University of Wisconsin Milwaukee

UWM Digital Commons

Theses and Dissertations

May 2023

Experiential Avoidance and Protective Factors Among Caregivers of Children with Medical Complexity: An Exploratory Investigation

Kevin Berridge University of Wisconsin-Milwaukee

Follow this and additional works at: https://dc.uwm.edu/etd



Part of the Psychology Commons

Recommended Citation

Berridge, Kevin, "Experiential Avoidance and Protective Factors Among Caregivers of Children with Medical Complexity: An Exploratory Investigation" (2023). Theses and Dissertations. 3124. https://dc.uwm.edu/etd/3124

This Thesis is brought to you for free and open access by UWM Digital Commons. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of UWM Digital Commons. For more information, please contact scholarlycommunicationteam-group@uwm.edu.

EXPERIENTIAL AVOIDANCE AND PROTECTIVE FACTORS AMONG CAREGIVERS OF CHILDREN WITH MEDICAL COMPLEXITY: AN EXPLORATORY INVESTIGATION

by

Kevin Berridge

A Thesis Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Master of Health
Psychology

at

The University of Wisconsin-Milwaukee

May 2023

ABSTRACT

EXPERIENTIAL AVOIDANCE AND PROTECTIVE FACTORS AMONG CAREGIVERS OF CHILDREN WITH MEDICAL COMPLEXITY: AN EXPLORATORY INVESTIGATION by

Kevin Berridge

The University of Wisconsin-Milwaukee. 2023 Under the Supervision of Professor W. Hobart Davies

Children with medical complexity (CMC) have more than one intensive medical need or chronic illness. Primary caregivers of CMC experience consistent stress related to social isolation, financial strain, and high caregiving burden, often producing emotional distress (ED). This exploratory analysis aims to investigate the relationship between resilience and self-compassion, emotional distress (depression and anxiety) and experiential avoidance. It is hypothesized that experiential avoidance will have significant negative correlations with self-compassion and resilience.

Online surveys were administered to twenty caregivers of CMC served by a pediatric Complex Care Program (CCP) in the Midwest. Caregivers were primarily female (95%), White (85%), non-Hispanic (80%). Caregivers completed the Connor-Davidson Resilience Scale (CD-RISC-10), the Self Compassion Scale-Youth, the 4-item forms of the Emotional Distress-Depression and Emotional Distress-Anxiety surveys from the Patient-Reported Outcomes Measurement Information System (PROMIS), and the Brief Experiential Avoidance Questionnaire (BEAQ). Data will be analyzed with descriptive statistics and Spearman's Rho.

TABLE OF CONTENTS

Chapter		Page
	Abstract	ii
I.	INTRODUCTION	
	Protective Factors	2
	Experiential Avoidance	
	Current Proposal	
II.	METHODS	
	Participants	5
	Procedure	
	Measures	6
	CD-RISC	6
	SCS-Y-4	7
	PROMIS	7
	BEAQ	8
	Data Analytic Plan	
III.	RESULTS	
IV.	DISCUSSION	10
	Implications	13
	Limitations	
	Future Directions	15
V.	References	24

Introduction

Children with medical complexity (CMC) are characterized by their medical complexity and high utilization of healthcare resources due to their multiple chronic conditions that require several medical and community-based services (Cohen et al., 2011). Parents or caregivers of CMC experience chronic stress, poor mental health, and elevated responsibility at home. The constant demands of their children's health management, financial strain, responsibility for other children, health care delivery, child's emotional wellbeing, and watching their child in pain and distress all contribute to chronic stress (Breneol et al., 2019; Dewan et al., 2022). Even when parents excel at caring for their children, their own health and wellbeing is rarely attended to and maintained (Hagvall et al., 2016; Shriver, 2021). Various points of stress are similarly associated with poor mental health outcomes, especially when caring for their children means sacrificing personal relationships, hobbies, careers, or even attention to their other children (Shriver, 2021). In certain instances, even when parents proclaim adequate social support, the results of an administered depression rating scale report high levels of depression (Wright-Sexton et al., 2020).

This population consistently relies on respite from family, community resources, and health care providers, yet obtaining such support entails significant barriers (Breneol et al., 2019). Often, programs aimed at reducing stress for parents of CMC include in-home medical aid, support groups, and transportation services but a noticeable absence of mental health services is frequently observed (Foster et al., 2022). Parents of CMC are uniquely susceptible to poor mental health outcomes such as depression and anxiety, more so than other populations of caregivers caring for sick children (Bayer et al., 2021). It is imperative to seek effective interventions for these parents, as their mental well-being not only influences their own quality

of life but can influence the health status of their children as well. (Ellzey et al., 2015). Given the predisposition to poor mental health outcomes, protective factors such as resilience and self-compassion become two factors of immense interest.

Protective Factors

The relationship between resilience and positive mental health outcomes is widely studied with results predominately supporting the assertion that higher resilience significantly impacts mental health status across most populations (Kelifa et al., 2021; Leys et al., 2021). Resilience is defined as the dynamic ability to "bounce back" in the face of adversity (Connor & Davidson, 2003). Studies show that individuals with higher resilience have overall higher well-being ratings and lower risk of developing psychopathology (Meng et al., 2018) with additional evidence of resilience negatively correlating with depression (Min et al., 2013). With positive outcomes in mind, resilience has been associated with better coping skills and affect regulation (Agaibi & Wilson, 2005). In other caregiving populations, resilience was reported to allow caregivers to manage and respond positively to stressful demands of care (Dias Lopes da Rosa et al., 2020).

Self-compassion similarly is understood to have similar influences on mental health outcomes, such that bolstering both factors in an individual will likely result in lower levels of poor mental health outcomes and lower severity of symptoms (Whitehead et al., 2021; Pérez-Aranda et al., 2021; Brophy et al., 2020; Murray et al., 2021). Research finds that depression levels among parents of CC patients are consistently high, despite reported perceptions of social support, provider support, and healthcare support (Wright-Sexton et al., 2020). Few studies reported mental health services being provided for these families, with some studies reporting the desire for mental health services to be provided or even accessible. Considering the overwhelming reports of stress, anxiety, and depression among this population, utilizing current

findings regarding protective factors may aid in improving the mental health status and quality of life for parents of CMC. While the relationship between protective factors and poor mental health outcomes has been established, considering different relationships can be beneficial in establishing effective interventions aimed at reducing poor mental health outcomes.

Experiential Avoidance

Experiential Avoidance is broadly defined as the tendency or unwillingness to stay in contact with unwanted internal experiences (i.e., emotions, memories, thoughts, or bodily sensations) first introduced by Hayes and colleagues (1996). Originally constructed to address syndromal classification's failure to identifying functional pathological processes, Hayes and colleagues (1996) focused on functional diagnostic dimensions (i.e., experiential avoidance) as a means to develop the functional diagnostic approach. Their initial study proposed that experiential avoidance, as a functional diagnostic dimension, has the potential to integrate a wide array of paradigms, research interests, and clinical domains that lead to testable approaches to behavioral disorders (Hayes et al., 1996).

The initial proposal of experiential avoidance as a functional diagnostic dimension, a vast systematical review relating experiential review was conducted, providing evidence for each domain. These included experiential avoidance relating to; basic experimental work, coping styles literature, psychotherapy process research, literature on clinical syndromes, substance abuse and dependence, obsessive compulsive disorder (OCD), panic disorder with agoraphobia, bipolar disorder (BPD), literature on nonsyndromal clinical problems, sequelae of childhood sexual abuse, and suicide (Hayes, et al., 1996). Each category was reviewed by summarizing the manifestation of experiential avoidance within each domain, while providing examples of ineffective avoidance strategies that were commonly applied, highlighting the paradigm shift that

was necessary for productive outcomes. An example includes the review of OCD, noted as avoidant in nature, which include various private experiences that the client seeks to avoid, such as invasive thoughts and compulsions. When these intrusive thoughts occur, some individuals may attempt to avoid and suppress these thoughts, where others develop rituals that serve as experiential escape (Hayes et al., 1996). By reviewing the presence of experiential avoidance in numerous domains of behavioral and psychological disorders and theory, experiential avoidance begins to emerge as an underlying factor that merits investigation and application in future research.

Since its development, experiential avoidance has been established to interact with emotional distress, worry-related symptomologies, momentary negative affect, anxiety, depression, perceived stress and other externalizing disorders (McCluskey et al., 2022; Gámez et al., 2014; Bardeen et al., 2013). Yela and colleagues (2022) have noted the covariate relationship between reductions in experiential avoidance and reductions in anxiety and depression, supporting the role of experiential avoidance in mental health outcomes. Additional research highlights the importance of analyzing the interplay between different processes of psychological inflexibility, such as experiential avoidance, in order to improve ways of addressing emotional problems (Fernández-Rodríguez et al., 2022).

Current Proposal

The purpose of this study is to establish a basis for further investigation of how experiential avoidance interacts with protective factors aimed at reducing negative mental health outcomes among parents of CMC. The current proposal is to explore the relationship between experiential avoidance and protective factors among parents of children with medical complexity (CMC) in a secondary data analysis. It is hypothesized that (i) experiential avoidance will have a significant

negative correlation with both self-compassion and resilience, (ii) the two emotional distress factors of anxiety and depression will have a significant negative correlation with self-compassion, and (iii) the two emotional distress factors od anxiety and depression will have a significant negative correlation with resilience.

Method

Participants

In April and May 2021, 25 primary caregivers of CMC were recruited from a pediatric Complex Care Program in the midwestern United States, in which 20 of the recruited parents participated. They were primarily female (95%), White (85%), non-Hispanic/Latinx (80%). Most of their children (Mage=8.2, SDage=3.8 years) had been in the Complex Care Program (CCP) for >2 years (90%). Specifically, participants described themselves as an average age of 39 years old, 95% female, 5% male, 85% white, 5% African American/Black, while 10% responded as another race or prefer not to answer. Participants reported as 80% non-Hispanic/Latinx, 5% Hispanic/Latinx, and 5% preferred not to answer. The sample consisted of parents who were 65% married, 25% single/never married, and 10% divorced. About 45% were high school graduates, 20% were associates degree graduates, and 35% were college graduates.

Their children were described as 55% female and 45% male. About 10% of the children were served by the CCP for 1-2 years, 45% served by CCP for 3-5 years, and 45% served by CCP for 6+ years.

Procedure

The Institutional Review Board (IRB) approved the procedure for participant recruitment and data collection for this study. Students will complete a training course in the ethical conduct

of human research. Students in an advanced psychology laboratory will recruit participants and direct them to Qualtrics to complete a questionnaire. Participants will be provided with a one-page information sheet, detailing the purpose of the study, ensuring confidentiality and privacy of their personal information, reminding individuals that their participation is voluntary, and the link to the survey.

Measures

The primary measures utilized for the study will be the Connor-Davidson Resilience Scale (CD-RISC-10; Connor & Davidson, 2003; Campbell-Sills & Stein, 2007), the Self Compassion Scale-Youth (SCS-Y; Neff, 2019, Neff et al., 2021), the 4-item forms of the Emotional Distress-Depression (ED-D) and Emotional Distress-Anxiety (ED-A) surveys from the Patient-Reported Outcomes Measurement Information System (PROMIS; Cella et al., 2010; Kroenke, 2019), and the Brief Experiential Avoidance Questionnaire (BEAQ; Gámez, 2014).

CD-RISC-10

The CD-RISC contains 25-items that each carry a 5-point range scale, with (0) not true at all, to (4) true nearly all of the time. The total scale ranges from 0-100, with higher scores reflecting greater resilience. The CD-RISC measures self-reported resilience ratings through 10 different items and was designed with the concept of resilience being relevant to treatment outcomes in anxiety, depression, and stress reactions. The overall goal of the CD-RISC is to quantify resilience and assess modifiability of resilience. Campbell-Sills and Stein (2007) refined the original CD-RISC using a 2-factor psychometric analysis, resulting in items 1, 4, 6, 7, 8, 11, 14, 16, 17, 19 from the original scale comprising the 10-item version (scored 0-40). The 10-item CD-RISC reported satisfactory reliability (α=.85, M=27.2, SD=5.84).

SCS-Y-4

The full form Self Compassion Scale (Neff et al., 2019) consists of six subscales assessing Self-Kindness versus Self Judgement, Common Humility versus Isolation and Mindfulness over Identification. Neff et al. (2019) states that the different components of self-compassion represent the emotional ways individuals react negative experiences, how they cognitively interpret their experience, and pay attention to their negative self-related feelings. Selfcompassion measured with the SCS has demonstrated negative relationships with depression, anxiety, and stress (MacBeth & Gumley, 2012). There have also been significant positive relationships reported between SCS measured self-compassion with psychological well-being (Zessin et al., 2015), resilience (Lefebvre et al., 2020), and happiness and optimism (Neff et al., 2007). The SCS-Y is the 4-item, youth version created by Neff et al. (2022) to make the language more accessible for participants. The Y-SCS was created with a total of 4 studies, with Study 1 (n=279) selecting items that had the strongest target loadings, relatively low crossloadings, adequate content validity, and good performance in subsequent re-estimated measurement models (Neff et al., 2022). Study 2 cross validated the factor structure of the SCS-Y with a second sample of youths (n=402). Reliability for the scale was good, with Cronbach's Alpha \geq .82 for a total SCS-Y score in both samples. Study 3 (n=102) reported support for testretest reliability (r=.83), while Study 4 (n=212) established construct validity by demonstrating significant associations between the SCS-Y and mindfulness, happiness, life-satisfaction, depression, resilience, and achievement goal orientation in expected directions.

PROMIS

The Patient-Reported Outcomes Measurement Information System (PROMIS; Cella et al., 2010) was created to address the lack of precision, standardization, and comparability of patient-

reported outcome (PROs) scores. The PROMIS scale specifically measures 7 domains including anxiety, depression, fatigue, pain interference, physical function, sleep disturbance, and social role. The 4-item version of the PROMIS was tested for validity and reliability using the previously identified domains, in addition to correlations with the longer versions of the PROMIS. Results indicated the 4-item version reliably measures a range of 3 standard deviations on the *T*-score metric across all tested domains, as well as statistical power correlations ranged between .083 and 0.89 with the long form versions (Cella et al., 2019).

BEAQ

The BEAQ consists of 15 items rated on a 6-point scale, ranging from 1 (strongly disagree) to 6 (strongly agree), with statements such as. "I feel disconnected from my emotions", "I try to put off unpleasant tasks for as long as possible" and, "Pain always leads to suffering". Scoring ranges from 15-90 (item six must be inverted) with higher scores reflecting greater experiential avoidance. The BEAQ was modeled using the Multidimensional Experiential Avoidance Questionnaire (MEAQ), converging the previous 62 items into 15 items based on item loadings on a single common factor via exploratory factor analysis (EFA). The resulting 15 items assess the avoidance of pain, uneasiness, effort, upset, unpleasantness, discomfort, emotions, painful emotions, feelings, bad feelings, upsetting feelings, fear/anxiety, unpleasant memories, and doubts (Gámez et al., 2014). To determine the internal consistency of the BEAQ, three separate phases consisting of three different populations (patients, students, community adults) were administered the questionnaire. The first phase reported adequate internal consistency (mean α = .86, mean average interitem correlation [AIC] = .30), with consistent moderate to high correlations between the MEAQ and BEAQ subscales. Specifically, among the patient (n=265), student (n=363), and community adults (n=215) the MEAQ subscales of Behavioral Avoidance and Distress Aversion (mean r= .80) were most closely related to the BEAQ. Phase two reported similar results with

internal consistency remaining adequate (α s= .80-.83; AICs = .21-.24), with similar subscale association to phase 1 (mean r= .75). Phase 3 included two new student (n=283) and community adult (n=295) samples, reporting similar internal consistency to the previous phases (mean α = .84, mean AIC= .27 across five phase 1 and 2 samples).

Data Analytic Plan

Due to the low statistical power of the sample, the initial approach to analysis was to run a bivariate correlation test, or Pearson's R, between experiential avoidance (BEAQ) and both self-compassion (SCS-Y) and resilience (CD-RISC). A bivariate correlation test was also conducted with the Emotional Distress-Depression (PROMIS) replacing experiential avoidance to act as a comparative model, with a final plan to use Pearson's R to analyze the relationship between experiential avoidance and the PROMIS depression and anxiety scales. After a normality test for the PROMIS scales was conducted (Table 2), it was determined that the Spearman Correlation was appropriate due to the non-normal distribution. The experiential avoidance and protective factors measures were consistent with a normal distribution (Table 1); however, the Spearman results were similar to Pearson's R, concluding in Spearman's Rho as the method of analysis for the entire dataset.

Results

Results of the bivariate correlational analysis, detailed in Table 4- Table 6, indicated that Experiential Avoidance (M= 49.7, SD= 14.29) had a significant negative correlation with Self-Compassion (M=8.9, SD= 1.78), rho (18) = -.486, p<.05. Additionally, Experiential Avoidance (M= 49.7, SD= 14.29) had a significant negative correlation with Resilience (M= 38.5, SD= 6.09), rho (18) = -.566, p<.01. As hypothesized, higher levels of Experiential Avoidance were associated with lower levels of self-compassion and resilience.

Levels of Self-Compassion and Resilience were also compared with the reported Anxiety (M=9.25, SD=3.73) and Depression (M=7.5, SD=3.32) subscales of the PROMIS. Results of the Anxiety (M=9.25, SD=3.73) subscale displayed a significant relationship to Self-Compassion (M=8.9, SD=1.78), (rho~(18)=-.515, p<.05) but no significant relationship with Resilience (M=38.5, SD=6.09), rho~(18)=-.418, p<.05. The Depression (M=7.5, SD=3.32) subscale displayed a similar relationship with Self-Compassion (M=8.9, SD=1.78), (rho~(18)=-.580, p<.05) and Resilience (M=38.5, SD=6.09), rho~(18)=-.636, p<.01. The relationship between Experiential Avoidance (M=49.7, SD=14.29) and the PROMIS measures of Anxiety (M=9.25, SD=3.73), (rho~(18)=.427, p<.05) and Depression (M=7.5, SD=3.32) were not significant, rho~(18)=.438, p<.05.

Discussion

The aim of this study was to investigate a relationship between experiential avoidance and both self-compassion and resilience among parents of children with medical complexity (CMC). As previous data regarding the population and factors of interest is limited, a bivariate correlational analysis (Pearson's R) was selected to establish a statistical relationship. It was expected that the self-compassion ratings described by the Self-Compassion Scale-Youth (SCS-Y) and the resilience ratings described by the Connor-Davidson Resilience Scale (CD-RISC) would positively correlate with experiential avoidance, outlined by the Brief Experiential Avoidance Questionnaire (BEAQ). Results of the Pearson correlation supported the hypothesis, describing significant correlations with self-compassion, resilience, and experiential avoidance. The level of experiential avoidance is consistent with the other studies reporting elevated experiential avoidance (Bardeen et al., 2013; Fernández-Rodríguez et al., 2022).

Reporting the results of the Depression and Anxiety subscales establishes the presence of negative outcomes associated with stress among the population. It additionally provides justification for further investigation of the experiential avoidance-protective factor relationship and the specific role it plays in the daily lives of the population. Secondarily, the results of the Depression and Anxiety measures can act as an informal comparison to the effects of experiential avoidance on protective factors, as a statistical effect size is limited due to small sample size. By comparing the two relationships, future studies can conclude that experiential avoidance can be just as, if not more, harmful to protective factors as depression and anxiety.

As a gap remains in literature focused on parents of CMC, contextualizing experiential avoidance using the framework developed by Hayes et al., (1996) can aid in describing the presence of experiential avoidance among the population. Introducing the concept of experiential avoidance can help explain previously observed processes displayed by parents of CMC, which could guide the development of new interventions or revisions of established ones. Each correlation reported between experiential avoidance and protective factors will be contextualized specifically for the experiences of CMC parents.

The negative correlations between self-compassion and experiential avoidance could be attributed to the process of experiential avoidance, avoiding or suppressing intrusive thoughts or feelings that if addressed, could aid in understanding how stressful life events may be out of a parent's control, thereby bolstering compassion for their specific situation (Hayes et al., 1996). For example, when a parent's child becomes severely ill, it may be beneficial for the parent to address and reflect on how others might respond to the inherent burdens associated with a chronically ill child, such as financial strain, health care management or the child's emotional wellbeing (Breneol et al., 2019; Dewan et al., 2022). However, if experiential avoidance

becomes a factor in the process, addressing such issues and burdens may be fully ignored, internalizing feelings of isolation and negative emotions about their own capabilities (Bayer et al., 2021).

An additional explanation for the negative correlation between self-compassion and experiential avoidance could be consistently encountering aversive environments that challenge salient attempts to avoid internalized thoughts or feelings. Such places could include the hospital or the home, due to CMC need for consistent and frequent care (Hagvall et al., 2016; Shriver, 2021). When a parent of CMC begins care for their child, previous sources of support or mental respite begin to dissipate such as personal relationships, hobbies, or careers (Shriver, 2021). When constant stressors are encountered in various environments, aversive internalized thoughts and emotions can become overwhelming to address and may increase the severity of common symptomologies of stress, thereby decreasing confidence or compassion for a parent's situation or capabilities (Whitehead et al., 2021; Pérez-Aranda et al., 2021; Brophy et al., 2020; Murray et al., 2021).

The negative correlation between resilience and experiential avoidance could be attributed to the avoidance of addressing the chronic nature of care associated with CMC (Cohen et al., 2011). Avoiding the chronic implications could possibly explain the correlation by consistent stressors being addressed in short-term steps, preserving resilience in single instances, but decreasing as burdens continue. Since resilience is associated with better coping skills, some parents may use the mechanism of addressing stressors as they are encountered, to avoid becoming overwhelmed. If a parent is relatively resilient at the beginning of care, perceiving the burden of care as temporary or isolated may be a helpful coping tool, however, by doing so they are effectively avoiding recognition of the ongoing burden that is inherent with CMC. This

interplay may represent a helpful short-term coping process but likely becomes maladaptive over time.

Another possible manifestation could be the cognitive use of experiential avoidance is substituted for resilience to achieve short term relief. If an individual can avoid the burdens associated with care for CMC, short term relief may be attributed to the absence of overt negative symptomologies that are being internally avoided. Without a clear demand to bolster or rely on resilience, the parent of CMC may continue their thoughts and cognitions that appear to be helping. Over time however, as experiential avoidance levels increase, their resilience may remain stagnant or decrease, resulting in lower well-being ratings and higher risk of developing pathology (Min et al., 2013).

Implications

The primary implication of the study regards the population of parents of CMC avoidance, such that there is minimal research that includes experiential avoidance as a factor of interest. Due to the absence of previous data, these preliminary results should be considered when conducting research aimed at understanding the stress process among parents of CMC. While the current study does not warrant altering or constructing new interventions for parents of CMC, it does justify further investigation and establishes a base for new approaches to intervention if replicated. While the covariate relationship between reductions in experiential avoidance and reductions in anxiety and depression has been established, there remains a need to specifically explore the interplay between stressors, experiential avoidance, and mental health outcomes among a population that is largely overlooked, yet uniquely susceptible to poor mental health outcomes (Yela et al., 2022; Bayer et al., 2021).

A secondary implication of the current study involves further exploration of experiential avoidance compared to anxiety and depression among parents of CMC. These findings report a rudimentary comparison between experiential avoidance and depression/anxiety, however, future investigation in their relationship could potentially result in more effective interventions aimed at reducing overall negative mental health outcomes for parents. While previous studies have focused on how experiential avoidance influences anxiety and depression, future research may provide evidence that interventions aimed at reducing experiential avoidance may be more effective than interventions aimed at lowering anxiety and depression directly.

The final implication of the study requires continuing research on the relationship between protective factors and experiential avoidance among parents of CMC. Research aimed at exploring the effect of protective factors on experiential avoidance, to confirm the covariate nature of the two. While the results of the study tested the relationship between experiential avoidance and protective factors, there remains a need to investigate how protective factors directly relate or influence experiential avoidance. Overall, the present study warrants future investigation on how experiential avoidance, protective factors, and mental health outcomes interact among parents of CMC.

Limitations

The following study was met with multiple limitations that could potentially affect the findings and implications. The most significant limitation was the limited sample size, specifically the overall statistical power produced by a limited sample size. This limitation additionally influences the overall generalizability of the results, despite a relatively low volunteer bias.

Results may likely only apply to the Complex Care Program families who experience similar situations. Another limitation to the study includes minimal literature relating parents of CMC

with experiential avoidance, leaving gaps such as larger population data. There was also a limitation regarding the resilience (CD-RISC) measure, as it was selected due to its broad nature, it does not include specific types of resilience nor cultural considerations that could influence the results of the study. Lastly, the measures used for the study relied on parent self-report information, with no provider ratings, co-parent ratings or observations that would support the data. Self-report information is susceptible to numerous confounders such as respondent fatigue and response bias. These limitations influence the implications of the study as well, where direct implications cannot be derived from the data and future research is necessary to make any assertions or statements.

Future Directions

As this study was an exploratory analysis, it served to establish an entry point for future research regarding experiential avoidance and parents of CMC. Future studies can improve upon multiple aspects of the current investigation. To begin, using a different resilience scale that includes specific types of resilience, such as emotional resilience, or resilience contextualized to CMC experiences, could help clarify whether the emotional toll of watching their child endure a chronic illness is more taxing on resilience compared to financial burden, increased medical responsibility, or increased social isolation. Additionally, cultural considerations regarding resilience should be examined to further understand and define resilience in the context of CMC parental stress. The impact of culture on resilience has become increasingly imperative in understanding how resilience is fostered, bolstered, and diminished; such that excluding considerations in future studies would be to ignore a major factor that could influence how resilience is understood.

Relatedly, future studies could include measures with wider ranges of stress that include specific subcategories, such as life events or distinct stressors, that discern how much stress stems from caregiving specifically. By understanding how stress uniquely manifests and interacts with other mechanisms among parents of CMC, future directions can pilot research that most accurately relates to the unique population. Lastly, experiential avoidance could be further investigated to determine the degree in which it impacts their lives.

Additional improvements to the study include a longitudinal model that provides comparisons on how experiential avoidance interacts with protective factors in individuals over time. Diary sampling could also supplement the longitudinal data so there is context to the results or evidence of respondent bias if the qualitative and quantitative data contradict.

If the results of the study are replicated, findings could lead to numerous intervention opportunities. New interventions could be developed to specifically address experiential avoidance or current interventions could be altered to consider experiential avoidance. Overall, the exploratory nature of the present study serves as a baseline for subsequent studies but also allows for a wide variety of improvements for future directions.

Figures

Figure 1

-Chronically ill child
-Caregiving role
-Financial burden
-Loss of hobbies, social life, career

-Experiential avoidance acts as mediator

-Chronically ill child
-Caregiving role
experiences (i.e.
emotions, thoughts, memories
-Experiential avoidance acts as mediator

-Increased depression levels
-Increased depression levels
-Increased feeling of isolation

Tables

Table 1Experiential Avoidance and Protective Factors Test of Normality

Variable	Kolmogorov-Smirnov ^a			Shapiro Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Experiential Avoidance	.114	20	.200*	.973	20	.817
Self-Compassion	.139	20	.200*	.943	20	.271
Resilience	.119	20	.200*	.941	20	.254

^{*.} This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Table 2

PROMIS scale Test of Normality

Variable	Kolmogorov-Smirnov ^a			Shapiro Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Depression	.170	20	.132	.889	20	.026
Anxiety	.220	20	.012	.897	20	.036

a. Lilliefors Significance Correction

Table 3

Descriptive Statistics

Variable	n	M	SD
Experiential Avoidance	20	49.70	14.29
Self-Compassion	20	8.90	1.78
Resilience	20	38.50	6.09
Depression	20	7.5	3.32
Anxiety	20	9.25	3.73

 Table 4

 Correlations Between Experiential Avoidance and Protective Factors

Variable	1	2	3	
1.Experiential Avoidance	-			
2.Self-Compassion	486*	-		
3.Resilience	566**	.521*	-	

^{*.} Correlation is significant at the .005 level (2-tailed).

 $^{^{\}ast\ast}.$ Correlation is significant at the .001 level (2-tailed).

Table 5

Correlations Between Protective Factors and PROMIS scale

Variable	1	2	3	4
1.Self-Compassion	-			
2.Resilience	.521*	-		
3.Depression	580*	636*	-	
4.Anxiety	515*	418	.608**	-

^{*.} Correlation is significant at the .005 level (2-tailed).

 $^{^{\}ast\ast}.$ Correlation is significant at the .001 level (2-tailed).

 Table 6

 Correlations Between Experiential Avoidance and PROMIS scale

Variable	1	2	3
1.Experiential Avoidance	-		
2.Depression	.438	-	
3.Anxiety	.427	.608**	-

^{*.} Correlation is significant at the .005 level (2-tailed).

 $^{^{\}ast\ast}.$ Correlation is significant at the .001 level (2-tailed).

References

- Agaibi, C. E., & Wilson, J. P. (2005). Trauma, PTSD, and resilience: a review of the literature. *Trauma Violence Abuse*, 6(3), 195–216. https://doi.org/10.1177/1524838005277438
- Bayer, N. D., Wang, H., Yu, J. A., Kuo, D. Z., Halterman, J. S., & Li, Y. (2021). A national mental health profile of parents of children with medical complexity. *Pediatrics*, *148*(2). https://doi.org/10.1542/peds.2020-023358
- Bardeen, J. R., Fergus, T. A., & Orcutt, H. K. (2013). Experiential avoidance as a moderator of the relationship between anxiety sensitivity and perceived stress. *Behavior therapy*, 44(3), 459–469. https://doi.org/10.1016/j.beth.2013.04.001
- Breneol, S., King, S. T., Best, S., McKibbon, S., & Curran, J. A. (2019). Respite care for children and youth with complex care needs and their families: A scoping review protocol. *JBI Database of Systematic Reviews and Implementation Reports*, 17(7), 1297–1304.

 https://doi.org/10.11124/JBISRIR-2017-003998
- Brophy, K., Brähler, E., Hinz, A., Schmidt, S., & Körner, A. (2020). The role of self-compassion in the relationship between attachment, depression, and quality of life. *Journal of affective disorders*, 260, 45–52. https://doi.org/10.1016/j.jad.2019.08.066
- Campbell-Sills, L., & Stein, M. B. (2007). Psychometric analysis and refinement of the Connordavidson Resilience Scale (CD-RISC): Validation of a 10-item measure of resilience. *Journal of traumatic stress*, 20(6), 1019–1028. https://doi.org/10.1002/jts.20271
- Cella, D., Choi, S. W., Condon, D. M., Schalet, B., Hays, R. D., Rothrock, N. E., Yount, S., Cook, K. F., Gershon, R. C., Amtmann, D., DeWalt, D. A., Pilkonis, P. A., Stone, A. A., Weinfurt, K., & Reeve, B. B. (2019). PROMIS® adult health profiles: Efficient short-form measures of seven

- health domains. *Value in Health*, 22(5), 537–544. https://doiorg.ezproxy.lib.uwm.edu/10.1016/j.jval.2019.02.004
- Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., Amtmann, D., Bode, R., Buysse, D., Choi, S., Cook, K., Devellis, R., DeWalt, D., Fries, J. F., Gershon, R., Hahn, E. A., Lai, J. S., Pilkonis, P., Revicki, D., Rose, M., ... PROMIS Cooperative Group (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *Journal of clinical epidemiology*, 63(11), 1179–1194. https://doi.org/10.1016/j.jclinepi.2010.04.011
- Connor, K. M., & Davidson, J. R. (2003). Development of a new resilience scale: the Connor-Davidson resilience scale (CD-RISC). *Depression and Anxiety*, 18(2), 76–82. https://doi.org/10.1002/da.10113.
- Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. K., Simon, T. D., & Srivastava, R. (2011).

 Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*, 127(3), 529–538. https://doi.org/10.1542/peds.2010-0910
- Dewan, T., Birnie, K., Drury, J., Jordan, I., Miller, M., Neville, A., Noel, M., Randhawa, A., Zadunayski, A., & Zwicker, J. (2022). Experiences of medical traumatic stress in parents of children with medical complexity. *Child: Care, Health and Development, 49*(2), 292–303. https://doi.org/10.1111/cch.13042
- Dias Lopes da Rosa, R., Simões-Neto, J. P., Santos, R. L., Torres, B., Baptista, M. A. T., Kimura, N. R. S., & Dourado, M. C. N. (2020). Caregivers' resilience in mild and moderate Alzheimer's disease. *Aging & Mental Health*, 24(2), 250–258. https://doi-org.ezproxy.lib.uwm.edu/10.1080/13607863.2018.1533520

- Ellzey, A., Valentine, K. J., Hagedorn, C., & Murphy, N. A. (2015). Parent perceptions of quality of life and healthcare satisfaction for children with medical complexity. *Journal of Pediatric Rehabilitation Medicine*, 8(2), 97–104. https://doi.org/10.3233/PRM-150323
- Fernández-Rodríguez, C., Coto-Lesmes, R., Martínez-Loredo, V., & Cuesta-Izquierdo, M. (2022).

 Psychological inflexibility, anxiety and depression: The moderating role of cognitive fusion, experiential avoidance and activation. *Psicothema*, 34(2), 240–248.

 https://doi.org/10.7334/psicothema2021.344
- Foster, C. C., Shaunfield, S., Black, L. E., Labellarte, P. Z., & Davis, M. M. (2022). Improving support for care at home: Parental needs and preferences when caring for children with medical complexity. *Journal of pediatric health care*. *36*(2), 154–164. https://doi.org/10.1016/j.pedhc.2020.08.005
- Gámez, W., Chmielewski, M., Kotov, R., Ruggero, C., Suzuki, N., & Watson, D. (2014). The brief experiential avoidance questionnaire: development and initial validation. *Psychological assessment*, 26(1), 35–45. https://doi.org/10.1037/a0034473
- McCluskey, D. L., Haliwa, I., Wilson, J. M., Keeley, J. W., & Shook, N. J. (2022). Experiential avoidance mediates the relation between mindfulness and anxiety. *Current Psychology*, 41(6), 3947–3957. https://doi.org/10.1007/s12144-020-00929-4
- Hagvall, M., Ehnfors, M., & Anderzén-Carlsson, A. (2016). Experiences of parenting a child with medical complexity in need of acute hospital care. *Journal of Child Health Care*, 20(1), 68–76. https://doi.org/10.1177/1367493514551308
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2012). Acceptance and commitment therapy: The process and practice of mindful change (2nd ed.). New York, NY: Guilford Press.

- Hayes, S. C., Wilson, K. G., Gifford, E. V., Follette, V. M., & Strosahl, K. (1996). Experiential avoidance and behavioral disorders: A functional dimensional approach to diagnosis and treatment. *Journal of Consulting and Clinical Psychology*, 64, 1152–1168.
- Kelifa, M. O., Yang, Y., Carly, H., Bo, W., & Wang, P. (2021). How adverse childhood experiences relate to subjective wellbeing in college students: The role of resilience and depression. *Journal of Happiness Studies: An Interdisciplinary Forum on Subjective Well-Being*, 22(5), 2103–2123. https://doi-org.ezproxy.lib.uwm.edu/10.1007/s10902-020-00308-7
- Lefebvre, J.-I., Montani, F., & Courcy, F. (2020). Self-compassion and resilience at work: A practice-oriented review. *Advances in Developing Human Resources*, 22(4), 437–452. https://doi.org/10.1177/1523422320949145
- Leys, C., Kotsou, I., Shankland, R., Firmin, M., Péneau, S., & Fossion, P. (2021). Resilience predicts lower anxiety and depression and greater recovery after a vicarious trauma. *International journal of environmental research and public health*, 18(23), 12608.

 https://doi.org/10.3390/ijerph182312608
- MacBeth, A., & Gumley, A. (2012). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*, *32*(6), 545–552. https://doi.org/10.1016/j.cpr.2012.06.003
- Meng, X., Fleury, M. J., Xiang, Y. T., Li, M., & D'Arcy, C. (2018). Resilience and protective factors among people with a history of child maltreatment: a systematic review. *Social Psychiatry & Psychiatric Epidemiology*, *53*(5), 453–475. https://doi.org/10.1007/s00127-018-1485-2.
- Min, J. A., Jung, Y. E., Kim, D. J., Yim, H. W., Kim, J. J., Kim, T. S., Lee, C. U., Lee, C., & Chae, J. H. (2013). Characteristics associated with low resilience in patients with depression and/or anxiety disorders. *Quality of Life Research*, 22(2), 231–241. https://doi.org/10.1007/s11136-012-0153-3.

- Murray, C. V., Jacobs, J. I., Rock, A. J., & Clark, G. I. (2021). Attachment style, thought suppression, self-compassion and depression: Testing a serial mediation model. *PloS one*, *16*(1), e0245056. https://doi.org/10.1371/journal.pone.0245056
- Neff, K. D., Bluth, K., Tóth-Király, I., Davidson, O., Knox, M. C., Williamson, Z., & Costigan, A. (2021). Development and validation of the Self-Compassion Scale for Youth. *Journal of personality assessment*, 103(1), 92-105.
- Neff, K. D., Rude, S. S., & Kirkpatrick, K. L. (2007). An examination of self-compassion in relation to positive psychological functioning and personality traits. *Journal of Research in Personality*, 41(4), 908–916. https://doi.org/10.1016/j.jrp.2006.08.002
- Neff, K. D., Tóth-Király, I., Yarnell, L. M., Arimitsu, K., Castilho, P., Ghorbani, N., Guo, H.
 X., Hirsch, J. K., Hupfeld, J., Hutz, C. S., Kotsou, I., Lee, W. K., Montero-Marin, J., Sirois, F.
 M., de Souza, L. K., Svendsen, J. L., Wilkinson, R. B., & Mantzios, M. (2019). Examining the factor structure of the Self-Compassion Scale in 20 diverse samples: Support for use of a total score and six subscale scores. *Psychological Assessment*, 31(1), 27–45. https://doi.org/10.1037/pas0000629
- Pérez-Aranda, A., García-Campayo, J., Gude, F., Luciano, J. V., Feliu-Soler, A., González-Quintela, A., López-Del-Hoyo, Y., & Montero-Marin, J. (2021). Impact of mindfulness and self-compassion on anxiety and depression: The mediating role of resilience. *International journal of clinical and health psychology: IJCHP*, 21(2), 100229. https://doi.org/10.1016/j.ijchp.2021.100229
- Shriver J. (2021). Cost of caregiving on parents of children with medical complexity and life-limiting conditions. *Pediatrics*, *148*(2). https://doi.org/10.1542/peds.2021-050222

- Whitehead, R., Bates, G., Elphinstone, B., & Yang, Y. (2021). The relative benefits of nonattachment to self and self-compassion for psychological distress and psychological well-being for those with and without symptoms of depression. *Psychology and Psychotherapy: Theory, Research and Practice*, 94(3), 573–586. https://doi-org.ezproxy.lib.uwm.edu/10.1111/papt.12333
- Wright-Sexton, L. A., Compretta, C. E., Blackshear, C., & Henderson, C. M. (2020). Isolation in parents and providers of children with chronic critical illness. *Pediatric crit care med.* 21(8). https://doi.org/10.1097/PCC.000000000000002344
- Yela, J. R., Crego, A., Buz, J., Sánchez, Z. E., & Gómez, M. M. Á. (2022). Reductions in experiential avoidance explain changes in anxiety, depression and well-being after a mindfulness and self-compassion (MSC) training. *Psychology and Psychotherapy: Theory, Research and Practice*, 95(2), 402–422. https://doi.org/10.1111/papt.12375
- Yıldırım, J. C., & Bahtiyar, B. (2022). The association between metacognitions and worry: The mediator role of experiential avoidance strategies. *The Journal of Psychology*, 156(8), 552–567. https://doi.org/10.1080/00223980.2022.2107977
- Zessin, U., Dickhäuser, O., & Garbade, S. (2015). The relationship between self-compassion and well-being: A meta-analysis. *Applied Psychology: Health and Well-Being*, 7(3), 340–364. https://doi.org/10.1111/aphw.12051