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HEALTH PSYCHOLOGY | RESEARCH ARTICLE

Illness perceptions and psychological adjustment of mothers of young adults with cystic fibrosis

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Abstract: This study examined predictors of the psychological adjustment of mothers of adolescents and young adults with CF. In our sample of 51 mothers (mean age 48 years) with at least one child with CF, aged between 16 and 25 years, high levels of anxiety and depression were found. Illness representations, in particular perceptions of the cyclical nature of CF and emotional representations of CF, were significantly associated with maternal psychological distress. Mother's work status was also found to be related to psychological adjustment. Mothers who had employment outside of the home were found to experience less psychological distress than mothers who did not work outside of the home. These findings have clinical implications for mothers of older children and young adults with CF. Annual screening of parental psychological adjustment is recommended. Interventions using extensions of cognitive behavioural therapy approaches to address negative illness perceptions may also have some utility for this population. Future research would benefit from also examining the role of factors such as child's clinical health status (e.g. BMI, frequency of hospitalisations) and treatment adherence, and financial implications of illness in predicting maternal distress.

Subjects: Behavioral Sciences; Health and Social Care; Social Sciences

Keywords: illness perceptions; depression; mother-child relationships; psychological adjustment; young adults; cystic fibrosis

1. Introduction

In the last three decades, there have been significant improvements in the treatment of Cystic fibrosis (CF). These changes have increased the lifespan of affected individuals from their early teens to 50 years and beyond (Canadian Cystic Fibrosis Association, 2008). Thus, many of the earlier studies which examined parental adjustment and its predictors now have less relevance to the adjustment

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PUBLIC INTEREST STATEMENT

This research highlights the importance of providing support for carers of individuals with chronic illness in addition to that needed for chronic illness patients themselves. This study highlights that a large percentage of mothers of teenagers and young adults with cystic fibrosis experience significant psychological distress. Factors such as not having employment outside of the home, knowing that their child's illness presents in regular "waves" and feeling overwhelmed by their child's CF were related to the mother's experience of distress.

of today's families. There is even less data available which examines correlates and predictors of parental adjustment in the context of having older teens and young adults with CF in the family (Quittner et al., 2014). The current study seeks to address this gap in the literature.

CF is a congenital illness which affects about one in every 2500 children born in Australia (Cystic Fibrosis Australia (CFA), 2015). Individuals affected by CF experience a number of physical symptoms including breathing difficulties, a propensity for recurrent chest infections, poor processing of lipids and unusually salty sweat. Treatment of CF is centred upon the preservation and protection of the respiratory and digestive systems and usually includes regular chest physiotherapy, prescription of a variety of antibiotics, enzyme supplements and salt replacement therapy and nutritional modifications.

Parents of children with CF face a number of increased responsibilities in caring for their children's well-being compared to parents of children without a chronic illness (Driscoll, Montag-Leifling, Acton, & Modi, 2009). The practical support given by parents can often continue into children's teen and young adult years with CF patients often transitioning away from the family home at a later age than peers without chronic illness (Graetz, Shute, & Sawyer, 2000; Hamlett, Murphy, Hayes, & Doershuk, 1996). Further individuals with CF can often find the transition from paediatric to adult care challenging and continue to seek support from their parents (Harris, Freeman, & Duke, 2011; Tuchman, Slap, & Britto, 2008).

Recent research suggests that up to 50% of parents of children with CF may experience clinically significant symptoms of anxiety and up to 35% may experience clinically significant symptoms of depression. Dual presentations are also common (Driscoll et al., 2009; Quittner et al., 2014). Driscoll et al. and Quittner et al.'s studies identified that both illness-specific and more general risk factors led to increased psychological distress for parents of children with CF. A caveat of reviewing this research for our discussion is that the children of parents included ranged from birth to 17 years, being younger than the majority of our participants' children. However, we are not aware of other studies which have examined correlates and predictors of parental adjustment of older teens and young adults.

Driscoll et al. (2009) reported that depressive symptoms of mothers were associated with decreases in their child's lung functioning and increases in their own anxiety levels. Quittner et al. (2014) also identified that mother's depression was related to children receiving intravenous antibiotics and being involved in psychotherapy. Another study by Driscoll and colleagues also examined predictors of depression in caregivers of children with CF or Type 1 diabetes (Driscoll et al., 2010). They found that increased family stress and lack of employment outside the home also contributed to caregivers' distress. Given the detrimental impact of depression on adaptive behaviours, such as adherence to treatment regimens, understanding factors which impact the development of depression in parents of children with chronic illness is a continuing research priority (DiMatteo, Lepper, & Croghan, 2000).

Illness perceptions have been found to be a strong predictor of the psychological adjustment of individuals with acute and chronic illness (Hagger & Orbell, 2003). Recent investigations have examined how illness perceptions can be used to understand caregiver's emotional and cognitive representations of a significant other's illness in illnesses such as heart disease and diabetes (Benyamini, Medalion, & Garfinkel, 2007; João Figueiras & Weinman, 2003; Olsen, Berg, & Wiebe, 2008).

Given that there is consistent evidence that holding negative illness perceptions (e.g. many symptoms and consequences of illness and low efficacy of available treatments) is associated with increased incidence of depression and anxiety in chronic illness patients (Hagger & Orbell) it appears promising that the illness perceptions of parents of children with chronic illnesses, such as CF, may also be related to their psychological adjustment. Two studies have examined the illness

perceptions of individual with CF (Bucks, Hawkins, Skinner, & Horn, 2009; Sawicki, Sellers, & Robinson, 2011). Bucks et al. found that adolescents with CF reported greater adherence to treatment when they perceived their illness as being chronic and the treatment offered as being efficacious. Sawicki et al. examined the illness perceptions of adults with CF and identified that they had a stronger relationship to psychosocial aspects of quality of life than health-related quality of life indicators. Our study is the first known to us to examine the illness perceptions of parents of CF patients.

To summarise, our study extends the body of research examining both adjustment of parents of older children with CF and the body of research examining illness perceptions and their ability to predict psychological adjustment of caregivers. We present data outlining the illness perceptions of mothers of children with CF aged 16–25 years and their relationships to maternal adjustment. Extending upon the research of Driscoll and Quittner and their colleagues (e.g. Driscoll et al., 2009, 2010), we also examine the role of children's lung functioning and maternal employment to identify their role in predicting maternal psychological distress. Taken together, we predict that negative illness perceptions, compromised lung functioning in children and lack of maternal employment outside of the home will be predictive of the psychological distress of mothers of older teenagers and young adults with CF.

2. Method

2.1. Participants and procedure

Participants were recruited through three state-based CF support organisations in Australia. Eligible families from the patient registries were contacted by administration staff from the state organisations and were forwarded a study information package. Willing participants contacted the primary researcher and provided written consent for their participation. The primary researcher then forwarded the pen and paper questionnaire package which were then returned to the researchers via prepaid post. The study gained ethics approval by the University ethics committee.

While 90 mothers consented to being sent a questionnaire package, only 51 mothers returned the questionnaire package ($M = 48.83$ years, $SD = 4.34$ years). All participants had at least one child with CF aged between 16 and 25 years ($M = 19.20$ years, $SD = 2.42$ years) and for the majority of families the child or children with CF lived at home (71%). The majority of mothers (98%) identified themselves as being Caucasian and most (84%) engaged in either part- or full-time employment. Other key demographic data are presented in Table 1. The cross-sectional data presented here were collected as a part of a larger, longitudinal study that also examined the adjustment of adolescents and young adults with CF (Beinke, 2011). All parents of children 16–25 years with CF were eligible to participate in the study. However, given that less than 10% of the respondents were fathers and that gender differences in prevalence and predictors of psychological adjustment of mothers and fathers have been identified in previous studies (e.g. Driscoll et al., 2009), we decided to focus our analysis on the experiences of mothers.

2.2. Measures

2.2.1. Demographics

Mothers completed a demographic questionnaire examining their age, ethnicity, education level, work status, annual household income and family structure.

2.2.2. Child lung functioning

For individuals with CF, lung functioning is most commonly assessed by comparing an individual's current lung capacity to the average lung capacity of individuals in the general population of the same sex and of a similar age and body composition. This is known as the percentage of predicted forced expiratory volume ($FEV_1\%$). A predicted $FEV_1\%$ above 90% is considered to be indicative of normal lung function, 71–90% indicative of mild impairment, 41–70% indicating moderate impairment and less than 40% indicating severe impairment (Cystic fibrosis Australia, 2010). The most

Table 1. Mothers' additional demographic data (N = 51)

	<i>n</i>	%
Family structure		
Both biological parents at home	38	77.66
Single parent family	6	12.20
Blended family	5	10.20
Household income		
<\$5,999	17	34.00
\$5,000–\$100,000	18	36.00
>\$100,000	15	30.00
Education status		
Year 10 certificate	18	35.30
Year 12 certificate	5	9.80
VET/TAFE/Undergraduate degree	15	29.40
Postgraduate degree	13	25.50

recent predicted FEV₁% provided by a medical professional was obtained for the children of the mothers participating in the current study via self-report.

2.2.3. Illness perceptions

Mothers' cognitive representations of illness were measured using the Illness Perceptions Questionnaire-Revised (IPQ-R; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002). This measure examines individuals' perceptions of illness symptomatology, timeline (chronicity and cyclical nature), cure/control, consequences, causality, illness understanding, and emotional representations of illness. The symptom subscale included a 14-item symptom checklist and required mothers to indicate whether or not they believed particular symptoms (e.g. weight loss, fatigue) are related to CF. This item was measured with yes/no dichotomous response options. A total score was calculated by summing together the number of "yes" responses on each symptom subscale.

Mothers' perceptions of symptom management and curability of illness were measured on two subscales; one six-item scale examining personal control of illness (e.g. "People with CF have the power to influence their illness") and one five-item subscale examining participants' perceptions of the effectiveness of medical treatment (treatment control) for CF (e.g. "My child's treatment can control their CF"). Next, the consequences of illness subscale examined mothers' anticipated outcomes and effects stemming from the illness (e.g. "CF causes difficulties for those who are close to my child with CF") with six items. Perceptions of the nature of CF over time were assessed with the four items on the timeline-cyclical subscale (e.g. "CF is very unpredictable"). The timeline-acute/chronic subscale from the original IPQ-R was not included in the current study as it was considered that little variability would be obtained on this measure and it may be considered insensitive by parents given the congenital nature of the illness. Mothers' overall understanding of CF and its implications was measured with the five-item illness coherence subscale (e.g. "CF is a mystery to me"). Finally, mothers' emotional representations of illness were examined on a six-item subscale (e.g. "When I think about my child's CF I become upset"). These final seven subscales of the IPQ-R required the participant to indicate the degree to which they endorsed each statement about CF on a five-point Likert-type scale (1—strongly disagree and 5—strongly agree). The causality subscale of the IPQ-R was not included in the current study as it was considered that all parents would be aware of the genetic cause of CF and little variability would be obtained.

Total scores for each of these subscales were calculated by summing each item in the subscale. The four-item scales had a possible score range of 4–16; for five-item scales the range was 5–25; and

the range was 6–36 for the six-item scales. A high score on the consequences, emotional representations, timeline-cyclical subscales indicated negative perceptions of these domains of CF. High scores on the personal control, treatment control and illness coherence subscales indicated more positive perceptions of CF.

Our data analysis identified moderate to excellent internal reliability coefficients for all IPQ-R subscales. This is consistent with psychometric data obtained in the small, but growing, body of research examining illness perceptions in non-clinical populations (e.g. Anagnostopoulos & Spanea, 2005; Benyamini et al., 2007). While this is the first study known to us to apply the IPQ-R to the examination of parental perceptions of CF, the IPQ-R has been applied to examining the association between illness perceptions and worry in partners of patients who have experienced heart attack (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009). Broadbent et al. (2009) reported that an intervention targeting negative illness perceptions reduced worry in the partners of heart attack patients. Thus, we considered that the IPQ-R was an appropriate measure to apply in the examination in the association between illness perceptions and psychological adjustment in parents of young people with CF.

2.2.4. Psychological adjustment

The brief version of the Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995) was used to measure mothers' adjustment. The DASS-21 consists of three subscales, each with seven items, assessing depression, anxiety and stress levels. The depression subscale examines symptoms such as disengagement, pessimism and gloominess (e.g. "I felt that I had nothing to look forward to"). The anxiety subscale examines autonomic arousal, and acute anxiety-related experiences (e.g. "I was worried about situations in which I might panic and make a fool of myself"); whereas the stress subscale examines features of chronic, non-specific anxious affect (e.g. "I found it difficult to relax").

Participants responded to questions in relation to their experiences in the past week on a 4-point Likert-type scale (0—did not apply to me at all to 3—applied to me very much, or most of the time). Items within each subscale of the DASS-21 were summed to give a preliminary total score and then doubled to allow interpretation of scores using criteria set for the DASS-42. While excellent internal consistency was obtained for all subscales, large and significant correlations were observed between the three subscales. Thus, it was considered that patient psychological functioning may best be represented with one global score of psychological adjustment incorporating participant's anxiety, stress and depression scores.

3. Results

3.1. Missing data

For the demographic, illness perception and adjustment data no more than 5% of missing data was identified on any one variable. Mean substitution procedures as recommended by relevant scale authors (i.e. Lovibond & Lovibond, 1995; Moss-Morris et al., 2002) were followed as appropriate for the IPQ-R and DASS. For lung functioning data (FEV₁%), there were significant missing data (42%). No replacements were made for this data.

3.2. DASS data

Table 2 displays descriptive data for the maternal IPQ-R and DASS ratings. On the depression and anxiety subscales, the mean scores were in the *mild* range of clinical impairment with reference to Lovibond and Lovibond's (1995) clinical severity categorisation guidelines. The mean stress score for mothers was in the *normal* range. While only 12.80% of mothers reported stress ratings in the mild, moderate or severe clinical range, 43.10% of mothers reported mild, moderate or severe symptoms of depression and 58.80% of mothers reported mild, moderate or severe symptoms of anxiety.

Table 2. Mothers' IPQ-R and DASS descriptive data (N = 51)

	M	SD	SE	Range
IPQ-R symptoms experienced	8.70	3.49	0.49	1–13
IPQ-R consequences	25.44	3.79	0.48	13–30
IPQ-R timeline cyclical	11.94	2.66	0.38	5–18
IPQ-R treatment control	14.88	3.35	0.47	6–20
IPQ-R personal control	22.44	3.80	0.53	14–30
IPQ-R illness coherence	21.68	3.37	0.48	10–25
IPQ-R emotional representations	20.32	4.79	0.67	7–30
DASS-depression	10.10	3.14	0.44	7–21
DASS-stress	11.48	3.56	0.50	7–23
DASS-anxiety	8.90	3.05	0.43	7–21
DASS-total	30.48	8.74	1.24	21–62

Associations between parent's ratings of depression, anxiety and stress were examined using Pearson's *r* correlation. All analyses were completed using SPSS version 22, with significance tested at $p = .05$. As shown in Table 3, strong correlations between the stress, anxiety and depression subscales were identified. Given the significant overlap between these subscales and the actual comorbidity of anxiety, stress and depression in the population (Lamers et al., 2011), we calculated a total distress score (consistent with recommendations of Lovibond & Lovibond, 1995) by summing the three DASS subscale totals (see Table 2 for descriptive statistics).

3.3. Identification of possible regression predictor variables

Our first analyses examined whether children's lung functioning status (predicted FEV₁%) and mothers' work status impacted mothers' overall distress ratings. Analysis of variance was used to examine the impact of predicted FEV₁% on distress ratings and a *t*-test was used to examine the impact of work status on distress ratings.

Table 3. Pearson's *r* correlations examining relationships between mothers' illness perception ratings and psychological adjustment indicators (N = 51)

	1	2	3	4	5	6	7	8	9	10	11
(1) Symptoms ^a	1.00	.23	-.32*	-.13	.32*	-.24	.29*	-.01	.17	.16	.12
(2) Consequences ^a		1.00	-.16	-.19	-.11	-.01	.48**	.14	.22	.08	.17
(3) Personal control ^a			1.00	.39**	-.24	.04	-.09	.30*	.08	.24	.23
(4) Treatment control ^a				1.00	.19	-.06	-.05	.14	.04	.21	.14
(5) Timeline-cyclical ^a					1.00	-.26	.03	.19	.31*	.25	.28*
(6) Illness coherence ^a						1.00	-.41*	-.19	-.27	-.17	.24
(7) Emotional reps ^a							1.00	.51**	.48*	.26	.47*
(8) Depression ^b								1.00	.69**	.73**	.89**
(9) Stress ^b									1.00	.71**	.90**
(10) Anxiety ^b										1.00	.90*
(11) Overall distress ^c											1.00

Notes: Bold values: relationship between IVs and psych distress.

^aIPQ-R subscale.

^bDASS subscale.

^cDASS total.

* $p < .05$.

** $p < .001$.

Distress ratings of mothers did not significantly differ between those whose children had normal lung functioning ($M = 35.75$, $SD = 13.32$, $SE = 6.66$) and mild ($M = 35.33$, $SD = 10.61$, $SE = 3.53$), moderate ($M = 26.67$, $SD = 4.55$, $SE = 1.57$), or severe lung impairment ($M = 32.00$, $SD = 7.11$, $SE = 3.55$); $F(3, 26) = 1.72$, $p = .191$, $\eta^2 = .19$. It is noted that there was significant missing data for this variable which likely impacted the outcomes of this analysis.

Mothers' work status, however, was found to have a significant impact on their distress ratings ($t(49) = 7.19$, $p = .010$, $d = .95$). Mothers who did not have employment outside the home ($M = 37.78$, $SD = 12.77$, $SE = 4.26$) reported more symptoms of distress than mothers who held full-time external employment ($M = 28.69$, $SD = 6.84$, $SE = 1.06$).

Pearson's r correlational analyses were used to examine relationships between mothers' perceptions of CF, as measured by the IPQ-R, and their psychological adjustment as measured by the DASS (see Table 3). Mothers' perceptions of cyclical nature of CF and their emotional representations of CF were significantly associated with distress ratings. Distress ratings increased as mothers' perceived their children's CF to have a greater cyclical nature and as mothers' frequency of negative emotions associated with CF increased.

Before the final regression analysis was completed, the impact of CF patient residential status on mother's illness perception and psychological adjustment variables were investigated with t -tests. The analyses identified that mothers whose children with CF lived at home did not differ from mothers whose children with CF did not reside at home on any of the IPQ-R and psychological distress variables included in the regression model. A chi-square analysis was also completed to identify possible differences in work status ratings between mothers who did and did not have children living at home with CF. Again, no significant differences were identified.

3.4. Regression analyses

Next, a multiple regression analysis was completed to determine the relative importance of work status, timeline (cyclical) representations and emotional representations of CF in predicting mothers' distress ratings. Work status was entered as a dummy coded variable. The regression model accounted for significant variance in mothers' distress ratings ($R^2 = .35$; $F(3, 47) = 8.29$, $p < .0001$).

Emotional representations of CF accounted for the largest proportion of variance (16%) in distress ($t(49) = 3.35$, $p = .002$). Work status made a marginally significant contribution to the model, accounting for 5% of the variance in distress ($t(49) = 1.94$, $p = .058$). Finally, perceptions of the cyclical nature of CF did not account for significant variance in the model ($sr^2 = .04$; $t(49) = 1.62$, $p = .112$). Thus, 10% of the variance in distress accounted for by the model was shared between the predictor variables.

4. Discussion

To our knowledge, this is the first study to examine the utility of illness perceptions, child's lung functioning, and maternal employment ratings in predicting psychological distress of mothers of adolescents and young adults with CF. Overall, the sample reported high ratings of depression and anxiety symptoms. While it is noted that different measures were used in our study and that of Driscoll et al. (2009) and Quittner et al. (2014) who investigated mothers of younger children with CF, mothers in our sample reported higher levels of depression (43% vs. 35%) and anxiety (59% vs. 50%). Mothers in our sample were also approximately 10 years older, on average, than those in Driscoll et al.'s and Quittner et al.'s research, which may have impacted these outcomes. It is also likely that the impact of being a key support person, facilitator of treatment and coping with fluctuations in their child's health for nearly two or more decades, not to mention the psychological burden of the potentially life-threatening nature of their child's illness, would likely contribute to the high levels of psychological distress reported by mothers in this study. However, it is also possible that mothers experiencing greater distress may have also been more likely to participate in the research

than those who are coping well as they may have found the research more relevant to their experiences.

Mothers' overall distress ratings did not appear to be impacted by child's lung functioning as it had been in research involving younger samples. It is possible that lung functioning of children may be a less important factor in maternal adjustment of teens and young adults with CF than it is for those with younger children with this illness. However, given the significant missing data from this variable, this finding needs to be interpreted with caution. It is also noted that the collection of lung functioning data from families via a self-report protocol was a limitation of our data collection procedures. Future research may benefit from obtaining data directly from the children's medical practitioners to reduce missing data and to ensure accuracy of data obtained.

As predicted, work status did have a significant relationship with the psychological distress in our study. Our results identified that mothers who did not have full-time work outside of the home experienced more symptoms of distress than mothers who had external employment. Future research would benefit from further investigating the relationship between maternal employment and distress ratings. There are several possibilities as to why this relationship may occur. Firstly, it is possible that mothers may not take on external work if their children experience a more severe CF presentation. While we considered maternal employment status to be a predictor of distress, it is also possible that mothers who experience more symptoms of distress may be less likely to seek or maintain external employment. Finally, it is also possible that experiences related to working outside of the home may serve as a protective factor for psychological adjustment.

Regarding the utility of illness perceptions in predicting maternal adjustment outcomes, perceptions of the cyclical nature of CF and emotional representations of CF were associated with maternal distress ratings. The identification of specific illness perceptions as factors which have significant relationships with maternal adjustment indicators builds upon the growing body of research which has identified associations between illness perceptions and psychological outcomes for a range of patient groups with chronic illness (Hagger & Orbell, 2003). However, it is noted that there were a number of subscales of the IPQ-R which did not correlate significantly with maternal distress. Namely, those which related to perceptions of CF symptoms, consequences of CF, personal and treatment controllability of CF and overall understanding of CF. Given that most individuals with CF in the 16–25 age group had transitioned from paediatric to adult care and begun to take responsibility for day-to-day management and treatment aspects of CF, the parent's role in CF management would be decreasing. This may contribute to perceptions of CF relating to these components of CF being less pertinent to parent adjustment. Therefore, we now consider that illness perceptions of CF may have more relevance to parents of younger CF patients than those of teens and young adults.

The regression analysis identified the individual contributions of maternal work status, emotional representations of CF and perceptions of the cyclical nature of CF in predicting maternal psychological distress. It was revealed in this analysis that emotional representations and work status accounted for significant and marginally significant variance in distress rating, respectively. While these results obtained appear promising in helping to understand potential predictors of distress in mothers of older teenagers and adolescents with CF, it is noted that the cross-sectional design and the small sample size of this study are limitations which impact the interpretation and application of these results. Longitudinal research with a larger sample size would be recommended for future investigations within these domains.

Further to areas for future research, as noted above it is now considered that some aspects of illness perceptions may be more suited to the experience of parents with younger children with CF. Replication and extension (longitudinal design) of this study with families of younger CF patients is recommended. Given that illness perceptions did not have as greater utility in predicting maternal distress as first considered, it is important that other factors which may contribute to maternal distress in families with older children with CF also be examined. In addition to lung functioning and

work status examined in our study, in a recent review Quittner et al. (2016) have identified that lower patient body mass index and treatment adherence, frequency of CF patient hospitalisations, cost of health care and worse health-related quality of life are important factors to consider in terms of parental adjustment in families coping with CF.

From a clinical perspective, our study identifies that mothers of older children with CF would benefit from assessment of depression, stress and anxiety symptoms, possibly as a component of their children's regular tune up assessments (Goldbeck, Fidika, Herle, & Quittner, 2015; Quittner et al., 2014, 2016). Our findings also suggested that therapeutic assessment of mother's illness perceptions of CF, in particular emotional representations of CF and perceptions of the cyclical nature of CF may also be beneficial. Cognitive behavioural therapy, and more recently, acceptance and commitment therapy protocols have been demonstrated to be efficacious in the treatment of depression and anxiety symptoms in the context of chronic illness (Butler, Chapman, Forman, & Beck, 2006; Hoffmann, Sawyer, Witt, & Oh, 2010). There is also emerging evidence regarding the applications of cognitive behavioural techniques to assist with addressing negative illness perceptions of individuals with chronic illness (Keogh et al., 2007; Petrie, Cameron, Ellis, Buick, & Weinman, 2002) and their partners (Broadbent et al., 2009). The outcomes of our study and correlates of parental adjustment identified in Quittner et al.'s (2016) research also suggest that a comprehensive clinical assessment of medical, familial, social and financial factors which may be impacting upon maternal well-being is important in the conceptualisation and treatment of mother's psychological distress. In addition to psychological therapy, links to community support services may be required to assist with factors such as financial difficulty or engaging in employment.

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Competing Interest

The authors declare no competing interest.

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References

- Anagnostopoulos, F., & Spanea, E. (2005). Assessing illness representations of breast cancer: A comparison of patients with healthy and benign controls. *Journal of Psychosomatic Research*, 58, 327–334. doi:10.1016/j.jpsychores.2004.09.011
- Beinke, K. (2011). *The psychosocial experience of cystic fibrosis: An investigation of personal adjustment, family relationships, and wider community perceptions of adolescents and young adults with cystic fibrosis* (Doctor of Philosophy in Clinical Psychology). Griffith University, Southport.
- Benyamini, Y., Medalion, B., & Garfinkel, D. (2007). Patient and spouse perceptions of the patient's heart disease and their associations with received and provided social support and undermining. *Psychology and Health*, 22, 765–785. doi:10.1080/14768320601070639
- Broadbent, E., Ellis, C. J., Thomas, J., Gamble, G., & Petrie, K. J. (2009). Can an illness perception intervention reduce illness anxiety in spouses of myocardial infarction patients? A randomized controlled trial. *Journal of Psychosomatic Research*, 67, 11–15. doi:10.1016/j.jpsychores.2008.11.006
- Bucks, R. S., Hawkins, K., Skinner, T. C., & Horn, S. (2009). Adherence to treatment in adolescents with cystic fibrosis: The role of illness perceptions and treatment beliefs. *Journal of Pediatric Psychology*, 34, 893–902. doi:10.1093/jpepsy/jsn135
- Butler, A. C., Chapman, J. E., Forman, E. M., & Beck, A. T. (2006). The empirical status of cognitive-behavioral therapy: A review of meta-analyses. *Clinical Psychology Review*, 26, 17–31. doi:10.1016/j.cpr.2005.07.003
- Canadian Cystic Fibrosis Association. (2008). *Canadian cystic fibrosis patient data registry report*. Retrieved January 10, 2011, from http://www.cysticfibrosis.ca/assets/files/pdf/CPDR_ReportE.pdf
- Cystic fibrosis Australia. (2010). *Cystic Fibrosis in Australia 2008: 11th annual report from the Australian cystic fibrosis data registry*. North Ryde: Author.
- Cystic Fibrosis Australia. (2015). *Cystic Fibrosis in Australia 2013: 16th annual report Australasian cystic fibrosis data registry*. Baulkham Hills: Author.
- DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment. *Archives of Internal Medicine*, 160, 2101–2107. doi:10.1001/archinte.160.14.2101
- Driscoll, K. A., Johnson, S. B., Barker, D., Quittner, A. L., Deeb, L. C., Geller, D. E., ... Silverstein, J. H. (2010). Risk factors associated with depressive symptoms in caregivers of children with type 1 diabetes or cystic fibrosis. *Journal of Pediatric Psychology*, 35, 814–822. doi:10.1093/jpepsy/jsp138

- Driscoll, K. A., Montag-Leifling, K., Acton, J. D., & Modi, A. C. (2009). Relations between depressive and anxious symptoms and quality of life in caregivers of children with cystic fibrosis. *Pediatric Pulmonology*, 44, 784–792. doi:10.1002/ppul.21057
- Goldbeck, L., Fidika, A., Herle, M., & Quittner, A. (2015). Cochrane corner: Psychological interventions for individuals with cystic fibrosis and their families: Table 1. *Thorax*, 70, 1089–1091. doi:10.1136/thoraxjnl-2015-207297
- Graetz, B. W., Shute, R. H., & Sawyer, M. G. (2000). An Australian study of adolescents with cystic fibrosis: Perceived supportive and nonsupportive behaviors from families and friends and psychological adjustment. *Journal of Adolescent Health*, 26, 64–69. doi:10.1016/S1054-139X(99)00026-9
- Hagger, M., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18, 141–184. doi:10.1080/088704403100081321
- Hamlett, K. W., Murphy, M., Hayes, R., & Doershuk, C. F. (1996). Health independence and developmental tasks of adulthood in cystic fibrosis. *Rehabilitation Psychology*, 41, 149–160. doi:10.1037/0090-5550.41.2.149
- Harris, M. A., Freeman, K. A., & Duke, D. C. (2011). Transitioning from pediatric to adult health care: Dropping off the face of the Earth. *American Journal of Lifestyle Medicine*, 5, 85–91. doi:10.1177/1559827610378343
- Hoffmann, S. G., Sawyer, A. T., Witt, A. A., & Oh, D. (2010). The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *Journal of Consulting and Clinical Psychology*, 78, 169. doi:10.1037/a0018555
- João Figueiras, M., & Weinman, J. (2003). Do similar patient and spouse perceptions of myocardial infarction predict recovery? *Psychology and Health*, 18, 201–216. doi:10.1080/0887044021000057266
- Keogh, K. M., White, P., Smith, S. M., McGilloway, S., O'Dowd, T., & Gibney, J. (2007). Changing illness perceptions in patients with poorly controlled type 2 diabetes, a randomised controlled trial of a family-based intervention: Protocol and pilot study. *BioMed Central: Family Practice*, 8. Retrieved from <http://biomedcentral.com/1471-2296/10/43>
- Lamers, F., van Oppen, P., Comijs, H. C., Smit, J. H., Spinhoven, P., van Balkom, A. J. L. M., ... Penninx, B. W. J. H. (2011). Comorbidity patterns of anxiety and depressive disorders in a large cohort study. *The Journal of Clinical Psychiatry*, 72, 341–348. doi:10.4088/jcp.10m06176blu
- Lovibond, S., & Lovibond, P. (1995). *Manual for the depression, anxiety, and stress scales* (2nd ed.). Sydney: Psychology Foundation.
- Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17, 1–16. doi:10.1080/08870440290001494
- Olsen, B., Berg, C. A., & Wiebe, D. J. (2008). Dissimilarity in mother and adolescent illness representations of type 1 diabetes and negative emotional adjustment. *Psychology and Health*, 23, 113–129. doi:10.1080/08870440701437343
- Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine*, 64, 580–586.
- Quittner, A., Abbott, J., Georgiopoulos, A. M., Goldbeck, L., Smith, B., Hempstead, S., ... Elborn, S. (2016). International committee on mental health in cystic fibrosis: Cystic fibrosis foundation and european cystic fibrosis society consensus statements for screening and treating depression and anxiety. *Thorax*, 71, 26–34. doi:10.1136/thoraxjnl-2015-207488
- Quittner, A., Goldbeck, L., Abbott, J., Duff, A., Lambrecht, P., Solé, A., ... Barker, D. (2014). Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: Results of the international depression epidemiological study across nine countries. *Thorax*, 69, 1090–1097. doi:10.1136/thoraxjnl-2014-205983
- Sawicki, G. S., Sellers, D. E., & Robinson, W. M. (2011). Associations between illness perceptions and health-related quality of life in adults with cystic fibrosis. *Journal of Psychosomatic Research*, 70, 161–167. doi:10.1016/j.jpsychores.2010.06.005
- Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development*, 557–563. doi:10.1111/j.1365-2214.2008.00844.x



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