

Is resilience associated with self-care? A cross-sectional study in patients with Cystic Fibrosis.

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English Abstract

Title Is resilience associated with self-care? A cross-sectional study in patients with Cystic Fibrosis.

Background Cystic Fibrosis (CF) is a life-threatening progressive genetic disease. Supporting and empowering patients in performing self-care, prevents exacerbations, improves well-being and decreases morbidity and mortality. The daily need to cope with CF and its adversities, might result in a strong sense of resilience among patients, but the association with self-care is unknown.

Aim The aim is to explore the association between resilience and self-care in patients with CF, aged 18 years or older.

Method A quantitative, cross-sectional study design was used. The study was conducted in the Netherlands, at the outpatient clinic of a tertiary (University) hospital. Data was collected between January 2020 – March 2020, with the use of questionnaires. The Resilience Evaluation Scale (RES) and the Self-Care of Chronic Illness Inventory (SC-CII) were used. Multiple regression analysis was used to quantify the association between resilience and self-care. Possible confounders were age, gender, education level, marital status, ppFEV₁ and depression.

Results 46 patients consented to participate and 40 patients returned the questionnaires. Mean age was 29 years (range 18-56) and 27 were female. Resilience was not significantly associated with the three self-care behaviours in univariate and multiple regression analysis ($p \geq .05$). After correcting for confounders, gender ($\beta = -.54$) and negative screening for depression ($\beta = .36$) were statistically significant associated with self-care monitoring and low education ($\beta = .63$) with self-care maintenance.

Conclusion The results of our study indicate that in patients with CF, resilience is not associated with self-care.

Recommendations This research is a start in identifying how resilience and self-care are associated. This association should be further researched, where self-care should be clearly defined and lack of continuity in self-care research should be prevented.

Keywords: Cystic fibrosis, self-care, cross-sectional, resilience, association.

Nederlandse samenvatting

Titel Is veerkracht geassocieerd met zelfzorg? Een cross-sectioneel onderzoek bij patiënten met Cystische Fibrose.

Achtergrond Cystische Fibrose (CF) is een levensbedreigende, progressieve, genetische ziekte. Met het ondersteunen van patiënten in het uitvoeren van zelfzorg, kunnen exacerbaties voorkomen worden, welzijn verhoogd en morbiditeit en mortaliteit verlaagd. Het

dagelijks omgaan met CF en bijbehorende tegenslagen, kunnen zorgen voor verhoogde veerkracht. Echter, de associatie met zelfzorg is niet bekend.

Doel Het doel is om de associatie te exploreren tussen veerkracht en zelfzorg bij patiënten met CF van 18 jaar of ouder.

Methode Een kwantitatief, cross-sectioneel design is gebruikt. Het onderzoek is uitgevoerd in een Nederlands tertiair (universitair) ziekenhuis, op de polikliniek. Dataverzameling vond plaats tussen januari 2020 - maart 2020, met gebruik van vragenlijsten. De 'Resilience Evaluation Scale' (RES) en de 'Self-Care of Chronic Illness Inventory' (SC-CII) werden gebruikt. Multipelle regressie analyse werd gebruikt om de associatie tussen veerkracht en zelfzorg te kwantificeren. Mogelijke confounders waren leeftijd, geslacht, educatie niveau, burgerlijke status, ppFEV₁ en depressie.

Resultaten 46 patiënten ondertekenden het toestemmingsformulier, 40 patiënten retourneerden de vragenlijst. De gemiddelde leeftijd was 29 jaar (range 18-56) en 27 waren vrouw. Veerkracht was niet significant geassocieerd met alle drie de zelfzorg gedragingen in de univariate en multivariate regressie analyse ($p \geq .05$). Na corrigeren voor confounders, waren geslacht ($\beta = -.54$) en negatieve screening op depressie ($\beta = .36$) statistisch significant geassocieerd met zelfzorg-monitoring en lage educatie ($\beta = .63$) met zelfzorg-behoud.

Conclusie De resultaten van deze studie laten zien dat bij patiënten met CF veerkracht niet geassocieerd is met zelfzorg.

Aanbevelingen Dit onderzoek is een start in het identificeren hoe veerkracht en zelfzorg geassocieerd zijn. Het wordt aanbevolen deze associatie verder te onderzoeken, waarbij zelfzorg duidelijk gedefinieerd wordt en gebrek in continuïteit in zelfzorg onderzoek voorkomen wordt.

Sleutelwoorden: Cystische Fibrose, zelfzorg, cross-sectioneel, veerkracht, associatie.

Introduction

Cystic Fibrosis (CF) is a life-threatening progressive genetic disease with over 38.000 cases currently registered in Europe¹, affecting roughly one in 2.000-2.500 live births among Caucasian populations.^{2,3} A gene mutation in the CF transmembrane regulator protein (CFTR), causes a disturbed regulation of salt and water movement across cell membranes.³ This disturbed regulation affects the mucus glands of several major organs, whereby the respiratory, gastrointestinal and reproductive organs are the most effected.⁴ The mucus production of patients with CF is thick and accumulates in the lungs and intestine. Nutritional deficiency can occur which results in poor growth. Furthermore, respiratory infections are common, which eventually causes permanent and fatal lung damage.^{3,5} Due to continuing advances in the management and treatment of CF, the median predicted survival in many countries is now between 30 to 40 years.⁶ Today, there are more adults than children with CF.⁷

The burden on adult patients with CF is high, considering the struggle of balancing family life, work, education and treatment activities.⁷ The daily required treatment activities are increasingly complicated and time consuming.⁶ It consists of disease specific activities such as chest physiotherapy, inhaling bronchodilators, taking enzymes, and receiving intravenous antibiotics at home.^{3,7} Furthermore, patients with CF must daily and routinely monitor and interpret their symptoms and changes as well.^{7,8} These disease specific activities and monitoring, together with regular interventions needed to prevent and manage exacerbations, make for an unusually demanding self-care regimen.⁷ Self-care for patients with CF is even more complicated, because the requisites can deviate significantly from healthy self-care norms.⁷

According to the middle range theory of self-care, self-care is defined as a process of maintaining health, through managing illness and health-promoting practices, in both healthy and ill states.^{7,9-11} Self-care maintenance, monitoring and management are seen as three key-concepts of the self-care process.⁹ Self-care maintenance refers to behaviours used by patients with CF to maintain physical and emotional stable. With self-care monitoring, patients monitor their signs and symptoms to early detect health change. Self-care management is the response to this health change. Patients with CF have to be actively involved in self-care, because day-to-day care is performed by the patient and family caregivers themselves for an estimated 99%.¹² Supporting and empowering patients with CF in performing self-care, not only prevents exacerbations, but also improves well-being and decreases morbidity and mortality.^{9,12}

Despite the relationship between good self-care and positive health outcomes, many patients find it difficult to perform self-care.^{9,11} Patients could be struggling with performing self-care, when adversities or difficult experiences interfere with the ability to perform self-

care.¹² Adult patients with CF are faced with increasingly complex adversities and difficult experiences, that go together with growing older with CF. For example, patients are faced with acceleration in lung function decline, a higher frequency of exacerbations and hospitalizations, disease disclosure to others and reproductive health concerns.¹³ Patients with CF might need resilience to recover and 'bounce back' from these adversities and difficult experiences, in order to perform self-care. In this context, resilience can therefore be seen as the process of adapting well when adversities or difficult experiences interfere with the ability to perform self-care.¹³

The daily need to cope with CF and its adversities, might result in a strong sense of resilience among patients¹⁴, but the association with self-care is unknown. Mitmansgruber et al.¹⁴ suggests that resilience and intolerance of uncertainty are associated with Quality of Life (QoL), but did not study the association with self-care. In another study, resilience moderated the effects of depressive symptoms through self-care confidence on self-care maintenance. However, the sample consisted of patients with Heart Failure.¹⁵

To understand the self-care process and to deepen the theoretical understanding of the self-care concept, it is important to understand which factors and underlying mechanisms influence self-care behaviours and eventually lead to better self-care.¹² The hypothesis is that higher levels of resilience, lead to better self-care.

Aim/Research question

The aim of this study is to explore the association between resilience and self-care in patients with CF, aged 18 years or older.

Method

Design

To study the association between resilience and self-care, a quantitative, cross-sectional study design was used with questionnaires. The cross-sectional design was suited because the relationship among two phenomena was described at a fixed point in time.¹⁶ Inclusion of patients was planned from January 2020 until May 2020. Due to the SARS-CoV-2 pandemic, inclusion ended in March.

Population and domain

This study was conducted in the Netherlands, at the outpatient clinic of a tertiary (University) hospital. The population base of this study consisted of patients with a diagnosis of CF and 18 years of age or older. The study population consisted of patients who are under specialist respiratory care at the hospital. The sample of patients consisted of patients who attended the outpatient clinic of the studied hospital for a control visit with their lung (nurse) specialist between January 2020 – March 2020. Three nurse specialists and three lung

specialists, specialised in CF care, work at the in- and outpatient clinic of the hospital. Control visits took place digitally in March.

To be eligible to participate, patients had to be able to speak and read the Dutch language and mentally and physically able to complete the questionnaires. Patients were not excluded based on other co-morbidities. However, patients living in a nursing facility, participating in other non-medical studies and patients after lung transplantation or who were on the waiting list were excluded.

Because the estimated effect size could not be drawn from earlier research, the sample size was calculated with the common rule of thumb, which states that for each determinant at least ten participants must be included.^{16,17}

Procedures

The lung (nurse) specialists assessed whether the patient was eligible to participate during the control visit. If so, the specialist asked if the patient agreed to be approached by the researcher. In January and February, patients were seen at the outpatient clinic, in March via telephone. Study information was provided verbally and on paper by the researcher to all patients who were willing to participate and patients were able to ask potential questions. After providing written informed consent (IC), the participating patients completed the questionnaires. It took approximately 20-25 minutes to fill in the questionnaires. Patients could fill in the questionnaires on site or at home.

Data collection

Data on self-care, resilience and demographic variables were collected with the use of questionnaires. Self-care was considered to be the dependent variable and was measured by the Self-Care of Chronic Illness Inventory (SC-CII), which measures self-care behaviours.¹⁰ The SC-CII is designed to capture the process of self-care within four subscales: maintenance (eight items), monitoring (five items), management (eight items and only for patients with symptoms) and confidence (ten items). Self-care confidence is not a part of the self-care process per se. However, it is an extremely important factor influencing the effectiveness of self-care. Therefore, this subscale is included in the questionnaire.¹⁸ Self-care management scores are only appropriate in persons who experience symptoms, because patients cannot manage their symptoms if the symptoms are not recognised.^{10,18} Except for two items, all items were rated on a 5-point ordinal scale and answers varied within the subscales. Scores are standardized within each subscale and higher standardised scores, indicate better self-care. Scores of 70 or greater considered adequate self-care.¹⁹ Content validity of the English version of the SC-CII was high. The reliability coefficient for the subscales 'monitoring' and 'management' were adequate.¹⁰ With the use of forward-backward translation, the SC-CII was translated from English in Dutch.

Resilience was considered to be the independent variable and was measured with the Resilience Evaluation Scale (RES).²⁰ The RES is developed in Dutch and operationalises psychological resilience. It is a 9-item questionnaire consisting of two underlying constructs of psychological resilience: self-efficacy (six items) and self-confidence (three items). All answers on the items vary within a 5-point range, from completely disagree (0) to completely agree (4). Higher scores indicated greater psychological resilience. The RES showed good convergent validity and internal consistency in English and Dutch language groups (with the exception of the subscale self-efficacy in the Dutch language group, who scored 'acceptable' for internal consistency).²⁰

Baseline characteristics retrieved from the medical record included age, gender, lung function as percentage predicted Forced Expiratory Volume in one second (ppFEV₁) and Cystic Fibrosis Related Diabetes (CFRD). Marital status, highest level of education completed, time per day consumed by the treatment and level of depression were asked in the questionnaire. Depression was measured by the Patient Health Questionnaire-2 (PHQ-2), which is a screening tool that asked the frequency of the symptoms of depressed mood and anhedonia.²¹ Scores range from 0 (not at all) to 3 (nearly every day). The PHQ-2 showed a sensitivity of .86 and a specificity of .78.²¹ A score of 3 was considered the optimal cut off point for screening purposes, where scores of 3 or higher indicated a positive screening for any depressive disorder.²²

Data analysis

Multiple regression analyses was used to quantify the association between resilience and all self-care behaviours (maintenance, monitoring and management).¹⁰

First, descriptive statistics were used to present patient's background and medical characteristics. Patient's background and medical characteristics consisted of gender, age (in years), ppFEV₁%, CFRD, education level (low, medium, high, other), marital status (married/cohabiting, divorced/widowed, living with parents, living alone, other), time per day consumed by the treatment (in minutes) and screening for depression (PHQ-2 of ≤ 2 or ≥ 3). Continuous variables were presented as mean, standard deviation and range. Categorical variables were presented as frequencies and percentages. For the RES and SC-CII mean, standard deviation, and range were calculated. Multiple Imputation (MI) was used to generate possible values for missing values. The pooled results generated by MI are generally more accurate than those provided by single imputation methods.²³ MI was only used for the RES, since the analysis of the SC-CII takes missing data into account.¹⁰ When a participant did not return the questionnaire but did sign the Informed Consent (IC), baseline characteristics retrieved from the medical record were used. MI was not applied in the case of non-returned questionnaires.

Second, possible confounders which could influence the association between resilience and self-care were identified by the research group. The predetermined possible confounders were age, gender, education level, marital status, ppFEV₁ and depression.

Finally, three regression models were built within each self-care behaviour, with the use of univariate and multiple regression, which allowed correcting for possible confounders. Building the regression models was predetermined by the research group and with the use of the 'Enter method', because this makes more sense biologically.²⁴ A crude model was first developed with the dependent variable self-care (each subscale separately) and independent variable resilience (model 1) with the use of univariate regression analysis. In the second model, the variables were corrected for the (possible) confounders age and gender (model 2). The third model (model 3) was additionally adjusted for ppFEV₁, education level, marital status and depression. Multiple regression analysis was used in model 2 and 3. All regression models presented the adjusted R-squared (R^2), the standardized beta (β), the 95% Confidence Interval (CI) and the p-values. A p-value of $\leq .05$ was considered to be statistically significant. The aim was to include at least 80 participants, because all variables together consisted of eight variables. Conditions for multiple regression were analysed with the help of a histogram, PP-Plot, QQ-Plot, and a scatterplot.^{24,25}

Data was analysed using the IBM Statistical Package for Social Sciences (SPSS) software (version 25).²⁶

Ethical issues

This study is conducted according to the principles of the Declaration of Helsinki (version 59, October 2008). In accordance with the Medical Research Involving Human Subjects Act (WMO), this study was reviewed by the Medical Ethical Committee (METC) and was not considered to fall within the scope of the WMO. The laws and regulations of the General Data Protection Regulation and the Medical Treatment Agreement Act were followed. All participants provided written informed consent.

Results

Participants

The sample of this study consisted of 63 patients. A total of six patients were excluded based on not being able to complete the questionnaire ($n = 5$) or not speaking or reading the Dutch language ($n = 1$). Of the remaining 57 patients who were eligible for inclusion, two patients declined participation and three patients were not asked by the lung (nurse) specialist for no reason. The reasons for refusing were lack of time ($n = 1$) or just receiving a bad news conversation ($n = 1$). Of the final sample of 52 participants, who were approached by the researcher, 46 participants signed the IC and 41 participants additionally returned the questionnaire. One participant only filled in the SC-CII, this questionnaire was excluded in

the data analysis. Due to SARS-CoV-2, the planned inclusion of at least 80 participants was not obtained. However, full data analysis was performed.

Demographic data

Sample characteristics are presented in Table 1. The mean age was 29 years (range 18-56 years) and 27 of the participants were female (58.7%). The mean ppFEV₁ of the participants was 66.59% and 16 participants (34.8%) had CFRD. The average education level of participants was medium (43.5%) or high (32.6). More than one third of the patients was married or cohabited (43.8%) or living with parents (28.3%). Participants spent a mean of 73 minutes per day on the treatment of CF. The PHQ-2 indicates that 5 participants screened positive for depression.

Insert Table 1.

The means, standard deviations, ranges and reference ranges of resilience, self-care and depression are presented in Table 2. The mean score on the RES was 27.50 (range: 20-36, reference range 0-36). MI was used for the missing data of 5.0% for the RES. Patients had inadequate scores on all self-care subscales of the self-care behaviours (scores < 70). Patients had an adequate self-care score on the subscale self-care confidence (74.19, SD 12.59).

Insert Table 2.

Regression analyses

Categorical variables with more than two categories (education level and marital status), were recoded into dummy variables. The categories 'medium education level' and 'married/cohabiting' were designated as reference categories, since the categories that represent the majority of people, usually represent the reference category.²⁷ For the categorical variable gender, the category 'female' represented the reference category.

Assumptions for multiple regression were checked for.^{24,27} Self-care maintenance and self-care monitoring met the assumptions. However, self-care management deviated significantly from normal ($D(38) = .17, p = .01$). Untransformed data was used in the analysis because comparison between the self-care categories is more difficult when one category is transformed.

Self-care maintenance.

As shown in Table 3, univariate analysis indicates that resilience was not significantly associated with self-care maintenance, also when the model was corrected for the confounders age and gender (model 2) and the determinants education, marital status, ppFEV₁ and PHQ-2 (model 3) with multiple regression analysis. Only age ($\beta = .35$) and gender ($\beta = -.30$) were significantly associated with self-care maintenance in model 2 ($p \leq .05$). In the third model, only the education category 'low' was significantly associated with self-care maintenance ($\beta = .63, p = .001$). This indicates that patients with a lower

educational level had better self-care maintenance. The adjusted R-squared increased from -.02 in model 1, to .19 in model 2 and eventually to .29 in model 3, which indicates that 29% of the variation of self-care maintenance is explained by the included variables. CI's were high in the second and third model in most of the variables.

Insert Table 3.

Self-care monitoring.

As shown in Table 4, univariate analysis indicates that resilience was not significantly associated with self-care monitoring, also when the model was corrected for the confounders age and gender (model 2) and the determinants education, marital status, ppFEV₁ and PHQ-2 (model 3) with multiple regression analysis. Only gender was significantly associated with self-care monitoring in model 2 ($\beta = -.47, p \leq .01$) and model 3 ($\beta = -.54, p \leq .01$). In model 3, the PHQ-2 was also significantly associated with self-care monitoring ($\beta = .36, p \leq .05$). This indicates that patients with a negative screening for depression had better self-care monitoring. The adjusted R-squared increased from -.03 in model 1, to .17 in model 2 and eventually to .29 in model 3, which indicates that 29% of the variation in self-care monitoring is explained by the included variables. CI's were high in the second and third model in most of the variables.

Insert Table 4.

Self-care management.

As shown in Table 5, univariate analysis indicates that resilience was not significantly associated with self-care management, also when the model was corrected for the confounders age and gender (model 2) and the determinants education, marital status, ppFEV₁ and PHQ-2 (model 3) with multiple regression analysis. Only gender was significantly associated with self-care management in model 2 ($\beta = -.35, p \leq .05$). The adjusted R-squared increased from -.00 in model 1, to .17 in model 2, and eventually decreased to .13 in model 3. This indicates that the variables in model 2 explained more of the variation in self-care management, than the variables in model 3. CI's were high in the second and third model in most of the variables.

Insert Table 5.

Discussion

To our knowledge, this is the first study which explored the association between resilience and self-care in patients with CF. The findings of our study suggest that there is no association between resilience and the self-care behaviours: maintenance, monitoring and management. Resilience alone does little, if any to explain the the variation in self-care. Gender is negatively associated with all self-care behaviours in all three models, where four out of six associations are statistically significant. This indicates that male patients have

lower levels of self-care behaviours. To our knowledge, gender differences in self-care in patients with CF have not been researched before. This finding, together with the findings of the positive association between 'low education level' and 'negative screening for depression' with self-care maintenance and monitoring respectively, contribute to the understanding which factors and underlying mechanisms influence self-care behaviours and lead to better self-care.

In concordance with a study in German patients with CF¹⁴, we measured elevated levels of resilience in our study sample. The total resilience and resilience subscale scores are slightly higher compared to the general healthy Dutch population, with a difference of 1.74 on the total RES score, .73 on self-confidence, and 1.01 on self-efficacy scores.²⁰ The daily need to cope with adversities which come with CF, might result in a strong sense of resilience. In contrast, all self-care behaviours were inadequate in our study sample (< 70). It is possible that during transition to adult health care, not all self-care behaviours are mastered by adults.^{28,29} The finding in this study that females have higher levels of self-care behaviours, is in accordance with studies in patients with Chronic Hepatitis B and patients with Diabetes type II, where females performed better self-care activities.^{30,31} Other studies suggest that gender was not related to self-care activities.^{32,33} However, these studies were conducted with participants from China and not always researched self-care behaviours, but self-care activities. The finding in our study that lower educational levels are associated with better self-care behaviours, could not be confirmed with other studies. Higher educational levels lead to better self-care activities in patients with Chronic Hepatitis B, Diabetes type II and patients with Chronic Heart Failure.^{30,34–36} Despite the fact that in the current study no association was found between resilience and self-care, resilience could be associated with other (mental health) outcomes, like QoL.¹⁴ There is also a possibility that other confounders in the multiple regression analysis, yield different results. Other possible confounders could be symptom severity or self-care confidence.^{15,36}

This study has several limitations that have to be kept in mind when interpreting the results. First, it is possible that SARS-CoV-2 had an influence on outcomes, for example the question 'How often or routinely do you see your healthcare provider for routine health care?' could be interpreted differently, because the outpatients clinic closed in the course of the study. Second, the SC-CII was not validated in Dutch. Results of this study could be used for a validation study. It is also the first time that the SC-CII is used in patients with CF. It could be possible that the questionnaire has to be altered for this specific group of patients, because questions could not always be interpreted the right way. For example, the question 'How often do you eat a special diet?' was most of the time answered with 'never', while achieving or maintaining a good nutritional status may be a challenge for patients with CF due to increased energy need and nutrient losses.³⁷ Third, the estimated sample size of 80

participants could not be obtained, which could explain wide CI's. Also, the self-care management scale deviated significantly from normal, so results should be interpreted cautiously. However, it could be argued that in samples with more than 30 participants, normality tests can be significant even for small and unimportant effects.²⁷

The strength of the study is the multiple regression analysis, where different models were built and resilience was corrected for different confounders. Second, the sample in our study is drawn from the largest CF Clinic in the Netherlands, which makes the sample more generalizable. Third, although causal relationships could not be described, the cross-sectional study design fits the research question. Our study could be seen as a first step in unraveling the processes of the association between resilience and self-care in patients with CF.

Implications.

Little is known about how resilience is associated with and influences self-care in chronically ill populations. This research is a start in identifying how resilience and self-care are associated. Future research should include larger samples and different populations. Resilience could also be a moderator between determinants and self-care¹⁵, so different pathways and corresponding analysis should be used in future research. It could also be possible that self-confidence, which is not a self-care behaviour, could influence outcomes of self-care. Finally, it is possible that the association works the other way around, in which self-care influences resilience. Complementary, fragmented activity and lack of continuity in self-care research should be prevented and the concept of self-care and its definition should be clearly defined in research.

Conclusion

The results of this study indicate that in patients with CF, resilience is not associated with self-care maintenance, self-care monitoring and self-care management. Our hypothesis that better resilience leads to better self-care, could not be confirmed with this study. However, this is the first study that shed some light on the processes of the association between resilience and self-care in patients with CF. Further research with larger samples and different chronically ill patient groups is needed in identifying how and if resilience and self-care are associated, how these processes work and if resilience could be a moderator.

Reference list

1. Calvo-Lerma J, Martínez-Jiménez C, Lázaro-Ramos J, Andrés Grau A, Crespo-Escobar P, Stav E, et al. An innovative approach for the self-management of cystic fibrosis patients in Europe: Development, validation and implementation of a new ehealth tool: The MyCyFAPP project. *J Pediatr Gastroenterol Nutr.* 2016;63:270.
2. Eckman MH, Kopras EJ, Montag-Leifling K, Kirby LP, Burns L, Indihar VM, et al. Shared Decision-Making Tool for Self-Management of Home Therapies for Patients With Cystic Fibrosis. *MDM policy Pract.* 2017;2(1).
3. Esmond G, Butler M, McCormack A. Comparison of hospital and home intravenous antibiotic therapy in adults with cystic fibrosis. *J Clin Nurs.* 2006;15(1):52–60.
4. Stark LJ. Can nutrition counselling be more behavioural? Lessons learned from dietary management of cystic fibrosis. *Proc Nutr Soc.* 2003;62(4):793–9.
5. Prevention Centers for Disease And Control. Facts about cystic fibrosis [Internet]. 1995 [cited 2019 Mar 25]; Available from: [http://www.cdc.gov/excite/ScienceAmbassador/ambassador_pgm/%0Alessonplans/high_school/Am I a Carrier for Cystic Fibrosis/%0ACystic_Fibrosis_Fact_Sheet.pdf](http://www.cdc.gov/excite/ScienceAmbassador/ambassador_pgm/%0Alessonplans/high_school/Am%20I%20a%20Carrier%20for%20Cystic%20Fibrosis/%0ACystic_Fibrosis_Fact_Sheet.pdf)
6. Sawicki GS, Tiddens H. Managing treatment complexity in cystic fibrosis: challenges and opportunities. *Pediatr Pulmonol.* 2012;47(6):523–33.
7. Greenop D, Glenn S, Ledson M, Walshaw M. Self-care and cystic fibrosis: a review of research with adults. *Health Soc Care Community.* 2010;18(6):653–61.
8. Parcel GS, Swank PR, Mariotto MJ, Bartholomew LK, Czyzewski DI, Sockrider MM, et al. Self-management of cystic fibrosis: a structural model for educational and behavioral variables. *Soc Sci Med.* 1994;38(9):1307–15.
9. Riegel B, Jaarsma T, Strömberg A. A middle-range theory of self-care of chronic illness. *ANS Adv Nurs Sci.* 2012;35(3):194–204.
10. Riegel B, Barbaranelli C, Sethares K, Daus M, Moser D, Miller J, et al. Development and initial testing of the self-care of chronic illness inventory. *J Adv Nurs.* 74(10):2465–76.
11. Jaarsma T, Cameron J, Riegel B, Stromberg A. Factors Related to Self-Care in Heart Failure Patients According to the Middle-Range Theory of Self-Care of Chronic Illness: a Literature Update. *Curr Hear Fail Rep.* 2017;14(2):71–7.
12. Riegel B, Dunbar S, Fitzsimons D, Freedland K, Lee C, Middleton S, et al. Self-care research: Where are we now? Where are we going? *Int J Nurs Stud.* 2019 Aug 23;103402. doi: 10.1016/j.ijnurstu.2019.103402.
13. Muther E, Polineni D, Sawicki G. Overcoming psychosocial challenges in cystic fibrosis: Promoting resilience. *Pediatr Pulmonol.* 53(3):86–92.
14. Mitmansgruber H, Smrekar U, Rabanser B, Beck T, Eder J, Ellemunter H.

- Psychological resilience and intolerance of uncertainty in coping with cystic fibrosis. *J Cyst Fibros*. 2016 Sep;15(5):689–95.
15. Chang L, Wu S, Chiang C, Tsai P. Depression and self-care maintenance in patients with heart failure: A moderated mediation model of self-care confidence and resilience. *Eur J Cardiovasc Nurs*. 2017 Jun;16(5):435–43.
 16. Polit D, Beck C. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th ed. Philadelphia: Wolters Kluwer; 2017.
 17. Maxwell S. Sample size and multiple regression analysis. *Psychol Methods*. 2000;5(4):434–58.
 18. Riegel B, Lee C, Dickson V, Carlson B. An Update on the Self-Care of Heart Failure Index. *J Cardiovasc Nurs*. 2009 Nov-Dec;24(6):485–97.
 19. Davis K, Himmelfarb C, Szanton S, Hayat M, Allen J. Predictors of heart failure self-care in patients who screened positive for mild cognitive impairment. *J Cardiovasc Nurs*. 2015 Mar-Apr;30(2):152–60.
 20. Meer C van der, Brake H te, Aa N van der, Dashtgard P, Bakker A, Olf M. Assessing Psychological Resilience: Development and Psychometric Properties of the English and Dutch Version of the Resilience Evaluation Scale (RES). *Front Psychiatry*. 2018;9:169.
 21. Arroll B, Goodyear-Smith F, Crengle S, Gunn J, Kerse N, Fishman T, et al. Validation of PHQ-2 and PHQ-9 to screen for major depression in the primary care population. *Ann Fam Med*. 2010;8(4):348–53.
 22. Kroenke K, Spitzer R, Williams J. The Patient Health Questionnaire-2: validity of a two-item depression screener. *Med Care*. 41(11):1284–92.
 23. IBM. IBM SPSS Missing Values 25 [Internet]. [cited 2020 Apr 24]; Available from: [file:///C:/Users/Aniekkamphuis/Downloads/IBM_SPSS_Missing_Values \(1\).pdf](file:///C:/Users/Aniekkamphuis/Downloads/IBM_SPSS_Missing_Values%20(1).pdf)
 24. Baldi N, Moore D. *The Practice of Statistics in the Life Sciences*. 3th ed. New York: W.H. Freeman and Company; 2014.
 25. Vocht A de. *Basishandboek SPSS 24, IBM SPSS Statistics*. 1st ed. Utrecht: Bijleveld Press; 2016.
 26. Corp I. *IBM SPSS Statistics for Windows, Version 25.0*. 2017;
 27. Field A. *Discovering Statistics using IBM SPSS Statistics*. 4th ed. London: SAGE Publications Ltd; 2013.
 28. Beacham B, Deatrick J. Health care autonomy in children with chronic conditions: implications for self-care and family management. *Nurs Clin North Am*. 2013 Feb;48(2):305–17.
 29. Lewis K, John B, Condren M, Carter S. Evaluation of Medication-related Self-care Skills in Patients With Cystic Fibrosis. *J Pediatr Pharmacol Ther*. 2016 Nov-Dec;

- 21(6):502–11.
30. Kong L, He S, Li L, Lei Q, Wang T, Yao Y. Factors for self-management activities among rural patients with chronic hepatitis B: A cross-sectional study. *J Clin Nurs* 2019 Sep;28(21–22):3949–56.
 31. Eh K, McGill M, Wong J, Krass I. Cultural issues and other factors that affect self-management of Type 2 Diabetes Mellitus (T2D) by Chinese immigrants in Australia. *Diabetes Res Clin Pr*. 2016 Jul;119:97–105.
 32. Huang M, Zhao R, Li S, Jiang X. Self-management Behavior in Patients With Type 2 Diabetes: A Cross-Sectional Survey in Western Urban China. *PLoS One*. 2014;9(4):e95138.
 33. Yang L, Wu Q, Hao Y, Cui Y, Liang L, Gao L, et al. Self-management behavior among patients with diabetic retinopathy in the community: A structural equation model. *Qual Life Res*. 2016 Sep;26(2):359–66.
 34. Jiang X, Jiang H, Li M, Lu Y, Liu K, Sun X. The Mediating Role of Self-Efficacy in Shaping Self-Management Behaviors Among Adults With Type 2 Diabetes. *Worldviews Evid Based Nurs*. 2019;16(2):151–60.
 35. Bukhsh A, Khan T, Nawaz M, Ahmed H, Chan K, Lee L, et al. Association of diabetes-related self-care activities with glycemic control of patients with type 2 diabetes in Pakistan. *Patient Prefer Adherence*. 2018 Nov;12:2377–85.
 36. Rockwell J, Riegel B. Predictors of self-care in persons with heart failure. *Hear Lung*. 2001 Jan-Feb;30(1):18–25.
 37. Hollander-Kraaijeveld F, van Lanen A, de Roos N, van de Graaf E, Heijerman H. Resting Energy Expenditure in Cystic Fibrosis Patients Decreases After Lung Transplantation, Which Improves Applicability of Prediction Equations for Energy Requirement. *J Cyst Fibros*. S1569-1993(20)30092-8.

Tables

Table 1:

Patient characteristics

Variables	Total sample
	Inclusion, <i>n</i> = 46
Gender	
Female	27 (58.7%)
Male	19 (41.3%)
Age, years	
Mean (SD)	29.46 (10.66)
Range	18-56
Lung function	
ppFEV ₁	66.59 (20.84)
Range	14.00-111.00
Cystic Fibrosis Related Diabetes	
Yes <i>n</i> (%)	16 (34.8%)
No <i>n</i> (%)	30 (65.2%)
Education level^a	(<i>n</i> = 40)
Low	3 (6.5%)*
Medium	20 (43.5%)*
High	15 (32.6%)*
Other	2 (4.3%)*
Marital status	(<i>n</i> = 40)
Married/cohabiting	16 (43.8%)*
Divorced/widowed	1 (2.2%)*
Living with parents	13 (28.3%)*
Living alone	7 (15.2%)*
Other	3 (6.5%)*
Time per day consumed by the	(<i>n</i> = 40)

treatment (in minutes)	
Mean (SD)	73.25 (78.16)
Range	0-360
PHQ-2	(<i>n</i> = 40)
≤ 2 Negative screening for depression	35 (76.1%)*
≥ 3 Positive screening for depression	5 (10.9%)*

^a Categories are based on the International Standard Classification of Education (ISCED)

* Percentage (not valid percentage).

Table 2:

Means, standard deviations, range and reference range (Ref Range) of Resilience (RES), Self-care (SC-CII) and Patient Health Questionnaire-2 (PHQ-2)

Variables	Total sample		
	Inclusion, <i>n</i> = 44		
	Mean (SD)	Range	Ref Range
RES (<i>n</i> = 40)	27.63 (4.52) ^a 27.50 (4.47) ^b	20-36	0-36
Self Confidence (<i>n</i> = 40)	9.2 (1.99)	3-12	0-12
Self Efficacy (<i>n</i> = 40)	18.47 (3.31) ^a 18.30 (3.35) ^b	13-24	0-24
SC-CII			
Self-care Maintenance (<i>n</i> = 40)	66.48 (13.96)	37.50-93.75	0-100
Self-care monitoring (<i>n</i> = 40)	64.38 (22.42)	15.00-100.00	0-100
Self-care Management:			
- Without symptoms (<i>n</i> = 2)	54.17 (5.89)	50.00-58.34	0-100
- With symptoms (<i>n</i> = 38)	61.46 (17.65)	14.28-89.28	0-100
Self-care Confidence (<i>n</i> = 40)	74.19 (12.59)	35.00-92.50	0-100
PHQ-2 (<i>n</i> = 40)	1.08 (1.16)	.00-4.00	0-6

^a Without Multiple Imputation.

^b With Multiple Imputation.

Table 3:

Regression model of resilience (RES) and the dependent variable self-care maintenance (n = 40).

	Model 1 (Block 1)			Model 2 (Block 1, 2)			Model 3 (Block 1, 2 3)		
	R ^{2a}	β ^b	95% CI	R ^{2a}	β ^b	95% CI	R ^{2a}	β ^b	95% CI
Block 1	-.015			.19			.29		
RES		-.10	-1.34-.70		-.16	-1.55-.46		.14	-.94-1.80
Block 2									
Age					.35*	.05-.83		.24	-.24-.85
Gender					-.30*	-16.74--.04		-.32	-18.00-.44
Block 3									
Education Low								.63**	13.04-53.73
Education High								.11	-8.39-14.44
Education Other								.02	-19.06-21.85
Divorced/Widowed								-.32	-65.30-3.27
Living with parents								-.25	-22.46-7.67
Living alone								-.07	-16.18-11.16
Living other								-.14	-25.87-11.21
ppFEV ₁								.10	-.173-.309
PHQ-2								.23	-1.18-6.75

^aAdjusted R²

^bStandardized Coefficient

*p ≤ .05

**p ≤ .01

Table 4:

Regression model of resilience (RES) and the dependent variable self-care monitoring (n = 40).

	Model 1 (Block 1)			Model 2 (Block 1, 2)			Model 3 (Block 1, 2 3)		
	R ^{2a}	β ^b	95% CI	R ^{2a}	β ^b	95% CI	R ^{2a}	β ^b	95% CI
Block 1	-.03			.17			.29		
RES		-.03	-1.79-1.51		.00	-1.53-1.57		.18	-1.30-3.08
Block 2									
Age					.06	-.51-.75		.09	-.69-1.06
Gender					-.47**	-34.59--7.50		-.54**	-38.72--9.18
Block 3									
Education Low								.04	-29.61-35.57
Education High								-.19	-27.15-9.41
Education Other								-.04	-36.71-28.84

Divorced/Widowed			-0.24	-90.59-23.01
Living with parents			.07	-20.81-27.47
Living alone			-.04	-24.27-19.54
Living other			.01	-28.98-30.43
ppFEV ₁			-.14	-.53-.24
PHQ-2			.36*	.68-13.37

^aAdjusted R²

^bStandardized Coefficient

*p ≤ .05

**p ≤ .01

Table 5:

Regression model of resilience (RES) and the dependent variable self-care management for patients with symptoms (n = 38)

	Model 1 (Block 1)			Model 2 (Block 1, 2)			Model 3 (Block 1, 2 3)		
	R ^{2a}	β ^b	95% CI	R ^{2a}	β ^b	95% CI	R ^{2a}	β ^b	95% CI
Block 1	-.00			.17			.13		
RES		-.15	-1.96-.72		-.23	-2.19-.37		-.29	-3.10-.80
Block 2									
Age					.23	-.07-.93		.15	-.55-1.01
Gender					-.35*	-23.26--1.47		-.32	-24.17-1.79
Block 3									
Education Low								.12	-20.58-36.34
Education High								.15	-11.37-21.87
Education Other								-.20	-44.61-13.71
Divorced/Widowed								-.11	-61.66-38.34
Living with parents								-.06	-23.83-19.10
Living alone								-.17	-27.56-11.63
Living other								.01	-25.59-26.55
ppFEV ₁								-.28	-.576-.10
PHQ-2								.02	-5.26-5.97

^aAdjusted R²

^bStandardized Coefficient

*p ≤ .05