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Abstract

The Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST-CF) conducts an early surveillance program (ESP) for children with cystic fibrosis (CF). The program has the potential to modify long term health outcomes for children through early detection of lung disease, long before signs and symptoms are apparent. The program is aimed specifically at infants and preschool children (~3 months to 6 years) who undergo annual, detailed and relatively invasive surveillance. Although the ESP has been operating for 10 years, how parents experience their child undergoing early surveillance of this nature, and the psychosocial factors that moderate these experiences, is largely unknown. To date there are no published studies that have examined how parents cope with CF in the context of an ESP. Consequently, care pathways for improved mental health and well-being for families involved with the ESP are incomplete. Therefore, the proposed study intends to explore parental experiences, including coping, related to their child's involvement in the ESP, and to understand what psychosocial factors are important within the context of the ESP. Understanding parental experiences related to the ESP, how parents cope and identifying the psychosocial factors associated with these experiences is essential to inform CF centres and researchers considering adopting this program, and has the potential to inform intervention strategies that aim to support the family and foster healthy coping mechanisms.

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**cystic fibrosis, chronic disease,
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On behalf of AREST CF

Introduction

Cystic Fibrosis

Cystic fibrosis (CF) is the most common childhood life-shortening inherited disorder of Caucasian people, affecting 1 in 2,500 live born infants (Toolan, 1988). Chronic, suppurative lung disease causes over 90% of the morbidity and mortality associated with CF, leading to premature death from respiratory failure often in early adulthood. AREST-CF Early Surveillance Program

The Australian Respiratory Early Surveillance Team for CF operates a unique clinical early surveillance program (ESP) between the paediatric CF clinics in Perth and Melbourne, Australia. It has the potential to modify long term outcomes for children with CF through early detection of lung disease, long before signs and symptoms are apparent. The program is aimed specifically at infants from diagnosis to preschool children (~3 months to 6 years) who undergo annual, detailed and relatively invasive surveillance involving general anaesthesia, chest CT scans, bronchoscopy and venipuncture. These investigations generate sensitive information about the progress of early lung inflammation, infection and structure that are not detectable through conventional measures. Whilst the ESP is currently unique to Perth and Melbourne, it is rapidly emerging as the likely framework for future therapeutic intervention trials in young children nationally and internationally. Anecdotal experiences of healthcare professionals (HCPs) working within the program are that parents seem to adapt to the program over time, although clearly some families experience, and cope with, the program better than others. Although the ESP has been operating in Perth for ten years and eight years in Melbourne, how parents and families cope with their child undergoing early surveillance of this nature is largely unknown. Due to the unique nature of the program, to date there are no published studies that have examined how parents experience, or cope with, the ESP in the context of CF. Therefore, what is not yet clear are the psychosocial sequelae of early surveillance and covert disease detection for parents of children with CF. Consequently, care pathways for improved mental health and well-being for families involved with the ESP are incomplete. Professionals conducting early pulmonary surveillance programs following diagnosis need to understand if families perceive the program to be adversely affecting their lives, as well as to identify psychosocial characteristics within the family that may be associated with adjustment and maladjustment or other positive and negative experiences. Although no published studies have examined experiences of these parents, anticipated experiences can be drawn from the literature in other diseases which require invasive procedures as part of care. These experiences include

anxiety (Bauchner et al., 1996, Menahem et al., 2008, Chundamala et al., 2009, Besier et al., 2011), stress (Hopia et al., 2005, Hutchinson et al., 2009, Da Silva et al., 2010), need for control over their child's care during hospitalisation (Hallstrom and Runeson, 2001, Brosig et al., 2007, Berrios-Rivera et al., 2008), and role strain (Quittner et al., 1992, Quittner et al., 1998). Repeated exposure to these experiences in the absence of supports may reflect adversely on the well-being of the family and crucially affect the child (Patterson et al., 1993, Turner-Cobb and Steptoe, 1998, Szyndler et al., 2005).

Rationale

The ESP has been operating for ten years and this will be the first study to explore parental experiences of this unique program. It is important for those currently running this program to understand what parents experience, and how they cope, so that psychosocial supports and strategies can be put in place to better support families of children with CF. Whether experiences and coping mechanisms evolve over time spent in the ESP remains uncertain. They are important to characterise so that supports can be targeted according to the level of experience of parents within the program, and likely issues can be anticipated at different time points during the ESP. Given the potential for this surveillance program to be adopted nationally and internationally, both as clinical surveillance for CF and as a framework for intervention trials, understanding what parents experience, and how they cope, is essential information for HCPs and researchers alike, and may guide both clinical practice and ethical considerations in trial development.

Aims and objectives

Aims

The overall aim of this study is to explore and understand parental experiences and how parents cope with their child being involved in early pulmonary surveillance.

Objectives

The specific study objectives are to explore the spectrum of coping styles and other parental psychosocial experiences of being involved with the ESP through semi structured interviews and thematic analysis, as well as to determine whether parental experiences and

copied strategies vary across age groups.

Proposed methodology

Study design

A qualitative design will discover and understand the unique experiences of parents involved with the ESP. As there are no published studies exploring parental experiences surrounding the ESP in CF care in the literature, a qualitative study best lends itself to eliciting data that reflect parental experiences of the ESP. More specifically, a phenomenological approach will be used which focuses on the lived experiences of people, and seeks to understand the nature of the phenomena (Becker, 1992), including how parents perceive the program, both pragmatically and emotionally, and from a personal and family perspective. Phenomenological interviewing involves an informal, interactive process and uses open-ended comments and questions (Moustakas, 1994).

Research methods

In-depth interviews will explore what coping means for parents involved in the ESP, including what coping strategies are employed for each of its clinical components, and whether coping evolves over time. A narrative study is appropriate to explore how parents experience, and cope with, the program on a pragmatic and emotional level, both from a personal and family perspective. A narrative approach requires participants to tell a story; a series of logically and chronologically related events (Toolan, 1988). Narratives require the narrator to order events temporally in sequences, including references to the past and current understandings, and have a structure around a plot or theme (Bertaux and Kohli, 1984).

Ethical considerations

The study has been approved by the Human Research Ethics Committee (HREC) of Princess Margaret Hospital for Children (reference number - 2023EP), the HREC at The Royal Children's Hospital (reference number - 33181A) and the HREC of Edith Cowan University (reference number - 8808). Ethical issues and dilemmas in qualitative research are emergent and contextual and therefore require situational responses. This means the biomedical model of most guidelines may unduly simplify human experience as understood by qualitative

researchers (Ryen, 2011). In qualitative research, the most important people are the participants themselves (Buchanan and Coulson, 2005). Therefore it is worthy to note a number of processes that will keep participants informed and safe for the duration of the study. Prior to the commencement of interviews, parents will be informed of the nature of the study and informed consent will be obtained for participation and for audio recording of interviews. At the completion of each interview, parents will be debriefed and informed of available support services should they be needed. Parents will be informed of their right to withdraw without prejudice to their child's clinical care prior to attaining consent. Clinicians within the paediatric CF clinics will not be part of the recruitment process. All data will be de-identified, and real names will not be used in any part of the study (Corbin and Strauss, 2008).

Theoretical perspectives

Several influential theories will underpin the framework of this research. The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin and McCubbin, 1993) which incorporates elements of Lazarus and Folkman's (1984) Transactional Model of Stress and Coping, and the Family-Systems Illness Model (Rolland, 1987) which incorporates the Family Life Cycle theory (McGoldrick and Carter, 1982) will be applied as the theoretical frameworks from which this study will develop.

Sample

The sample will be drawn from the AREST-CF population of 120 families of children (~3 months to 6 years) with CF attending Princess Margaret Hospital for Children (Perth) and Royal Children's Hospital (Melbourne) CF clinics. The population will be separated into two groups from each site, stratified by child's age (under 3 years and over 3 years). A convenience sample of approximately 15 parents within each group will be selected for qualitative interviews. Stratification of participants by child's age will provide information about both the breadth of issues across the entire sample, as well as long term involvement in the program of the child's first six years of life. Stratification of age will also allow for a representation of the child's stage of development in relation to parents' ability to cope. Stratification

of participants by CF clinic will allow for detection of possible differences in implementation of the ESP between study centres. The sample size will be dictated by information saturation, and is expected to be within the suggested range for this type of qualitative research (Polkinghorne, 1989, Miles and Huberman, 1994, Burgess-Limerick and Burgess-Limerick, 1998, Patton, 2002).

Analysis

Data obtained from interviews will be analysed using thematic analytic procedures to learn from participants' experiences (Braun and Clarke, 2006). Thematic analysis involves the identification of themes within the data (Liamputtong, 2009). Themes are consistent patterns across data sets that are important in describing the phenomena under investigation. The themes become the categories for analysis (Fereday and Muir-Cochrane, 2006). This will provide a rich set of data about parents' coping and other experiences in relation to the different aspects of the ESP. Thematic analysis is performed through the process of coding in six phases to create established, meaningful patterns. These phases are: familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report (Braun and Clarke, 2006). Coding is the primary process for developing themes within the raw data by recognising important moments in the data and encoding it prior to interpretation (Boyatzis, 1998). Codes are labels given to sections of data that represent interpreted meaning. The data are then reduced by grouping similar categories and codes and identifying the most significant themes. As codes and themes are connected and clustered together the transcript is checked for accuracy (Smith, 2003, Liamputtong, 2009). This process is continued with subsequent interviews. Themes from previous cases are used to orientate subsequent analyses and constant comparative analysis is applied to develop and check for accuracy of theme boundaries. Constant comparative analysis involves comparing subsequent transcripts to previous ones using identified themes from the first transcript to analyse the rest (Janesick, 1994, Strauss and Corbin, 1994). At this point, several thematic mind-maps are created to consider how different

codes may combine to form overarching themes, which provide graphical representation of links and associations between codes and themes (Braun and Clarke, 2006). Once a candidate thematic map is decided upon the themes will be reviewed for internal homogeneity and external heterogeneity; this means that themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes (Patton, 2002). All collated extracts for each theme will be considered for whether they appear to form a coherent pattern representative of each theme. Additional coding of data within themes that are missing in earlier coding stages also occur at this stage (Braun and Clarke, 2006). New themes may be added and some themes dropped as they either do not fit well in the emerging structure, or are not very rich in evidence within the transcripts. Themes are then defined and labelled. During identification of the meaning of each theme, consideration is given to how each theme fits into the overall understanding of the data in relation to the research questions (Braun and Clarke, 2006). Finally, a summary table of structured themes with quotations which illustrate each theme will be produced (Willig, 2001). To assist in data reduction and accuracy of interpretation, transcripts will be subjected to a question ordered matrix, which examines for consistencies and common themes (Miles and Huberman, 1994). NVivo qualitative statistical computer package will be used for data management.

Rigour

In qualitative research, rigour is the concept for quality of data and integrity of the findings, to which the researcher can demonstrate the findings are worth paying attention, and taking into account (Lincoln and Guba, 1985). Rigour in qualitative research is relevant to the notions of validity and reliability in quantitative research, and therefore to the reduction of bias. In qualitative research, validity does not carry with it the same meaning as it does in quantitative research, nor is it a companion of reliability or generalisability (Creswell, 2003). Therefore, the concepts of reliability and validity need to be reconceptualised to suit qualitative methods. Terminology abounds in the qualitative literature that speaks of this idea, terms such as rigour, trustworthiness,

authenticity and credibility (Creswell and Miller, 2000). There are several elements of rigour within the qualitative research process that need to be achieved to accomplish adequate levels. Often viewed as the 'gold standard' for rigorous qualitative research, Lincoln and Guba's (1985) framework of quality criteria suggests four criteria for developing rigour in qualitative research; credibility, dependability, confirmability, and transferability. These criteria represent parallels to the positivists' criteria of internal validity, reliability, objectivity, and generalisability, respectively (Polit and Beck, 2014). Credibility is a fundamental element in qualitative research that refers to confidence in the truth value of the data and the resultant interpretative findings, that is, confidence in the truth of the findings for the participants and contexts within the research. Two aspects of qualitative research are essential to achieving credibility; conducting research in such a way that enhances believability of findings; and implementing processes that demonstrate credibility to individuals external to the research. Its quantitative equivalent is internal validity, which when applied and adapted to the qualitative paradigm ensures that the findings represent the multiple constructions of an experience adequately, and that the reconstructions that have been arrived at are credible. Dependability refers to stability of data over time and across contexts. This is achieved through replication of findings with the same (or similar) participants in the same (or similar) context. Credibility cannot be achieved in the absence of dependability, just as validity cannot be achieved cannot be achieved in the absence of reliability in quantitative research. Confirmability is the potential for congruence between two or more independent people about the data's accuracy, relevance and meaning. This

element of rigour is concerned with establishing that the information participants provide is representative of the data, and that interpretations of data are not created by the researcher. This is achieved by displaying that the findings reflect participants' voices and the conditions of the research, and are not the product of the researcher's motivations, perspectives, or biases. Confirmability relates to the concept of objectivity because it demonstrates where and how findings of the research are determined by the participants and conditions of the research and not by the biases, motivations, or perspectives of the researcher. Transferability, analogous to generalisability, is the extent to which the findings can be transferred or to have applicability in other groups or settings. As the very nature of qualitative methodology is fundamentally different to quantitative methodology (that is, participant strategies, conceptual elements of hypothesis development), generalisability is impossible to achieve and indeed does not suit the framework or aims of qualitative research. The qualitative researcher can only provide sufficient information by which consumers can evaluate the applicability of the data to other contexts by drawing their own conclusions about whether transfer can be considered a possibility.

Limitations of research design

The sampling technique may yield only parents who have well-informed ideas about their experiences, while it may not capture those who are less confident exploring the topics. It is also possible that parents who choose to participate are confident in discussing their experiences. Although these could potentially bias results, it is intended that the research be a stepping stone in identification of experiences and issues faced by parents whose children undergo early surveillance of CF lung disease.

Dissemination of findings

Results will be published in peer-reviewed journals and presented at international and national conferences, and reports will be sent to respective HRECs. Parents directly involved in the study will be provided with a de-identified summary report if they so wish.

Significance of outcomes for families undergoing Early pulmonary surveillance

The information gained from the interviews will describe the range of coping strategies and styles, together with pertinent experiences among families of children undergoing this type of surveillance. The information will highlight maladaptive coping or experiences that may adversely affect the well-being of the family and child, as well as strengths or positive experiences that can potentially be enhanced through education and support. It may demonstrate differences between coping with the ESP versus the whole gamut of factors around the CF diagnosis and disease, and may detect trends in positive and negative coping strategies across age groups.

Conclusions

The proposed exploratory study will lay the foundations for development of clinical care and psychosocial interventions to support families of young children undergoing early pulmonary surveillance in CF. It will provide insight of experiences and coping styles of parents as they navigate and deal with the processes of early surveillance for their child. Ultimately the findings of this study will direct and inform psychosocial interventions to improve psychosocial outcomes for children and their parents; and contribute to the scientific literature surrounding chronic childhood disease and the impact of invasive procedures in early life.

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