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The effects of resilience on temporal satisfaction with life in parents of children with cystic fibrosis – the role of posttraumatic growth

Resilience a temporalna satysfakcja z życia u rodziców dzieci z mukowiscydozą – rola potraumatycznego wzrostu

Abstract: The purpose of this study was to examine the correlation between resilience and temporal satisfaction with life and the mediation effects of posttraumatic growth (PTG) in parents of children with cystic fibrosis (CF). CF is a rare, life-limiting, severe, and burdensome disease. Most studies reveal increasing rates of psychopathology in parents of children with CF. Still, parents of severely ill children may also experience satisfaction with their life despite the adversities. Although resilience is considered a protective factor promoting high levels of life satisfaction, so far neither the nature of mutual relations between these variables in parents of children with CF nor the mediating role of PTG on it have been examined. The cross-sectional study was conducted in a group of 172 parents of children with CF. The average age of the child with CF was 8.13 ($SD = 4.40$). The research method was a diagnostic survey. The current analyses confirmed an indirect correlation between trait resilience and temporal satisfaction with life via PTG. Changes

in self-perception and Changes in relations to others were particularly important mediators of the relationships between resilience and both present and future satisfaction with life. Resilience correlates with temporal satisfaction with life in the presence of a mediator: PTG and its three dimensions: Changes in self-perception, Changes in relations to others, and Appreciation of life. Therapeutic programs for parents of children with CF may include strengthening resilience and PTG interventions to support satisfaction with life, with particular emphasis on the time perspective.

Keywords: cystic fibrosis, resilience, parents, posttraumatic growth, temporal satisfaction with life.

Introduction

Cystic fibrosis (CF) is the most common autosomal recessive disease that affects over 70 000 people in the United States and Europe (DeBoeck, 2020; Yan et al., 2019). Its qualification as a rare disease implies the need to manage specific challenges while planning multi-targeted research and organizing multi-specialistic diagnosis and therapy processes (Austin et al., 2017). In the case of pediatric patients with CF, the main family members involved in fulfilling complex treatment procedures and responsible for children's well-being are the parents (Fitzgerald and George, 2018).

Caring for a child with CF can be an extremely stressful experience due to the life-limiting character of the illness, its multiple, burdensome, and concealable symptoms, and the therapeutic regime based mainly on everyday several hours of chest physiotherapy, the supply of pancreatic enzymes, the diet, and the treatment of disorders in other systems (Oliver, Free, et al., 2014). According to Davies, Rowbotham, Smith, et al. (2020) patients with CF may undergo six to fifteen treatment procedures. A systematic review based on 72 empirical studies on caregiver burden revealed that the greatest burden resulting from treating children with CF is experienced by parents of younger children (0-9 years old) compared to the caregivers of adolescents and adults (Daly, Ruane O'Reilly, Longworth and Vega-Hernandez, 2022). Parents of children with CF may feel burdened with the awareness that they are carrying a damaged gene and they can be exhausted by the struggle to access highly specialized medical care dedicated to patients with rare diseases especially if they live in Eastern European countries (Walicka-Serzysko, Peckova, Noordhoek, Sands and Drevinek, 2018).

Many researchers confirm the occurrence of adaptive disorders in parents of children with cystic fibrosis (Abbott, et al 2019; Besier, Born, et al.,

2011; Neri, Lucidi, et al., 2016; Quittner, Goldbeck, et al., 2014). There are also reports of a good adaptation and well-being of the mentioned population in comparison with the parents of children with other chronic diseases and parents of healthy children (Foster, et al., 1998; Herzer, et al., 2010; Thompson, Gustafson, Hamlett, et al., 1992).

One of the consistent components of subjective well-being is life satisfaction (Pavot and Diener, 2008). It is defined as a judgmental process that helps individuals to assess the quality of their life based on their own unique set of criteria (Pavot and Diener, 1993). The cognitive processes involved in formulating life satisfaction judgments may be understood in two ways. First, it is vertically evaluated considering all one's life aspects right now, and second, it is temporally summed assessing one's whole life (Pavot and Diener, 2008). According to Pavot et al. (1998), the temporal perspective allows a more extensive examination of the present, past, and future levels of global life satisfaction. The temporal life satisfaction construct has not been empirically verified yet in the group of parents of children with CF. However, Besier et al. (2011) reported significantly less general and health-related life satisfaction in these parents compared to the general population. Analyzing satisfaction with life among parents of children with CF using three temporal perspectives seems reasonable because of the dynamic course of the illness and its negative prognosis.

Life satisfaction was found to be correlated with a vast array of positive personal, psychological, social, interpersonal, and intrapersonal outcomes (Liu, Wang et al. 2012) and resilience is one of its protective factors (Martinez-Marti and Ruch 2017). Resilience has been conceptualized in several ways (Rutter, 2003), mainly as: a trait that makes a person able to "bounce back" from traumatic events, a process of positive adaptation, and an outcome (Rosenberg et al. 2013). Trait resilience can be defined as a stable personality characteristic that involves the ability to recover from both negative life events and minor everyday stressors (Genet and Siemer, 2011).

Caring for critically ill children may be perceived as an extremely stressful experience and, thus, conceptualized as posttraumatic stress (Bronner et al., 2007). However, seeking positive characteristics of parental functioning (such as resilience) may be significant for strengthening personal resources and, thus, for buffering the negative influence of the child's illness on family life. The studies on resilience in parents of children with severe health problems proved the existence of fewer resilience resources than in the general population (Rosenberg et al., 2014a), negative correlations between resilience and psychological distress (Rosenberg et al., 2014b), and depression

and anxiety (Edraki and Rambod 2018; Rothschild et al., 2020). A few studies on resilience among adolescents and young adults were conducted in the CF population (Mitmansgruber et al., 2016, Toprak et al., 2020), whereas scientific works related to parental resilience are scarce (Byra et al., 2021). Theoretical reviews (Muthé et al., 2018; Prieur et al., 2021) and European Cystic Fibrosis Society documents (Castellani et al., 2018), equally emphasize the importance of promoting resilience and emotional wellness in therapeutic practice both in CF patients and their parents.

Another positive phenomenon that may be experienced by individuals as a consequence of traumatic events that concerns both cognitive and affective processes is posttraumatic growth (PTG). The term PTG defined by Tedeschi and Calhoun refers to the positive psychological change experienced as a result of the struggle with highly challenging life circumstances (Tedeschi and Calhoun, 2004). Despite the similarity to resilience, the construct of post-traumatic growth has qualities of transformation, or a change of functioning (Tedeschi and Calhoun, 2004), whereas resilience, interpreted as a trait, is stable. Well-documented studies conducted in populations of children affected by a severe chronic illness and their parents (Picoraro et al., 2014; Rodriguez-Rey and Alonso-Tapia, 2019; Siden and Steele, 2015; Stephenson et al., 2017) proved the existence of PTG processes in the examined groups.

Previous studies have shown a positive relationship between PTG and resilience in various groups, including fathers of children with disabilities (Byra and Ćwirynkała, 2022) and mothers of children with cancer (Rosenberg et al., 2014b). A longitudinal study conducted by Rodriguez-Rey and Alonso-Tapia (2019) in a group of parents of critically ill children revealed a significant indirect effect of resilience on PTG (through the bias of positive emotions) in mothers and parents, although the direct relations between both variables were not stated. So far the nature of the correlations between resilience and PTG has not been established because of the differences in interpreting resilience (Rodriguez-Rey and Alonso-Tapia, 2019).

The aim of our study was to verify the correlation between resilience and temporal satisfaction with life and the mediation effects of posttraumatic growth in parents of children with cystic fibrosis. We wondered if the result of active transformation achieved after the parent has coped with adversity might be a factor strengthening the correlation between their stable positive characteristic of resilience and well-being perceived in different time perspectives. We expected that the dynamic and unpredictable character of CF and caregiving tasks that can vary on various treatment stages can differentiate parental perception of satisfaction with their past, present, and future life.

We assumed that posttraumatic growth may have a mediating effect on the correlation between parents' trait resilience and parental satisfaction with life perceived in three temporal perspectives. We made the assumption regarding the relationship between the variables fully aware of the fact that it is difficult to prove it directly in a cross-sectional study.

Methods

Participants and procedure

The sample consisted of 172 Polish parents of children with CF. To determine the minimum sample size for the current study, G*Power version 3.1. was used. The sample size required for analyses with six independent variables to achieve a power of 0.80 to detect a low effect ($f^2=0.15$) at a significance level of 0.05 was 151.

One hundred and thirty-eight (80.23%) participants were mothers, and 34 (19.76%) were fathers. The average age of the respondents was 37.7 ($SD = 7.01$) and most of them (61.46%) lived in the city. Educational attainment ranged from primary education (1.17%), through vocational (5.23%), secondary (38.95%) to higher education (54.65%). According to EUROSTAT (2021), in 2020, the number of representatives of upper secondary/postsecondary and tertiary/higher education in Poland was respectively: 60,4% and 33.2%. Over half of the surveyed parents (54.65%) were unemployed, whereas the remaining 45.35% were active in the labor market, working full-time. The declared average monthly income per family was 1838.27 PLN ($SD = 2297.50$) (414 EUR). Respondents assessed their financial situation as average ($M = 2.43$; $SD = 0.65$). Most parents raised one child with cystic fibrosis (91.28%), 7.56% of parents had 2 children, and one parent reported raising 3 children with CF. The average age of the child with CF was 8.13 ($SD = 4.40$); there was a similar number of girls (47.67%) and boys (52.33%). The average age when the child was diagnosed with CF was 1.48 years ($SD = 1.69$).

Parents were recruited by the CF MATIO Foundation. Following recruitment, parents were requested to provide demographic information and data related to their child with CF and complete a set of questionnaires. All the respondents agreed to complete the measures voluntarily. Inclusion criteria were being a parent of a child with CF and a ward of the Polish Foundation for Patients with CF MATIO. The exclusion criterion was the child's age: max. 21. Respondents were recruited during the annual meeting of the foundation. They received a set of questionnaires during the meeting, then they were informed of the aim of the study and all details related to completing the tools. They returned completed questionnaires after the

annual meeting. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Instruments

Data were collected using three instruments:

The Resilience Assessment Scale (SPP-25) by Ogińska-Bulik and Juczyński contains 25 items rated on a 5-point scale, from 0 (*definitely not*) to 5 (*definitely yes*). Sample items of the scale: I try to cope no matter how difficult the problem is; I can see the funny side of events I deal with. The total score of the SPP-25 is the sum of the results obtained in the 5 subscales. Higher scores imply greater resilience (Ogińska-Bulik and Juczyński, 2008). SPP-25 has satisfactory indicators of reliability (Cronbach's α in this sample = 0,90).

The Posttraumatic Growth Inventory (PTGI), adapted by Ogińska-Bulik and Juczyński, contains 21 items rated on a 6-point scale, from 0 – *I did not experience this change as a result of my crisis*, to 5 – *I experienced this change to a very great degree as a result of my crisis*. Sample items of the scale: I changed my priorities regarding what is important in life; I appreciate the value of my life more. The Polish version of PTGI has a four-factor structure: (1) changes in self-perception – CHSP (Cronbach's α = 0.88), (2) changes in relations to others – CHRO (Cronbach's α = 0.86), (3) appreciation of life – AL (Cronbach's α = 0.77), and (4) spiritual changes – SCH (Cronbach's α = 0.67). Cronbach's α for the PTGI Total was 0.96. The total score of the PTGI is the sum of the results obtained in the 4 subscales and ranges from 0 to 105. Higher scores imply greater PTG (Ogińska-Bulik and Juczyński, 2010).

The Polish version of *The Temporal Satisfaction with Life Scale (TSWLS)* by Pavot, Diener, and Suh (1998). TSWLS contains 15 items on a 7-point scale, from 1 – *I strongly disagree* to 7 – *I definitely agree*. Sample items of the scale: If I could relive my past, I wouldn't change anything; I am happy with my past. TSWLS is used to assess an individual's past, present, and future life satisfaction (Byra, 2013). The Polish version of TSWLS has satisfactory indicators of reliability (Cronbach's α in this sample = 0,92).

Statistical analysis

Analyses were conducted in two stages using SPSS 24. First, Pearson's correlation coefficients were calculated. Second, the mediation effects of PTG on the relationship between resilience and temporal satisfaction with life were tested using the PROCESS macro through bootstrapping 5000 subsamples.

Three separate serial mediation analyses were tested with references to the TSWLS subscales: past, present, and future life satisfaction.

Results

Table 1 shows correlations between resilience, temporal satisfaction with life, and PTG.

Table 1. Correlations (Pearson's *r*) between the analyzed variables

	1	2	3	4	5	6	7	8	9
1.SSP-T	-								
2.S-Past	.30***	-							
3.S-Present	.32***	.48***	-						
4.S-Future	.36***	.50***	.72***	-					
5.PTGI-CHSP	.46***	-.02	.20**	.31***	-				
6.PTGI-CHRO	.17*	.01	.44***	.31***	.76***	-			
7.PTGI-AL	.25**	-.44***	.03	.32***	.51***	.48***	-		
8.PTGI-SCH	.05	.06	.30***	.15	.53***	.58***	.36***	-	
9.PTGI-T	.34**	.27**	.33***	.32***	.93***	.92***	.63***	.69***	-

SPP-T: Total score resilience; S-past: Satisfaction with past life; S-Present: Satisfaction with present life; S-Future: Satisfaction with future life; PTGI –CHSP: Changes in self-perception; PTGI –CHRO: Changes in relations to others; PTGI –AL: Appreciation of life; PTGI –SCH: Spiritual changes; PTGI-T: Total score PTG;

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

As presented in Table 1, resilience was positively related to past, present, and future satisfaction with life. Resilience was also related to PTG (total score and individual dimensions, except Spiritual changes). Total PTG was positively related to satisfaction with past life, while Appreciation of life was negatively related to it. PTG (total score and individual dimensions) showed positive correlations with satisfaction with present life (except Appreciation of life) and satisfaction with future life (except Spiritual changes).

Parents' age (S-Past: $r = 0.04$; S-Present: $r = -0.12$; S-Future: $r = -0.13$) and the child's age (S-Past: $r = -0.00$; S-Present: $r = -0.09$; S-Future: $r = -0.13$) showed no significant correlations with satisfaction with life.

To examine whether PTG mediated the relationship between resilience and temporal satisfaction with life in parents of children with CF, we performed mediation analyses using the Process macro for SPSS. Resilience was a predictor, PTG (total score and individual dimensions) was a mediator, and satisfaction with life (past, present, and future), was the outcome variable. Results are presented in fig. 1-3.

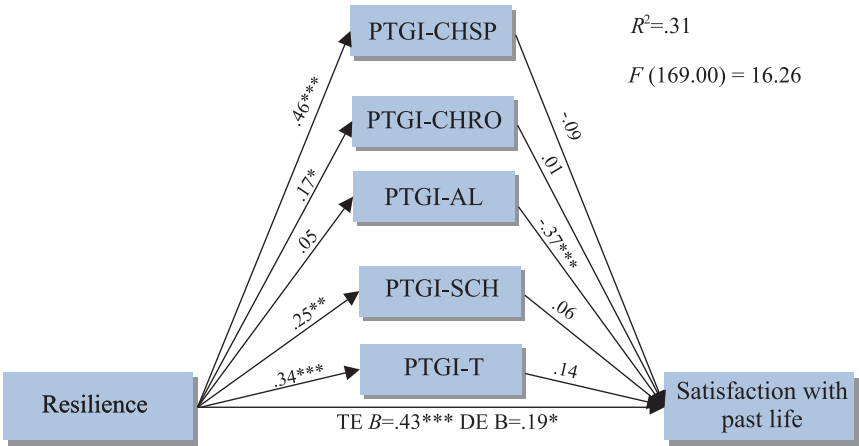


Figure 1. The indirect effect of resilience on satisfaction with past life via PTG (standardized coefficients)
* $p < .05$; ** $p < .01$; *** $p < .001$
PTGI –CHSP: Changes in self-perception; PTGI –CHRO: Changes in relations to others;
PTGI –AL: Appreciation of life; PTGI –SCH: Spiritual changes; PTGI-T: Total score PTG

In the relationship between resilience and satisfaction with past life, the dimension of PTG: Appreciation of life was negatively associated with satisfaction as a mediator (Ryc. 1). This means that lower satisfaction is related to higher scores in this dimension of PTG. The total effect (TE) of resilience ($B = .43, p < .001$) on satisfaction with past life was not reduced to non-significance with the inclusion of the mediators ($DE B = .19, p = .011$) indicating partial mediation. There was an indirect effect through Appreciation of life ($B = -.04, CI_{95\%} = [.011 .098]$) The mediation model explained 31% of the variance of satisfaction with past life ($F(169.00) = 16.26; p < .001$).

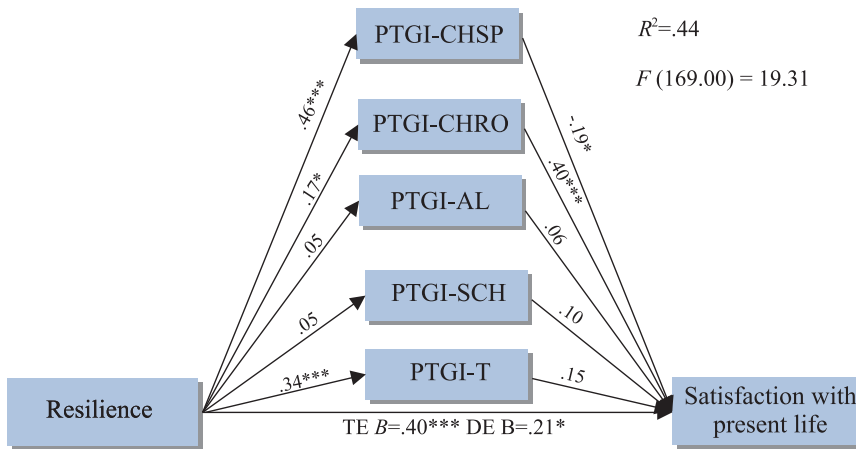


Figure 2. The indirect effect of resilience on satisfaction with present life via PTG (standardized coefficients)

* $p < .05$; ** $p < .01$; *** $p < .001$

PTGI –CHSP: Changes in self-perception; PTGI –CHRO: Changes in relations to others; PTGI –AL: Appreciation of life; PTGI –SCH: Spiritual changes; PTGI-T: Total score PTG

Secondly, the relationship between resilience and satisfaction with present life was tested (Ryc. 2). Two dimensions of PTG: Changes in self-perception and Changes in relations to others were positively associated with satisfaction with present life as mediators. The total effect (TE) of resilience ($B = .40$, $p < .001$) on satisfaction with past life was not reduced to non-significance with the inclusion of the mediators (DE $B = .21$, $p = .009$) indicating partial mediation. There was an indirect effect through Changes in self-perception ($B = .07$, $CI_{95\%} = [.057 .142]$) and Changes in relations to others ($B = .07$, $CI_{95\%} = [.034 .102]$). The model explained 44% of the variance of Transforming comparative-status values into asset values ($F(169.00) = 19.31$; $p < .001$).

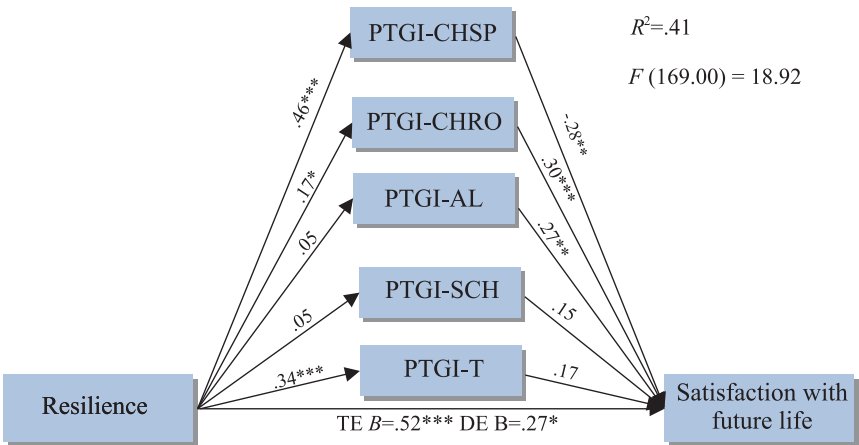


Figure 3. The indirect effect of resilience on satisfaction with future life via PTG (standardized coefficients)

* $p < .05$; ** $p < .01$; *** $p < .001$
PTGI –CHSP: Changes in self-perception; PTGI –CHRO: Changes in relations to others;
PTGI –AL: Appreciation of life; PTGI –SCH: Spiritual changes; PTGI-T: Total score PTG

Finally, the relationship between resilience and satisfaction with future life was tested (Ryc.3). Two dimensions of PTG: Changes in relations to others and Appreciation of life were positively associated with satisfaction with future life as mediators, whereas Changes in self-perception were negatively correlated with the mentioned variable. The total effect (TE) of resilience ($B = .52$, $p < .001$) on satisfaction with future life was not reduced to non-significance with the inclusion of the mediators ($DE B = .27$, $p = .005$) indicating partial mediation. There was an indirect effect through Changes in self-perception ($B = .06$, $CI_{95\%} = [.013 .065]$), Changes in relations to others ($B = .04$, $CI_{95\%} = [.001 .061]$), and Appreciation of life ($B = .06$, $CI_{95\%} = [.034 .101]$). The described mediation model explained 41% of the variance of satisfaction with future life ($F(169.00) = 18.92$; $p < 0.001$).

Discussion

Contemporary pediatric care related to CF issues focuses mainly on the child’s health often excluding considerations of parents’ health and wellness. Burdensome symptoms of a rare genetic illness and its time-consuming treatment, struggle with uncertainty, grief, social isolation, family discord, mental health challenges, and economic hardship are factors contributing to the deterioration of mothers’ and fathers’ well-being which may cause traumatic stress (Georgiopoulos part I, 2020). At the same time, previous research reports on the response to traumatic situations of parents

of terminally ill children justify the need to search for positively oriented factors of how caregivers of patients with CF function.

The present study examined the correlation between resilience and temporal satisfaction with life in parents of children with CF, exploring the mediating effect of PTG. Taking into account differences in interpreting resilience in positive psychology, in our study we understood it as a trait. We followed the theory proposed by Block and Cremen (1996), and Fredrickson (2001) who see resilience as a permanent individual resource that often manifests itself in the aftermath of experiencing serious difficulties or threats (Ogińska-Bulik, 2019).

A positive correlation between resilience and satisfaction with life is evidenced by many studies (Liu, Wang and Zhou 2014), most of which analyzed the direct association between these variables. The dependence was stated in highly representative groups of adults (Martinez-Marti and Ruch 2017), older adults (Zheng et al., 2020), men (Beutel et al, 2010), and aging women (Beutel et al., 2009). In populations with health disturbances, resilience turned out to be related to satisfaction with life in patients after spinal cord injury during their rehabilitation process (White et al., 2010) and parents of insulin-dependent children and adolescents (Edraki and Rambod, 2018).

To our knowledge, the current study is the first to show a mutual relationship between trait resilience and temporal satisfaction with life in parents of children with CF. We differentiated the caregivers' perception of life satisfaction by asking them to consider three temporal perspectives (past, present, and future), to broaden the scope of our analyses. According to Diener et al. (1998), temporal focus can be particularly useful in examining the experience of life satisfaction across different portions of the life span or examining life satisfaction in individuals who have experienced or anticipate significant life changes. It might show sharp contrasts in levels of life satisfaction between past, present, and future temporal frames.

Our study results show a positive relationship between resilience and PTG. The bounce back after trauma which coexists with growth was also revealed by studies conducted in the general population (Duan et al, 2015). Moreover, a similar correlation was confirmed in studies related to caregivers of chronically ill individuals (Li et al., 2012; Luo, Zhang and Liu, 2020) and mothers of children with intellectual disabilities (Byra and Ćwirynkało, 2022). The association between resilience and posttraumatic growth was found by the authors of the PTG concept (Tedeschi and Calhoun, 2004), but its nature is still being discussed (Li et al., 2012).

The current analyses confirmed an indirect correlation between trait resilience and temporal satisfaction with life via PTG. Two PTG dimensions: Changes in self-perception and Changes in relations to others were found to be particularly important mediators of the relationships between resilience and both: present and future satisfaction with life in parents of children with CF. Interestingly, Changes in self-perception positively mediate the association between trait resilience and present life satisfaction but they are also a negative mediator in correlations with future life satisfaction.

Self-perception of parents of children with CF is undoubtedly linked to their acquisition of competencies related to caring for their sick child (Melnik, Feinstein, Moldenhouer and Small, 2001). In the current time perspective, changes in self-perception strengthen the positive relationship between resilience and life satisfaction, whereas the reasons for the negative correlation found in relation to the future remain unclear. One of the explanations may be related to the anxiety of facing potential future traumatic challenges in CF treatment, complications in the course of the disease due to lung degeneration (Fitzgerald et al., 2018), and difficulties in accessing lung transplantation. In Poland, the average survival rate for cystic fibrosis is two times lower than in Western Europe and the USA (Sands, 2019).

Changes in relations to others are a positive mediator in the present and future temporal perspective of life satisfaction. Strong positive attitudes towards other people may be connected with the fact that all participants are members of the MATIO association for CF patients and families, thus they have many capabilities to build positive interrelations with other parents of ill children based on common experiences in coping with the CF challenges. The possibility to use a supportive environment may be a resource that strengthens the positive relationship between resilience and well-being in the surveyed parents. Parents of children with CF are forced to seek informational, organizational, and financial support to meet the challenges of their child's treatment. Thus, their social skills are a valuable resource that can help them take action to effectively improve the quality of life of their sick child and their own well-being.

The third significant mediator of the relationship between resilience and temporal satisfaction with life is Appreciation of life. The obtained results revealed that higher resilience strengthens parents' awareness of positive aspects of their life resulting in lower satisfaction with past life. At the same time, Appreciation of life positively mediates the association between resilience and future life satisfaction. A higher ability to perceive personal life as a valuable experience favors optimistic dispositions and

positive attitudes toward the future. Appreciation of life might be built on early, traumatic experiences of caregiving for a child with a severe, rare, multisymptomatic, disease such as CF. These former experiences may be perceived by parents as extremely complicated (Glascoe et al., 2007). The challenges parents face during the early childhood of their children refer not only to accepting a traumatic diagnosis but also to implementing a complex treatment, initiating new therapies (particularly daily nebulization), the initial onset of CF-related infections such as *Pseudomonas aeruginosa*, and first hospitalizations or surgeries for CF-related complications (Muther, Polineni, and Sawicki, 2018). Neri et al. (2015) confirmed that higher caregiving strain was associated with poorer life satisfaction in the population of parents of adolescents with CF. By developing their skills related to medical treatment and their coping capabilities, parents become stronger and more self-confident. This may result in the coexistence of opposite values: high appreciation of life and low estimation of previous life experiences. Still, the ambiguous contribution of the variable Appreciation of life in explaining the relationship between resilience and life satisfaction in different time perspectives needs to be explained in further research.

In the current study, Spiritual Changes were the only dimension of PTG that did not correlate with resilience. The lack of relations between this variable was revealed by Rodriguez-Ray et al. (2017) in a study with pediatric intensive care personnel but it also applied to other aspects of PTG. We cannot compare with other research results due to methodological limitations, e.g. in the Chinese version of the PTGI Inventory, 2 items of Spiritual Change were eliminated because study participants did not express their religious beliefs (Li et al., 2012). Moreover, in our study, Spiritual Changes were the only dimension of PTG that did not correlate with temporal life satisfaction. In the general population of adults, the interrelations between spirituality/religiosity and life satisfaction are ambiguous (Szcześniak et al., 2020), which may be caused by cultural differences between the examined populations. Interpretation of the results may be also complicated due to a specific, widely discussed conceptual scope of the phenomenon of spirituality. Spiritual resources may not be an important factor in the perception of satisfaction with life. The fact that parents of children with CF do not use spiritual resources was revealed in studies on coping conducted by Byra et al. (2020). Extending research on spirituality in the families of patients with genetic burdens would be interesting to better understand the psychosocial adaptation in this population.

Summing up, the obtained results support the formulated hypothesis that resilience correlates with temporal satisfaction with life but in the presence of a mediator: PTG and its dimensions: Changes in self-perception, Changes in relations to others, and Appreciation of life. The strongest mediating effect of posttraumatic growth was revealed in the correlation between resilience and future life satisfaction (the mediation model explained 41% of the variance of satisfaction with future life). This finding is in line with the results obtained by Liu et al. (2012) who revealed that positive affect is a mediator between resilience and life satisfaction creating a positive correlation.

The conducted research has the following limitations:

1. Purposeful sampling for data selection: the participants are clients of a foundation working for patients with CF. Using this form of social support, they strengthen their positive resources. Thus, it is difficult to draw generalized conclusions about the entire population of Polish parents of children with CF.
2. Most respondents were mothers and a low representation of fathers in the study makes generalization impossible.
3. We did not take into account variables other than PTG as a mediator of the relationship between resilience and temporal life satisfaction. Future research should examine the mediating role of personal factors such as self-efficacy or coping. Moreover, a variable that might have been taken into account as a mediator is social support. It is a significant determinant of well-being in the population of parents who bring up children with severe health problems, as found by Boettcher et al (2020). However, conducting research in a relatively small population affected by a rare disease made it practically impossible because of the assumed criterion for selecting the sample for research. Being a member of a foundation for patients with CF is synonymous with being a recipient of social support.
4. It seems that in the course of future research, apart from addressing the above limitations, it would be worthwhile to deepen the topic of spirituality and its significance for the relationship between resilience and life satisfaction in parents of children with CF.

Practical Implications

The obtained research results became the basis for formulating practical implications and conclusions:

1. Therapeutic interventions addressed to parents of children with cystic fibrosis should be aimed at strengthening resilience and PTG (especially its component related to self-perception). Such support should give parents the possibility to derive satisfaction from life, despite the burdens resulting from the progressive and life-shortening nature of their child's disease. Studies that focused on dispositional and philosophical patterns of resilience show that interventions based on support, tai chi, music, and video, bolster patients' internal strength.
2. To strengthen the posttraumatic growth in parents of children with CF, therapists should pay attention to PTG dimensions, such as self-perception and openness to relationships with others, as well as life appreciation by implementing, a.o. mindfulness therapy, person-centered therapy, social skills training, and other psychosocial interventions.
3. As part of the work of the Cystic Fibrosis Teams, it would be advisable to pay special attention to the retrospective analysis of parental experiences, especially in the case of parents who were not covered by psychological care when their child was diagnosed and during the implementation of the rehabilitation procedures. Dealing with past trauma will allow parents to gain strength and motivation for personal development (growth despite the trauma) and take on current and future challenges related to caring for an ill child.

References:

- Abbott, J., Havermans, T., Jarvholm, S., Landau, E., Prins, Y., Smrekar, U., ECFS Mental Health Working Group. (2019). Mental Health screening in cystic fibrosis centres across Europe. *Journal of Cystic Fibrosis*, 18(2), 299-303.
- Austin, C. P., Cutillo, C. M., Lau, L., Jonker, A. H., Rath, A., Julkowska, D., International Rare Diseases Research Consortium (IRDiRC) (2018). Future of Rare Diseases Research 2017-2027: An IRDiRC Perspective. *Clinical and Translational Science*, 11(1), 21-27.
- Besier, T., Born, A., Henrich, G., Hinz, A., Quittner, A.L., Goldbeck, L, TIDES Study Group (2011). Anxiety, depression, and life satisfaction

- in parents caring for children with cystic fibrosis. *Pediatric Pulmonology*, 46(7), 672-82.
- Beutel, M. E., Glaesmer, H., Decker, O., Fischbeck, S., Brähler, E. (2009). Life satisfaction, distress, and resiliency across the life span of women. *Menopause*, 16(6), 1132-1138.
- Beutel, M. E., Glaesmer, H., Wiltink, J., Marian, H., Brähler, E. (2010). Life satisfaction, anxiety, depression and resilience across the life span of men. *The Aging Male*, 13(1), 32-39.
- Block, J., Kremen, A. M. (1996). IQ and ego-resiliency: conceptual and empirical connections and separateness. *Journal of Personality and Social Psychology*, 70(2), 349-360.
- Boettcher, J., Denecke, J., Barkmann, C., Wiegand-Grefe, S. (2020). Quality of life and mental health in mothers and fathers caring for children and adolescents with rare diseases requiring long-term mechanical ventilation. *International Journal of Environmental Research and Public Health*, 17(23), 75-89.
- Bregnballe, V., Boisen, K. A., Schiøtz, P. O., Pressler, T., Lomborg, K. (2017). Flying the nest: a challenge for young adults with cystic fibrosis and their parents. *Patient Preference and Adherence*, 11, 229-237.
- Bronner, M. B., Knoester, H., Bos, A. P., Last, B. F., Grootenhuys, M. A. (2008). Follow-up after paediatric intensive care treatment: parental posttraumatic stress. *Acta Paediatrica*, 97(2), 181-186.
- Byra, S. (2013). Personal resources and temporal satisfaction of life in men with spinal cord injury. *Advances in Rehabilitation*, 71(1), 13-22.
- Byra, S., Ćwirynkało, K. (2022). Resilience, Coping, and Posttraumatic Growth in Fathers of Children with Intellectual Disabilities: Stress as Moderator. *Family Relations*, 72(4), 2178-2193.
- Byra, S., Zubrzycka, R., Wójtowicz, P. (2021). Sense of Stress and Posttraumatic Growth in Mothers of Children with Cystic Fibrosis-The Moderating Role of Resilience. *Journal of Developmental & Behavioral Pediatrics*, 42(9), 8-14.
- Byra, S., Zubrzycka, R., Wójtowicz, P. (2020). Positive orientation and post-traumatic growth in mothers of children with cystic fibrosis - mediating role of coping strategies. *Journal of Pediatric Nursing*, 57, 1-8.
- Castellani, C., Duff, A. J. A., Bell, S. C., Heijerman, H. G. M., Munck, A., Ratjen, F., Drevinek, P. (2018). ECFS best practice guidelines: the 2018 revision. *Journal of Cystic Fibrosis*, 17(2), 153-178.

- Daly, C., Ruane, P., O'Reilly, K., Longworth, L., Vega-Hernandez, G. (2022). Caregiver burden in cystic fibrosis: a systematic literature review. *Therapeutic Advances in Respiratory Disease*, 16, 43-57.
- Davies, G., Rowbotham, N. J., Smith, S., Elliot, Z. C., Gathercole, K., Rayner, O., Smyth, A. R. (2020). Characterising burden of treatment in cystic fibrosis to identify priority areas for clinical trials. *Journal of Cystic Fibrosis*, 19(3), 499-502.
- De Boeck, K. (2020). Cystic fibrosis in the year 2020: A disease with a new face. *Acta Paediatrica*, 109(5), 893-899.
- Duan, W., Guo, P., Gan, P. (2015). Relationships among trait resilience, virtues, posttraumatic stress disorder, and post-traumatic growth. *PloS One*, 10(5), 17-28.
- Edraki, M., Rambod, M. (2018). Psychological predictors of resilience in parents of insulin-dependent children and adolescents. *International journal of community base nursing and midwifery*, 6(3), 239-249.
- Elborn, J. S. (2016). Cystic fibrosis. *The Lancet*, 388, 2519- 2531.[https://doi.org/10.1016/s0140-6736\(16\)00576-6](https://doi.org/10.1016/s0140-6736(16)00576-6)
- Fitzgerald, C., George, S., Somerville, R., Linnane, B., Fitzpatrick, P. (2018). Caregiver burden of parents of young children with cystic fibrosis. *Journal of Cystic Fibrosis*, 17(1), 125-131.
- Foster, C. L., Bryon, M., Eiser, C. (1998). Correlates of well-being in mothers of children and adolescents with cystic fibrosis. *Child: Care Health and Development*, 24(1), 41- 56.
- Fredrickson, B. (2001). The role of positive emotions in positive psychology: the broaden-and build theory of positive emotions. *American Psychologist*, 56, 218-226.
- Garrido-Hernansaiz, H., Rodriguez-Rey, R., Alonso-Tapia, J. (2020). Coping and resilience are differently related depending on the population: a comparison between three clinical samples and the general population. *International Journal of Stress Management*, 27(3), 304-309.
- Genet, J. J., Siemer, M. (2011). Flexible control in processing affective and non-affective material predicts individual differences in trait resilience. *Cognition and Emotion*, 25(2), 330-338.
- Georgiopoulos, A. M., Christon, L. M., Filigno, S. S., Mueller, A., Prieur, M. G., Boat, T. F., Smith, B. A. (2021). Promoting emotional wellness in children with CF, part II: mental health assessment and intervention. *Pediatric Pulmonology*, 56, S107-S122.

- Kim, G. M., Lim, J. Y., Kim, E. J., Park, S. M. (2019). Resilience of patients with chronic diseases: A systematic review. *Health and Social Care in the Community*, 27(4), 797-807.
- Glasscoe, C., Lancaster, G. A., Smyth, R. L., Hill, J. (2007). Parental depression following the early diagnosis of Cystic Fibrosis: A matched, prospective study. *Journal of Pediatrics*, 150, 185- 191.
- Herzer, M., Godiwala, N., Hommel, K. A., Driscoll, K., Mitchel, M., Crosby, L. E. Piazza-Waggoner, C., Zeller, M. H., Modi, A. C. (2010). Family Functioning in the Context of Pediatric Chronic Conditions. *Journal of Developmental and Behavioral Pediatrics* 31(1),26- 34.
- Karataş, Z., Tagay, Ö. (2021). The relationships between resilience of the adults affected by the covid pandemic in Turkey and Covid-19 fear, meaning in life, life satisfaction, intolerance of uncertainty and hope. *Personality and Individual Differences*, 172, 162-174.
- Li, Y., Cao, F., Cao, D., Wang, Q., Cui, N. (2012). Predictors of posttraumatic growth among parents of children undergoing inpatient corrective surgery for congenital disease. *Journal of Pediatric Surgery*, 47(11), 2011-2021.
- Liu, Y., Wang, Z. H., Li, Z. G. (2012). Affective mediators of the influence of neuroticism and resilience on life satisfaction. *Personality and Individual Differences*, 52(7), 833- 838.
- Liu, Y., Wang, Z., Zhou, C., Li, T. (2014). Affect and self-esteem as mediators between trait resilience and psychological adjustment. *Personality and Individual Differences*, 66, 92-97.
- Luo, R. Z., Zhang, S., Liu, Y. H. (2020). Short report: relationships among resilience, social support, coping style and posttraumatic growth in hematopoietic stem cell transplantation caregivers. *Psychology, Health and Medicine*, 25(4), 389-395.
- Martínez-Martí, M. L., Ruch, W. (2017). Character strengths predict resilience over and above positive affect, self-efficacy, optimism, social support, self-esteem, and life satisfaction. *Journal of Positive Psychology*, 12(2), 110-119.
- McGarry, M. E., William, W. A., McColley, S.A. (2019). The demographics of adverse outcomes in cystic fibrosis, *Pediatric Pulmonology*, 54, S74-S83.
- Melnik, B. M., Feinstein, N. F., Moldenhouer, Z., Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, 27(6), 548.

- Mitmansgruber, H., Smrekar, U., Rabanser, B., Beck, T., Eder, J., Ellemunter, H. (2016). Psychological resilience and intolerance of uncertainty in coping with cystic fibrosis. *Journal of Cystic Fibrosis*, 15(5), 689-695.
- Muther, E. F., Polineni, D., Sawicki G. S. (2018). Overcoming psychosocial challenges in cystic fibrosis: Promoting resilience. *Pediatric Pulmonology*, 53, S86-S92.
- Neri, L., Lucidi, V., Catastini, P., Colombo, C., LINFA Study Group. (2016). Caregiver burden and vocational participation among parents of adolescents with CF. *Pediatric Pulmonology*, 51(3), 243-252.
- Ogińska-Bulik, N., Juczyński, Z. (2010). Rozwój potraumatyczny – charakterystyka i pomiar. [Posttraumatic growth – characteristics and measurement]. *Psychiatria*, 4, 129-142.
- Ogińska-Bulik, N., Juczyński, Z. (2008). Skala pomiaru prężności – SPP-25 [The scale measuring resilience – SPP-25]. *Nowiny Psychologiczne*, 4, 39-55.
- Ogińska-Bulik, N., Michalska, P. (2019). Type D personality and post-traumatic stress symptoms in adolescents – the mediating role of resilience. *Advances in Psychiatry and Neurology*, 28(4), 241-256.
- Pavot, W., Diener, E. (1993). Review of the Satisfaction With Life Scale. *Psychological Assessment*, 5(2), 164-172.
- Pavot, W., Diener, E. (2008). The satisfaction With Life Scale and the emerging construct of life satisfaction. *Journal of Positive Psychology*, 3(2), 137-152.
- Pavot, W., Diener, E., Suh, E. (1998). The Temporal Satisfaction with Life Scale. *Journal of Personality Assessment* 70(2), 340-354.
- Picoraro, J. A., Womer, J. W., Kazak, A. E., Feundtner, C. (2014). Posttraumatic growth in parent and pediatric patients. *Journal of Palliative Medicine*, 17(2), 209-218.
- Prieur, M. G., Christon, L. M., Mueller, A., Smith, B. A., Georgiopoulos, A. M., Boat, T. F., Filigno, S. S. (2021). Promoting emotional wellness in children with cystic fibrosis, Part I: Child and family resilience. *Pediatric Pulmonology*, 56, S97-S106.
- Quittner, A. L., Abbott, J., Georgiopoulos, A. M., Goldbeck, L., Smith, B., Hempstead, S. E., 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(1), 26-34.
- Quittner, A. L., Goldbeck, L., Abbott, J., Duff, A., Lambrecht, P., Sole, 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.
- Rodríguez-Rey, R., Alonso-Tapia, J. (2019). Predicting posttraumatic growth in mothers and fathers of critically ill children: a longitudinal study. *Journal of Clinical Psychology in Medical Settings*, 26(3), 372-381.
- Rodríguez-Rey, R., Palacios, A., Alonso-Tapia, J., Pérez, E., Álvarez, E., Coca, A., Belda, S. (2017). Posttraumatic growth in pediatric intensive care personnel: Dependence on resilience and coping strategies. *Psychological Trauma: Theory, Research, Practice, and Policy*, 9(4), 407-415.
- Roepke, A. M. (2015). Psychosocial interventions and posttraumatic growth: A meta-analysis. *Journal of Consulting and Clinical Psychology*, 83(1), 129-142.
- Rosenberg, A. R., Baker, K. S., Syrjala, K. L., Back, A. L., Wolfe, J. (2013). Promoting resilience among parents and caregivers of children with cancer. *Journal of Palliative Medicine*, 16(6), 645-652.
- Rosenberg, A. R., Starks, H., Jones, B. (2014). "I know it when I see it." The complexities of measuring resilience among parents of children with cancer. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 22(10), 2661-2668.
- Rosenberg, A. R., Wolfe, J., Bradford, M. C., Shaffer, M. L., Yi-Frazier, J. P., Curtis, J. R., Syrjala, K. L., Baker K. S. (2014). Resilience and psychosocial outcomes in parents of children with cancer. *Pediatric Blood Cancer*, 61, 552-557.
- Rothschild, Ch., Rychlik, K. L., Goodman, D. M., Charleston, E., Brown, M. L., Michelson, K. (2020). Association between resilience and psychological morbidity in parents of critically ill children. *Pediatric Critical Care Medicine*, 21(4), 177-185.
- Rutter, M. (2003). *Genetic influences on risk and protection. Implications for understanding resilience*. In: Luthar S. S. (Eds). *Resilience and Vulnerability. Adaptation in the Context of Childhood Adversities* (s. 489-509). Cambridge: Cambridge University Press.
- Sands, D. (red.) (2019). *Opieka nad chorymi na mukowiscydozę w Polsce. Stan obecny i rekomendacje poprawy. Raport*. Warszawa-Kraków: Polskie Towarzystwo Mukowiscydozy.
- Shiyko, M. P., Hallinan, S., Naito, T. (2017). Effects of mindfulness training on posttraumatic growth: a systematic review and meta-analysis. *Mindfulness*, 8, 848-853.

- Stephenson, E., DeLongis, A., Steele, R., Cadell, S., Andrews, G. S., Siden, H. (2017). Siblings of children with a complex chronic health condition: maternal posttraumatic growth as a predictor of changes in child behavior problems. *Journal of Pediatric Pulmonology*, 42(1), 104-113. .
- Szcześniak, M., Kroplewski, Z., Szałachowski, R. (2020). The mediating effect of coping strategies on religious/spiritual struggles and life satisfaction. *Religions*, 11(4), 195-206.
- Tedeschi, R. G., Calhoun, L. G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry*, 15, 1-8.
- Thompson, R. J., Gustafson, K. E., Hamlett, K. W., Spock, A. (1992). Stress, coping and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. *Journal of Pediatric Psychology*, 17(5), 573- 585.
- Toprak, D., Nay, L., McNamara, S., Rosenberg, A. R., Rosenfeld, M., Yi-Frazier, J. P. (2020). Resilience in adolescents and young adults with cystic fibrosis: A pilot feasibility study of the promoting resilience in stress management intervention. *Pediatric Pulmonology*, 55(3), 638-645.
- Triplett, K. N., Tedeschi, R. G., Cann, A., Calhoun, L. G., Reeve, C. L. (2012). Posttraumatic growth, meaning in life, and life satisfaction in response to trauma. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(4), 400-410.
- Walicka-Serzysko, K., Peckova, M., Noordhoek, J. J., Sands, D., Drevinek, P. (2018). Insight into the cystic fibrosis care in Eastern Europe: Results of survey. *Journal of Cystic Fibrosis*, 17, 475-477.
- White, B., Driver, S., and Warren, A. M. (2010). Resilience and indicators of adjustment during rehabilitation from a spinal cord injury. *Rehabilitation Psychology*, 55(1), 23-31.
- World Health Organization. (2002). *Towards a common language for functioning, disability, and health: ICF. The international classification of functioning, disability and health*. Genewa.
- Yan, Z., McCray Jr, P. B., Engelhardt, J. F. (2019). Advances in gene therapy for cystic fibrosis lung disease. *Human Molecular Genetics*, 28(R1), R88-R9.
- Zheng, W., Huang, Y., Fu, Y. (2020). Mediating effects of psychological resilience on life satisfaction among older adults: A crosssectional study in China. *Health & Social Care in the Community*, 28(4), 1323-1332.