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Original Article

Breaking bad news, the diagnosis of cystic fibrosis in childhood

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Abstract

Background: The day parents are told their child has cystic fibrosis (CF) is imprinted in their memory. Parents often show strong emotions (e.g. shock, anxiety); they need to cope with bad news and restructure their lives taking into account CF.
Aims: The aims of this study are (1) to explore how parents recall circumstances of the CF diagnosis and the information they received and (2) to investigate their current coping styles.
Methods: Parents (n = 38) of 20 children (diagnosed during the past 5 years) were interviewed using a semi-structured interview. Coping was assessed using the Utrecht Coping List. The association between coping and time since diagnosis/severity of illness was investigated.
Results: Fifteen parents first heard the term 'CF' from their local pediatrician or GP. All were informed in detail by the CF specialist. All parents recalled specifics about the information, the attitude of the doctor, their thoughts and emotions. Most parents were satisfied with the content and manner in which they had received information. Nineteen appreciated the doctor showing some emotions during the talks. One couple criticized the doctor for not showing emotions. Parents reported higher use (than normative scores) of the active coping style 'social support seeking' and the accommodative coping styles 'palliative reaction pattern' and 'comforting cognitions'. Perception of severity of illness was associated with higher scores on palliative coping.
Conclusions: This study shows the importance of physicians and CF teams to tailor the way of providing bad news to parents' needs and preferences. It is important to help and encourage parents to use active or accommodative coping strategies. The diagnosis is the starting point of a long-term relationship. 'Doing things well from the start' helps families to learn to live with CF and treatment.

Keywords: Bad news; Cystic fibrosis diagnosis; Parents; Communication; Coping

1. Introduction

The diagnosis cystic fibrosis (CF) is, by definition, bad news: "information that changes ones' view of the future in a negative way [1]. The impact of bad news can be observed in a persons' coping behaviors and in the emotional response, both of which may persist for some time after the news is received. The present paper reports on parents hearing the diagnosis CF in their young child. It explores parent's appraisal of the received information, recall of their emotions and thoughts at the time of the diagnosis as well as their current coping styles.

1.1. Bad news

A serious childhood disease arouses strong emotions, such as anxiety, shock, grief and feeling out of control [2–4]. The way a diagnosis is given influences these emotions and informing parents with bad news is challenging to the physician [3,5]. In CF, two studies have been conducted on how parents received the CF diagnosis [3,4]. Jedlicka-Köhler [3] reported that parents who were told about the CF diagnosis were often receiving a kind of lecture. This lecture contained more information than parents could

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possibly assimilate, especially because of the incompatibility of the emotional distress and optimum learning. As a result, Jedlicka-Köhler [3] recommended frequent interviews with both parents and the provision of written and audiovisual materials. They also stressed that the initial discussion is only the beginning of an ongoing learning process necessary to enable long-term adjustment to a serious disease. Borowitz et al. (2009) included this recommendation in the guidelines for the management of infants with CF [6] and they are incorporated in the recent ECFS Standards of Care document [7].

1.2. Coping with chronic illness

Coping styles are the behaviors and cognitions a person uses to deal with a stressful situation [8–10]. The perception of the controllability of a stressful situation is important and three distinct coping styles have been described [11,12]: 1. *active coping*, where a person tries to change the stress (e.g. finding out information, learning new skills); 2. *accommodative coping*, where a person tries to adapt to the stress by changing his/her emotions (e.g. distraction, meditating, relaxation) or cognitions (e.g. altering goals, humor) and 3. *passive coping* where a person avoids the stress (e.g. relying on others, helplessness). There is ample research on coping in chronic illness, though limited in CF. An *active* coping style seems to reduce the overall emotional impact of a chronic illness. It is associated with a better adaptation to illness [13–17] and is positively associated with adherence [18]. *Accommodative* coping is also related to better adjustment, probably because it helps to adapt to the uncontrollability of a chronic illness [8–17]. *Passive* coping is related to poorer adjustment to chronic illness, mostly because avoidant and passive behaviors are generally associated with poorer psychological functioning (e.g. depression) [8,17]. An unclear coping strategy is ‘denial’: on one hand denial can be temporarily beneficial, for example when trying to deal with the uncontrolled stress of a chronic illness. However, on the long term denial is not helpful when it leads to non-adherence to treatment [18].

In the present study, parental experiences when hearing the CF diagnosis were further investigated in settings that aim to deliver the CF diagnosis as recommended [6,7]. First we need to note that neonatal screening is not yet available in Belgium and the information parents typically receive minimally includes the diagnosis (also explaining genetics), treatment, expected outcome, prognosis and day-to-day management. The focus of this study was on (1) how parents recall *in what way* the diagnosis was given, (2) how parents recall their *emotions and thoughts* about the diagnosis and (3) how they now *perceive the sufficiency* of specific items of information they received. In addition, current parental coping was examined. Differences in coping styles between mothers and fathers were investigated as well as differences between parents and a normative comparison group. Furthermore, associations between coping styles, time since diagnosis and severity of illness at diagnosis were assessed. Coping styles are relatively stable, though in principle, changeable and they differ between individuals due to learning experiences, personality traits or behavioral styles [10]. Because of the immediate stressful situation parents have to cope with, the hypothesis was that nearer the time of diagnosis and/or with more severe illness, parents score *higher* on passive coping styles and *lower* on active or accommodative coping styles. The results give insight into parents’ experiences around the diagnosis and help to identify families that may need more help and counseling from the start.

2. Method

2.1. Participants and recruitment

The study was approved by the Medical Ethical Committee of the University Hospital Leuven. From September 2012 to August 2013, 29 children with CF (diagnosed between 12 and 71 months [or 1 year and 5 years 11 months] prior to interview) were in follow-up at the CF clinic of the University Hospital Leuven. This period was chosen to keep the retrospective timespan manageable and to ensure that parental recall was drawn from a similar developmental phase, namely from infancy through early childhood. All parents were invited to take part in this study. Since two families had two children with CF, twenty-seven families were approached. In total parents of 20 children participated: four families declined because of lack of time, two families were not fluent in Flemish and one family was not approached because of severe familial problems at the time (divorce). When there was more than one child with CF, the first born was included as the reference child. For two families, only mothers participated. In total 20 mothers and 18 fathers participated (Table 1). Parents were invited to participate during outpatient clinics. After consent an appointment was made for the interview, either at the family’s home or at the hospital. All but two families preferred the home situation.

3. Measures

3.1. Interview schedule

A semi-structured interview was constructed based on the literature concerning bringing bad news and the impact of the diagnosis [3,5,6,19]. The semi-structured interview consists of three parts:

1) Parents’ recall of how the diagnosis was communicated and circumstances and characteristics of the diagnostic process. Questions were in open-ended format, multiple choice or rating scales. Examples of questions are ‘How many times did the doctor talk to you about the diagnosis?’ and ‘Who was present at the talks?’.
2) Parents’ recall of their emotions and thoughts about the diagnosis. Parents were asked to rate their emotion and thoughts on a five point rating scale (Table 2). Parents were also asked to describe their experiences in their own words.
3) A list of topics of information (Table 3) was provided and parents were asked to rate the sufficiency of the information they received on a five point Likert scale (1 = insufficient–5 = sufficient).

It is important to keep in mind that the focus is on the way parents recall their thoughts and emotions, which makes them valid