The Moderating Role of Psychological Flexibility in The Relationship Between Perceived Stress and Well-being in Informal Caregivers

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Abstract

Informal caregivers have large economic value and make a valuable contribution to healthcare, relieving the burden of formal caregivers. Research shows that caregivers experience high levels of stress that has detrimental consequences to their overall well-being. Psychological flexibility (PF) appears to be an important psychological resource for informal caregivers to cope with the stress they experience. This mixed-methods, cross-sectional study investigated the relationship between perceived stress, well-being and PF in informal caregivers using an online survey (*n* = 88) and qualitative interviews (*n* =3). Results showed a negative relationship between perceived stress and well-being, supporting the hypothesis that higher stress correlates with lower well-being. Additionally, PF did not moderate this relationship but partially mediated it, indicating that high stress diminishes PF, subsequently reducing well-being. Qualitative data indicated how informal caregivers experience stress and how it impacts their well-being and PF. The common PF processes included acceptance, committed action, self as context and values. The present study highlights the stress informal caregivers experience, the negative impact of stress on well-being, and the importance of PF to cope with stressful circumstances. Future avenues of research could explore the use of Acceptance and Commitment Therapy to increase PF in combination with state-provided practical support to support the well-being of informal caregivers and their care recipients. These findings highlight the systemic issues that must be addressed to enhance informal caregiver well-being.

Keywords: Informal caregivers, Acceptance and Commitment Therapy, Psychological flexibility, perceived stress, well-being, Psy-Flex, Perceived stress scale, MHC-SF 14, mixed methods

The Moderating Role of Psychological Flexibility in The Relationship Between Perceived Stress and Well-being in Informal Caregivers

Informal caregivers play a valuable role in society by providing unpaid care to a family member, partner or friend who cannot cope without their support due to illness, frailty or disability (Kim et al., 2023). Care recipients are typically; children with an illness or disability who are cared for by young adult parents; adult children with disability or illness who are cared for by middle-aged parents; and older adults who receive care from their spouses or children (Schulz et al., 2020). Additionally, non-kin informal caregivers refer to friends or neighbours providing unpaid care (Broese van Groenou et al., 2013). Research shows that informal caregivers have a large economic value by relieving the burden of formal healthcare providers (Coe et al., 2021). As informal caregivers are not typically accounted for in policy discussions, the demands of caregiving often exceed their capacity to provide care due to a lack of adequate training, follow-up services, revaluation of care arrangements or referrals to state-provided services (Arno et al., 1999). It is well-documented that the nature of stress experienced by caregivers negatively impacts their mental and physical well-being (del-Pino-Casado et al., 2021; Gérain & Zech, 2019). As informal caregivers are the foundation of the care system they must be effectively supported in their role. Supporting informal caregiver's well-being not only benefits the caregiver, but also improves the quality of care received, and care recipient outcomes and may also influence care coordination (Atefi et al., 2023). The present study aims to offer insight into the stress experienced by informal caregivers and what factors contribute to how this stress impacts their well-being and what can do done to moderate this stress.

Informal Caregiver Stress

While caregiving can be a rewarding and gratifying experience, research shows that informal caregivers report exposure to persistent, unpredictable and chronic stressors (Fredriksen-Goldsen et al., 2023). The Caregiver Stress Model (Pearlin et al., 1990), adapted by Broese van Groenou et al (2013) explains how stress experienced by caregivers varies based on objective stressors such as the caregiving context and the care recipient's characteristics, and subjective evaluations like the caregiver's burden and positive feelings towards caregiving. Informal caregivers of critically ill family members face challenges such as monitoring diseases, emotionally supporting their loved ones and sharing the financial burden (Fu et al., 2021). Spousal caregivers report higher burdens due to their closer, more intensive caregiving roles but also higher positive evaluations due to commitment and rewarding aspects of caregiving. Adult children caregivers face challenges in balancing caregiving with other responsibilities while, other caregivers, who appear to have less obligations and are perhaps involved in less intense caregiving, typically report lower burdens and higher satisfaction (Gérain & Zech, 2019). Although the role of informal caregiving varies, the typical domains of this role include: helping with household and self-care tasks, mobility, emotional support, the maintenance of social network, health and medical care, supervision, advocacy and care coordination (Schulz et al., 2020). Caregivers experience great emotional strain, physical demands, financial burdens and social isolation. Caregivers often have to navigate complicated healthcare systems and social services, balance their caregiving responsibilities with other roles and relationships and have little time for self-care or leisure (Teahan et al., 2021).

Informal Caregiver Well-being

Carers of children with Autistic Spectrum Disorder (ASD) have been found to exhibit chronic psychological distress. Biological consequences of this persistent distress include dysregulation of the hypothalamic-pituitary-adrenal axis, a pro-inflammatory state of the immune and central nervous system, and gut microbiome imbalance (Dijkstra-de Neijs et al., 2020). Further, the psychological and physical consequences of caregiving can lead to autonomic imbalance and heightened risk of health issues such as disease, cancer, cardiovascular disease and premature death (Teixeira et al., 2019). Informal caregivers of children with mental disorders suffer occupational consequences including a loss of income, a change in employment status and an excess of mental health problems (Jensen et al., 2023).

Women make up the majority of informal caregivers for family members, likely due to the societal and cultural demands put onto women to adopt this role (Sharma et al., 2016). Gender differences have been observed in informal caregiving psychosocial outcomes, males reported higher levels of loneliness and depressive symptoms while females report lower affect (Zwar et al., 2020). However, Hazell et al (2020) found that younger (under 50), female informal caregivers also appear to have lower levels of well-being. In addition to age and gender, employment status, relationship status, and duration of care appear to predict well-being in informal caregivers (Möller-Leimkühler & Wiesheu, 2012). Research showed that this is an isolating and demanding role which significantly impacts overall well-being and social lives. Caregivers often experience a reduced quality of life and are at an increased risk of illness (Maguire & Maguire, 2020). Further, this stress and its consequences are a public health concern and it is in our best interest to provide additional interventions for these individuals, to mitigate stress and its detrimental consequences to caregivers and their families (Broxson & Feliciano, 2020**).** The effects of caregiving are highly individual, it is widely accepted that stress experienced by caregivers causes a decline in physical and mental health and an overall decreased quality of life (Bevans & Sternberg, 2012). Although caregiver burden is linked to objective stressors such as the duration and intensity of care, as well as the recipient's impairments, it can be moderated by the caregiver's psychological and social resources in addition to secondary stressors like balancing work and family (Gérain & Zech, 2019).

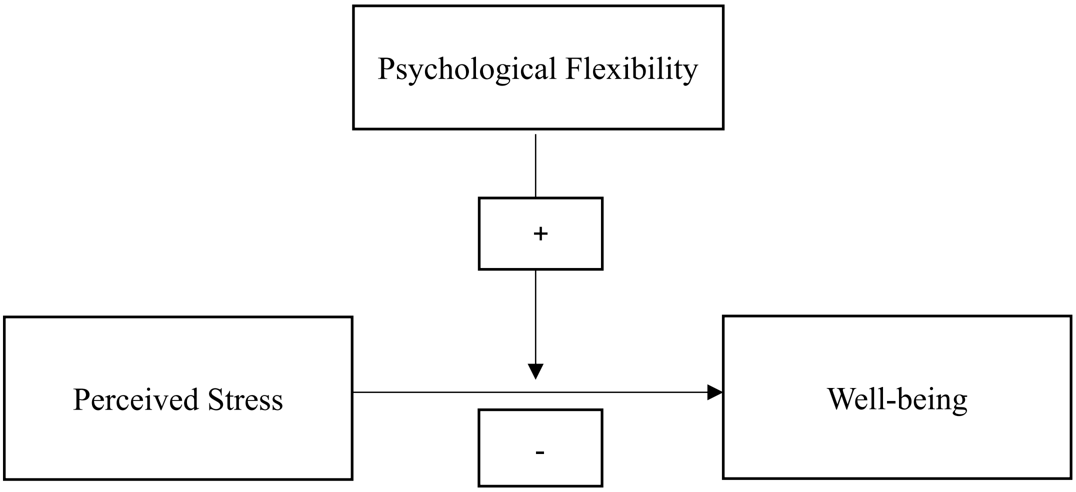
Psychological Flexibility

Psychological flexibility (PF) is seen as a fundamental aspect of health (Kashdan & Rottenberg, 2010) and appears to be an important psychological resource for informal caregivers (Atefi et al., 2023). PF refers to the ability to adapt and adjust one's thoughts, emotions, and behaviours in response to different situations and challenges. It involves being open to experiences, accepting of difficult emotions and committed to acting in line with one's values (Hayes, 2023). An extensive amount of research supports the role of PF in chronic pain management (McCracken, 2024) , healthcare professionals' well-being and patient care (Hayes, 2023), reducing caregiver burden and employee well-being (Garner et al., 2023). PF is a key resilience process that can lead to positive outcomes, such as greater compassion satisfaction and lower compassion fatigue. It is associated with increased resilience and enhanced mental health and quality of life (Klein et al., 2023). PF promotes well-being and adapting to challenging circumstances, a vital characteristic for informal caregivers (Jansen et al., 2017). Recent research has illustrated the relationship between PF and lower levels of caregiver burden, depression, and anxiety symptoms. Morimoto (2024) found that informal caregivers of family members with dementia with high levels of PF exhibited greater life satisfaction than caregivers who had lower PF profiles. Further, caregivers with low PF displayed higher levels of depression, anxiety, and work-family conflict. Additionally, defusion and acceptance were found to be more beneficial than commitment to personal values in moderating distress. The moderating role of PF has been shown in the relationship between appraisals and outcomes amongst informal caregivers (Kishita et al., 2020). This is also the case in parents of children with disabilities with PF enhancing parental functioning and was positively associated with reduced stress, anxiety, depression and burnout (Gur & Reich, 2023).

The present study aims to build on previous research investigating the role of PF in informal caregiver stress and wellbeing and will offer insight into how PF can be utilised to ameliorate the negative impacts of informal caregiving. This will be done by investigating the relationship between and perceived stress (PS) and well-being in a sample of self-identified informal caregivers and by testing to see if PF plays a moderating role in this relationship. We are interested in what the relationship is between PS and well-being in informal caregivers. Specifically, it is hypothesised that perceived stress will be associated with lower well-being in informal caregivers (H_1). Secondly, we are interested in whether PF moderates this relationship. Based on previous research, it is expected that PF moderates the relationship between perceived stress and well-being in informal caregivers, such that individuals with higher levels of PF will demonstrate a weaker negative impact of perceived stress on well-being compared to individuals with lower levels of PF (See Figure 1) (H_2). Further, the current study also aims to explore the daily experiences of caregivers, specifically their daily stressors, coping practices and how they utilise PF in daily life.

Figure 1

Conceptual Diagram of the Hypothesised Moderation Model



Methods

Research Design

This cross-sectional study utilised a mixed methods approach, integrating quantitative data from an online survey with qualitative insights from semi-structured interviews. The survey, consisting of psychometric measures and demographic questions, measured perceived stress, well-being, and psychological flexibility. Three semi-structured interviews with informal caregivers provided additional qualitative data (Braun & Clarke, 2014).

Participants

Quantitative data

Participants were recruited via online advertisements on social media platforms (LinkedIn, Instagram, WhatsApp groups), caregiver-specific Reddit threads, and Facebook groups. From April 2nd to May 15th, 2024, 150 participants responded. Inclusion criteria were: (1) being a self-identified informal caregiver, (2) aged 18 years or older, (3) providing informed consent. Data were excluded if participants did not complete all survey sections (n=63) or were not current informal caregivers (n=4). The final sample included 88 participants (84 females, 2 males, 2 non-binary). Forty participants did not provide their age; the remaining 48 ranged from 23 to 64 years (M = 46.7, SD = 10). This may have been due to privacy concerns (Kabacińska et al., 2020) or fear of stigma (Cary & Chasteen, 2015). Table one illustrates an overview of participant demographic information.

Table 1.

Sample Demographic Characteristics

Variable	*n*	%
Gender		
Female	83	94.3
Male	3	3.4
Non-binary	2	2.3
Relationship to care recipient		
Parent	53	60.2
Child	21	23.8
Partner	5	5.7
Sibling	3	3.4
Other relative	5	5.7
Non-relative	1	1.1
Marital status		
Married	56	63.6
Widowed	2	2.3
Divorced	3	3.4
Separated	7	7.9
Never married	20	22.7
Cultural background		
Western (e.g., European, North American)	85	96.6
Eastern (e.g. Asian)	1	1.1
Hawaiian	1	1.1
Hispanic	1	1.1
Occupation		
Employed	42	47.7
Not employed, looking for work	4	4.55
Not employed/able to work	23	26.14
Self-employed	5	5.68
Employed part-time	3	3.41
Retired	10	11.36

Qualitative Data

Three self-identified informal caregivers took part in semi-structured interviews where they were asked open-ended questions related to stress, PF and well-being. Recruitment was done through the online survey, where they agreed to be contacted for an interview. Informed consent was obtained before the interview. Participants were female with a mean age of 52 (SD = 9.81).

Table 2

Demographic information of interview participants

Participant	Nationality	Marital Status	Occupation	Cares for
Participant 1 (P1)	Irish	Married	Retired	Father with Alzheimer's
Participant 2 (P2)	Irish	Married	Employed full-time	Child with Down Syndrome
Participant 3 (P3)	American	Divorced	Unemployed, unable to work due to caregiving responsibilities	Elderly man with physical disability, Man with a traumatic brain injury

Instruments

Quantitative data

An online cross-sectional survey was developed and administered using Qualtrics. The survey consisted of six sections: (1) an information and informed consent form (see Appendix B), (2) mental health-related measures, (3) a demographic questionnaire, and (4) an invitation to provide consent to be contacted for an interview.

Psy-Flex. The Psy-Flex (Gloster et al., 2021), a brief, contextually sensitive measure that assesses the presence of the core skills of PF in the last seven days was used to measure PF. The psy-flex is a valid and reliable tool that accurately measures psychological flexibility. It includes six questions rated on a 5-point Likert scale, responses range from 1 to 5, "very often" to "very rarely". Higher scores indicate greater levels of psychological flexibility. The present study exhibited a Cronbach's α of 0.75, indicating good internal consistency.

Perceived Stress Scale The Perceived Stress Scale (Cohen et al., 1983) was used to measure perceived stress. The PSS is concise, easy to administer, and has been widely used and validated in diverse populations, including caregivers (Abramowitz & Deacon, 2006). It focuses on the degree to which individuals believe their life has been unpredictable, uncontrollable, and overloaded over the past month, which aligns well with common stressors experienced by caregivers. It utilised a 5-point Likert scale rating from 0 indicating “never”, to 4 indicating “very often”. The present study exhibited Cronbach’s α of 0.90 indicating excellent internal consistency.

Mental Health Continuum – Short Form. The Mental Health Continuum – Short From (MHC-SF; Kelley, 2002), a brief survey that derives from the long form (MHC-LF) was used to measure well-being and mental health in a holistic manner that goes beyond the scope of stress or burden often associated with caregiving role. The MHC-SF consists of 14 items (3 emotional well-being items, 6 psychological well-being items, 5 social wellbeing items) to reflect eudemonic wellbeing. The questions refer to experiences in the past month. Responses were given on a 6-point Likert scale ranging from 0 “never” to 5 “everyday”. It is validated and widely used in research to measure well-being across diverse groups. The present study exhibited Cronbach’s α of 0.92 indicating excellent internal consistency.

Demographic Questions. Participants were asked to answer questions related to their age in years, gender, occupation, relationship to the individual they care for and the cultural background they most closely identify with

Qualitative data

Topic List. The online interviews followed a semi-structured format and the topic list outlined in Appendix D. The topic list consisted of six sections: general introduction, caregiving experience, stressors associated with caregiving, well-being, psychological flexibility, and additional questions. The general introduction included an explanation of the study’s scope and verbal informed consent.

Online Communication Platform. Interviews took place on Microsoft Teams due to its accessibility and scheduling element.

Data Collection

Quantitative Data

After ethical approval, data were collected via an anonymous online survey. Participants consenting to an interview provided contact details for follow-up.

Qualitative Data

Participants were interviewed via Microsoft Teams. Interviews were recorded, transcribed, and anonymised for analysis.

Data Processing and Analysis

Quantitative Data

Data Preparation. The collected data was downloaded from Qualtrics as a csv file and imported into R studio Version 2023.12.1+402. The survey responses were scored according to instrument guidelines, resulting in three variables for each participant and demographic variables.

Preliminary Data Screening. Data were cleaned to address incomplete, incorrect, or improperly formatted entries. A visual inspection identified any missing values or outliers, but no substantial outliers were found. Mean imputation replaced randomly missing values. Participants who did not meet inclusion criteria or had significant missing data were excluded. Scores for Psy-Flex, Perceived Stress, and MHC-SF were calculated. The cleaned data were tested for normality, linearity, homoscedasticity, and multicollinearity.

Data Analysis. Power analysis using G*Power (version 3.1.9.6) revealed that a sample of 81 was required to detect a large effect size ($f^2 = 0.8$). R studio was used to conduct data analysis. Descriptives of all variables were obtained. Correlation matrix was conducted to identify correlations between perceived stress, well-being and psychological flexibility.

Multiple linear regression analysis was used to assess the relationship between perceived stress and well-being, and moderation analysis was used to identify a moderating effect of psychological flexibility on this relationship. An exploratory mediation analysis was also conducted.

Qualitative Data

Data Preparation. Transcriptions were reviewed, adapted and anonymised according to the interview recording to ensure accuracy and promote familiarity with the data as recommended by Braun & Clarke, (2006).

Analysis. Transcriptions were thematically analysed following Braun and Clarke's (2006) six-phase methodology (familiarisation, coding, searching for themes, reviewing themes, defining and name themes and write up) using NVivo.

Results

Quantitative Data

Descriptive Statistics

Table 2 illustrates descriptive statistics, including intercorrelations, means and standard deviations. Perceived stress was, as hypothesised significantly negatively related to well-being and psychological flexibility. Further, psychological flexibility was significantly positively associated with well-being.

Table 2.

Means, standard deviation and correlations between variables Psy-Flex, MHC-SF and Perceived Stress Scale

Variable	*M*	*SD*	1	2	3
1. Perceived-Stress	23.27	6.97	-		
2. Well-being	32.26	14.54	- 0.70**	-	
3. Psychological Flexibility	20.81	4.15	- 0.53**	0.48**	-

**p < .001

Note. N = 84. *M* = mean score, *SD* = standard deviation

Inferential Statistics

Hypothesis 1. Multiple Linear Regression Analysis

A multiple linear regression analysis examined the relationship between perceived stress (PS) and well-being (MHC-SF) controlling for gender, cultural background, marital status, relationship to care recipient and occupation.

The results showed that PS significantly predicted well-being ($\beta = -1.44$ SE = 0.19, $p < 0.001$), with higher levels of perceived stress being associated with lower well-being. However, none of the demographic control variables (gender, occupation, marital status, cultural background and relationship to care recipient) showed a significant effect on well-being.

The overall regression model was statistically significant, F(20, 66) = 4.31, $p < .001$, indicating that the combination of PS and demographic variables significantly explained variance in well-being. The model accounted for approximately 56.7% of the variance in mental health scores ($R^2 = 0.57$, Adjusted $R^2 = 0.44$).

Hypothesis 2. Moderation Analysis

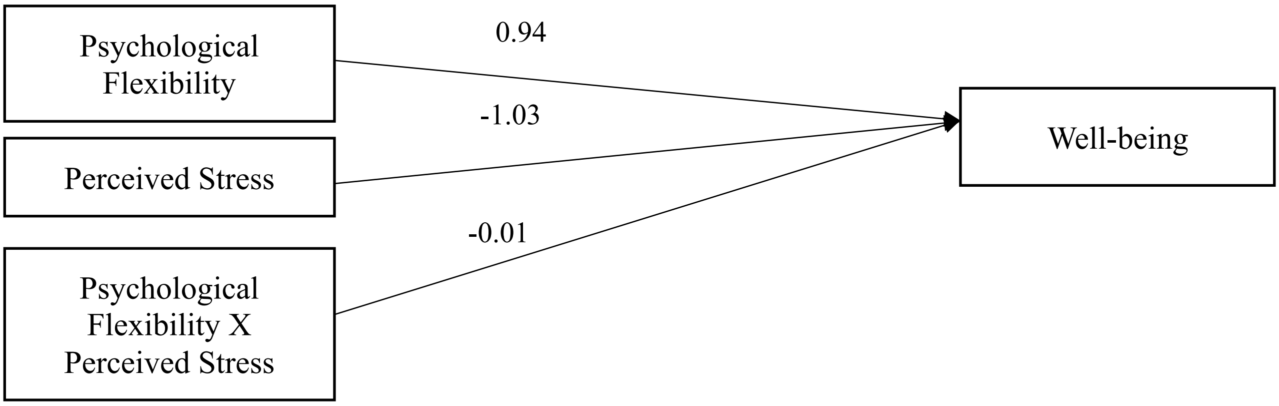
A multiple linear regression was conducted to examine the relationship between well-being (DV) and PS and PF (IVs) and their interactions. Gender, cultural background, marital status, occupation and relationship to the care recipient were controlled for. Figure 2 shows the statistical model for moderation including the interaction between PF and PS.

The results revealed that neither PS ($\beta = -1.03$, $p = 0.314$) nor PF ($\beta = 0.94$, $p = 0.444$) had a significant direct effect on well-being. Similarly, none of the control variables (gender, relationship status, occupation, and relationship to the care recipient) showed significant effects on mental health scores. The interaction term between PS and PF did not significantly moderate the relationship with well-being ($\beta = -0.01$, $p = 0.834$).

The overall regression model was statistically significant, $F(22, 64) = 4.12$, $p < .001$, indicating that the combination of PS, PF and control variables explained a significant proportion of the variance in well-being. The model accounted for approximately 58.6% of the variance in well-being ($R^2 = 0.59$, Adjusted $R^2 = 0.44$).

Figure 2

Statistical Diagram of the Moderation Model



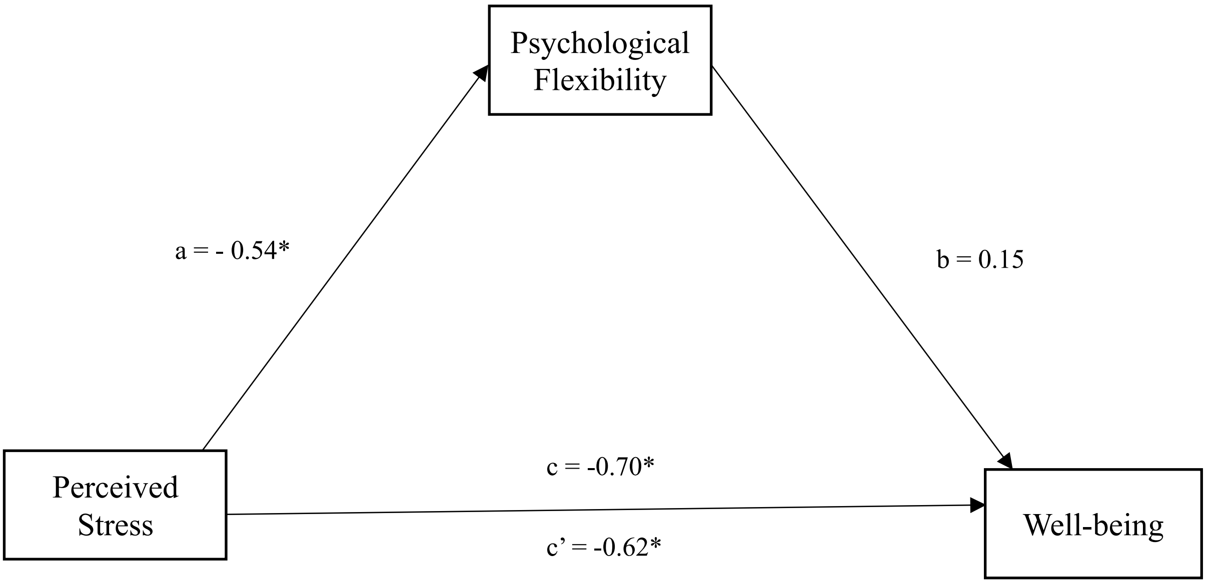
Note. Total N =84

Exploratory Mediation Analysis

An exploratory mediation analysis revealed that PS had a significant direct effect on well-being ($\beta = -1.30$, $t(85) = -6.93$ $p < .001$) as well as an indirect effect through PF ($\beta = -0.17$, 95% CI [-0.30, -0.05] $p < .05$). PF partially mediated the relationship between PS and wellbeing, accounting for approximately 14% of the total effect (95% CI [0.07, 0.25], $p < .05$)

Figure 3

Diagram of Standardised Path Coefficients of the Mediation Model



*p < .01

Qualitative Data

Analysis of interviews revealed consistent expressions of caregiving stress and its impact on well-being. A varied expression of PF was detected with some participants practicing elements of PF through therapy. Main sources of stress included lack of support from the state/community, constant vigilance and the impact of caregiving on other important relationships. Ten key themes were identified (See appendix F) according to three categories: Stress (emotional strain and stress, constant pressure, demands outweigh caregivers capacity to provide, lack of support from state or community), Well-being (impact of stress on physical health, impact of caregiving on relationships, importance of support systems) and Psychological flexibility (acceptance, committed action and self as context, values).

Stress

Emotional strain and stress

All participants indicated feelings of emotional strain and stress concerning their caregiving responsibilities. All participants reported that they felt high levels of stress every day, they described feeling overwhelmed, frustrated, undervalued and emotional (Quotation 8, Table 1) with two participants referencing losing their temper at times (Quotation 4, Table 1).

Constant pressure

Each participant discussed how they must remain available via the phone (Quotation 11, Table 1). Caregivers experienced relentless stress, even when away, impacting their personal lives and work. Additionally, all participants described difficulty during normal, seemingly easy or stress-free tasks (Quotation 22, Table 1). Additionally, two participants described not being able to drop their caregiving responsibilities because there would be no one else who could do it (Quotation 30, Table 1)

Demands outweigh the caregiver's capacity to provide

Two participants reported having significant difficulties acquiring specialised support referencing long waiting lists, lack of resources or unsatisfactory treatments (Quotation 38,

Table 1). One participant reported the process of organising formal care being extremely stressful due to dynamics with fellow caregivers. The other two participants expressed the desire to receive additional help with caregiving and often feel overwhelmed by their responsibilities.

The lack of support from the state or community

All participants reported feeling unsatisfied with state-provided services and were left to compensate for their lack of support. One participant reported being mainly satisfied with her personal experience with private formal caregiving and her community due to her sharing her caregiving role with several others and having the financial abilities to fund formal caregiving. Two participants reported the lack of support from their community and state as detrimental to their well-being and the care their care recipient(s) receive, both expressed their desire for state-provided respite care (Quotation 47, Table 1). Two participants (one caregiving alone and the other with her husband) described having no one from their community that they could reach to for support and that the few state-provided resources (if any) were unsatisfactory due to religious affiliations, long waiting lists, staffing issues and inappropriate opening hours (Quotation 46, Quotation 53, Table 1). In addition, two participants described that the community-provided activities were unsuitable for their care recipients, with one being excluded from extra-curricular activities due to her disability.

Well-being

Impact of stress on physical health

All participants reported poor sleep, tiredness and stress-related ailments (Quotation 61, Table 1). All participants felt tired frequently. One participant and her partner suffered serious illnesses within the last three years and thought it was due to caregiving-related stress (Quotation 65, Table 1).

Impact of caregiving on relationships

Caregiving caused conflicts and tension in relationships, with only one participant maintaining a satisfactory social life through shared caregiving duties (Quotation 69, Table 1). Tensions and disagreements with other caregivers occurred often. Further, one participant reported feeling that her non-caregiving loved ones do not understand the gravity of her situation and another participant had no social circle due to her caregiving responsibilities dominating her life (Quotation 76, Table 1). Two participants had young children who they cannot dedicate as much time to as they would like because of caregiving (Quotation 77, Table 1)

Importance of support systems

Support from others, including formal caregivers, significantly reduced stress. However, one participant lacked any support system, increasing her stress and loneliness. (Quotation 74, Table 1).

Psychological Flexibility

Acceptance

All participants exhibited feelings of acceptance towards their situation and acknowledged the lifestyle changes and adaptations they have had to make to facilitate caregiving. Additionally, one participant described accepting the differences between herself and the other caregivers and understanding the limits to their caregiving abilities (Quotation 88, Table 1). One participant also emphasised acceptance as a coping skill Quotation 94, Table

1). Two participants exhibited acceptance following receiving therapy (Quotation 90, Table 1).

Committed Action and self as context

Seeking therapy and setting boundaries helped manage stress for some participants. (Quotation 96, Table 1). These participants also discussed the relief they received through paying for some formal caregiving (Quotation 100, Table 1). One participant did not have the resources to get help but described the importance of taking time to herself each morning before beginning her caregiving responsibilities (Quotation 104, Table 1).

Values

Focusing on important values (Quotation 108, Table 1) and maintaining a positive outlook provided joy and fulfilment despite caregiving challenges (Quotation 106, Table 1).

Mixed Methods

Quantitative results showed a significant negative correlation between perceived stress and well-being: higher stress levels corresponded to lower well-being. supported by qualitative descriptions of caregiving stress's adverse effects. Additionally, psychological flexibility (PF) was positively associated with well-being. Although PF did not moderate the stress-well-being relationship, exploratory analysis suggested that PF mediates this relationship. Qualitative interviews showed all participants exhibited elements of PF, acceptance, mindfulness, and boundary setting, which helped participants cope with caregiving stress.

The first participant demonstrated PF through acceptance, mindfulness, and boundary-setting, aligning with ACT principles. Two participants utilized therapy to manage stress through mindfulness, breathwork, and recognizing their worth as caregivers. The second participant, despite high stress, exhibited PF through acceptance, value commitment, and cognitive defusion. The third participant also showed PF through staying present, acceptance, and committed action.

Discussion

The present mixed-methods study aimed to investigate the relationship between perceived stress, well-being and psychological flexibility (PF) in the context of informal caregivers. In addition, the experiences of informal caregivers were qualitatively examined to obtain a holistic view of how caregiver's experience stress, well-being and PF. On average, participants exhibited moderate to high levels of perceived stress, aligning with the existing literature on the high stress experienced by caregivers (Kim et al., 2023). A significant, negative effect of perceived stress on well-being was detected supporting H_1 such that that higher levels of perceived stress are associated with lower levels of well-being among informal caregivers. However, PF did not moderate the relationship between perceived stress and well-being, deviating from H_2. An exploratory mediation analysis showed that PF partially mediated this relationship. Specifically, the analysis indicated that higher levels of perceived stress led to lower PF which in turn leads to lower well-being. The qualitative data added contextual insights to these findings. Participants consistently reported emotional strain, constant pressure, and caregiving demands that exceeded their capabilities. In terms of PF, participants mentioned acceptance, values and committed action which they described as important or helpful. Despite this, results aligned with previous findings that caregiving stress negatively impacts well-being (Longobardo et al., 2023). Participants experienced a lack of sleep (Brewster et al., 2024), feeling isolated (Boamah et al., 2024), illness (Christian et al., 2023), physical symptoms, pervasive low mood, sadness, and anxiety (Chakraborty et al., 2023).

These findings highlight the detrimental effects of caregiver stress and positive effects of PF on overall well-being. Further, the results suggests that despite PF contributing to well-being, it does not significantly moderate the negative effects of stress on well-being amongst caregivers. This finding contrasts with the existing literature from the general population (Gloster et al., 2017), and in caregivers (Landi et al., 2021) where a moderating role of PF against adverse experiences was detected (Pakenham et al., 2020). This indicates that regardless of how psychologically flexible or inflexible a caregiver is, the negative relationship between stress and well-being remains consistent. The mediation analysis however showed that PF can partially mediate the relationship. It appears that high levels of perceived stress negatively impact the ability to remain psychologically flexible. As PF diminishes, individuals may struggle more with stress, thus negatively impacting well-being. This aligns with prior studies (Jansen et al., 2017), suggesting that PF plays a role in the way in which stress impacts well-being, though it may not completely buffer the impact of stress

The distinction between moderation and mediation is important for understanding the mechanisms by which PF influences the well-being of caregivers (Aguinis et al., 2017). There are some possible reasons for why the moderating effect of PF was not significant. The overwhelming stress reported by participants may be so pervasive that PF is unable to alter its direct impact on wellbeing (Fredriksen-Goldsen et al., 2023). Essentially, even though PF is a powerful resource for informal caregivers (Jansen et al., 2017), it may not solely mitigate the adverse effects of such intense stress on well-being (Sheehan et al., 2021). The qualitative data supports this. Despite the discussed stressors, several elements of PF, such as acceptance, values, and other ACT principles were evident among participants. While these attitudes and practices were described as helpful or important, participants still reported a detrimental effect of stress on their personal well-being and cited the systemic issues that have made their life as caregiver much more difficult than it should be. This finding suggests that while PF techniques can provide relief (Atefi et al., 2023), they may not be sufficient on their own to counteract the high levels of stress experienced by caregivers.

These findings have several important implications for the development of interventions aimed at supporting informal caregivers. Firstly, this study emphasised the urgent need for systemic change in the way informal caregivers and their recipients are treated in society. A system must be put in place to provide caregivers support in a person-centred, needs-based matter (Kirvalidze et al., 2023). State provided, accessible training in PF techniques have potential to give caregivers the mental resources to cope with their stresses (Atefi et al., 2023). This should be put in place in combination with practical support such as respite care, education and accessible mental health services (Gemito et al., 2024). The improvement of state provided services, easier access to formally trained caregivers, waiting list reductions, financial support, community activities appear to reduce stress in caregivers (Lindt et al., 2020; Price et al., 2020). Further, not only does stress impact the individual and their care recipients (Atefi et al., 2023), but this stress may also lead to a higher demand of healthcare resources (Arno et al., 1999). This issue extends beyond caregivers and care recipients but also for larger society. It is known that the population is aging and with that comes a demand for care of elderly and chronically ill patients (Cristea et al., 2020), supporting informal caregivers is mandatory to facilitate care systems and promote wellbeing in the population (Lindt et al., 2020)

Limitations of the Present Study

While this study provides valuable insights due to its' mixed method approach (McKim, 2017) there are some limitations that must be addressed. The sample of mainly females with a western cultural background may limit the generalisability of the findings. Research shows different attitudes to caregiving across cultures, ages (Lindt et al., 2020) and genders (Price et al., 2020) extending this research to a more diverse sample would provide a more comprehensive understanding of caregiver stress and PF. Age could not be controlled for during analysis due to half of the participants abstaining from providing their age, future research could ask participants to provide age ranges instead so that this can be controlled for. Further, the cross-sectional design and use of self-report measures in this study limits the ability to make causal conclusions and may be subject to bias. Longitudinal studies that examine these relationships over time, using objective measures of stress and well-being such as physical indicators (König v. Borstel et al., 2017) could enhance the robustness of these results. Future avenues of research could also examine the role PF in combination with practical support to illustrate the importance of providing caregiver support and to better understand the complex interactions between stress, well-being and PF.

Conclusion

This study shed light on the relationship between perceived stress, well-being and PF in informal caregivers. PF appears to be an important resource in enhancing well-being, but does not effectively moderate the negative effects of stress. Systemic issues such as long waiting lists, and lack of resources must be addressed. This, along and the implementation of PF-enhancing interventions have potential for reducing caregiver stress, improving their well-being and the care they provide. Future avenues of research could address this study's limitations to better inform effective caregiver support interventions.

Data collection

Quantitative

For the quantitative analysis, a survey developed by the researcher with Qualtrics was used to measure perceived stress, well-being, and psychological flexibility amongst self-identified informal caregivers. Prior to publication, the survey was piloted by three individuals to ensure accessibility. The survey was distributed with a poster (created on Canva), QR code and anonymous link (generated with Qualtrics) via social media posts on Instagram stories, and caregiver groups on Facebook and Reddit. It was also sent to family and friends via email and WhatsApp who were encouraged to share with any informal caregivers that they know.

Qualitative

Three email addresses were randomly selected from the participants who provided their email to be contacted for an interview ($n = 34$). This was done by generating the responses to this question in the Results tab on Qualtrics. These participants were emailed and invited to provide a time when they could meet over Microsoft Teams and the meetings were scheduled. Videos were recorded and transcribed using Microsoft Teams. Interview questions were piloted to an informal caregiver known to the researcher, which were not included in analysis.

References

Abramowitz, J. S., & Deacon, B. J. (2006). Psychometric properties and construct validity of the Obsessive–Compulsive Inventory—Revised: Replication and extension with a clinical sample. *Journal of Anxiety Disorders*, *20*(8), 1016–1035. https://doi.org/10.1016/j.janxdis.2006.03.001

Aguinis, H., Edwards, J. R., & Bradley, K. J. (2017). Improving Our Understanding of Moderation and Mediation in Strategic Management Research. *Organizational Research Methods*, *20*(4), 665–685. https://doi.org/10.1177/1094428115627498

Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs (Project Hope)*, *18*(2), 182–188. https://doi.org/10.1377/hlthaff.18.2.182

Atefi, G. L., de Vugt, M. E., van Knippenberg, R. J. M., Levin, M. E., Verhey, F. R. J., & Bartels, S. L. (2023). The use of Acceptance and Commitment Therapy (ACT) in informal caregivers of people with dementia and other long-term or chronic conditions: A systematic review and conceptual integration. *Clinical Psychology Review*, *105*, 102341. https://doi.org/10.1016/j.cpr.2023.102341

Bevans, M., & Sternberg, E. M. (2012). Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients. *JAMA*, *307*(4), 398–403. https://doi.org/10.1001/jama.2012.29

Boamah, S. A., Weldrick, R., Yous, M.-L., Gao, H., Garnett, A., Dal Bello-Haas, V., & Kaasalainen, S. (2024). “Picturing a Way Forward”: Strategies to Manage the Effects of COVID-19-Related Isolation on Long-Term Care Residents and Their Informal Caregivers. *The Gerontologist*, *64*(1), gnad035. https://doi.org/10.1093/geront/gnad035

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brewster, G. S., Wang, D., McPhillips, M. V., Epps, F., & Yang, I. (2024). Correlates of Sleep Disturbance Experienced by Informal Caregivers of Persons Living with Dementia: A Systematic Review. *Clinical Gerontologist*, *47*(3), 380–407. https://doi.org/10.1080/07317115.2022.2139655

Broese van Groenou, M. I., de Boer, A., & Iedema, J. (2013). Positive and negative evaluation of caregiving among three different types of informal care relationships. *European Journal of Ageing*, *10*(4), 301–311. https://doi.org/10.1007/s10433-013-0276-6

Broxson, J., & Feliciano, L. (2020). Understanding the Impacts of Caregiver Stress. *Professional Case Management*, *25*(4), 213. https://doi.org/10.1097/NCM.0000000000000414

Cary, L. A., & Chasteen, A. L. (2015). Age Stereotypes and Age Stigma: Connections to Research on Subjective Aging. *Annual Review of Gerontology and Geriatrics*, *35*(1), 99–119. https://doi.org/10.1891/0198-8794.35.99

Chakraborty, R., Jana, A., & Vibhute, V. M. (2023). Caregiving: A risk factor of poor health and depression among informal caregivers in India- A comparative analysis. *BMC Public Health*, *23*(1), 42. https://doi.org/10.1186/s12889-022-14880-5

Christian, L. M., Wilson, S. J., Madison, A. A., Prakash, R. S., Burd, C. E., Rosko, A. E., & Kiecolt-Glaser, J. K. (2023). Understanding the health effects of caregiving stress: New directions in molecular aging. *Ageing Research Reviews*, *92*, 102096. https://doi.org/10.1016/j.arr.2023.102096

Coe, N. B., Konetzka, R. T., Berkowitz, M., Blecker, E., & Van Houtven, C. H. (2021). The Effects of Home Care Provider Mix on the Care Recipient: An International, Systematic Review of Articles from 2000 to 2020. *Annual Review of Public Health*, *42*, 483–503. https://doi.org/10.1146/annurev-publhealth-090419-102354

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, *24*(4), 385–396.

Cristea, M., Noja, G. G., Stefea, P., & Sala, A. L. (2020). The Impact of Population Aging and Public Health Support on EU Labor Markets. *International Journal of Environmental Research and Public Health*, *17*(4), Article 4. https://doi.org/10.3390/ijerph17041439

Dijkstra-de Neijs, L., Leenen, P. J. M., Hays, J. P., van der Valk, E. S., Kraaij, R., van Rossum, E. F. C., & Ester, W. A. (2020). Biological Consequences of Psychological Distress in Caregivers of Children with Autism Spectrum Disorder and its Potential Relevance to Other Chronic Diseases Including Cancer. *Current Epidemiology Reports*, *7*(3), 139–148. https://doi.org/10.1007/s40471-020-00237-2

Fredriksen-Goldsen, K., Shuman, A., Jen, S., & Jung, H. H. (2023). Stress and Resilience among Sexual and Gender Diverse Caregivers. *Research on Aging*, *45*(9–10), 654–665. https://doi.org/10.1177/01640275231156191

Fu, W., Li, J., Fang, F., Zhao, D., Hao, W., & Li, S. (2021). Subjective burdens among informal caregivers of critically ill patients: A cross-sectional study in rural Shandong, China. *BMC Palliative Care*, *20*(1), 167. https://doi.org/10.1186/s12904-021-00858-4

Gemito, L., Alves, E., Moreira, J., Marques, M. F., Caldeira, E., Ferreira, R., Bico, I., Pinho, L., Fonseca, C., Sousa, L., & Lopes, M. (2024). Programmes Addressed to Informal Caregivers' Needs: A Systematic Literature Review. *Geriatrics*, *9*(3), Article 3. https://doi.org/10.3390/geriatrics9030071

Gérain, P., & Zech, E. (2019). Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving. *Frontiers in Psychology*, *10*. https://doi.org/10.3389/fpsyg.2019.01748

Gloster, A. T., Block, V. J., Klotsche, J., Villanueva, J., Rinner, M. T. B., Benoy, C., Walter, M., Karekla, M., & Bader, K. (2021). Psy-Flex: A contextually sensitive measure of psychological flexibility. *Journal of Contextual Behavioral Science*, *22*, 13–23. https://doi.org/10.1016/j.jcbs.2021.09.001

Gloster, A. T., Meyer, A. H., & Lieb, R. (2017). Psychological flexibility as a malleable public health target: Evidence from a representative sample. *Journal of Contextual Behavioral Science*, *6*(2), 166–171. https://doi.org/10.1016/j.jcbs.2017.02.003

Hayes, L. L. (2023). Psychological flexibility is the ACE we need: A commentary on ACEs screening in adolescent primary care: Psychological flexibility as a moderator. *Families, Systems, & Health*, *41*(2), 274–275. https://doi.org/10.1037/fsh0000810

Hazell, C. M., Hayward, M., Lobban, F., Pandey, A., Pinfold, V., Smith, H. E., & Jones, C. J. (2020). Demographic predictors of wellbeing in Carers of people with psychosis: Secondary analysis of trial data. *BMC Psychiatry*, *20*, 269. https://doi.org/10.1186/s12888-020-02691-0

Jansen, J. E., Haahr, U. H., Lyse, H.-G., Pedersen, M. B., Trauelsen, A. M., & Simonsen, E. (2017). Psychological Flexibility as a Buffer against Caregiver Distress in Families with Psychosis. *Frontiers in Psychology*, *8*. https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2017.01625

Jensen, J. H., Flachs, E. M., Gensby, U., Thorup, A. A., We, H. M., Hidalgo, M. A. A., & Albertsen, K. (2023). P-152 Mental health and employment consequences among informal caregivers at work a Danish nationwide register-study. *Occupational and*

Environmental Medicine, *80*(Suppl 1), A42–A43. https://doi.org/10.1136/OEM-2023-EPICOH.101

Kabacińska, K., Sharma, N., Kaye, J., Mattek, N., Kuzeljevic, B., & Robillard, J. M. (2020). Investigating the concept of participant burden in aging technology research. *BMC Geriatrics*, *20*, 50. https://doi.org/10.1186/s12877-020-1441-3

Kashdan, T. B., & Rottenberg, J. (2010). Psychological flexibility as a fundamental aspect of health. *Clinical Psychology Review*, *30*(7), 865–878. https://doi.org/10.1016/j.cpr.2010.03.001

Kim, Y., Lin, J., Epel, E. S., & Carver, C. S. (2023). A Lens on Caregiver Stress in Cancer: Longitudinal Investigation of Cancer-Related Stress and Telomere Length Among Family Caregivers of Adult Patients With Cancer. *Psychosomatic Medicine*, *85*(6), 527. https://doi.org/10.1097/PSY.0000000000001220

Kirvalidze, M., Abbadi, A., Dahlberg, L., Sacco, L. B., Morin, L., & Calderón-Larrañaga, A. (2023). Effectiveness of interventions designed to mitigate the negative health outcomes of informal caregiving to older adults: An umbrella review of systematic reviews and meta-analyses. *BMJ Open*, *13*(4), e068646. https://doi.org/10.1136/bmjopen-2022-068646

Klein, R. J., Jacobson, N. C., & Robinson, M. D. (2023). A psychological flexibility perspective on well-being: Emotional reactivity, adaptive choices, and daily experiences. *Emotion*, *23*(4), 911–924. https://doi.org/10.1037/emo0001159

König v. Borstel, U., Visser, E. K., & Hall, C. (2017). Indicators of stress in equitation. *Applied Animal Behaviour Science*, *190*, 43–56. https://doi.org/10.1016/j.applanim.2017.02.018

Landi, G., Pakenham, K. I., Benassi, M., Giovagnoli, S., Tossani, E., & Grandi, S. (2021). A Model of the Effects of Parental Illness on Youth Adjustment and Family Functioning:

The Moderating Effects of Psychological Flexibility on Youth Caregiving and Stress. *International Journal of Environmental Research and Public Health*, *18*(9), Article 9. https://doi.org/10.3390/ijerph18094902

Lindt, N., van Berkel, J., & Mulder, B. C. (2020). Determinants of overburdening among informal carers: A systematic review. *BMC Geriatrics*, *20*(1), 304. https://doi.org/10.1186/s12877-020-01708-3

Longobardo, L. M. P., Rodríguez-Sánchez, B., & Oliva, J. (2023). Does becoming an informal caregiver make your health worse? A longitudinal analysis across Europe. *Economics & Human Biology*, *50*, 101264. https://doi.org/10.1016/j.ehb.2023.101264

Maguire, R., & Maguire, P. (2020). Caregiver Burden in Multiple Sclerosis: Recent Trends and Future Directions. *Current Neurology and Neuroscience Reports*, *20*(7), 18. https://doi.org/10.1007/s11910-020-01043-5

McCracken, L. M. (2024). Psychological Flexibility, Chronic Pain, and Health. *Annual Review of Psychology*, *75*(1), 601–624. https://doi.org/10.1146/annurev-psych-020223-124335

McKim, C. A. (2017). The Value of Mixed Methods Research: A Mixed Methods Study. *Journal of Mixed Methods Research*, *11*(2), 202–222. https://doi.org/10.1177/1558689815607096

Möller-Leimkühler, A. M., & Wiesheu, A. (2012). Caregiver burden in chronic mental illness: The role of patient and caregiver characteristics. *European Archives of Psychiatry and Clinical Neuroscience*, *262*(2), 157–166. https://doi.org/10.1007/s00406-011-0215-5

Pakenham, K. I., Landi, G., Boccolini, G., Furlani, A., Grandi, S., & Tossani, E. (2020). The moderating roles of psychological flexibility and inflexibility on the mental health impacts of COVID-19 pandemic and lockdown in Italy. *Journal of Contextual Behavioral Science*, *17*, 109–118. https://doi.org/10.1016/j.jcbs.2020.07.003

Price, M. L., Surr, C. A., Gough, B., & Ashley, L. (2020). Experiences and support needs of informal caregivers of people with multimorbidity: A scoping literature review. *Psychology & Health*, *35*(1), 36–69. https://doi.org/10.1080/08870446.2019.1626125

Schulz, R., Beach, S. R., Czaja, S. J., Martire, L. M., & Monin, J. K. (2020). Family caregiving for older adults. *Annual Review of Psychology*, *71*, 635–659. https://doi.org/10.1146/annurev-psych-010419-050754

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family—Caregivers of people with mental illnesses. *World Journal of Psychiatry*, *6*(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Sheehan, O. C., Haley, W. E., Howard, V. J., Huang, J., Rhodes, J. D., & Roth, D. L. (2021). Stress, Burden, and Well-Being in Dementia and Nondementia Caregivers: Insights From the Caregiving Transitions Study. *The Gerontologist*, *61*(5), 670–679. https://doi.org/10.1093/geront/gnaa108

Teahan, Á., Lafferty, A., Cullinan, J., Fealy, G., & O'Shea, E. (2021). An analysis of carer burden among family carers of people with and without dementia in Ireland. *International Psychogeriatrics*, *33*(4), 347–358. https://doi.org/10.1017/S1041610220000769

Teixeira, R. J., Remondes-Costa, S., Graça Pereira, M., & Brandão, T. (2019). The impact of informal cancer caregiving: A literature review on psychophysiological studies. *European Journal of Cancer Care*, *28*(4), e13042. https://doi.org/10.1111/ecc.13042

Zwar, L., König, H.-H., & Hajek, A. (2020). Psychosocial consequences of transitioning into informal caregiving in male and female caregivers: Findings from a population-based panel study. *Social Science & Medicine*, *264*, 113281. https://doi.org/10.1016/j.socscimed.2020.113281

Appendix A

Ethical Approval

P.O. Box 80140, 3508 TC Utrecht The Board of the Faculty of Social and Behavioural Sciences Utrecht University P.O. Box 80.140 3508 TC Utrecht	**Faculty of Social and Behavioural Sciences** Faculty Support Office Ethics Committee **Visiting Address** Padualaan 14 3584 CH Utrecht

Our Description Telephone E-mail
Date

Subject

24-0604
030 253 46 33 FETC-fsw@uu.nl 27 March 2024 Ethical approval

ETHICAL APPROVAL

Study: The moderating role of psychological flexibility in the relationship between stress and wellbeing in carers

Principal investigator: R.M. Henderson Moran Supervisor: Michaela Schok

The study is approved by the Ethical Review Board of the Faculty of Social and Behavioural Sciences of Utrecht University. The approval is based on the documents sent by the researchers as requested in the form of the Ethics committee and filed under number 24-0604. The approval is valid through 01 June 2024. The approval of the Ethical Review Board concerns ethical aspects, as well as data management and privacy issues (including the GDPR). It should be noticed that any changes in the research design oblige a renewed review by the Ethical Review Board.

Yours sincerely,

Peter van der Heijden, Ph.D.
Chair
This is an automatically generated document, therefore it is not signed

Appendix B

Survey Consent Form

Stress and well-being in informal caregivers

General Information

Thank you for participating in our research into stress and well-being in informal caregivers. Please read through this information before agreeing to participate by ticking the 'I consent' box below.

We are interested in investigating the relationship between stress and well-being in informal caregivers. Informal caregiver refers to an individual who provides unpaid care for a family member, partner or friend who cannot cope without their support due to illness, frailty or disability. This study is completed by Roisin Henderson Moran, under the supervision of Dr Michaela Schok at Utrecht University, Netherlands. This questionnaire will ask you questions related to your current well-being, stress and also how you adapt to changes, manage difficult situations, and stay true to what matters to you in your role as a caregiver. You will also be asked to answer some demographic questions. You will be asked to fill out the questionnaires according to your own experience and point of view. The survey will take about 10-20 minutes to complete.

Do I have to take part?
Participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the 'Exit' button/ closing the browser.

How will my data be used?
We will take all reasonable measures to ensure that data remain confidential. The research has been approved by the Ethics Commission (FETC) of the Faculty of Social Sciences at Utrecht University and thus complies with the ethical guidelines.

Who do I contact if I have a concern, or I wish to complain?
If you have any questions or comments regarding this study, do not hesitate to contact the researchers at the following email: r.m.hendersonmoran@students.uu.nl. If you would rather communicate with the study's supervisor, please mail Dr. Michaela Schok at m.l.schok@uu.nl. In case of formal complaints, please contact the complaints officer: klachtenfunctionaris-fetcsocwet@uu.nl.

Thank you for your attention and consideration to participate in this research.

Appendix C

Interview Consent Form

Are you a caregiver? Please participate in our research on stress and well-being in caregivers!

General Information

Thank you for participating in our research into stress and well-being in informal caregivers. Please read through this information before agreeing to participate by ticking the 'I consent' box below.

We are interested in investigating and learning more about the daily lives of informal caregivers, the stress they experience and how that can impact their well-being. *Informal caregiver refers to an individual who provides unpaid care for a family member, partner or friend who cannot cope without their support due to illness, frailty, or disability*. This study is completed by Roisin Henderson Moran (master student Clinical Psychology), under the supervision of Michaela Schok, PhD, at Utrecht University, Netherlands.

During this interview, you will be asked questions relating to your day-to-day life as an informal caregiver and, the challenges you face in your role as a caregiver.

Confidentiality:

Your responses will be kept confidential. The data collected will be anonymized, and any identifiable information will be removed or altered before analysis. Recordings and transcripts will be stored securely and only accessible to the research team.

How will my data be used?

We will take all reasonable measures to ensure that data remains confidential. The information you provide may be used in research publications and presentations. Quotes may be used verbatim but will not be attributed to you by name or any identifiable characteristic. The research has been approved by the Ethics Commission (FETC) of the Faculty of Social Sciences at Utrecht University and thus complies with the ethical guidelines.

Who do I contact if I have a concern, or I wish to complain?

If you have any questions or comments regarding this study, do not hesitate to contact the researchers at the following email: r.m.hendersonmoran@students.uu.nl. If you would rather communicate with the study's supervisor, please mail Michaela Schok, PhD, at m.l.schok@uu.nl. In case of formal complaints, please contact the complaints officer: klachtenfunctionaris-fetcsocwet@uu.nl.

Consent:

☐ I consent to participate in this research study.

Signature: ______________________________

Date: __________________________________

Thank you for your attention and consideration to participate in this research.

Appendix D

Semi-structured Interview Topic List

Interview Questions

Introduction

[Please give short introduction of yourself, the aim of the interview and the duration of the interview. Then ask if it is okay to record the interview. Then start the recording..]

Background

Can you tell me about your role as a caregiver?

Who do you provide care for and how long have you been a caregiver?

What is your age? Gender? Cultural background?

Do you work or study? How many hours?

Are you married? Have a family? Children? What age?

Experience as a Caregiver

What does a typical day look like for you if you are being a caregiver?

What are the most time-consuming tasks?

What are some of the challenges you face in your caregiving role?

Can you share a particularly rewarding experience you've had while providing care?"

Stress

How stressful is it for you to be a caregiver? For example do you experience daily stress, more than 5 days a week, regular (2 tot 4 days a week), sometimes, not at all. Or you could ask this on a scale from 0 to 10 (with 10 being stressful all the time).

Have there been times when the stress of caregiving has felt overwhelming? How did you handle that situation?

How do you usually cope with stress related to caregiving? Are there any strategies you find particularly helpful?

How has caregiving affected your relationships with family, friends, and the person you're caring for?

Well-being

How do these challenges affect your daily life and personal well-being?

How has your role as a caregiver influenced your emotional and mental health?

Can you share any experiences where caregiving has had a positive or negative impact on your well-being?

Psychological Flexibility

How did caregiving change your life and well-being?
In what ways have you had to adjust your lifestyle or expectations due to your caregiving responsibilities?

Can you give an example of a situation where you had to adapt or be flexible in your caregiving role?

What are the most important values that guide you in your role as a caregiver? How do you stay committed to these values, even when it's difficult?

How do you balance caregiving and other areas of your life, such as personal interests or time for yourself?

Are you able to stay present during your daily tasks? How much of the time do you experience autopilot during caregiving tasks?

Are there practices or techniques you use to stay present and focused when caregiving becomes particularly demanding?

How do you handle situations when things don't go as planned in your caregiving duties?

Have you had to change any of your behaviours to better support the person you are caring for?

Do you ever have unwanted thoughts that bother you during your caregiving tasks? And how do you manage them?

How do you see yourself as a caregiver?

Additional Questions

What kind of support do you have or wish you had as a caregiver?

How do you usually seek help when you need it, and what has been most helpful?

Is there anything you think could be done (by you, the community, or the healthcare system) to improve your experience as a caregiver?

What do you recommend other caregivers – how to deal with this responsibility?

Appendix E

R Script

```
setwd("/Users/roisinmoran/Desktop/Thesis")

library(dplyr)
library(readxl)
library(car)
library(ggplot2)
library(GGally)
library(psych)
install.packages("corrplot")
library(corrplot)

data <- read_xlsx("thesis_data.xlsx")

## Data cleaning

# remove first row
data <- slice(data, -1)

# remove emails and irrelevant information
data <- data %>%
  select(-(1:5), -(7:12), -54)

data <- data %>%
  mutate(`Q6...18` = dplyr::recode(`Q6...18`,
                   "Not at all useful" = "very seldom",
                   "Slightly useful" = "seldom",
                   "Moderately useful" = "from time to time",
                   "Very useful" = "often",
                   "Extremely useful" = "very often"))


psyflex_columns <- c("Q1...13", "Q2...14", "Q3...15",
"Q4...16","Q5...17","Q6...18")
library(psych)
library(dplyr)
library(forcats)


# Recode the values in the specified columns
data <- data %>%
  mutate_at(vars(any_of(psyflex_columns)),
            ~ dplyr::recode(., "very seldom" = 1,
                     "seldom" = 2,
                     "from time to time" = 3,
                     "often" = 4,
                     "very often" = 5))
```

```
# mental health continuum shortform
mhc_columns <- c("Q1...19", "Q2...20", "Q3...21",
"Q4...22","Q5...23","Q6...24","Q7","Q8","Q9","Q10","Q11","Q12"
,"Q13","Q56")

# Recode the values in the specified columns
data <- data %>%
  mutate_at(vars(any_of(mhc_columns)),
            ~ dplyr::recode(., "Never" = 0,
                   "Once or twice" = 1,
                   "About once a week" = 2,
                   "About 2 or 3 times a week" = 3,
                   "Almost every day" = 4,
                   "Every day" = 5))


# perceived stress scale
pss_columns <-
c("Q63","Q64","Q65","Q66","Q67","Q68","Q69","Q70","Q71","Q72")

# Recode the values in the specified columns
data <- data %>%
  mutate_at(vars(any_of(pss_columns)),
            ~ dplyr::recode(., "never" = 0,
              "almost never" = 1,
              "sometimes" = 2,
              "fairly often" = 3,
              "very often" = 4))

# reverse code q4,5,7,8
pss_columns_reverse <- c("Q66","Q67","Q69","Q70")

# reverse code apply
data <- data %>%
  mutate_at(vars(any_of(pss_columns_reverse)),
            ~ dplyr::recode(., "4" = 0,
                   "3" = 1,
                   "2" = 2,
                   "1" = 3,
                   "0" = 4))


data_complete <- data %>%
  filter(Finished == "True")

data_incomplete <- data %>%
  filter(Finished == "False")

data_complete <- slice(data_complete, -c(15, 26))
```

```
### Data splitting
# psyflex
psyflex_df <- data_complete %>%
  select(psyflex_columns)

# mhc
mhc_df <- data_complete %>%
  select(all_of(mhc_columns))

# pss
pss_df <- data_complete %>%
  select(all_of(pss_columns))

pss_df <- pss_df %>%
  mutate_at(vars(any_of(pss_columns_reverse)),
            ~ dplyr::recode(., "4" = 0,
                     "3" = 1,
                     "2" = 2,
                     "1" = 3,
                     "0" = 4))

# Mean imputation
# psyflex
psyflex_imputed <- apply(psyflex_df, 1, function(x) {
  x[is.na(x)] <- mean(x, na.rm = TRUE)
  return(x)
})

psyflex_imputed <- t(psyflex_imputed)
psyflex_imputed <- as_tibble(psyflex_imputed)

# calculate the psyflex scores
psyflex_imputed <- psyflex_imputed %>%
  mutate(psyflex_score = rowSums(., na.rm = TRUE))

# mhc
mhc_imputed <- apply(mhc_df, 1, function(x) {
  x[is.na(x)] <- mean(x, na.rm = TRUE)
  return(x)
})

mhc_imputed <- t(mhc_imputed)
mhc_imputed <- round(mhc_imputed)
mhc_imputed <- as_tibble(mhc_imputed)

# calculate the mental health continuum scores
mhc_imputed <- mhc_imputed %>%
  mutate(mhc_score = rowSums(., na.rm = TRUE))


# pss
```

```
pss_imputed <- apply(pss_df, 1, function(x) {
  x[is.na(x)] <- mean(x, na.rm = TRUE)
  return(x)
})

pss_imputed <- t(pss_imputed)
pss_imputed <- round(pss_imputed)
pss_imputed <- as_tibble(pss_imputed)

# reverse again
pss_imputed <- pss_imputed %>%
  mutate_at(vars(any_of(pss_columns_reverse)),
            ~ dplyr::recode(., "4" = 0,
                     "3" = 1,
                     "2" = 2,
                     "1" = 3,
                     "0" = 4))

# calculate the pss scores
pss_imputed <- pss_imputed %>%
  mutate(pss_score = rowSums(., na.rm = TRUE))

imputed_scores <- bind_cols(psyflex_imputed$psyflex_score,
mhc_imputed$mhc_score, pss_imputed$pss_score)
colnames(imputed_scores) <- c("psyflex_score", "mhc_score",
"pss_score")

# remove raw data
data_final <- data_complete %>%
  select(-(1:31))

data_final <- bind_cols(data_final,imputed_scores)

names(data_final)[names(data_final) == "Q1"] <- "Age"
names(data_final)[names(data_final) == "Q2"] <- "Gender"
names(data_final)[names(data_final) == "Q3"] <- "Caring_for"
names(data_final)[names(data_final) == "Q4"] <- "Relationship"
names(data_final)[names(data_final) == "Q5"] <-
"Cultural_background"
names(data_final)[names(data_final) == "Q6"] <- "Occupation"
names(data_final)[names(data_final) == "Q76"] <- "Interview"

data_final$Cultural_background <-
factor(data_final$Cultural_background)
data_final$Gender <- factor(data_final$Gender)

# Dealing with others
data_final$Caring_for[data_final$Q3_4_TEXT == "Sibling"] <-
"Sibling"

#parent
```

```
other_parents <- c("Son", "2 children with additional needs",
"Daughter 8","Parent to 3, whom I care for")
data_final$Caring_for[data_final$Q3_4_TEXT %in% other_parents]
<- "Parent"

#partner
other_partners <- c("mother and husband","Both my parent and
my spouse")
data_final$Caring_for[data_final$Q3_4_TEXT %in%
other_partners] <- "Partner"

#relative
other_relatives <- c("Both my parent and my spouse", "Father-
in-law", "Grandparent", "Daughter in law", "stepbrother")
data_final$Caring_for[data_final$Q3_4_TEXT %in%
other_relatives] <- "Other Relative"

#child
other_child <- c("I'm a parent and I mind dad as well")
data_final$Caring_for[data_final$Q3_4_TEXT %in% other_child]
<- "Child"

#non-relatives
non_relatives <- c("Elderly lady in my community")
data_final$Caring_for[data_final$Q3_4_TEXT %in% non_relatives]
<- "Non-relative"

# non-caregivers
non_caregivers <- c("I cared toe my mother , uncle , aunt ,
all now RIP","Just patient :)","Nurse","Private Caregiver")
data_final <- data_final[!(data_final$Q3_4_TEXT %in%
non_caregivers), ]

#Occupation
non_workers <- c("Full time carer to my son","Full-time Career
unable to work","Carer",'Texas won’t pay full time, family
caregivers',"Full time care giver","Full time
carer","Carer","Full time care giver at home.","Full time
carer and mother","Homemaker and carer","Carer","24/7
carer","Carer","Unpaid carer of child with a
disability","Carer","Disabled","Stay at home mom","On sick
leave from work")
data_final$Occupation[data_final$Q6_5_TEXT %in% non_workers]
<- "Not employed/able to work"

part_time <- c("Part-time employed","Part time employed",
"Part time")
data_final$Occupation[data_final$Q6_5_TEXT %in% part_time] <-
"Employed part-time"
```

```
self_employed <- c("Self-employed (barely working)","Self
employed","self employed temporary work","Self employed part
farming")
data_final$Occupation[data_final$Q6_5_TEXT %in% self_employed]
<- "Self-employed"

employed <- c("employed FT and PhD student FT","Employed, on
leave")
data_final$Occupation[data_final$Q6_5_TEXT %in% employed] <-
"Employed"

#Cultural background
westerners <- c("White", "Catholic", "Irish", "Irish", "Irish
Catholic", "Irish", "Nederland", "Irish")
data_final$Cultural_background[data_final$Q5_5_TEXT %in%
westerners] <- "Western (e.g., European, North American)"

data_final$Cultural_background <-
as.character(data_final$Cultural_background)

data_final$Cultural_background <-
as.character(data_final$Cultural_background)

latin <- c("Hispanic")
data_final$Cultural_background[data_final$Q5_5_TEXT %in%
latin] <- "Hispanic"

Hawaiian <- c("Hawaiian")
data_final$Cultural_background[data_final$Q5_5_TEXT %in%
Hawaiian] <- "Hawaiian"

names(data_final)[names(data_final) == "Caring_for"] <-
"Carer_is"

#Column order
data_final <- data_final[, c("pss_score", "mhc_score",
"psyflex_score","Gender", "Cultural_background",
"Relationship","Occupation", "Age","Carer_is")]

names(data_final)

### Calculate Cronbach's Alpha

# Psyflex
psyflex_alpha <- alpha(psyflex_df)
print(psyflex_alpha)

# MHC
mhc_alpha <- alpha(mhc_df)
print(mhc_alpha)
```

```
# PSS
pss_alpha <- alpha(pss_df)
print(pss_alpha)

## Data complete
data_final$Cultural_background <-
factor(data_final$Cultural_background)
data_final$Occupation <- factor(data_final$Occupation)
data_final$Relationship <- factor(data_final$Relationship)
data_final$Carer_is<- factor(data_final$Carer_is)
data_final$Age <- as.numeric(as.character(data_final$Age))

#Descriptives
summary(data_final)
age_summary <- summary(data_final$Age)
age_sd <- sd(data_final$Age, na.rm = TRUE)
print(age_sd)

print(summary(data_final))
str(data_final$Age)

  summarise(
    mean_psyflex_score = mean(psyflex_score, na.rm = TRUE),
    sd_psyflex_score = sd(psyflex_score, na.rm = TRUE),
    mean_pss_score = mean(pss_score, na.rm = TRUE),
    sd_pss_score = sd(pss_score, na.rm = TRUE),
    mean_mhc_score = mean(mhc_score, na.rm = TRUE),
    sd_mhc_score = sd(mhc_score, na.rm = TRUE)
  )
print(summary_stats)

#Correlation matrix
selected_data <- data_final %>% select(psyflex_score,
pss_score, mhc_score)
cor_matrix <- cor(selected_data)
print(cor_matrix)
corrplot(cor_matrix, method = "circle")

#Sig levels for correlation matrix
# Compute the correlation matrix and p-values
install.packages("Hmisc")
library(Hmisc)
cor_results <- rcorr(as.matrix(selected_data))
cor_matrix <- cor_results$r
p_values <- cor_results$P
print(cor_matrix)
print(p_values)

# Visualize the correlation matrix
corrplot(cor_matrix, method = "circle", p.mat = p_values,
sig.level = 0.05)
```

```
#Preliminary analysis

#Data Visualisation
str(data_final)
library(ggplot2)
ggplot(data_final, aes(x = pss_score, y = mhc_score)) +
geom_point() + labs(x = "PSS Score", y = "MHC Score") +
theme_minimal()

correlation <- cor(data_final$pss_score, data_final$mhc_score)
correlation

model <- lm(mhc_score ~ pss_score + Gender + Occupation +
Cultural_background, data = data_final)

residuals <- residuals(model)

hist(residuals, main = "Histogram of Residuals", xlab =
"Residuals")
par(mar = c(5, 4, 4, 2) + 0.1)  # Adjust the margin parameters
as needed
hist(residuals, main = "Histogram of Residuals", xlab =
"Residuals")

options(repr.plot.width=6, repr.plot.height=4)  # Adjust the
width and height as needed
hist(residuals, main = "Histogram of Residuals", xlab =
"Residuals")

install.packages("ppcor")
library(ppcor)
partial_correlation_matrix <- pcor(data_final)$estimate
print(partial_correlation_matrix)
correlation_matrix <- cor(data_final[, c("pss_score",
"mhc_score", "psyflex_score")])
print(correlation_matrix)


#Hypothesis 1, the relationship between perceived stress and
wellbeing
#Testing assumptions of multiple linear regression

#Fit the model
model <- lm(mhc_score ~ pss_score + Gender +
Cultural_background + Occupation + Carer_is + Relationship,
data = data_final)
summary(model)
#Linearity
plot(model$fitted.values, model$residuals)
abline(h = 0, col = "red")
```

```
#homoskedasticity
#Breusch-Pagan test
library(lmtest)
bptest(model)

#Independence of Errors
#Durbin-Watson test
dwtest(model)

#Normality
# Q-Q plot
qqnorm(model$residuals)
qqline(model$residuals, col = "red")
#Shapiro-Wilk Test
shapiro.test(model$residuals)

#Independence of Independent Variables
#Check for multicollinearity
vif_values <- vif(model)
print(vif_values)

#Interpretation of the model
summary(model)

#Visuals
#Scatterplot
ggplot(data = data_final, aes(x = pss_score, y = mhc_score)) +
geom_point() +  labs(x = "Perceived Stress", y = "Mental
Health Continuum Score") + ggtitle("Scatterplot of Perceived
Stress vs. Mental Health Continuum Score")
ggpairs(data_final, aes(color = Carer_is))

#Partial Regression
avPlots(model, id.n = 1)
plot(model, which = 1)


#Hypothesis 2
#Fit the model
model <- lm(mhc_score ~ pss_score * psyflex_score, data =
data_final)
model <- lm(mhc_score ~ pss_score * psyflex_score + Gender +
Cultural_background + Relationship + Occupation + Carer_is,
data = data_final)
summary(model)

#Linearity
plot(model$fitted.values, residuals(model))
abline(h = 0, col = "red")
```

```
#Homoscedasticity
plot(model$fitted.values, residuals(model))

#Independence of Errors
dwtest(model)

#Normality
hist(residuals(model))
qqnorm(residuals(model))
qqline(residuals(model))
shapiro.test(residuals(model))

#Interpret Results
model <- lm(mhc_score ~ pss_score * psyflex_score, data =
data_final)
summary(model)

#Visuals
#Interaction plot
library(ggplot2)
ggplot(data_final, aes(x = psyflex_score, y = mhc_score, color
= pss_score)) + geom_line() + labs(x = "Psychological
Flexibility", y = "Mental Health Continuum Score", color =
"Perceived Stress") + ggtitle("Interaction Plot: Perceived
Stress moderating effect of Psychological Flexibility on
Mental Health Continuum Score")

library(interactions)
plot(interaction_plot(model, pred =
"psychological_flexibility", modx = "perceived_stress"))

# alpha
print(data_complete)

#Exploratory analysis
library(mediation)
library(dplyr)

# Define all factor levels consistently
data_final$Gender <- factor(data_final$Gender, levels =
c("Female", "Male", "Non-binary"))
data_final$Cultural_background <-
factor(data_final$Cultural_background, levels = c("Eastern
(e.g., Asian)", "Hawaiian", "Hispanic", "Western (e.g.,
European, North American)"))
data_final$Relationship <- factor(data_final$Relationship,
levels = c("Divorced", "Married", "Never married",
"Separated", "Widowed"))
data_final$Occupation <- factor(data_final$Occupation, levels
= c("Employed", "Employed part-time", "Not employed, looking
```

```
for work", "Not employed/able to work", "Retired", "Self-
employed"))
data_final$Carer_is <- factor(data_final$Carer_is, levels =
c("Child", "Non-relative", "Other Relative", "Parent",
"Partner", "Sibling"))

# Install packages
install.packages("psych")
install.packages("lavaan")
install.packages("ggplot2")
install.packages("readxl")
install.packages("semPlot")

# Load packages
library(psych)
library(lavaan)
library(ggplot2)
library(readxl)
library(semPlot)

library(mediation)

# Mediation
mediator_model <- lm(psyflex_score ~ pss_score, data =
data_final )
outcome_model <- lm(mhc_score ~ pss_score + psyflex_score,
data = data_final)
summary(mediator_model)
summary(outcome_model)

# Extract coefficients
b1 <- coef(mediator_model)["pss_score"]
b3 <- coef(outcome_model)["psyflex_score"]

# Calculate indirect effect
indirect_effect <- b1 * b3
indirect_effect

#Standardised Coefficients
data_final$pss_score_z <- scale(data_final$pss_score)
data_final$psyflex_score_z <- scale(data_final$psyflex_score)
data_final$mhc_score_z <- scale(data_final$mhc_score)

#Fit the model
model1 <- lm(psyflex_score_z ~ pss_score_z, data = data_final)
summary(model1)
model2 <- lm(mhc_score_z ~ pss_score_z + psyflex_score_z, data
= data_final)
summary(model2)

model_c <- lm(mhc_score_z ~ pss_score_z, data = data_final)
```

```
summary(model_c)
```

Appendix F

Complete Set of Themes, Codes and Quotes*

Table 1

Complete set of themes and quotations

Categories	Themes	Quotations
Stress	Emotional strain and stress	1. “There had to be new rebalancing of the whole family structure, I had to go to counselling, that for about two to three sessions, and because I was full of anger and anxiety and grief, you know?” (P1) 2. “It was more about, as I said there was six other people that I had to constantly you know, keep happy and the conflict for that for me, was more distressing than to see Dad (in his condition) for me. (P1) 3. “I feel a bit like a misery guts” (P1) 4. “I don't know what made me go up Dad, and he was heading out with no trousers on, and his walking stick and I just lost it.” (P1)

		5. “I don't think either people should feel embarrassed about that, or annoyed about that or guilt that you don't want to do personal care for your father. Now I do it, but it's not easy.” (P1)
		6. “You look back and you go, how the hell did we ever survive that? But we did somehow.” (P2)
		7. “There is no value place to what you do and therefore it’s hard for you to value yourself” (P2)
		8. “Well, there's a lot of crying. I hid under my desk a few times and just you get at that point of where you feel like you're in crisis and you know there's no way out.” (P3)
		9. “There's definitely been some episodes where I just went and hid under my desk for 10 or 20 minutes and just cried” (P3)
		10. “I have no idea how do I see myself as a caregiver as probably a very stressed out, angry looking, 40 year old white woman. I I guess that would probably be my perceptions.” (P3)
	Constant pressure	11. “So yeah, even on holidays, you were constantly alert on the yeah.” (P1)

12. “It's all wrong and then you've got these texts flying back and forth. I found that absolutely exhausting, exhausting.” (P1)
13. “I would be every morning around 9 provided I didn't get a phone call to say things weren't working and I needed to go up earlier.” (P1)
14. “you're constantly on the phone.” (P1)
15. “So you would be always sleeping with your ear open.” (P1)
16. “you could be in the middle of something and that's it and you have to drop everything and charge up and make sure hes been fed or whatever has to be done” (P1)
17. “I mean, you know, 10:00 o'clock at night and the phone binging. Yeah. And then you have answer (anything could be happening) you know?” (P1)
18. “Something happened with the carer, or somebody didn't arrive. We're constantly on really constantly on.” (P1)
19. “And I suppose one thing is my daughter doesn't sleep, so she's up at night. So someone is up at night with her” (P2)
20. “You know, the routine has to go. You cannot skip a step. You cannot go quickly through a step. She has to do the exact same things and the exact same order every day.

And if something goes in that routine, like if her hearing aid breaks in the morning when she's trying to put it on. Well, then there's a meltdown.” (P2)

21. “But one time she did disappear. The guards were out and she was missing for two hours and it was the worst 2 hours of my life because she's no, she has no sense of safety, of consequences, of danger.” (P2)
22. “Yeah, I suppose it's the routine tasks in life that should be simple to do or never simple to do. And that's every day that you're dealing with this, I suppose.” (P2)
23. “You know, if she’s (my other child) standing outside waiting to be picked up and we're at home having this row about putting on shoes.” (P2)
24. “Like, you know, like that trying to navigate your care to her and also the fact that you have a job, responsibilities and work.” (P2)
25. “It was just a complete nightmare and it that I and I found then very hard to focus on work because you're constantly or who's going to bring her in, who's going to collect her? Like, what am I doing this week and work like, can I? Can I take 1/2 day there to go collect her? Can I, like, can negotiate with my boss to come in like 1/2 hour late? Trying to focus on work with all of that going on was difficult, yeah.” (P2)

26. “And it is very hard to do all of the things because everything is, everything is a struggle. Nothing is straightforward. So we, like you're fighting for therapies, then you're trying to mind her. Then you're trying to get her engaged. And I find activities and getting get her engaged, keep her engaged.” (P2)
27. “It pretty much monopolizes my life” (P3)
28. “Because even when everything is calm, you still have a very bored 70-year-old man sitting in a chair with the TV blasting all day, and also a slightly bored and low attention span, brain injury victim wandering around who has a serious penchant for getting into trouble” (P3)
29. “And there's no relief besides just abandoning the responsibilities that you've agreed to, and you don't. I don't want to do that, of course.” (P3)
30. “It always comes around to the mental conclusion that if I leave, these guys are in some serious trouble. There is nobody else that is going to step up and take care of them” (P3)
31. “And if I do show up, I'm tethered to the phone and usually get asked to come back home within an hour.” (P3)

		32. “My daily life is 100% caregiving, and the couple hours a day that I managed to dedicate to school, which the couple hours a day for school” (P3)
		33. “It it, it has been a fight to make room for me to go to school and I only do halftime with school.
	Demands outweigh capacity to provide	34. “I felt, you know, it needs to, he needs more professional care at this stage needs the team around him.” (P1)
		35. “And I think now they (my siblings) feel (better) you know it is because he is going into the final stage of his Alzheimer’s and really, you know, his physical needs are getting (bigger).” (P1)
		36. “Because it is a huge responsibility when you're 65 and you're retired and you, you have your dad in front of you and you're not going to get them back. But you still have a responsibility to him.” (P1)
		37. “I said that this man should not be on his own at night, he's not able to get his breakfast and they proceeded then to put cameras, there were cameras all around and that was their way of monitoring if Daddy was on the floor or not. well, cameras isn't a way to mind a person with Alzheimer's” (P1)

	38. “I suppose, like term time is one thing, but she's, like, finished going (to school) at the end of May, so, then she's off for three months, and then there's that three months that has to be filled. And I suppose, yeah when she's in school, it's getting her out the door, and then it's the evening getting her to get to bed because that is even she's not to go to bed” (P2)
Lack of support from state, loved ones or community	39. (Caring) creates complex within a family. There is no doubt about it.” (P1)
	40. “We've got that we could have done with a bit of maybe even day rest bite or some sort of care, but that there is nothing, there is absolutely nothing available and I think that's another part of the stresses that I know my daughter needs therapy and like she needs speech therapy, she needs physiotherapy. She doesn't get any of that like the Cdnt has said she's an urgent case for speech therapy because she has Down syndrome and she's hearing impaired, which we don't get. The speech therapy do you know? And you know, she needs it and you see every year going by that she's not getting it” (P2)
	41. “The turnover in staff and those cdnts is just massive. Do you know like and as soon as you get someone good who's like, you know, we had this great speech therapist and she was really helping (my daughter). And then she left because she couldn't afford to live

in Dublin anymore … but then we are left with no speech therapy. Then we got a few sessions with another therapist, but she took a totally different approach. So, the work we were doing and the approach the other therapist was taking, which seemed to me to be working, then this therapist has another view of how we should do it and she introduced another way of doing things, which (my daughter) just didn't take to at all. And then anyway, then we got we got a small block there. And then we've had nothing since and that's a year ago.

42. “It's not just carers. It's all the kind of vulnerable groups that are just given no regard” (P2)
43. “Because no one ever tells you you're doing a good job as a carer, no one” (P2)
44. “Like I think the government like they the way they treat children with disabilities is Pauling, like, none of those cdnts work properly like those whole progressing services for children with disabilities been absolute disaster. I mean, I don't know any parent who's getting better services as a result of it. It's a nightmare. So like, they're not providing the services and it's, you know, for the kids themselves, they can't realise their

full potential. Then if the government does want to think of it from a purely economic base.” (P2)

45. “It’s denying their child the chance to reach their full potential, like that's that. That's inexcusable” (P2)
46. “(we need) proper supports and therapies and like integrate therapies with school like, because children with who have special needs need to be in school more than any other child and they are constantly being pulled out (of school) because, you know, therapy services only operate between 9:00 and 15:00. Like, what is this 9-3 like every child is in school between 9:00 and 3:00 Can we not do like 4 to 6 this kind of thing? (P2)
47. “People are paying huge amounts of taxes and really there is an onus on the government to use those taxes better, you know, because that is also people's contribution to services. You know, this is they're paying tax every single week. And on every euro they earn, they pay taxes and the government needs to use that better because that's, I mean, that's part of the pact, isn't it? You work, you pay your taxes. The government used those taxes to provide services, provide services for people that need them.” (P2)

48. “I do think there needs to be some like state provided longer breaks for families with children, with needs like there does need to be something and it does it like if they can't do it every week” (P2)
49. “She was excluded from so many things she wasn't allowed to do after school activities.” (P2)
50. “But like there's no one we don't have anyone really that we can leave (my daughter) with that night” (P2)
51. “My personal well-being is my problem and only my problem and I've realized that there is no one who is going to come to my rescue or no one who is going to help me with my personal well-being.” (P3)
52. “So, they were very, I mean, the opposite of supportive they were. They (the family) made things much harder to deal with and it's been a long road.” (P3)
53. “I cannot call his family for support. I cannot call any state workers for Support. There is no one to help me or give me a break. Ever.” (P3)
54. “So it it grinds me that it's expected that I should gravel in front of a church organization just for getting like 1/2 a day break and I'm not willing to do that.” (P3)

		55. “I thought surely the state would take care of an adult that can't take care of themselves but as it turns out, they don't” (P3)
		56. “Respite care (is what is most difficult (P3)
		57. “There is one provider in town that provides mental health care on an income basis. They're state subsidized, but they're very overwhelmed.” (P3)
		58. “Most of them (the available resources) are church groups and most of them are not gonna do anything. Yeah.” (P3)
Wellbeing	Impact of stress on physical health	59. “So you didn’t get a good night’s sleep, so after that now you were pretty wrecked” (P1)
		60. “I think it does take a toll on your personal well-being and I myself, I have a had a few tiny little medical problems.” (P1)
		61. “When you reflect I I ended up midstream with Dad, with dreadful back pain. Now I was working at the time I was working as an actual fact I went to this lovely physio and she said “you’re very sick” and I went “what do you mean? It’s my back” You know, and in actual fact it was all the stress’ (P1)
		62. “I was hunched over like an old lady, and that was about two years ago when things were quite fraught.” (P1)

		63. “he has had (my husband) a lot of health problems at the end of last year and it’s like from a health point of view, he just can't work anymore. So he's had to stop working.” (P2)
		64. “I was diagnosed with cancer there at the end of 2021 and that probably was just the most stressful period for our family because I was quite sick. My husband was trying to, I suppose manage family life and the kids.”
		65. “I do honestly believe like I got cancer like, you do feel it's distress from caring” (P2)
		66. The signs of stress are you know, I see myself in the mirror every day and I'm sure nobody else is looking at closely but to me, the signs of stress are are pretty apparent the furrowed forehead here from making that face all the time.” (P3)
		67. “The Gray hair has started about two years ago, nobody in my family turned Gray until about 50. I started at 38.” (P3)
	Impact of caregiving on relationships	68. “I think and that definitely with my siblings em you know, we are starting to heal a bit. But there were times that things were quite fraught” (P1)
		69. “But yeah I suppose with my husband, we would’ve had our row or disagreement you know, saying “What are you doing that for?” ”Why are you on the phone the whole

time?" when I'm looking to see if there's what's happening with Dad, because the phone is in, everything can be checked so quickly and you know, and then texting each way." (P1)

70. "It was more about so I, as I said there was six other people that I had to constantly and you know, keep happy and the conflict for that for me, was more distressing than to see Dad for me. yeah, for me, that was the biggest problem" (P1)
71. "My sibling, she's obviously (younger than me,) so she's a texter and she texts and throws out out these bombs and that, you know, that and then worrying about things, you know, late at night, it's desperate, you know, desperate. No.
72. "she's challenging to deal with because she just thinks in a different way to the rest of us and and then I suppose that does create tension at home because You know. Losing your temper is not going to work. It's going to aggravate things. So trying to be calm and trying to be whatever and like for both of us to be trying to be calm, trying to be whatever. Like it's to stay and then if someone is either of us, is losing the head, well then the other one gets even closer. But it's it. I think it is that stress of she can be

difficult to manage and then it's that we both need to be on sync to manage her the same way.” (P2)

73.

74. “I think like my closest friend group now will be parents who also have a child with additional needs because they're the only people who get it, like they really are the only people who understand what you're going through. And I think sometimes there's this misconception that children with Down syndrome are easy like that.” (P2)

75. “I mean, she could have helped there and she didn't. So I suppose that does put a kind of a stress on your relationship because you're kind of thinking, why do you think it's OK for us to take on all this” (P2)

76. “My (family member) has absolutely 0 concept of what we're dealing with” (P2)

77. “And there are definitely some days where it comes around to our evening play time and I'm too tired or too stressed out or just too angry in my head to focus on playing with her (my daughter) and I have to explain that to her and tell her why I want to take a night off and just go straight to bed and it can't.” (P3)

		78. “I have no real friends because I can’t ever show up so it's more more hurt than it is fun to try to do anything with friends.” (P3)
		79. “My daughter has more adult realizations than most kids her age” (P3)
	Importance of support systems	80. “And since that has gone into the nursing home, I don't worry. It's like a weight has been lifted off my shoulder, you know?” (P1)
		81. “In actual fact now that he's in the nursing home, I've stepped back and if he needs personal care (because it is 80 grand a year) I get them to do it.” (P1)
		82. “It's their responsibility to make sure he is cared for. So I think that is made a bit lighter, you know.” (P1)
		83. “like it does put stress on us, we can kind of understand that we are under stress and we can when things have calmed down and say look what Jesus, we're dealing with an awful lot like you know and appreciate that we're both there for each other. That's like, you know, neither of us decide to throw in the town and say fact, this is too hard. I'm go, I'm gone, you know. Yeah. Yeah.” (P2)
		84. “I suppose that's easier now that my husband is at home” (P2)
		85. “Support is out of reach” (P3)

Psychological Flexibility	Acceptance	86. “that’s just the way it was” (P1) 87. “you know, and everyone has their own way and their own lives to lead, they have (my siblings) have jobs” (P1) 88. “I'm only one of seven, I'm not one. So you know, I had to come to terms with that in my own heart and my own head.” (P1) 89. “Well, there was nothing more anyone could’ve done for Daddy. and inside our family, we were doing the best, more than the best we could.” (P1) 90. “(It’s important) to acknowledge that the situation you're in is more difficult than what other people are dealing with. So like, accept that, because if you, if you know if you're trying to pretend that your life is the same as everyone else, you're only going to drive yourself demented like, you know, accept that you are where you are and also like another thing that the councillor said. And I think this is something that maybe carers don't do, is to acknowledge that you're doing a good job. Because like before I was.” (P2) 91. “Take a deep breath and roll with the punches.” (P3)

		92. “That's, I mean there is absolutely no point in getting hung up on what could have been or the way he wanted it to be. The easiest way to deal with it I have found is acceptance and then just taking the new information, make decisions based on the information you have.” (P3)
		93. “'I’ve had to be careful about those and kind of watch and think about before the words that come out and how he's going to perceive it in relation to himself because he has a lot of time to sit around and think about his own perspective and he doesn't have a lot of social interaction with other people to kind of pull him to other perspectives” (P3)
	Committed action and self-as context	94. “I had to go to counselling, that for about two to three sessions” (P1)
		95. “So, you do your bit you know? She said your father has had his life. You have to have yours” (P1)
		96. “I would use you know, know your limits and there is a time that you have to hand over care” (P1)
		97. ‘OK, you can give get all the support you can, but there is a time where you have to think of is your immediate family, you know and your own health and your own health, you know.” (P1)

98. “She (private carer) comes in for three hours and it really is just for us to kind of get the ordinance, like the shopping done, clean the house and that kind of stuff. Because once she's gone, well, then someone has to be caring for (my daughter) or like, there's so ask me someone like at someone's job to mind her all the time” (P2)
99. “I think you can cope with so much and then if something else comes in on top, that's when you really struggle and then that's when I got sick that I really did struggle. But I have to say the counselling and I got counselling through Family Carers Ireland really helped me” (P2)
100. “She helped me to see was to recognise when you're heading into that kind of, I don't know, you're having a meltdown yourself in your head, but you'd like to do that. But even just in 2 minutes, like, that's nearly enough to just, I don't know, break that.” (P2)
101. “(Talking about the tennis club) None e of the people who run the tennis activity. have children with special needs, but yet, and they're like, this is your hour to sit down and have a chat and we're here to make you a cup of coffee and whatever. We need a little break. And this little hour that their kids are doing tennis, we're going to, you

	know, mind them as well. And that's just lovely. It's lovely when other people completely outside the loop who aren't being paid to do this, you know, decide. Well, look, we're going to do this for these mums, which is lovely. It's just lovely.” (P2)
	102. “Even if you have to sneak through the house and go hide, start your morning out with just 10 or 15 minutes by yourself. Just having that that few minutes of baseline in the morning without having any contribution into your head into your mental space of I need or I want or I'm bored makes a big difference” (P3)
	103. “so it's just kind of like, even if it hurts, I know that I have to suck it up and deal with it and and that's always the conclusion that I come around to and I come in touch with my coping skills that I've learned from other parts of life, breathing and meditating and mindfulness and all those good things to kind of help work my body through that crisis moment so that I can get back to work.” (P3).
	104. “'I’ve had to give up a lot that I would have otherwise invested some of my time and energy in” (P3)
Values	105. “I am able to say, uh, I'm happy with Dad. , you know, continue minding him to the best of my ability, but I only said it to my very good friend, I said, you know, I am

content now I'm happy I'm fine and I'm just relieved that he has good people looking after him and they're very good and he's fine." (P1)

106. "There is joy in minding them. There really is, it is fulfilling with whatever you do and whatever, bit of fun you get out of that" (P1)

107. "I think you have to remember that the whole time and try and take the little, the little glimmers of light that you get, you know, and thank God, you know he, he he he is happy now he he he's in a good place" (P1)

108. "OK, we're carers and we're under pressure and all but we're actually very privileged in other ways as well because, you know, like up to recently, both my husband and I were working with good income coming in. We have a nice house. And for my children to be aware and obviously less so for (my daughter), but that you are in a position you're very privileged and you're privileged by an accident of birth. It's not that we're any better than anybody else. And to have that understanding and compassion for others

	109. “Sometimes she can be hilariously funny, like off the wall. Funny. Like she, I mean, you're just like she comes down and she's dressed up as God knows what and she's doing a show.” (P2)
	110. “Having him off of that (drug addiction) and getting through the two trips to rehab and the constantly staying on him and always having him within sight for the two years while we got him through rehab an did the journey to get him sober. That was amazing” (P3)
	111. “He's super intelligent. Very interesting to sit and talk to and him here as one of my recipients has has made it easier to write off the rest of the social circles that you would traditionally have” (P3)

Note. *N* = 3. The themes divided according to Stress, Well-being and psychological flexibility and listed according to frequency within each category. P1: Participant 1, 65-year-old female, P2: Participant 2, 50-year-old female, P3: Participant 3, 40-year-old female. *Direct quotations have occasionally been restructured into complete sentences for clarity.