

Acceptance and well-being in **adolescents and young adults** with cystic fibrosis: a
prospective study

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Abstract

Objective: To prospectively investigate the role of acceptance in well-being in adolescents and young adults with cystic fibrosis.

Method: Forty adolescents and young adults with cystic fibrosis (ages 14-22) completed questionnaires assessing acceptance, anxiety and depressive symptoms, physical functioning, role functioning, emotional functioning, and social functioning. After six months, 28 of them completed the questionnaires on anxiety and depressive symptoms, physical functioning, role functioning, emotional functioning, and social functioning a second time.

Results: More acceptance (Time 1) was related to less depressive symptoms (Time 1 and 2), and to better role, emotional, and social functioning (Time 1).

Conclusions: Results indicate that accepting the limitations imposed by chronic disease and readjusting life goals may have a positive effect upon well-being in adolescents and young adults with cystic fibrosis. Further research is needed to clarify whether acceptance-based interventions are useful in promoting well-being in adolescents and young adults with cystic fibrosis.

KEYWORDS: acceptance, cystic fibrosis, well-being

Introduction

Cystic fibrosis (CF) is the most common life-shortening genetic disease amongst the Caucasian population, affecting 1 in 2500 newborn children (Cystic Fibrosis Worldwide, 2005; Ratjen & Döring, 2003). The disease is marked by an increased viscosity of the exocrine secretions throughout the body. These hyper viscous secretions mainly affect the lungs and the pancreas by plugging the airways and pancreatic ducts. Mucus plugging then triggers recurrent cycles of infection and inflammation what results in irreversible tissue damage (Ratjen & Döring, 2003; Rosenstein & Zeitlin, 1998). Given the physical consequences of the disease, CF also has negative consequences on other domains of functioning (Glasscoe & Quittner, 2008).

Due to substantial improvements in specialised care, almost half of the children and adolescents with CF nowadays survive into adulthood (Cystic Fibrosis Foundation, 2010). As a consequence, attention to their long-term well-being has become increasingly important (Badlan, 2006; Glasscoe & Quittner, 2008). Well-being refers to a broad area of experiences that encompasses positive and negative affect, general life satisfaction, and satisfaction with specific domains of life (Diener, 1984; Diener, Suh, Lucas, & Smith, 1999). With regard to well-being, adolescents and young adults with CF seem to be confronted with two major challenges: managing the affective impact of CF and maintaining a satisfactory life (Glasscoe & Quittner, 2008; Quittner et al., 2008; Schwartz & Drotar, 2009). Crucial in handling these challenges is to balance the limitations (e.g., functional disability) and demands of having CF (e.g., disease management) with **the pursuit of important** developmental goals **in order to pass on to adulthood** (e.g, **planning for the future, becoming independent, forming** close relationships, **preparing for a job, making decisions about family life, becoming socially responsible, and moving away from home**) (Badlan, 2006; Gjengedal et al., 2003; Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009). Examples of this balance may be the

adjustment of developmental goals that have become unrealistic due to CF (e.g., working part-time instead of full-time, postpone university studies and first get health back on track, only going out in non-smoking places) or the integration of disease management and important developmental goals (e.g., doing aerosol therapy while studying). **For individuals with CF, adolescence is a particularly challenging period as from then on the limitations and demands of having CF typically increase (Ernst et al., 2010). Therefore, it is essential to understand how adolescents and young adults with CF maintain their well-being despite the growing burden of having CF.**

Despite the finding that the challenges of having CF can severely impact upon well-being (Glasscoe & Quittner, 2008; Quittner et al., 2008; Riekert, Bartlett, Boyle, Krishnan, & Rand, 2007; Schwartz & Drotar, 2009), research has shown that not all individuals with CF struggle to maintain well-being. Indeed, while some research findings indicate that adolescents and young adults with CF experience difficulties in several components of well-being such as elevated levels of depression (Quittner et al., 2008), elevated levels of anxiety (Pfeffer, Pfeffer, & Hodson, 2003), and an affected quality of life (Goldbeck & Schmitz, 2001; Pfeffer et al., 2003), other findings indicate no significant differences between adolescents and young adults with and without CF (Anderson, Flume, & Hardy, 2001; Bregnballe, Thastum, & Schiøtz, 2007; Goldbeck & Schmitz, 2001; Havermans, Colpaert, & Dupont, 2008; Pfeffer et al., 2003; Szyndler, Towns, van Asperen, & McKay, 2005). Hence, understanding why certain adolescents and young adults maintain their well-being despite the burden of CF is of utmost importance.

A process that may account for the individual variability in well-being is *acceptance*. Acceptance can be defined as “recognizing the need to adapt to chronic illness while perceiving the ability to tolerate the unpredictable, uncontrollable nature of the disease and handle its averse consequences” (Evers et al., 2001, p.1027). Acceptance thus comprises the

ability to reconcile to the limitations the disease/illness involves, and to face the variable demands imposed by the disease, while staying engaged in a valuable life (Badlan, 2006; Evers et al., 2001; Gjengedal et al., 2003). As CF is an incurable disease with concomitant limitations, acceptance may be a key factor in the well-being of affected individuals (Ernst, Johnson, & Stark, 2010).

The role of acceptance in well-being has already been examined in several chronic conditions. Among adults with chronic pain (e.g., McCracken, Carson, Eccleston, & Keefe, 2004; McCracken & Vowles, 2008; McCracken & Zhao-O'Brien, 2010; Viane et al., 2003), cancer pain (Gauthier et al., 2009), chronic fatigue syndrome (Van Damme, Crombez, Van Houdenhove, Mariman, & Michielsen, 2006), tinnitus (Westin, Hayes, & Andersson, 2008), and multiple sclerosis (Evers et al., 2001; Pakenham, 2006), acceptance was significantly associated with positive outcomes such as less anxiety and depression, better mood, better emotional, social, and physical functioning, less physical complaints, better work status, and less disability. To our knowledge, only one study examined acceptance in adolescents and young adults with CF, demonstrating that acceptance was related to less anxiety, depression and disability (Casier et al., 2008). This study, however, was cross-sectional and did not focus on well-being in general. The present study extends this research by investigating the long-term effects of acceptance on well-being. Identifying the effects of acceptance on well-being over time is important as it may point to processes that promote a valuable and meaningful life in the context of a life-shortening illness (Ernst et al., 2010). Furthermore, investigating the associations between acceptance and well-being may provide indications whether acceptance-based interventions (Hayes, 2004; Hayes et al., 2006) are useful for the preservation and enhancement of these adolescents' and young adults' well-being, and, if so, these findings may further guide the development of these interventions in the context of CF (Hayes, 2004; Hayes et al., 2006).

Well-being was operationalised in terms of anxiety and depressive symptoms, and health-related quality of life. These are important components of well-being, and can be detrimentally affected in individuals with CF (Anderson et al., 2001; Diener et al., 1999; Pfeffer et al., 2003; Quittner et al., 2008; White, Miller, Smith, & McMahon, 2009). In line with expert consensus, health-related quality of life was operationalised as a subjective construct that fundamentally includes four core domains: physical functioning, emotional functioning, social functioning, and role functioning (Cella, 1998; Spilker, 1996). We hypothesized that higher levels of adolescents' and young adults' acceptance at Time 1 are related to less anxiety and depressive symptoms, and to better physical, emotional, social, and role functioning at both Time 1 and 2 (6 months later) (see Evers et al., 2001; McCracken, et al., 2004; Pakenham, 2006).

Method

Participants

All adolescents and young adults with CF attending the University Hospitals of Antwerp, Brussels, or Ghent, and the Sint-Vincentius Hospital, Antwerp, Belgium who were 14-22 years of age and met the following criteria were invited to participate: understanding the Dutch language, no developmental disorder, and no (planned) lung transplantation. Adolescents and young adults who had/were awaiting lung transplantation were not included as they find themselves in a situation that is very different from the situation of individuals in the pre-transplant period (e.g., very high level of symptoms, being terminally ill, intertwining of end of life issues and hope of transplantation, risk of post-transplant complications, dramatic change of illness status) (Bourke et al., 2009; Kurland & Orenstein, 2001). Seventy-three adolescents and young adults met these criteria. The participating centres did not contact 9 of these adolescents and young adults because they had serious physical and/or psychosocial problems. Sixty-four adolescents and young adults were invited

to participate by letter and/or approached during routine clinic visits by the psychologist from the respective hospital (time period of recruitment: 13 months). Subsequently, adolescents and young adults agreeing to participate were contacted by phone by a research assistant. Forty adolescents and young adults (23 boys; 17 girls) were enrolled in our study (response rate = 62.50 %). The main reasons for not participating were a lack of time or motivation ($N = 14$), too many requests for participating in scientific research ($N = 7$), and not wanting to be unnecessarily confronted with the disease ($N = 2$). Mean age was 18.40 years ($SD = 2.87$). To determine disease severity, the US CF Foundation guidelines for severity of lung disease were used (Cystic Fibrosis Foundation, 2008). Disease severity ranged from not severe/normal lung function ($FEV_1\%$ predicted $\geq 90\%$) to severe ($FEV_1\%$ predicted $< 40\%$). Mean disease severity indicated mild lung disease ($M_{FEV_1\%} = 83.01\%$). Of all adolescents and young adults, 32.50% had normal lung function ($FEV_1\%$ predicted $\geq 90\%$), 42.50% mild lung disease ($89\% \geq FEV_1\%$ predicted $\geq 70\%$), 22.50% moderate lung disease ($69\% \geq FEV_1\%$ predicted $\geq 40\%$), and 2.5% had severe lung disease ($FEV_1\%$ predicted $< 40\%$). Mean time since diagnosis was 16.84 years ($SD = 3.82$). All adolescents and young adults were of Caucasian origin. Because of confidentiality, no data about the characteristics of the non-participants were available.

Procedure

At time 1, a research assistant visited the participants at their home. During this house visit, written parent consent and/or adolescents and young adult assent/consent were obtained, and a booklet of questionnaires (assessing acceptance, anxiety, depression, and health-related quality of life) were filled out. At Time 2, all adolescents and young adults were contacted again and asked to complete follow-up questionnaires (assessing anxiety, depression, and health-related quality of life). The follow-up questionnaires were sent by mail. Twenty-eight of the 40 adolescents and young adults (70%) returned the Time 2

questionnaires. Drop-out analyses showed that there were no significant differences in age ($t(38) = -1.03, ns$), disease severity ($t(38) = -.61, ns$), acceptance ($t(38) = -1.48, ns$), anxiety ($t_{anxiety}(38) = .64, ns$), depression ($t_{depression}(38) = 1.13, ns$), and health-related quality of life ($t_{physical\ functioning}(38) = -.98, ns$; $t_{role\ functioning}(38) = -1.08, ns$; $t_{emotional\ functioning}(38) = -1.91, ns$; $t_{social\ functioning}(38) = -.92, ns$) between the adolescents and young adults who responded at Time 2 and those who did not. This study was approved by the ethical committees of the University Hospitals of Antwerp, Brussels, and Ghent, and the Sint-Vincentius Hospital, Antwerp and was carried out in accordance with universal ethical principles (Emanuel, Wendler, & Grady, 2000).

Measures

Acceptance was assessed by the Dutch version of the Illness Cognition Questionnaire (ICQ; Evers et al., 2001). This 18-item questionnaire contains 3 subscales: ‘acceptance’, ‘helplessness’, and ‘perceived benefits’. Only the acceptance scale was used. Acceptance is conceptualised as the perceived ability to live with the illness and to master its negative consequences (6 items, e.g. “I can handle the problems related to my illness”). Items are rated on a 4-point Likert scale (1 = ‘not at all’, 4 = ‘completely’). The total score for acceptance varies between 6 and 24, with higher scores indicating higher levels of acceptance.

Psychometric research in samples of Dutch-speaking adults with rheumatoid arthritis, multiple sclerosis, chronic pain and chronic fatigue demonstrated the adequate reliability and validity of the ICQ (Evers et al., 2001; Lauwerier et al., 2010). Reliability of the acceptance scale in this sample was good with a Cronbach’s α of .90 (see Table 1).

Health-related quality of life was assessed by the Dutch version of the Cystic Fibrosis Questionnaire-Revised Teen/Adult Version (CFQ-R Teen/Adult Version; Klijn et al., 2004; Quittner, Modi, Watrous, & Davis, 2003). The CFQ-R Teen/Adult Version consists of 50 items assessing 9 quality of life domains and is sensitive to the specific concerns of

individuals (aged 14 and older) with CF: ‘physical functioning’, ‘role functioning’, ‘vitality’, ‘emotional functioning’, ‘social functioning’, ‘body image’, ‘eating’, ‘treatment burden’, and ‘overall health perception’. The CFQ-R Teen/Adult Version also assesses three symptom scales: ‘weight’, ‘respiratory’, and ‘digestion’. Because no higher order summary scores are available, only the subscales measuring the core domains of health-related quality of life were included. In line with expert consensus (Cella, 1998; Spilker, 1996), the following subscales were used: physical functioning (8 items, e.g. “Difficulty to walk as fast as others”), role functioning (4 items, e.g. “Trouble keeping with school, work or daily activities”), emotional functioning (5 items, e.g. “Felt worried”), and social functioning (6 items, e.g. “Stayed at home more than you wanted) (Quittner et al., 2003; Quittner, Buu, Messer, Modi, & Watrous, 2005). Items are rated in terms of a frequency response on a 4-point Likert scale (1 = ‘all the time’, 4 = ‘never’), a difficulty rating on a 4-point Likert scale (1 = ‘a lot of difficulty’, 4 = ‘no difficulty’), a true-false response on a 4-point Likert scale (1 = ‘very true’, 4 = ‘very false’), or a selection of a particular statement (4- or 5-point Likert scale). Total scores vary from 0 to 100, with higher scores representing better quality of life (Quittner et al., 2000). Reported psychometric properties of the CFQ-R Teen/Adult Version subscales were average to good (Quittner et al., 2003). In the current sample, the internal consistencies (Cronbach’s α) at Time 1 were .92 for physical functioning, .81 for role functioning, .63 for emotional functioning, and .44 for social functioning. Internal consistencies (Cronbach’s α) at Time 2 were .84 for physical functioning, .37 for role functioning, .55 for emotional functioning, and .60 for social functioning (see Table 1).

The Dutch version of the Hospital Anxiety and Depression Scale (HADS; Spinhoven et al., 1997; Zigmond & Snaith, 1983) was used to assess anxiety and depressive symptoms. The HADS consists of 14 items to be rated on a 4-point Likert scale, and has two subscales: ‘anxiety’ (7 items, e.g. “Do you feel tense and wound up?”) and ‘depression’ (7 items, e.g.

“Do you feel cheerful?”). Total scores range between 0 and 21, with higher scores indicating higher levels of anxiety and/or depressive symptoms (Snaith, 2003). For depression, scores between 7 and 9 are indicative of possible depression, scores above 9 of probable depression. Cut-off scores for anxiety are 9 (possible emotional disorder) and 12 (probable emotional disorder) (White, Leach, Sims, Atkinson, & Cottrell, 1999). The HADS is designed for use in medical practice. It is proven reliable and valid as a screening instrument in adolescents, adults, and elderly subjects with or without a medical condition (Spinhoven et al., 1997; White et al., 1999; Zigmond & Snaith, 1983). Cronbach’s α in this study for anxiety was .71 at Time 1 and 2. For depression Cronbach’s α was .73 at Time 1 and .76 at Time 2 (see Table 1).

Disease severity was determined by using forced expiratory volume in one second (FEV₁% predicted). FEV₁% predicted was taken from the medical chart of each adolescent or young adult. The most recent pulmonary function test before the administration of the questionnaires was selected ($M_{days} = 35.56$, $SD = 27.29$, range 1 – 106 days). Pulmonary function tests are the standard for measuring respiratory functioning and lung damage for individuals with cystic fibrosis. FEV₁% predicted, was used as a continuous variable, with lower values indicating poorer respiratory functioning and more lung disease (Ramsey & Boat, 1994). Tests were carried out by trained and experienced medical personnel, using a Jaeger MasterScreen™ Body (CareFusion Germany 234 GmbH, Hoechberg, Germany). During this procedure, individuals are seated in a glass cabin where they perform inspiratory and expiratory manoeuvres through a mouthpiece (CareFusion, 2009).

Socio-demographic information (age, gender and time since diagnosis) was verbally inquired before administration of the questionnaires.

Statistical analyses

All analyses were performed using SPSS 15.0. Tests of normality were performed for all continuous variables. Descriptive statistics were computed for all variables of interest. Pearson's correlations were performed to determine whether age, time since diagnosis, disease severity and acceptance were related to anxiety and depressive symptoms, and health-related quality of life. Furthermore, *t*-tests were performed to examine gender differences in anxiety and depressive symptoms, and/or health-related quality of life, and to identify potential differences between the Time 1 and Time 2 dependent variables.

Separate hierarchical regression analyses were used to investigate the role of acceptance (Time 1) in anxiety and depressive symptoms (Time 1 and 2) and health-related quality of life (Time 1 and 2). For regressions with the dependent variable measured at Time 1, socio-demographic and disease-related variables that were significantly related to the outcome measures were entered as control variables in a first step. Acceptance was entered in the second step. Anxiety and depressive symptoms, and physical, role, emotional, and social functioning at Time 1 were entered as dependent variables. For regressions with the dependent variable measured at Time 2, socio-demographic and disease-related variables that were significantly related to the outcome measures were entered as control variables in a first step. In the second step, we controlled for the corresponding Time 1 measure of respectively anxiety and depressive symptoms, and physical, role, emotional, and social functioning. In the third step, acceptance was entered. Anxiety and depressive symptoms, and physical, role, emotional, and social functioning measured at Time 2 were used as dependent variables. As we had a priori hypotheses about the direction of effects, one-tailed tests of significance were used (Kline, 2004; Martin & Bateson, 1993, 2007; Wonnacott & Wonnacott, 1985). Alpha level was set at $p < .05$. To control for multiple testing and balance the amount of type I and type II errors, the Benjamini and Hochberg false discovery rate (i.e., the expected proportion of rejected true null hypothesis among rejected hypotheses) was used (Benjamini &

Hochberg, 1995; Benjamini, Krieger, & Yekutieli, 2006). The False Discovery Rate level was set at 5%, assuring that in each set of hierarchical regression analyses (i.e., analyses at Time 1 and at Time 2) no more than 5% of the significant relationships found are false-positive (Benjamini et al., 2006).

The initial sample ($N = 40$) had sufficient power (.86) to detect large effects (see Casier et al., 2008) in multiple regressions ($f^2 = .35$) with 3 variables. The second sample ($N = 28$) had a power of .65 to detect large effects in multiple regressions ($f^2 = .35$) with 3 variables (Vacha-Haase & Thompson, 2004).

Results

Descriptive statistics

Means, standard deviations, and internal consistencies (Cronbach's α) of variables are reported in Table 1. The mean score for acceptance was 18.55 ($SD = 4.16$), which is in line with a previous study on acceptance in adolescents and young adults with CF (Casier et al., 2008). Mean scores for anxiety and depressive symptoms were indicative of low psychological distress. At Time 1, 85 % of the adolescents and young adults scored beneath the cut-off for probable anxiety, and 97.50 % beneath the cut-off for probable depression (White et al., 1999). The percentage of adolescents and young adults scoring beneath this cut-off at Time 2 was 88.90 % for anxiety and 96.30 % for depression. Mean levels of physical, role, emotional, and social functioning varied between 71.39 and 85.71. Paired sample t-tests revealed that there were no significant differences between the Time 1 and Time 2 dependent variables. Tests of normality revealed that none of the variables included were skewed.

Identification of relevant control variables

Correlations between age, time since diagnose, disease severity, acceptance and anxiety and depressive symptoms, and health-related quality of life are reported in Table 1. Socio-demographic and disease-related variables that were significantly related to the

outcome measures were entered as control variables in the hierarchical regression analyses.

Furthermore, t-tests revealed that gender was related to emotional functioning at Time 1

($M_{male} = 78.84$, $SD_{male} = 13.43$; $M_{female} = 67.84$, $SD_{female} = 19.18$; $F(1,38) = 4.56$, $p < .05$), and

to social functioning at Time 1 ($M_{male} = 75.85$, $SD_{male} = 11.68$; $M_{female} = 65.36$, $SD_{female} = 17.07$; $F(1,38) = 5.33$, $p < .05$).

Role of acceptance (Time 1) in anxiety and depressive symptoms (Time 1 and 2)

Table 2 summarizes the results of the multiple regression analyses. As none of the socio-demographic and disease-related variables were significantly related to anxiety and depressive symptoms, these variables were not included in the analyses. More acceptance was significantly related to less anxiety symptoms at Time 1 ($\beta = -.29$, $t = -1.86$, $p < .05$, 95% CI [-.51, .02]). Contrary to our expectations, no significant association was found between acceptance at Time 1 and anxiety symptoms at Time 2. Overall, acceptance explained an additional variance of 8% in anxiety symptoms at Time 1 ($F_{change}(1, 38) = 3.46$, $p < .05$). Furthermore, more acceptance was significantly related to less depressive symptoms at Time 1 ($\beta = -.35$, $t = -2.33$, $p < .05$, 95% CI [-.33, -.02]), and less depressive symptoms at Time 2 ($\beta = -.31$, $t = -1.71$, $p \leq .05$, 95% CI [-.56, .05]). Overall, acceptance explained an additional variance of 13% in depressive symptoms at Time 1 ($F_{change}(1, 38) = 5.43$, $p < .05$), and 9% in depressive symptoms at Time 2 ($F_{change}(1, 25) = 2.92$, $p \leq .05$). Examination of Tolerance and VIF of all regression analyses revealed no problems of multicollinearity. After controlling for multiple comparisons, all of the initially identified significant associations remained statistically significant, except for the association between acceptance and anxiety symptoms at Time 1 (false discovery rate of 11%) (Benjamini & Hochberg, 1995; Benjamini et al., 2006).

Role of acceptance (Time 1) in health-related quality of life (Time 1 and 2)

Table 3 summarizes the results regarding quality of life. Acceptance was not related to physical functioning at both Time 1 and 2. Furthermore, more acceptance was related to better role functioning ($\beta = .32, t = 2.20, p < .05, 95\% \text{ CI } [.11, 2.67]$) at Time 1, but not Time 2. Acceptance at Time 1 accounted for an additional variance of 10% in role functioning at Time 1 ($F_{\text{change}}(1, 37) = 4.83, p < .05$). More acceptance was also related to better emotional functioning ($\beta = .34, t = 2.18, p < .05, 95\% \text{ CI } [.10, 2.68]$) at Time 1, but not Time 2. Acceptance at Time 1 accounted for an additional variance of 9% in emotional functioning at Time 1 ($F_{\text{change}}(1, 36) = 4.74, p < .05$). Finally, more acceptance was also related to better social functioning ($\beta = .48, t = 3.12, p < .01, 95\% \text{ CI } [.60, 2.84]$) at Time 1, but not Time 2. Acceptance at Time 1 accounted for an additional variance of 18% in social functioning at Time 1 ($F_{\text{change}}(1, 37) = 9.70, p < .01$). Examination of Tolerance and VIF of all regression analyses revealed no problems of multicollinearity. After controlling for multiple comparisons, all of the initially identified significant associations remained statistically significant (Benjamini & Hochberg, 1995; Benjamini et al., 2006).

Discussion

This study is the first to provide insights in the relationship between acceptance and well-being in CF, measured at different time points. The current findings are in line with those from a previous study on acceptance in adolescents and young adults with CF (Casier et al., 2008). This study extends research by incorporating health-related quality of life and investigating the relationships prospectively.

Consistent with previous research (Casier et al., 2008; McCracken & Vowles, 2008; Van Damme et al., 2006), our findings reveal that greater acceptance was related to less depressive symptoms measured at the same point in time, and 6 months later. Contrary to our expectations and to research in chronic pain (see McCracken & Eccleston, 2005), acceptance was not related to anxiety symptoms at Time 1 and 2. This lack of association may most

likely be due to our small sample size. It also may reflect the relatively low levels of anxiety symptoms and high levels of acceptance in the current sample. Moreover, it is possible that acceptance is rather related to illness-specific than to general anxiety (McCracken & Eccleston, 2005). The significant relationship between acceptance and depressive symptoms at both Time 1 and 2 is in line with the conceptualisation of acceptance. An important feature of acceptance is to resist the idea that acceptance of illness is a sign of weakness, failure, helplessness, or inferiority (Risdon, Eccleston, Crombez, & McCracken, 2003). Acceptance involves acknowledging the reality of being chronically ill without resigning or surrendering (Evers et al., 2001; Hayes et al., 2006; Risdon et al., 2003). The belief that illness does not imply the end of a meaningful life is indeed inconsistent with depressive symptoms.

Acceptance was also related to several domains of health-related quality of life. More specifically, greater acceptance was related to better role, emotional, and social functioning measured at the same time. This is consistent with research in other chronic conditions such as chronic pain, chronic fatigue syndrome, and multiple sclerosis (Evers et al., 2001; McCracken & Vowles, 2008; Van Damme et al., 2006). Contrary to our expectations, acceptance at Time 1 was not related to physical, role, emotional, and social functioning 6 months later. The most likely explanation for this lack of association may be the small sample size. Despite the lack of association with the Time 2 outcomes, the Time 1 findings are in line with the conceptualisation of acceptance. Acceptance includes broadening a focus upon illness to other domains of life. This engagement in important and achievable developmental goals (e.g., further education, work, hobbies), within the context of a life-shortening illness, seems a prerequisite for a valued life (Evers et al., 2001; Hayes et al., 2006; Risdon et al., 2003).

The present study contributes to the increasing support that acceptance has positive effects on the adjustment to chronic illness, beyond the effects of socio-demographic and

disease-related variables. In the context of CF, acceptance comprises the ability to face the demands and limitations characteristic to CF, and to reconcile to the unpredictable and uncontrollable nature of CF (Badlan, 2006; Evers et al., 2001; Gjengedal et al., 2003). The current findings indicate that acceptance is related to less depressive symptoms and better health-related quality life at the same time point, and to less depressive symptoms 6 months later. These findings suggest that the role of acceptance may be central during adolescence and young adulthood. Indeed, from adolescence on, CF and its burden typically become more severe (e.g., more frequent symptoms, more exacerbations, more disability, more intensive treatment) (Ernst et al., 2010). This means that the trade-off between CF-related demands and developmental demands (e.g., doing aerosol therapy while studying, learning a new language/reading books/make drawings while hospitalised, choosing a job that fits with one's physical capabilities) becomes essential during this period (Badlan, 2006; Gjengedal et al., 2003; Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009). Acceptance may impact this trade-off as it may help adolescents and young adults with CF to keep pursuing important developmental goals (e.g., independence, close relationships, academic achievement, family life, occupation) in the development towards adulthood (Ernst et al., 2010; Gjengedal et al., 2003). The finding that in the current sample acceptance was unrelated to disease severity may indicate that the effects of acceptance rather refer to the subjective experience of CF instead of one's objective medical condition.

Further research is needed to verify whether adolescents and young adults with CF benefit from psychological interventions developed to stimulate acceptance of disease. These interventions may prevent loss of well-being and/or enhance well-being when affected. Approaches that incorporate acceptance, such as Acceptance and Commitment Therapy (ACT; Hayes, 2004; Hayes et al., 2006), already exist for several conditions such as depression, psychosis, cancer, substance abuse, chronic pain, etcetera and reveal promising

results (Hayes et al., 2006; Powers, Zum Vörde Sive Vörding, & Emmelkamp, 2009; Vowles, Wetherell, & Sorrell, 2009). Within ACT (Hayes, 2004; Hayes et al., 2006), acceptance is considered as a means of increasing action that is directed toward important life goals, in spite of being ill (Bach & Hayes, 2002; Evers et al., 2001; Hayes et al., 2006). This may be particularly relevant during adolescence and young adulthood as the ultimate challenge of adolescents and young adults with CF is to balance the pursuit of CF-related goals (i.e., disease management) with the pursuit of other important developmental goals (e.g., independence, close relationships, academic achievement, family life, occupation) (Badlan, 2006; Gjengedal et al., 2003; Glasscoe & Quittner, 2008; Schwartz & Drotar, 2009). By acknowledging the reality of having CF without struggle or resignation, by believing that CF does not imply the end of a meaningful life and, by choosing actions that stimulate to strive for important developmental goals despite having CF, a meaningful life and well-being can be sustained (Ernst et al., 2010; Hayes et al., 2006; Risdon et al., 2003). In this context, it may be useful to consider ACT (Hayes, 2004; Hayes et al., 2006) for individuals with CF. However, to determine the usefulness of ACT (Hayes, 2004; Hayes et al., 2006) for adolescents and young adults with CF it is necessary to (a) further investigate the role of acceptance and related processes in the context of CF, (b) identify factors that influence acceptance, (c) modify existing ACT (Hayes, 2004; Hayes et al., 2006) approaches for individuals with CF, (d) conduct feasibility studies, and (e) conduct randomized controlled trials (Gauthier et al., 2009; Glasscoe & Quittner, 2008). Furthermore, as male adolescents/young adults and adolescents/young adults with higher disease severity demonstrated worse outcomes on particular aspects of well-being, special attention should be paid to these adolescents' and young adults' well-being.

There are some limitations to this study. First, the sample size of the present study was small and consequently it is possible that small and medium effects remained undetected.

At Time 1, the current study only had sufficient power to detect large effects. At Time 2, power was low, even for the detection of large effects. Furthermore, we controlled for the corresponding Time 1 dependent variable in the regression analyses for the Time 2 outcomes. As the Time 1 dependent variables captured a great amount of the variance in the Time 2 outcomes, this may be another reason for the null findings for anxiety and health-related quality of life at Time 2. Second, part of our findings are cross-sectional and therefore do not indicate causal effects. The prospective part of the current study is an advancement on cross-sectional findings, but only provides a first indication of the long-term effects of acceptance. To truly investigate long-term effects, future research should include measurements at, at least, 3 consecutive time points. Third, adolescents and young adults reported on average a relatively good well-being. As previous research often reports worse levels of well-being for adolescents and young adults with CF in comparison with healthy peers (Goldbeck & Schmitz, 2001; Quittner et al., 2008; Pfeffer et al., 2003), it cannot be assumed that the current findings apply to the general population of adolescents and young adults with CF. Further research in more diverse samples is needed to generalise the current findings. Fourth, 40 of 64 adolescents and young adults consented to participate. As this may reflect sample bias, we should be careful in generalising our results to other samples. Of the 24 non-participants, 2 declined participation because they did not want to be unnecessarily confronted with their CF, what may point to a lack of acceptance. As the mean score for acceptance was quite high in the current sample, it is possible that the current findings may not generalize to samples who score lower on acceptance. Fifth, the questionnaires were administered in two different ways: during a house visit under the supervision of a research assistant at Time 1 and after receiving the questionnaires by mail at Time 2. It is possible that this difference in approach may have affected our results (e.g., low response rate at Time 2). Sixth, acceptance was only measured once. As a consequence, we were unable to detect

possible changes in acceptance and to identify if changes in acceptance over time concur with changes in well-being. Seventh, reliabilities for role functioning (Time 2) and social functioning (Time 1) of the CFQ-R Teen/Adult Version were quite low. Therefore, the results for these outcomes should be interpreted with caution. Eighth, acceptance, anxiety and depressive symptoms, and health-related quality of life were only assessed using self-report scales. A multi-method approach (e.g., objective indicators of health-related quality of life, ratings by parents, caregivers, or nurses) would contribute to the generality of the current findings. What concerns acceptance, more instruments should be developed that are usable in individuals with CF or chronic conditions in general, and focus more particular on certain facets of acceptance such as acceptance of difficult thoughts and feelings related to illness and the choice for action driven by important life goals despite being ill. These instruments could be based on the Acceptance and Action Questionnaire (AAQ; Hayes, et al., 2004), a generic measure that assesses ACT processes such as acceptance, values-based action, and psychological flexibility. The AAQ has already been adjusted for specific conditions such as chronic pain (Chronic Pain Acceptance Questionnaire; McCracken, Vowles, & Eccleston, 2004) and diabetes (Acceptance and Action Diabetes Questionnaire; Gregg, 2004, in Hayes et al., 2004), but not yet for CF.

To our knowledge, this is the first prospective analysis of the role of acceptance in anxiety and depressive symptoms, and health-related quality of life of adolescents and young adults with CF. The promising findings from this study indicate that acceptance may play a protective role in the well-being of these adolescents and young adults. These encouraging results stimulate to replicate the current findings and to investigate other processes related to acceptance such as the pursuit of important developmental goals. The relationship between acceptance and the pursuit of important developmental goals has, to our knowledge, not yet

been studied. Future research should address this relationship and should examine if the relationship between acceptance and well-being is mediated by goal pursuit.

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Table 1. Means (*M*), standard deviations (*SD*), internal consistency (Cronbach's α) and Pearson product-moment correlations of acceptance (Time 1), anxiety, depression, physical functioning, role functioning, emotional functioning, and social functioning. Correlation coefficients above the diagonal are at Time 1, coefficients beneath are with the outcomes measured at Time 2.

	<i>Time 1</i>		<i>Time 2</i>		1	2	3	4	5	6	7	8	9	10
	<i>M(SD)</i>	α	<i>M(SD)</i>	α										
1. Age	18.40 (2.87)	-	18.70 (2.80)	-	-	.73*	-.45*	-.03	.02	.10	-.06	-.22	-.21	.05
2. Time since diagnosis	16.84 (3.82)	-	16.99 (4.07)	-	.69*	-	-.43*	-.07	-.03	.17	-.08	-.16	-.28*	-.02
3. Disease severity	83.01 (19.7)	-	84.26 (16.34)	-	-.31	-.36*	-	-.10	-.14	-.21	.32*	.34*	.14	.07
4. Acceptance	18.55 (4.16)	.90	-	-	-.14	-.14	-.16	-	-.29*	-.35*	.15	.29*	.45*	.54*
5. Anxiety	4.88 (3.49)	.71	3.79 (4.04)	.71	.18	.06	-.27	-.12	-	.49*	-.49*	-.56*	-.61*	-.44*
6. Depression	1.53 (2.05)	.73	1.07 (2.96)	.76	.12	-.03	-.03	-.35*	.65*	-	-.52*	-.58*	-.57*	-.53*
7. Physical functioning	81.46 (20.04)	.92	85.71 (13.82)	.84	-.18	-.23	.54*	.05	-.41*	-.25	-	.50*	.59*	.39*
8. Role functioning	83.13 (17.95)	.81	85.42 (11.02)	.37	-.28	-.05	.36*	-.08	-.16	-.14	.36*	-	.55*	.32*
9. Emotional functioning	74.17 (16.82)	.63	76.19 (12.63)	.55	-.10	-.01	.22	.05	-.51*	-.22	.50*	.24	-	.68*
10. Social functioning	71.39 (14.97)	.44	74.01 (13.70)	.59	.00	.11	.22	.34*	-.42*	-.65*	.38*	.22	.43*	-

One-tailed significance test

* $p < .05$

Table 2. Hierarchical regression analyses of acceptance at Time 1 and anxiety and depression at Time 1 and 2.

Dependent variable	Step	Predictor	β	R ²	ΔR^2	Adj. R ²
Anxiety (Time 1)	1	Acceptance (Time 1)	-.29*	.08*	.08*	.06*
Depression (Time 1)	1	Acceptance (Time 1)	-.35*	.13*	.13*	.10*
Anxiety (Time 2)	1	Anxiety (Time 1)	.63*	.39*	.39*	.37*
	2	Acceptance (Time 1)	.01	.39	.00	.34
Depression (Time 2)	1	Depression (Time 1)	.31*	.13*	.13*	.10*
	2	Acceptance (Time 1)	-.31*	.22*	.09*	.16*

One-tailed significance test

* $p < .05$

Table 3. Hierarchical regression analyses of acceptance at Time 1 and physical, role, emotional, and social functioning at Time 1 and 2.

Dependent variable	Step	Predictor	β	R ²	ΔR^2	Adj. R ²
Physical functioning (Time 1)	1	Disease severity	.34*	.10*	.10*	.08*
	2	Acceptance (Time 1)	.19	.14	.03	.09
Role functioning (Time 1)	1	Disease severity	.37*	.11*	.11*	.09*
	2	Acceptance (Time 1)	.32*	.22*	.10*	.17*
Emotional functioning (Time 1)	1	Gender	-.20	.21*	.21*	.17*
		Time since diagnosis	-.28*			
	2	Acceptance (Time 1)	.34*	.30*	.09*	.24*
Social functioning (Time 1)	1	Gender	-.14	.12*	.12*	.10*
	2	Acceptance (Time 1)	.48*	.31*	.18*	.27*
Physical functioning (Time 2)	1	Disease severity	.41*	.29*	.29*	.26*
	2	Physical functioning (Time 1)	.56*	.59*	.31*	.56*
	3	Acceptance (Time 1)	.09	.60	.01	.55
Role functioning (Time 2)	1	Disease severity	.26	.13*	.13*	.09*
	2	Role functioning (Time 1)	.32	.22*	.09*	.16*
	3	Acceptance (Time 1)	-.01	.22*	.00*	.12*
Emotional functioning (Time 2)	1	Emotional functioning (Time 1)	.56*	.27*	.27*	.24*
	2	Acceptance (Time 1)	-.13	.29	.02	.23
Social functioning (Time 2)	1	Social functioning (Time 1)	.73*	.56*	.56*	.55*
	2	Acceptance (Time 1)	.06	.57	.00	.53

One-tailed significance test

* $p < .05$