for distress associated with NBS and the results that follow (Tluczek & De Luca, 2013).

The need for information varies over time and changes during the hospital stay, following discharge, and across the illness trajectory (Hummelinck & Pollock, 2005; Reid, et al., 2007). Following diagnosis it is common for parents to seek information about the disease to find answers to questions, to be prepared, and to supplement hospital literature (Hummelinck & Pollock, 2005; Jessup et al., 2013). The Internet is increasingly being used by parents as a method to source information (De Roucke & Leys, 2013; Jessup, et al., 2014). Some parents used Google/Internet to make up for the scarceness of information they received about CF between appointments (Jessup et al., 2014). This, however, has been seen to result in negative outcomes as the Internet provides unregulated information, and it is often hard to identify reputable and relevant evidence (De Rouck & Leys, 2013; Jessup et al., 2013). Parents need assistance to navigate and guide Internet usage, assess current knowledge gaps and correct misconceptions (De Rouck & Leys, 2013). Mis-information creates additional stress and potential conflict between parents and health care providers (Jessup et al., 2014); effective communication is essential.

Effective communication is key to doing more good than harm when disclosing results and ensuring understanding and retention of information (Duff & Brownlee, 2008; Salm, et al., 2012; Tluczek & De Luca, 2013). It is fundamental to supportive care, where good support is associated with less parental stress (Jones, et al., 2007; Duff & Brownlee, 2008; Sweet & Mannix, 2012) and for increasing participation and shared understanding (Hummelinck & Pollock, 2005).

Sawyer and Glazner (2004) propose that the initial interactions with health care providers have a significant impact on the emotional effects of results about a CF diagnosis, and families have expectations regarding these interactions. Additionally, the effects of CF diagnosis can have implications for family functioning and planning, along with future pregnancies (Collins, et al., 2001; Manning, 2012). Creating a sense of partnership and tailoring communication to individual needs as part of this process was found to be not only an expectation, but also a fundamental part of an effective engagement with health care providers (Deledda, et al., 2013). This requires adequate assessment of individual priorities and needs.

Stress and anxiety can be minimised with effective communication, preferably beginning in the prenatal period, to increase chances of information retention and comprehension (Duff & Brownlee 2008). Additionally, health care providers can help to reduce parents' initial stress by being well informed, honest and calm, pacing information according to needs, and by facilitating prompt referrals (Sawyer & Glazner, 2004; Salm et al., 2012; Sweet & Mannix, 2012; Tluczek & De Luca, 2013; Jessup et al., 2014). Repetition of information and assessment of coping is a fundamental task of health care providers during this period (Sawyer & Glazner, 2004; Jessup et al., 2014). Moreover, providing up to date, evidence-based information assists parents to make informed decisions about their child's treatment and care plan (Rogers, 2011). This information exchange can result in increased patient control and participation in care, and increased compliance with treatment regimens (Hummelinck & Pollock, 2005; Farrell & Christopher, 2013).

Having knowledge of a particular topic means individuals can prioritize and organize information more effectively, thus encouraging recall (Dillard et al., 2008). Establishing the right environment for communication is imperative. This can be done by ensuring privacy, a quiet

room, comfort, reduction of distractions, appropriate body language and eye contact, commitment and guidance, presence, and being culturally aware (Cone, 2007).

Many barriers to effective communication have been identified, including inadequate, conflicting, confusing and vague information, and dismissing mothers' rights and skills (Jones et al., 2007; De Rouck & Leys, 2009). Hummelinck and Pollock (2005) found that inconsistent and/or contradictory information occasionally led to confusion and decreased confidence in health professionals. Medical jargon and information overload can be barriers influencing the initial understanding and retention of information (Farrell, et al., 2008). There is no "one size fits all", and information needs to be timely, relevant, and delivered in a way that is appropriate for the individual and for families (Jessup et al., 2014). The preferred content of information along with the method of delivery and timing should thus be examined.

Varying priorities for the content of information following CF diagnosis exist. However, parents experience a sense of information overload (Hummelinck & Pollock, 2005; Tluczek et al., 2006; Jessup et al., 2014) particularly with statistical information surrounding lifespan predictions (Jessup et al., 2013), and many parents noted feeling as though they were not provided with adequate information about CF in one or more areas (Hummelinck & Pollock, 2005; Jessup et al., 2013).

In regards to method of communication, parents want faced-to-face communication with an experienced CF health care professional who is able to consistently, truthfully, and accurately provide information and answer questions (Duff & Brownlee, 2008; Hayeems, et al., 2008; Salm et al., 2012; Collins et al., 2013; Jessup et al., 2013). Hayeems et al. (2008) found that parents preferred, and understood information more easily this way.

The timing of information delivery affects the experience of parents during results disclosure (Collins et al., 2013). Some parents want information before the results, whereas others found it made them more anxious (Tluczek et al, 2006). At the time of diagnosis, health care providers- especially nurses - have a window of opportunity where, usually, both parents are present, making this an optimal time to facilitate engagement and encourage the participation of both parents whilst correcting any misconceptions (Jedlicka-Köhler, et al., 1996).

Some parents describe receiving too much information too quickly, resulting in increased anxiety (Tluczek et al., 2006). Many are unable to accept, comprehend, and retain the information received at early stages due to the complexity of the condition and their emotional state (Tluczek, et al., 2009). Nonetheless, health care providers should adapt information provided according to the illness trajectory and tailor the provision of information, both verbal and written, to the readiness of parents (Oliver, et al., 2004; Reid et al., 2007; Grob, 2008; De Rouck & Leys, 2013; Jessup et al., 2014). "It should be the parents who determine how information is shared, not the providers" (Grob, 2008, p. 1062).

Written material such as pamphlets, brochures, simple fact sheets, illustrations, screening results and contact information of support groups/referrals are appropriate sources of information (Canam, 1986; Jedlicka-Köhler, et al., 1996; Oliver et al., 2004; Sawyer & Glazner, 2004; Duff & Brownlee, 2008; Tluczek et al., 2009; Collins et al., 2013; Jessup et al., 2014), and electronic resources are valuable tools as they empower parents with knowledge, peer support and self-efficacy (McDonald, et al., 2013), as do educational DVDs (Tluczek et al., 2009), which may decrease anxiety and increase knowledge (Hayeems et al., 2008).

In conclusion, there is a gap in research about information needs and priorities of this group of parents. Chronic illnesses such as CF can have significant impacts on family functioning and overall health outcomes, calling for increased support and education. Parents turn to the Internet as an additional source of information to meet their needs, but this can have varying positive and negative outcomes. It is therefore recommended that nurses assist parents to navigate and guide Internet usage, assess current knowledge gaps and correct misconceptions (Cargnin Plmentel, et al., 2013; De Rouke & Leys, 2013). Creating a sense of partnership and tailoring communication to individual needs as part of this process is not only an expectation but also a fundamental part of an effective engagement with health care providers. This requires adequate assessment of individual priorities and needs. Timing, content and method of information delivery all play a role in the educational and post diagnosis experience and thus need further examination in order to provide relevant, accurate and tailored material to families to meet their individual needs. Information surrounding the child's illness is needed by parents in order to gain a sense of control, to reduce anxiety and stress; for coping, and as a means of engaging in family-centred care (FCC) which forms the theoretical framework for this study (De Rouck & Leys, 2009; Jessup, et al., 2013). How parents prioritise and seek relevant information about CF requires further investigation so that relevant, accurate information can be developed and provided in a way that is readily accessible (Jessup, et al., 2014).

Significance

A qualitative study examined the information needs of parents of children recently diagnosed with CF and was used to develop the questionnaire being used for this study (Jessup et al., 2014). No quantitative research identifying the information needs and priorities of parents of infants newly diagnosed with CF was found. This study will generate evidence which will enable education and communication programmes to be developed. These will ensure that parents of newly diagnosed infants with CF are given the necessary accurate information in a timely manner and in ways that suit their needs and priorities. Consequently, CF treatment and subsequent physical and psychosocial outcomes will be optimised for the family (Jessup et al., 2014).

Aim of study:
To use a validated questionnaire prospectively to investigate information needs, priorities, and information seeking behaviours of parents with an infant diagnosed with CF, aged 4-6 months, within Queensland.

Hypotheses:
For parents with an infant newly diagnosed with CF:

1. There are specific information needs of parents that vary at different time points during the diagnostic and education periods.
2. Current services do not adequately meet the information needs of families.
3. Parents prioritise prognostic and psychosocial information over medical and treatment information in the diagnostic interview.

Research questions:
1. What are the information needs of parents of children newly diagnosed with CF?
2. What information is most important for parents following the diagnosis of CF in their child?
3. Are parents satisfied with the current level of information provided to them?
4. Where are parents sourcing their information?
5. Which sources of information are most helpful?

Methods

Theoretical framework:
Family-centred care (FCC) underpins this study – when a child is ill, care must be planned around the whole family, not just the individual child, as all family members are affected (Shields, et al., 2012a; Shields, et al., 2012b). This is particularly important in a chronic, potentially life-limiting condition such as CF (Shields et al., 2013). Family-centred care is defined as "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients" (Shields, et al., 2006, p. 1318). For this group of particularly vulnerable families, FCC is an essential model and therefore an appropriate framework for this study.

This prospective, quantitative survey will use a validated questionnaire to collect data. The questionnaire was developed and piloted in a cohort of CF parents in Perth, Western Australia, and will be used with parents of infants aged 4-6 months recently diagnosed with CF in Queensland.

Setting:
The questionnaire was developed at Princess Margaret Hospital for Children in Perth, with parents throughout Western Australia. It will now be used in Queensland through the auspices of the CF centre at The Royal Children's Hospital, the only tertiary referral specialist CF centre in Queensland. This centre treats all children in Queensland, with outreach services to rural and remote areas (Thomas, et al., 2008).

Participants:
Parents with an infant aged between 4-6 months diagnosed with CF, and registered with the Royal Children's Hospital CF centre will be invited to participate. The rationale for this age range was to achieve a balance between parental accuracy of recall of the time of diagnosis and education, and the influence of psychological distress on both parental recall and motivation and capacity to engage in the study. Standardising age at recruitment is necessary to minimise the influence of time and psychological distress associated with diagnosis on the accuracy of parental recall, and the value of data generated. A convenience sample of 40 families in Queensland will be eligible to participate over a 12 month period.

Inclusion Criteria: Parents (any person/s defined by the family itself as the primary caregiver/s for the children) of infants aged 4-6 months recently diagnosed with CF in Queensland.

Exclusion Criteria: Parents whose infant has an unclear diagnosis of CF, or who have an acute or chronic, moderate – severe mental health illness that may limit their ability to cooperate, or who may be at risk of psychological deterioration resulting from participation. These parents will be identified by the staff of the CF centre in Brisbane.

Sampling (Method/size):
The sampling method used for this study is convenience sampling, a type of non-probability sampling. A convenience sample is defined as "people who fall within the boundaries of the population of interest and who make themselves available and accessible" (Nagy, et al., p. 100). Questionnaires will be sent out to 20 parents, estimated to be the number of parents of this group available in the Brisbane CF centre. Because the study does not involve formal comparisons of different groups of respondents, power calculations are not appropriate. The results will mostly be in the form of proportions, for example, proportions (or percentages) of respondents with particular information needs. For a sample of this size, the confidence interval for each estimated proportion is expected to be within approximately 0.15 of the estimated proportion.

Recruitment:
Eligible participants will be identified by the Brisbane CF Centre, and will be contacted by them (acting as a third party). Questionnaires with an attached information sheet, a self-addressed return envelope will be sent to each parent. The questionnaires will be anonymous, and consent will be implied by their return. Where appropriate, both parents (mothers, fathers and other parent dyads) will each be invited to complete a questionnaire.

Data collection tool:
A comprehensive quantitative questionnaire developed by the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST-CF) over an 18-month period using a sample of parents from Perth and a panel of experts (parents and health professionals) will be used. It is being piloted in Perth in 2014 and validation will be completed in time for data collection.

The questionnaire comprises mainly closed-ended questions separated into five sections (A-E) and takes roughly 15-20 minutes to complete. Section A (eight questions) asks for general information about the individual parent and his or her family. Section B (eight questions) assesses experiences at the time of CF education following diagnosis. It includes questions regarding where the parent met the health professionals involved, and the settings in which he or she first learned about the child's care. Section C (eight questions) asks questions regarding how information was organised and delivered during the first CF education session. Section D looks at the ways that the individual searched for additional information about CF, how much he or she knew prior to diagnosis, and what sources of information were most valuable. Finally, Section E allows for additional comments.

Questionnaire-based studies are valuable means for examining the perceptions and opinions of a large numbers of respondents (Saw & Ng, 2001), and

are therefore an appropriate method to evaluate parent information needs around the time of diagnosis. They may be self-administered and therefore confer anonymity to respondents and are cost-effective. A copy of the questionnaire is available on application.

Validity/reliability:
The questionnaire has been developed using standard questionnaire development techniques (Oppenheim, 2001) and prior to distribution for this study, a full range of statistical reliability tests will have been completed. A group of six parents of children aged between one and three years of age, and a panel of experts working within CF teams are evaluating the questionnaire for item clarity, internal consistency, content validity (using the Content Validity Index), and reliability (using Cronbach's alpha). These methods are approved and appropriate measures of validity and reliability for instruments using Likert scales (Nagy, et al., 2010).

Data collection:
After distribution by the Brisbane CF centre, questionnaires will be completed by parents in their own time and returned to the researcher for analysis via stamped, self-addressed return envelopes. The rationale for this is firstly that the respondents can participate anonymously, and that although response rates are highest when personally collected, this is impractical due to the participants being located over a widely dispersed area (Nagy et al, 2010).

Data management/analysis:
Data entry will begin as soon as the questionnaires begin to arrive. Once all data are entered, they will be cleaned and checked by members of the research team.

Questions answered by a Likert scale will be described and expressed as percentages. Descriptive statistics are useful in that they provide an overall picture of the data in a summary form, in this case percentages, where results can be calculated to show the proportion of one particular response compared to the total (Nagy et al., 2010). For each of the open-ended questions, responses will be grouped into themes and described. Thematic analysis is often used when the aim is to relate the research project to themes, essences or patterns (Nagy et al., 2010).

Ethics considerations
This study will be conducted in accordance with the National Health and Medical Research Council (NHMRC) guidelines. The pilot study has approval from the Human Research Ethics Committee (HREC) of Princess Margaret Hospital for Children, Perth (1870EP), and for the Queensland context, the James Cook University HREC and the HREC of the Royal Children's Hospital will review all appropriate study documentation in order to safeguard the rights, safety and wellbeing of the participants. Data collection will commence once HREC approval has been obtained.

Information sheets give full details of the project, and informed consent will be implied by return of the questionnaires, which will remain anonymous. While a distribution list will be kept, anonymity means that no-one will know who has participated, and so parents who choose not to participate, and their families, will not experience any adverse consequences as a result of their decision. If reminder letters are required, they will be sent to all prospective participants.

Study records will be stored in a locked cupboard in the Tropical Health Research Unit at James Cook University. All electronic data will be stored in a password-protected database in a locked office. Access to data will be limited to the researchers. Data will be retained for a minimum of five years according to NHMRC guidelines. There are no restrictions on publications, and results of the overall study will be disseminated at appropriate conferences and venues. No individual participants will be identifiable in any reports, publications and presentations of the results of the study.

Limitations
We use a small sample size and convenience sample that is not randomised and therefore will be unable to make any claims about the generalizability of the results to other populations. Differing experiences between Queensland parents and those from the pilot study in Perth may be of influence. We also acknowledge that surveys often suffer from poor response rates, and that participants may respond as they think they are expected to. The anonymous nature of the questionnaire may help to increase the number of surveys returned and the willingness of parents to disclose their real information needs and priorities. Other limitations include the short-term design of the study; and specific cultural perspectives which may result in findings being relevant only to Australia.

Dissemination of findings
In accordance with best principles of research ethics, the findings of this study will be disseminated, via the following methods, so that the results can be translated into clinical practice:
1. Thesis for the degree of Bachelor of Nursing Science (Honours), James Cook University,
2. Reports to relevant Human Research Ethics Committees,
3. Reports to the AREST-CF Group,
4. Reports to CF organisations around Australia,
5. Publications in peer reviewed journals,
6. Conference oral papers and posters as appropriate.

Conclusion

Cystic fibrosis is an inherited disorder affecting many Australians. Initial diagnosis occurs soon after birth, and education of parents as to how to care for their child begins immediately. Little research to date has examined how parents receive this education and information about CF in general. This protocol outlines a study which is being undertaken for an Honours degree in nursing. It aims to investigate the information needs and priorities of parents of newly diagnosed CF infants in Queensland, Australia, and ultimately will inform education and communication of parents by CF teams internationally. A questionnaire specifically developed for this study and piloted in Western Australia will be used.

The study will take place over two years and results will be disseminated to parents of CF children via CF organisations, to health services, HRECs, and published in peer reviewed journals and conference presentations. Ultimately, the health and well-being of families with a child with CF will be supported by this research

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