Caring for someone with an acquired brain injury

Abstract

Background: Caring for someone with an acquired brain injury (ABI) is associated with increased psychological distress and reduced satisfaction with life. Caregiver negative appraisals predict these poor outcomes, and social support and adaptive coping buffers these effects. Psychological flexibility is beneficial in dementia caregiving but has not been studied in ABI and never in comparison to known predictors of caregiver distress. This study examined known predictors and psychological flexibility in predicting depression, anxiety and life satisfaction in ABI caregiving. Methods: A cross sectional online survey gathered responses of 145 ABI caregivers, recruited through social media, charities and National Health Services. Standardised measures of disability, appraisals, social support, coping, psychological flexibility, depression, anxiety and life satisfaction were analysed with correlation, regression and conditional process analysis. Results: Correlations were in theoretically specified directions, regression analysis showed that psychological flexibility was the strongest predictor of depression (β = -.37, p < .001) and anxiety (β = -.38, p < .001), whilst caregiver appraisals were strongest in life satisfaction (β = -.34, p < .001). Furthermore, caregiver appraisals mediated the relation between care-recipients' disability and caregiver outcomes. Psychological flexibility moderated this effect on depression, whilst problem-focused coping moderated this effect on life satisfaction. Conclusion: These constructs could be potential targets for interventions, such as Acceptance and Commitment Therapy or traditional Cognitive Behavioural Therapy. Psychological flexibility plays an important role that adds to our understanding of caregiver distress in the specific context of ABI caregiving.

Keywords: caregiving; ABI; brain injury; psychological flexibility; Acceptance and

Commitment Therapy

Introduction

Acquired brain injury (ABI) refers to a sudden injury to the brain that occurred at any time following birth including traumatic brain injury (TBI), stroke, infectious disease, brain tumour and anoxic injury. ABI can result in significant impairment of functioning. Family and friends often become caregivers, offering emotional support, medical care and assistance with activities of daily living (Fisher et al., 2019). Compared to other conditions, ABI involves distinct challenges for the caregiver including the sudden onset without opportunity for adjustment or preparation, and the prospect of providing care indefinitely.

Negative outcomes, such as reduced wellbeing and psychological distress, are more prevalent amongst caregivers of adults with ABI compared to the general population, and tends to persist over time (Loh et al., 2017; Vogler et al., 2014). Caregiver distress has also been found to impact negatively on the neuropsychological recovery of the person with the ABI (Covey et al., 2013).

Whilst distress is common amongst caregivers of people with ABI, personal growth and positive outcomes have also been reported (Cohen, Colantonio, & Vernich, 2002). Further research is needed to better understand and predict outcomes, and ultimately to advance interventions.

Predictors of Caregiver Outcomes

Clinical factors such as the severity of the injury or the type of ABI appear to be weak predictors of caregiver outcomes beyond the acute phase (Jackson et al., 2009; Sander et al., 1997). The level of functional disability of the survivor, as perceived by the caregiver, has however been associated with caregiver Quality of Life (QoL; Chronister et al., 2016).

Psychological variables of the caregiver are of particular interest due to the potential to modify these to alleviate suffering and improve wellbeing. Suitable theoretical

frameworks for this purpose could be the Stress-Process Model (SPM) and the Psychological

Flexibility model.

The Stress-Process Model

Based on Lazarus and Folkman's (1984) stress and coping theory, the Stress-Process

Model (SPM) has been proposed to explain distress amongst ABI caregivers (e.g. Bakas &

Burgener, 2002; Chronister & Chan, 2006). The model suggests that caregiver outcomes are

dependent on how the caregiving situation is appraised and what coping skills and resources

are accessible to the individual.

Within the SPM, perceived burden has been conceptualised as the individual's

subjective negative *appraisal* of the stressful caregiving situation (Chwalisz, 1996). This

includes beliefs that the demands of caregiving are overwhelming, unending, depleting and

that the caregiver is isolated, not good enough, and has lost control of their own life.

Perceived burden has consistently been found to predict psychological distress and QoL in

caregivers of people with ABI (Chronister, Chan, Sasson-Gelman et al., 2010; Sander et al.,

1997). According to the SPM, negative appraisal (i.e. perceived burden) has a mediating role

between caregiving stressors (e.g. disability of the care-recipient) and outcomes (Chronister

et al., 2016; Harris, Godfrey, Partridge et al., 2001).

A further element of the SPM is coping. Avoidant coping (e.g. denial, distraction,

substance misuse) has been associated with poor psychological adjustment amongst ABI

carers (Chronister et al., 2010). Problem-focused coping (e.g. taking action, seeking advice,

problem-solving) has been associated with reduced distress (e.g. Chwalisz, 1996), whereas

other studies have found it to have a negative association with QoL (e.g. Chronister et al.,

2010). Similar inconsistencies have been found for emotion-focused coping (e.g. positive

reframing, acceptance, emotional support; Chronister & Chan, 2006; Sander et al., 1997).

These equivocal findings could be due to disparities between studies in how coping is defined and, thus, measured (Livneh, 2019). Alternatively, the impact of coping may vary across outcomes for caregivers. A specific strategy may reduce psychological distress momentarily *and* restrict someone's life, limiting their QoL in the long term.

Social support is another established construct from the SPM, and a buffer against stress (Ergh, Rapport, Coleman, & Hanks, 2002). Chronister and colleagues (2016) found that social support moderated the relationship between perceived burden and QoL, suggesting that caregivers who appraise their circumstances as burdensome can still maintain their wellbeing through social support.

Constructs from the SPM would be potential targets for psychological interventions aimed at improving the wellbeing of caregivers. Cognitive Behavioural Therapy (CBT) has been suggested as a suitable approach, and preliminary findings have been demonstrated amongst caregivers of people with stroke (Panzeri et al., 2019). For caregivers of other ABIs, there is a lack of trials evaluating CBT interventions.

Psychological Flexibility

Psychological flexibility is defined as "the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends" (Hayes et al., 2006, p. 7). From a carer's perspective, the present moment could involve difficult internal (e.g., guilt, self-criticism) and external experiences (e.g., loss, caregiving tasks). Behaviours serving values could encompass social relationships, engaging in hobbies, or activities related to providing care to a loved one.

Psychological flexibility involves six overlapping and interdependent processes together referred to as the Hexaflex model: defusion, acceptance, present moment awareness, values, committed action, and self as context (Hayes et al., 2006). More

recently, psychological flexibility has been conceptualised as three clusters (open, aware and active) where flexibility is thought to increase through a more open, aware and engaged approach to life (Hayes et al., 2012).

Whilst there is a good deal of evidence to support the SPM, psychological flexibility might enhance our understanding of contextual influences on its constructs. Negative appraisals in ABI caregiving may be rational responses to a challenging context. Caregivers with greater psychological flexibility may be less emotionally and behaviourally affected by their thoughts, and may engage in valued behaviour instead of avoidance strategies (Lappalainen et al., 2021; Márquez-González et al., 2013). As such, psychological flexibility may act as a moderator buffering the association between appraisals and outcomes amongst ABI caregivers, as demonstrated in other populations faced with chronic challenging contexts (Landi et al., 2021, McAteer & Gillanders, 2019).

Greater psychological flexibility is associated with greater life satisfaction and reduced distress amongst caregivers of people with dementia (Kishita et al., 2020; Lappalainen et al., 2021). Jansen and collegues (2017) found psychological flexibility predicted distress in caregivers of people with psychosis, whilst controlling for caregiving burden.

The psychological flexibility model has direct links to intervention, namely Acceptance and Commitment Therapy (ACT), which aims to foster psychological flexibility. ACT has been found to be an effective intervention for a range of conditions, particularly chronic illness including neurological conditions (Gloster et al., 2020; Graham et al., 2016; Robinson et al., 2019). Studies have found that ACT works through increasing psychological flexibility (Stockton et al., 2019).

Meta-analytical and systematic review findings suggest that ACT can improve psychological flexibility and alleviate distress amongst caregivers of other conditions (Collins & Kishita, 2019; Han et al., 2020). Losada and collegues (2015) compared ACT to conventional CBT in a Randomised Controlled Trial (RCT) with dementia caregivers and found both interventions efficacious for depression and anxiety.

Qualitative accounts have outlined acceptance, living in the present and engagement in value-based behaviours as themes linked to better adjustment amongst ABI carers (Lond & Williamson, 2018; Williams et al., 2014). To date, no RCT has been conducted to investigate the efficacy of ACT for caregivers of adults with ABI, and no cross-sectional study has been published on the role of psychological flexibility in this specific population. Nor has any study explored the influence of psychological flexibility on the SPM.

The Present Study

The present study explored the role and relative strength of psychological flexibility in explaining ABI caregiver outcomes, compared to the established constructs of perceived burden, coping, social support and perceived functional disability of the care-recipient.

It was predicted that psychological flexibility would explain unique variance in depression, anxiety, and satisfaction of life after controlling for perceived burden, coping, social support and functional disability. To further explore the specific role of psychological flexibility, in relation to the other constructs, conditional process analysis was used. Specific models were selected apriori, based on theory. It was predicted that perceived burden (negative appraisal) would mediate the direct relationship between functional disability and caregiver outcomes, in accordance with the SPM. Secondly, it was predicted that psychological flexibility, coping and social support would each moderate the indirect effect of perceived burden on outcomes.

Methods

Design

The present study used a quantitative cross-sectional design. The study protocol was pre-registered prior to data collection (*details redacted for the purpose of blinding*). Participants completed an online survey of standardised questionnaires measuring satisfaction with life, psychological distress, functional disability of the care-recipient, psychological flexibility, coping, social support and perceived burden. Demographic information was gathered as part of the online survey including information about the caregiver, the care-recipient and the caregiver context. All responses were anonymised, and informed consent was obtained from each participant. Full ethical approval was obtained from an NHS Research Ethics Committee (*details redacted for the purpose of blinding*).

Recruitment

Participants were recruited through convenience sampling between March and December 2020. Clinicians in the National Health Service and several UK-wide brain injury organisations advertised the study online on social media platforms (Twitter and Facebook).

Participants

Caregivers self-identified as eligible to participate. Informal caregivers over the age of 16 could participate if they could read written English and cared for an adult who had suffered an ABI after the age of 16, and who had been discharged from hospital for more than three months. Individuals who cared for a person with a degenerative or progressive brain injury (e.g. dementia or multiple sclerosis) were excluded. 145 participants completed the survey.

Measures

Dependent Variables

The Depression Anxiety Stress Scale – short version (DASS-21). DASS-21 is a 21 item measure of psychological distress with three subscales of depression, anxiety, and stress (Lovibond & Lovibond, 1995). Higher scores indicate greater level of distress. The subscales have good internal consistency (Cronbach's α of .88, .82, and 90, Henry & Crawford, 2005). Cronbach α values for the present sample were .91, .81 and .86.

Satisfaction With Life Scale (SWLS). The SWLS is a five item scale measuring perceived global life satisfaction (Diener, Emmons, Larsem et al., 1985). Higher scores indicate better life satisfaction. The scale has good internal consistency (α = .87) (Diener et al., 2013). For the present study α was .88.

Predictor Variables

The Patient Competency Rating Scale – Relative version (PCRS – R). The PCRS-R assesses functional disability of the care-recipient, as rated by the caregiver (Prigatano, 1986). Higher scores mean greater disability. The scale has high internal consistency (α = .93), and has been previously used with ABI caregivers (Chronister et al., 2016; Ergh et al., 2002). For the present study α was .94.

Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT). The CompACT is a 23-item scale assessing psychological flexibility (Francis et al., 2016). Higher scores indicate greater psychological flexibility. For the present study, the total score was used. The CompACT has been found to have excellent (α = .91) internal consistency (Francis et al., 2016). In the present sample α was .88.

The Brief Coping Orientation to Problems Experienced (COPE) scale. The brief COPE is a 28 item measure of three styles of coping: emotion-focused; problem-focused and avoidant coping (Carver, 1997). Higher scores indicate more frequent use of that style. The

subscales have good internal consistency in caregiving samples (α = 0.72, 0.84, 0.75; Cooper,

Katona, & Livingston, 2008). In the present sample α was .71, .80 and .73.

The Interpersonal Support Evaluation List-12 (ISEL-12). The ISEL-12 is a 12-item

measure of social support (Cohen, Mermelstein, Kamarck, & Hoberman, 1985). Higher

scores indicate greater availability of social support. It has been used in ABI caregiver

samples and has good internal consistency (α = .77; Cohen & Hoberman, 1983; Perrin et al.,

2013). In the current sample α was .91. The language on some items was adapted to suit a

UK demographic (e.g., the word *apartment* was changed to *flat*), and a minor modification

was made to the instructions for clarity.

The Modified Caregiver Appraisal Scale (MCAS). The MCAS measures appraisals of

the caregiving situation (Struchen, Atchison, Roebuck et al., 2002). The MCAS has four

subscales: perceived burden, mastery, satisfaction, and ideology. The perceived burden

subscale was used to measure negative caregiver appraisal. The subscale consists of 15

items, and higher scores indicate greater perceived burden. The subscale is widely used on

its own in ABI caregiver research with good internal consistency (α = .91) and convergent

validity with other subjective burden scales (Lawton et al., 1989). For the present study, α

was .92.

Data analysis plan

Preliminary analysis

The final sample was 144 after excluding one complete case due to 96% missing

data. No other case had more than 3% missing data. The remaining amount of missing data

in the final sample (*N* = 144) was 0.1%. Visual inspection of a missing data analysis indicated

that data were Missing Completely At Random (MCAR). The assumption that data were

MCAR was further corroborated by Little's MCAR test (X^2 = 1743.71, *df* = 1742, *p* = .484 *ns*).

The Expectation Maximisation (EM) algorithm in SPSS was used to impute missing data

(Newman, 2014). The assumptions for parametric analysis were met. Visual inspection of

histograms and P-P plots indicated normal distribution of data on all variables, which was

confirmed by Skewness and Kurtosis indeces between -2 to +2 and -7 to +7, respectively

(Tabachnick & Fidell, 2012). All data analyses were conducted using SPSS (version 25: IBM

Corp., 2017).

Covariates

Differences between demographic groups and sample characteristics were explored

to identify covariates to control for in subsequent analyses using analysis of variance

(ANOVA) and correlation coefficients (Pearson's *r*).

Correlation

Correlational analysis was used to examine the relations between key study variables

using Cohen's (1992) definition of effect sizes. The strength of the correlations also

influenced which coping variable to include in regression models. These decisions were

taken in order to limit the number of variables in the regression analysis to focus on the

most relevant constructs, whilst preserving power (Tabachnick & Fidell, 2012).

Regression

Three hierarchical multiple linear regression analyses were conducted to explore the

predictive strength of each construct on the dependent variables. Hierarchical regression is

a suitable, and conservative, approach to explore incremental validity of a new construct of

interest, such as psychological flexibility. The variance of theoretically established variables

is accounted for in the initial steps of the analysis whilst more recent constructs are entered

into the model subsequently. The models were decided apriori based on theory and

previous findings, with established constructs entered prior to more recent or less

theoretically established constructs. Variables were entered into the regression in this

sequence: 1) covariates 2) established factors from the SPM 3) coping 4) psychological

flexibility. Full regression tables illustrating each step of the analysis for each dependent

variable are provided as supplementary material, with final models for each dependent

variable are provided in Table 4. The assumptions for regression analyses were met for each

analysis including checks for homoscedasticity, linearity, independence and normality of

errors and absence of multicollinearity (Field, 2013). Effect sizes were calculated using $f^2 =$

$adjR^2 \setminus 1 - adjR^2$.

Conditional Process Analysis

Conditional process analysis (Hayes, 2018) was used to explore apriori models that

were constructed based on previous research and theory. Simple mediation models

(PROCESS model 4) were used to statistically test if disability of the care-recipient was

associated with each outcome, and if this relationship was mediated by perceived burden

(i.e. appraisal of the caregiver situation). Moderated mediation models (PROCESS model 58)

were used to test if coping, social support and psychological flexibility moderated the

influence of appraisals. All models were tested using Hayes (2018) PROCESS macro version

3.0 for SPSS version 25.

Power

Power estimations were conducted a-priori, using G*power (version 3.1) and

Green's rule of thumb. The highest estimation was $N = 111$ in order to have sufficient power

(.80) to detect a medium effect size (e.g. Chronister et al., 2010; 2016) with seven predictors

in the regression analysis (Faul et al., 2007; Green, 1991). For the conditional process

analyses, Fritz and MacKinnon (2007) suggested a minimum sample size of 75 would be

required.

Results

Description of Sample

The analysed sample consisted of 144 caregivers, of which the majority (87%) identified as female. Sample characteristics are described in Table 1, with descriptive statistics in Table 2. These two tables also present comparison demographics and data from similar populations. Most caregivers were employed (66%), and the majority were spouses (65%). Seventy-nine percent had no access to professional care and the majority (70%) reported that they were the only person providing care to the care-recipient. Caregivers (*M* = 50.90) were slightly older than care-recipients (*M* = 49.42). There was a range of ABIs represented in the sample. The current sample was similar to data reported by Jackson and colleagues (2009) in terms of caregiver gender, age and relationship to the care-recipient, whilst time since injury was less in this sample. In terms of outcome variables, the present sample had greater mean anxiety and depression scores, and lower mean satisfaction of life compared to comparison data (Table 2).

< Table 1 here: Characteristics of the sample >

< Table 2 here: Descriptive data of predictors and outcomes >

Covariates

For depression, the age of the care-recipient correlated positively with caregiver depressive symptoms (*r* = .19, *p* < .05). Caregivers who did not have access to help from additional caregivers reported significantly greater levels of depressive symptoms compared to those who had access to this help (No help mean = 8.98, *SD*: 5.83; Help mean = 6.84, *SD*:

4.89 , *F(1, 142) = 4.47, p* < .05), as did caregivers who spent more than twelve hours caring

each day (> 12 hours *M* = 10.09 , *SD*: 6.53; < 12 hours *M* = 7.57 , *SD*: 5.04 , *F*(1, 142) = 6.34 , *p*

< .05). These three factors were entered into the regression model for depression as

covariates. For anxiety, no covariates were identified. The age of the caregiver and the age

of the care-recipient significantly correlated with satisfaction with life (Caregiver age: *r* = -

.30, *p* < .001; Care-recipient age: *r* = - .22, *p* < .001). Significant differences were found on

time spent caring with the same pattern as for depression (> 12 hours *M* = 11.77, *SD*: 5.94; <

12 hours *M* = 17.90, *SD*: 6.53, *F*(1, 142) = 28.43 , *p* = < .001). These three variables were

entered into the regression model for satisfaction with life as covariates.

Correlation Analysis

Pearson's correlation coefficients are presented in Table 3. Moderate to strong

correlations were found between predictors in theorised directions, with the exception of

coping variables. Contrary to prediction, problem-focused coping did not correlate

significantly with depression or anxiety. Emotion-focused coping was not associated with

levels of anxiety.

< Table 3 here: Correlation Matrix >

Multivariate Analysis

Table 4 presents the results of the hierarchical multiple regression analysis testing

the predictive power of variables on depression, anxiety and satisfaction of life. The final

models for each dependent variable are presented in Table 4 (see supplementary material

for results of each step of the hierarchical regression analysis of each outcome).

Prediction of Depressive Symptoms

The final model included eight variables and accounted for 50% of the variance in depression (Adj. R^2 = .50), which was highly significant ($F_{[8, 135]}$ = 18.58, $p < .001$) and represented a large effect size (f^2 = 1.0). Avoidant coping (β = .18, $p < .05$) and psychological flexibility (β = -.37, $p < .001$) were the only significant predictors. The age of the care-recipient (β = .12, $p = .056$, ns) and the functional disability of the care-recipient (β = .14, $p = .057$, ns) approached significance.

Prediction of Symptoms of Anxiety

The final model included five variables and accounted for 35% of the variance (Adj. R^2 = .35), which was highly significant ($F_{[5, 138]}$ = 16.29, $p < .001$), and represented a large effect size (f^2 = .54). Functional disability (β = .27, $p = .001$), avoidant coping (β = .22, $p < .05$) and psychological flexibility (β = -.38, $p < .001$) were all significant predictors.

Prediction of Satisfaction of Life

The final model included eight variables and accounted for 53% of the variance (Adj. R^2 = .53), which was highly significant ($F_{[8, 135]}$ = 21.40, $p < .001$) and demonstrated a large effect size (f^2 = 1.14). Functional disability (β = -.18, $p < .01$), perceived burden (β = -.34, $p < .001$) and problem-focused coping (β = .17 $p < .01$) were all significant predictors. Of the three covariates, time spent caring (β = -.19 $p < .01$) and age of the caregiver (β = -.19 $p < .01$) remained significant in the final model.

< Table 4 here: Hierarchical regression analysis >

Conditional Process Analysis

Figures 1 to 3 depict diagrams of the two theoretical models that were tested on each outcome. Numbers on the lines represent beta coefficients (unstandardised) and only

significant paths are presented for clarity. The total variance for each model is presented

below the diagram together with a table describing the regression coefficients onto the

dependent variable in each model. The boxes on indirect (mediator) paths represents the

indirect effect of the mediator at different levels of the moderator. This is to illustrate how

the indirect effect of burden on outcomes varies as the level of the moderator increases or

decreases. The indirect effect of the mediator is shown at low (-1 *SD*), mean, and high (+1

SD) levels of the moderator. All boot-strapped confidence intervals are of 5000 resamples.

Depression as Dependent Variable

Figure 1a presents the mediation model used to explore if the relationship between

functional disability of the care-recipient and caregiver depression is mediated by perceived

burden, as theorised from the SPM. The total model accounted for 32% of the variance in

depression, which was significant (R^2 = .32, p < .001). Functional disability only had an

indirect impact on depression via perceived burden (*B* = .06, 95% LLCI = .03, ULCI = .09). This

suggests that the level of functional disability of a person with ABI is associated with

caregiver depression only via the caregiver's appraisal (i.e. perceived burden).

Figures 1b to 1d represent the models in which avoidant coping, social support and

psychological flexibility were explored as moderators of the mediated path between

functional disability and depression, via perceived burden. There was no moderating effect

of avoidant coping or social support, and the mediating indirect path between disability and

depression via perceived burden remained significant. The absence of moderation is

illustrated in the boxes in Figure 1b and 1c, where the indirect path remains significant at

different levels of the moderator. The direct path between functional disability and

depression became significant when avoidant coping was entered as a moderator (Figure

1b). Psychological flexibility (Figure 1d) was found to significantly moderate the influence of

perceived burden (B = -.002, p < .05). At high levels of psychological flexibility, perceived

burden no longer mediated the path between disability and caregiver depression (B = .01,

95% LLCI = -.01, ULCI = .03). This suggests that psychological flexibility acts as a buffer

against the impact of negative appraisals (i.e. perceived burden) on caregiver depression.

< Figure 1 here: Conditional process analysis models with depression as DV >

Anxiety as Dependent Variable

The mediation model in Figure 2a accounted for 16% of the variance in anxiety,

which was significant (R^2 = .16, p < .001). Functional disability had a direct influence on

anxiety (B = .05, p < .01). Perceived burden mediated the path between disability and

anxiety (B = .02, 95% LLCI = .004, ULCI = .004). The disability of the care-recipient was

associated with the level of anxiety amongst caregivers directly and via their appraisal of the

caregiving situation (i.e. perceived burden).

In the moderated mediation models depicted in Figures 2b to 2d, no significant

moderating role of avoidant coping, social support or psychological flexibility was

demonstrated.

< Figure 2 here: Conditional process analysis models with anxiety as DV >

Satisfaction with Life as Dependent Variable

The mediation model (Figure 3a) accounted for 51% of the variance in satisfaction of

life, which was highly significant (R^2 = .51, p < .001). Functional disability directly influenced

satisfaction with life (B = -.07, p < .01), and also indirectly via perceived burden (B = -.07, 95% LLCI = -.10, ULCI = -.04).

The model depicted in Figure 3b demonstrates a moderating effect of problem focused coping on the indirect influence of perceived burden (B = -.02, p < .05). Unexpectedly, higher level of problem-coping strategies (e.g. taking action, seeking advice, problem-solving) strengthened the influence of cognitive appraisals (i.e. perceived burden) on satisfaction with life. In model 3c and 3d, there were no moderating effects of social support or psychological flexibility, and the indirect path between disability and satisfaction with life, via perceived burden, remained significant. Both covariates (time caring, age of caregiver) remained significant predictors of satisfaction with life in all four models depicted in Figure 3.

< Figure 3 here: Conditional process analysis models with satisfaction with life as DV >

Discussion

This study investigated the role of psychological flexibility amongst caregivers of adults with ABI. The aim was to examine the relative strength of psychological flexibility and its specific role in explaining caregiver outcomes, compared to established constructs. Functional disability of the care-recipient, perceived burden, coping, social support and psychological flexibility were all explored as predictors of depression, anxiety and satisfaction with life.

Psychological Flexibility

Psychological flexibility was the strongest predictor of both depression and anxiety in the regression models, when established constructs had been accounted for, as

hypothesised. This finding is in line with studies on caregivers of other conditions, such as dementia and psychosis (Jansen et al., 2017; Kishita et al., 2020). The present study is the first to establish psychological flexibility as a significant predictor of depression and anxiety in caregivers of adults with ABI, after controlling for known predictors.

In contrast to our hypothesis; psychological flexibility was not a significant predictor of satisfaction of life. This finding has been observed in comparable samples (e.g., Lappalainen et al., 2021; McAteer & Gillanders, 2019). Psychological factors may not be enough to moderate the QoL, to the same extent as distress, of someone faced with highly demanding and chronic circumstances. Further, the SWLS is oriented towards the hedonic component of wellbeing (i.e., pleasure attainment and avoiding suffering; Vanhoutte & Nazroo, 2014). It may be that psychological flexibility is a stronger predictor of a eudaemonic conceptualisation of wellbeing (i.e., self-realisation, valued living, and growth) in this population.

The functional disability of the care-recipient is only associated with levels of caregiver depression indirectly via the caregiver's negative appraisal of burden (i.e. perceived burden), in line with the SPM. This indirect path was moderated by psychological flexibility, suggesting a buffering role. The effect of negative appraisals was diminished, and became non-significant, with higher levels of psychological flexibility. This outcome was in line with predictions, and in accordance with psychological flexibility theory. This finding is particularly relevant for the caregiver population as negative appraisals and difficult thoughts are common and a difficult target to alter (Márquez-González et al., 2013).

Psychological flexibility was not found to have a moderating role for anxiety or satisfaction with life. The results suggest that being an ABI caregiver is associated with anxiety, and that naturally occurring psychological flexibility is not enough as a buffer

against it. It will be for intervention studies to explore how increasing levels of psychological flexibility interacts with anxiety.

The Stress Process Model

Perceived burden was the strongest predictor of variance in satisfaction with life but was not a significant predictor in regression models of depression or anxiety. In accordance with previous findings, perceived burden mediated the direct path between disability of the care-recipient and all three outcomes in simple mediation models (Chronister et al., 2016; Harris et al., 2001). However, the strength of these associations diminished when other constructs were included in the models, to the extent that the indirect path became non-significant for the anxiety models. A limitation of previous research is that appraisals are compared to concepts from within the SPM, but rarely to external theoretical frameworks, such as psychological flexibility theory.

The results of the present study suggest that negative appraisals are important for life satisfaction amongst caregivers, but less fundamental than expected for depression and anxiety, for which psychological flexibility may be a stronger influence. Caregivers who demonstrate negative cognitive biases are prone to global negative biases in their subjective evaluation of their satisfaction with life. The strength of psychological flexibility as a predictor may have cancelled out the effects of these biases on depression and anxiety.

Social support correlated with outcomes in expected directions but was not a significant predictor of variance of any outcome, or a moderator in conditional process analyses. These results suggest that social support is an important factor associated with distress and satisfaction of life, consistent with previous research (Ergh et al., 2002). However, social support has a comparatively weaker influence on distress and satisfaction with life when psychological flexibility and the additional constructs from the SPM are

accounted for in this sample. This finding highlights the importance of considering theoretical frameworks, rather than individual factors.

Consistent with theory, avoidant coping was a significant predictor of anxiety and depression. Avoidant coping did not moderate appraisals, but when avoidant coping was entered into the moderated mediation model the direct link between functional disability and depression became significant. This pattern suggests that avoidant coping is a strong predictor of depression inhibiting the direct influence of perceived burden, which is further supported by the regression analysis. The adverse influence of avoidant strategies is consistent with behavioural theory and a fundamental aspect of the psychological flexibility model and ACT (Hayes et al., 2012).

Interestingly, higher levels of problem-focused coping strengthened the mediation effect of appraisals on satisfaction with life. It appears that negative cognitions have a stronger adverse influence on satisfaction of life if someone also reports a rigid adherence to problem-focused strategies. One explanation to this could be that many issues in the caregiving context are long-standing and not always resolvable, and so a problem-solving approach may not produce the intended outcome.

Implications for Practice

The findings from the present study suggest that psychological flexibility, negative appraisals and avoidance strategies could be modifiable targets for interventions to help caregivers. ACT would be a suitable intervention as it aims to increase psychological flexibility and to reduce experiential avoidance (Hayes et al., 2012). ACT-based approaches could offer strategies to increase awareness of appraisals and to relate more openly and self-compassionately to difficult thoughts and emotions. Caregivers may benefit from a strengthened connection to values intrinsic in providing care to someone, and support to

maintain their own activities and self-care repertoire, which is often reduced or put on hold.

It should be noted that psychological flexibility and avoidant coping were not predictors of

satisfaction of life, and selective targeting of these constructs may not be beneficial across

all ABI caregiver outcomes. A more traditional cognitive behavioural approach (e.g. Beck,

1976) could target appraisals, and avoidant strategies, with cognitive restructuring and

behavioural activation. Research on caregivers of people with dementia has indicated that

both ACT and CBT are efficacious (Losada et al., 2015).

Limitations

Several limitations of the present study should be considered. The design was cross-

sectional and causal relationships cannot be inferred from the results. The use of

convenience sampling through an online survey advertised via ABI organisations reduces the

generalisability of the findings. Similarly, all participants were self-selecting and may not be

representative of the caregiver population, and self-report measures involve an inherent

risk of common response biases.

Perceived functional disability of the person with the ABI was assessed by the

caregiver. Relative-reports introduce a possible bias in that individuals with negative

appraisals could rate the disability as worse than it is. Objective measures of function or

disability could address this issue.

Caregiver appraisals were defined and measured as perceived burden. The study

may therefore have overlooked positive aspects of caregiving which could influence

wellbeing and adjustment (Cohen et al., 2002). Time spent caring was one of the covariates

associated with satisfaction of life. This variable was measured categorically and is

susceptible to ceiling effects.

Lastly, recruitment to this study took place during the COVID-19 pandemic. From Table 2, slightly higher mean level anxiety and depression is observed in the present sample compared to a comparative sample recruited prior to COVID-19. It is difficult to speculate in what direction this could impact on our data.

Future Directions

Future research should replicate the current findings using longitudinal or controlled treatment designs to establish causality, and larger samples could be analysed using structural equational modelling to allow for several dependent variables simultaneously. The current study provides useful data for estimations of effect sizes and sample sizes required for future studies. No significant differences were found between caregivers of different types of brain injuries. Future studies are encouraged to continue to include a variety of ABI conditions.

Conclusions

Compared to established constructs from the SPM, psychological flexibility was found to be the strongest factor in explaining variance in anxiety and depression amongst caregivers of adults with ABI. Psychological flexibility was found to moderate the effect of caregiver appraisal on depression. Caregiver appraisals were the strongest predictor for satisfaction of life and mediated the relation between levels of care-recipient functional disability and caregiver outcomes.

The findings of this study have added to the SPM and to our understanding of caregiver distress and wellbeing. As in many other populations, psychological flexibility appears to play a central role for outcomes amongst caregivers of adults with ABI and further exploration into this area is warranted.

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Table 1 Characteristics of the Sample

Variable	*n*	%	Mean	*SD*	*M*	*SD*	%
					Comparative data		
Age	144		50.9	11.7	54[a]	10.9[a]	
Gender							
Female	125	87					81[a]
Male	17	12					19[a]
Other	1	1					
Status of employment							
Full time	64	44					
Part-time due to caring responsibilities	14	10					
Part-time due to other reasons	10	7					
Unemployed due to caring responsibilities	26	18					
Unemployed due to other reasons	7	5					
Student	3	2					
Retired	20	14					
Role of caregiver							
Parent	28	19					37[a]
Spouse	94	65					59[a]
Child	13	9					2[a]
Sibling	8	6					2[a]
Friend	1	1					-
Time spent caring daily							
1-3 hours	42	29					
3-6 hours	33	23					
6-9 hours	14	10					
9-12 hours	10	7					
12-24 hours	44	31					
Care from professional (paid) carers							
Professional care	30	21					
Hours per week			34.63	49.03			
No professional care	114	79					
Help from additional informal caregivers							
Others also help	43	30					
No other informal caregivers	101	70					
Additional caring responsibilities							
Solely caring for one person with ABI	92	64					
Caring for additional individuals	49	34					
Age of care-recipients	144		49.42	15.36	46[a]	13.5[a]	
Years since injury			5.19	4.71	10[a]		
Type of ABI							
TBI	40	28					49[a]
Stroke	31	22					26[a]
Brain tumour	16	11					-
Infectious (e.g. encephalitis or meningitis)	48	33					18[a]
Anoxia/Hypoxia	3	2					4[a]
Aneurysm	6	4					-

Note. a = Jackson et al., 2009

Table 2 Descriptive Data on Predictor Variables and Outcomes

	Scale Range	Min	Max	M	SD	Comparative data M	SD
Dependent Variables							
SWLS Satisfaction with life	5-35	5	31	16.03	6.94	23.51[a]	5.28[a]
DASS Anxiety	0-21	0	21	5.42	4.27	2.31[b]	2.74[b]
DASS Depression	0-21	0	21	8.34	5.64	3.14[b]	3.82[b]
Predictor Variables							
PCRS-R Functional disability of CR	30-150	45	143	96.22	20.50	95.20[c]	21.85[c]
CompACT Psychological flexibility	0-138	24	134	69.31	20.94	not available	
COPE Problem-focused coping	6-24	6	24	15.83	3.89	21.41[d]	4.79[d]
COPE Emotion-focused coping	10-40	13	38	24.19	5.13	36.53[d]	7.73[d]
COPE Avoidant coping	12-48	12	38	23.56	5.36	18.97[d]	4.98[d]
ISEL Social support	12-48	12	48	31.61	8.97	35.74[e]	na
MCAS Perceived burden	15-75	17	75	51.28	12.77	not available	

Note. CR = Care Recipient

a = Ergh et al., 2003; b = Simpson et al., 2020; c = Chronister et al., 2016; d = Chronister et al., 2010; e =

Perrin et al., 2013

Table 3 Correlation Matrix of Predictor Variables and Outcomes

	1	2	3	4	5	6	7	8	9	10
1. SWLS Satisfaction with life	1									
2. DASS Depression	-.47**	1								
3. DASS Anxiety	-.24**	.74**	1							
4. PCRS-R Functional Disability of CR	-.48**	.38**	.36**	1						
5. MCAS Perceived burden	-.61**	.54**	.33**	.47**	1					
6. ISEL Social Support	.48**	-.48**	-.29**	-.28**	-.58**	1				
7. COPE Problem-focused coping	.28**	-.14	-.05	-.10	-.12	.31**	1			
8. COPE Emotion-focused coping	.27**	-.30**	-.16	-.08	-.19*	.34**	.57**	1		
9. COPE Avoidant coping	-.28**	.48**	.43**	.06	.40**	-.29**	-.10	-.23**	1	
10. CompACT Psychological flexibility	.43**	-.64**	-.55**	-.31**	-.53**	.48**	.30**	.37**	-.60**	1

Note. CR = Care Recipient

*Correlation is significant at the .05 level (2-tailed), **Correlation is significant at the .01 level (2-tailed).

Table 4 Final Models from Hierarchical Regression Analysis of Depression, Anxiety and Satisfaction of Life

DV	Variables	β	t	p	R^2	Adj.R^2	ΔR^2	Δp	$F_{(k,143-k)}$	p	f^2
Depression					.52	.50	.07	<.001	18.58	<.001	1.0
	Time caring[a]	.05	0.74	.463							
	Additional caregivers[b]	-.01	-0.21	.833							
	Care-recipient age	.12	1.92	.056							
	Functional disability	.14	1.92	.057							
	Perceived burden	.11	1.22	.223							
	Social support	-.12	-1.59	.114							
	Avoidant coping	.18	2.30	.023							
	Psychological flexibility	-.37	-4.32	<.001							
Anxiety					.37	.35	.07	<.001	16.29	<.001	0.54
	Functional disability	.27	3.42	.001							
	Social support	-.03	-0.29	.772							
	Perceived burden	-.10	-1.05	.297							
	Avoidant coping	.22	2.50	.014							
	Psychological flexibility	-.38	-3.91	<.001							
Satisfaction With Life					.56	.53	.01	.129	21.40	<.001	1.14
	Time caring[a]	-.19	-2.94	.004							
	Age	-.19	-3.17	.002							
	Care-recipient age	-.08	-1.31	.190							
	Functional disability	-.18	-2.60	.010							
	Perceived burden	-.34	-4.15	<.001							
	Social support	.04	0.58	.561							
	Problem- focused coping	.17	2.65	.009							
	Psychological flexibility	.11	1.53	.129							

Note. DV = Dependent Variable, β = standardised beta; R^2 = R square; ΔR^2 = R square change; k = number of predictors

a = Time caring was coded 0 = <12h daily, 1 = >12h; b = Additional caregivers was coded 0 = no additional caregivers, 1 = additional caregivers
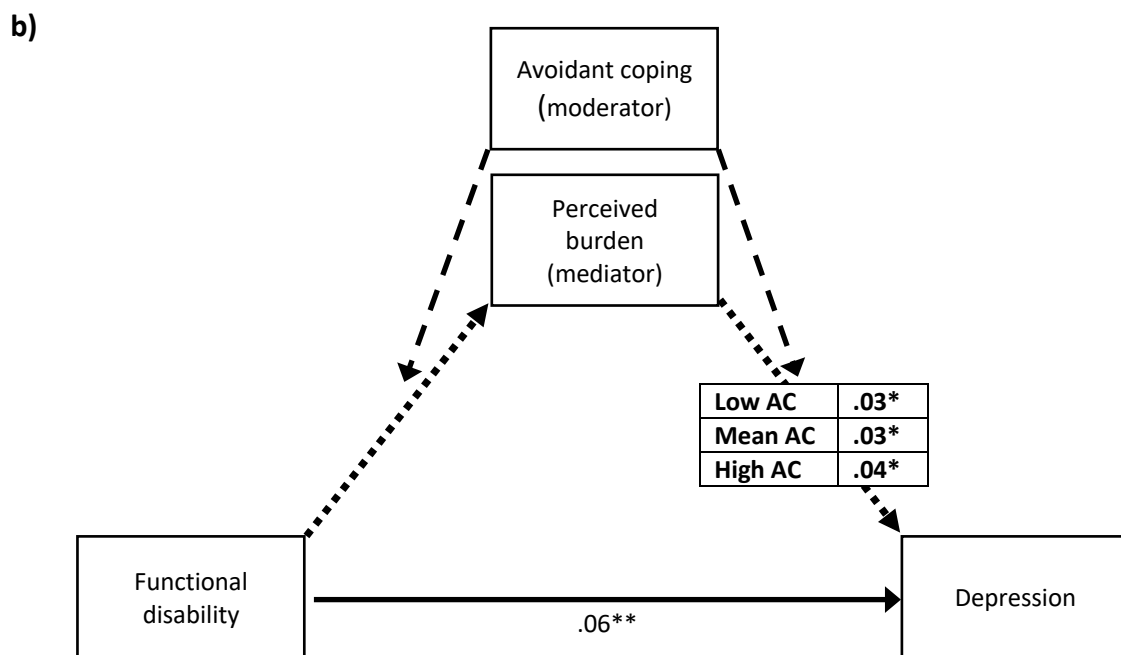
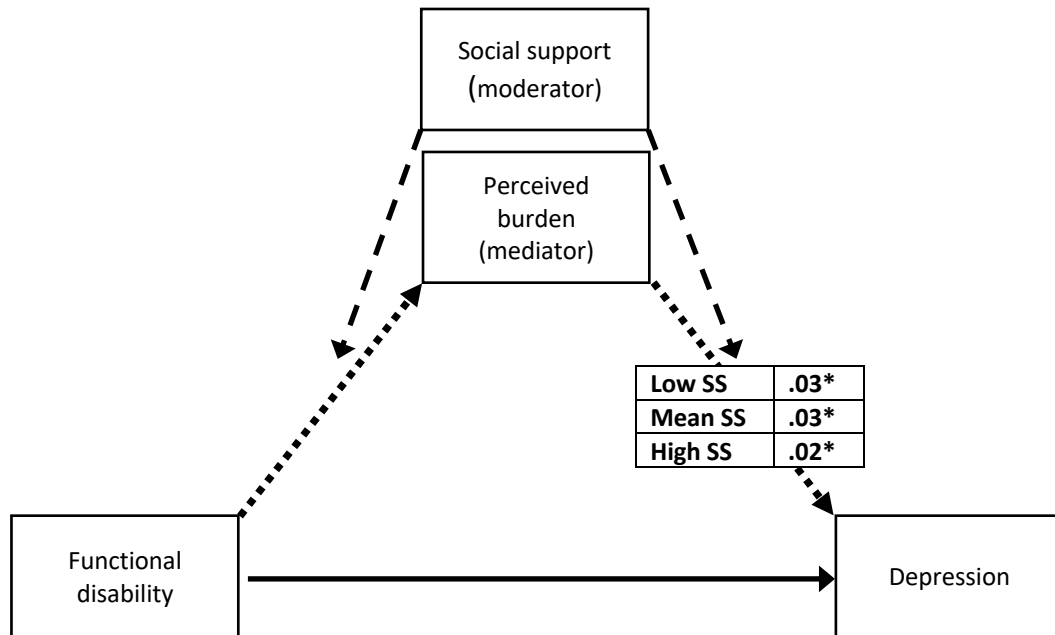**Figure 1** Conditional Process Analysis Models with Depression as Dependent Variable
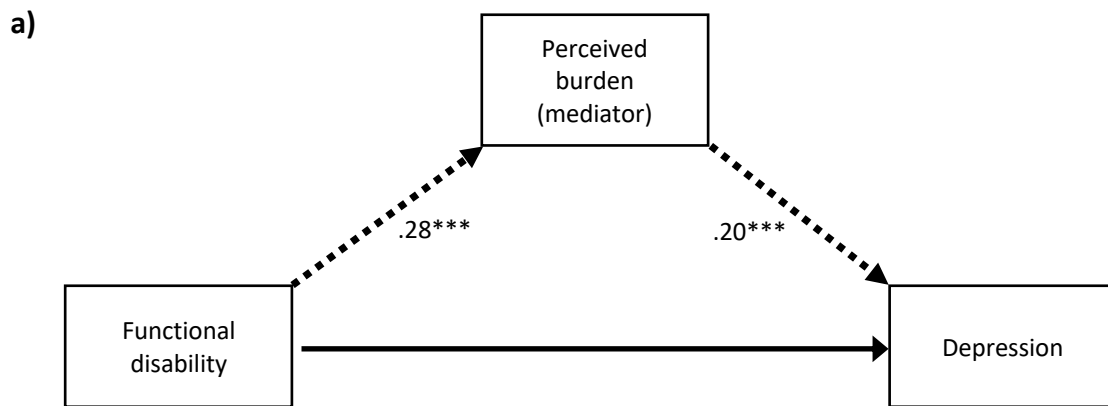
a)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 1a

	B	LL BCI	UL BCI	p
Functional disability	.04	- .001	.09	.054, ns
Perceived burden	.20	.13	.27	<.001
CR age (covariate)	.03	-.20	.08	.226, ns
Indirect path of mediator	.06	.03	.09	<.05
Total model: R^2 = .32, p < .0001, f^2 = .47				

b)
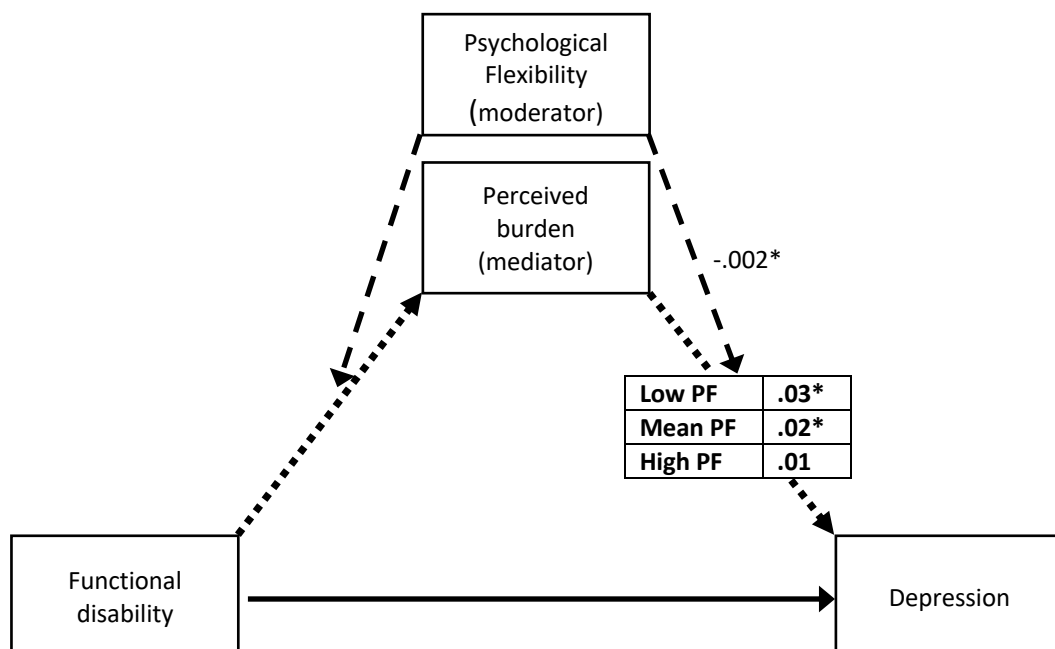

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 1b

	B	LL BCI	UL BCI	p
Functional disability	.06	.02	.09	.004
Perceived burden	.04	-.20	.28	.759, ns
Avoidant coping	.19	-.34	.72	.473, ns
Burden x avoidant coping	.004	-.01	.01	.470, ns
CR age (covariate)	.04	.10	-.01	.102, ns
Total model: R^2 = .43, p < .0001, f^2 = .75				

c)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 1c

	B	LL BCI	UL BCI	p
Functional disability	.04	-.002	.08	.059, ns
Perceived burden	.27	.03	.50	.028
Social support	.05	-.32	.41	.800, ns
Burden x social support	-.004	-.01	.003	.260, ns
CR age (covariate)	.03	-.02	.08	.275, ns

Total model: R^2 = .37, p < .0001, f^2 = .59

d)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 1d

	B	LL BCI	UL BCI	p
Functional disability	.03	-.004	.07	.080, ns
Perceived burden	.27	.10	.43	.002
Psychological flexibility	-.01	-.12	.10	.819, ns

Burden x psychological flexibility	-.002	-.004	-.0004	.021
CR age (covariate)	.04	-.002	.09	.064, *ns*

Total model: R^2 = .51, p < .0001, f^2 = 1.04
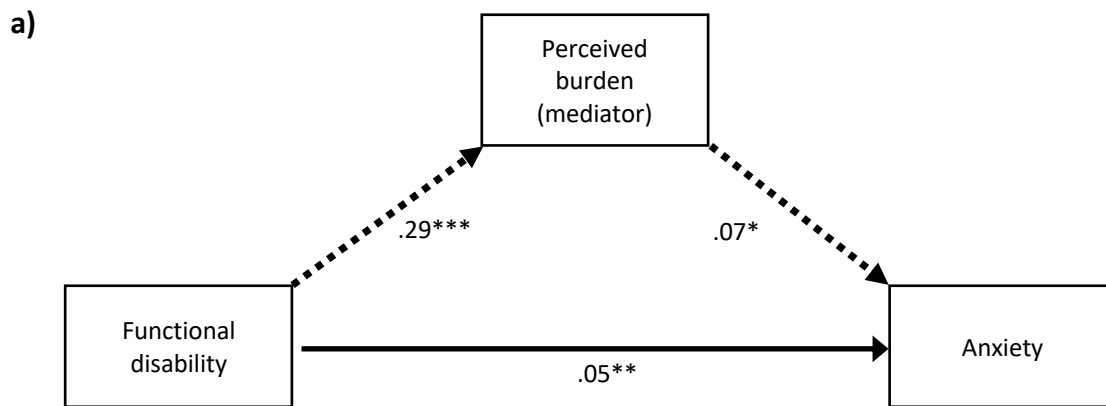
Key: ⟶ Direct path   ┅┅▶ Indirect path   ╌ ╌ ╌ ▶ Moderator

* p < .05 ** p < .01 *** p < .001; BCI = Bootstrapped confidence interval; LL = Lower Limit;

UL = Upper Limit; CR = Care-recipient; AC = Avoidant coping; SS = Social support; PF =

Psychological flexibility

Figure 2 Conditional Process Analysis Models with Anxiety as Dependent Variable

a)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 2a

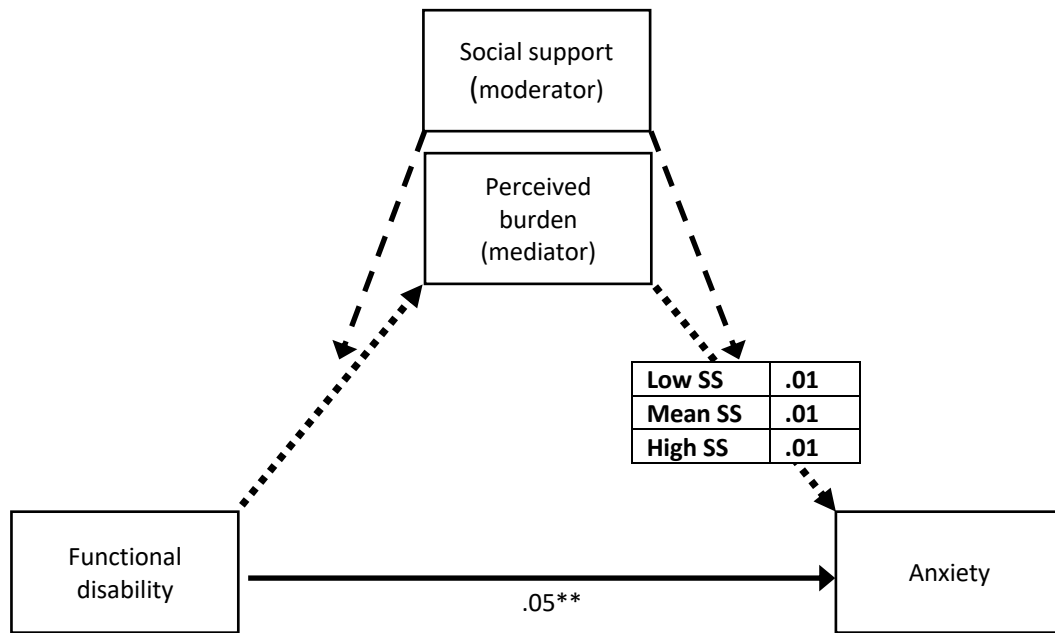|	B	LL BCI	UL BCI	p
Functional disability	.05	.02	.09	.004
Perceived burden	.07	.01	.13	.020
Indirect path via mediator	.02	.004	.04	<.05
Total model: R^2 = .16, $p < .0001$, f^2 = .19				
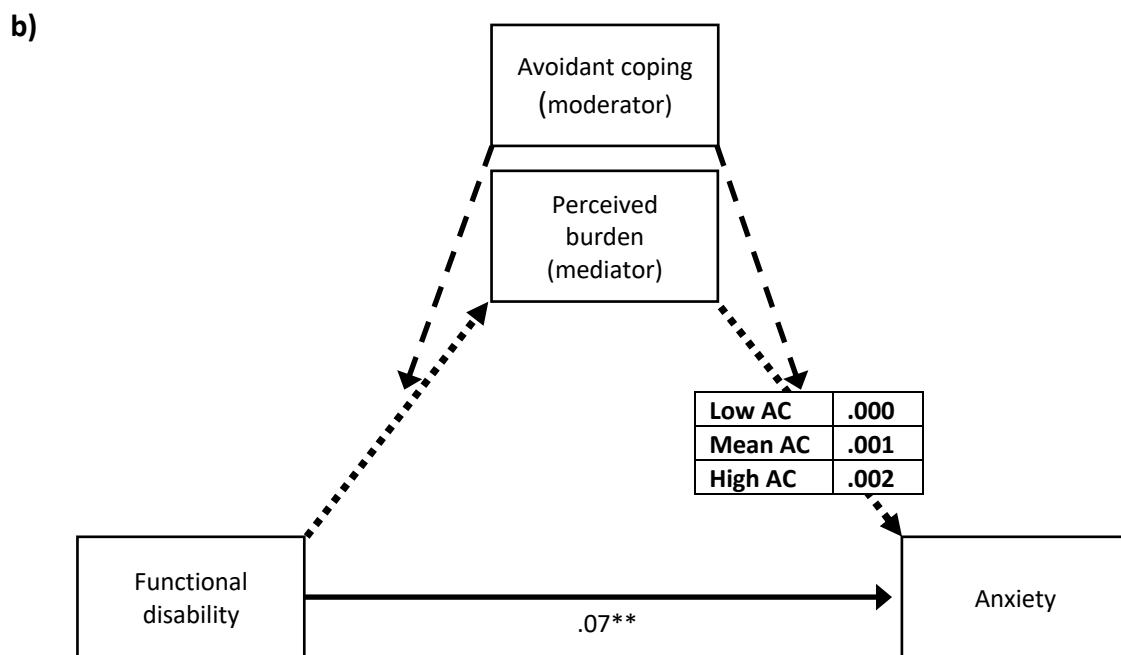
b)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 2b

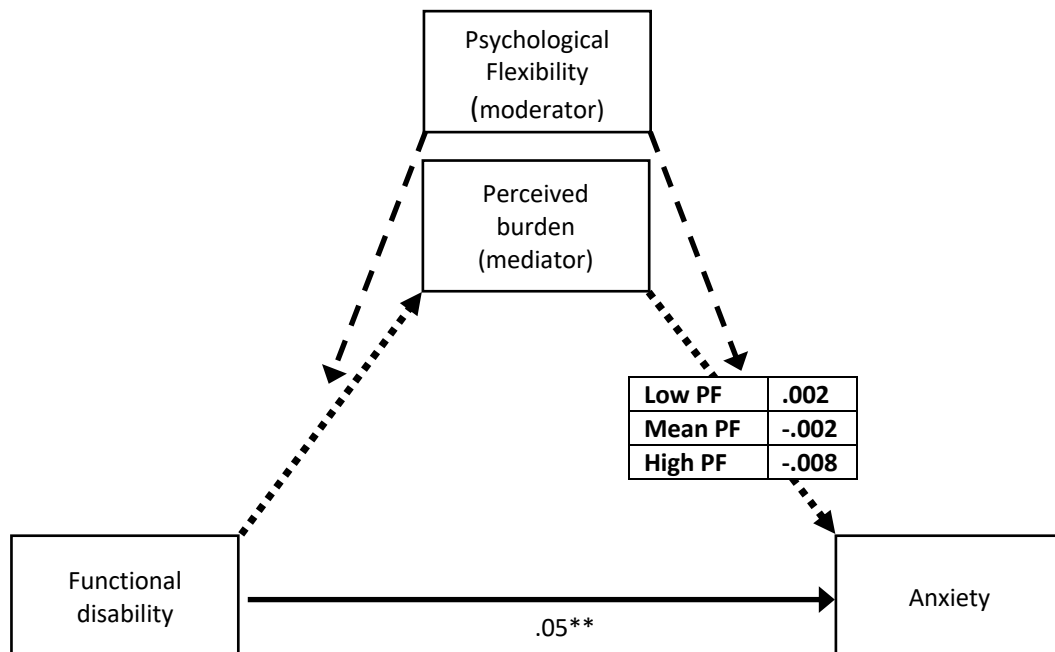|	B	LL BCI	UL BCI	p
Functional disability	.07	.03	.10	<.001
Perceived burden	-.01	-.21	.19	.925, *ns*
Avoidant coping	.29	-.16	.73	.200, *ns*
Burden x avoidant coping	.001	-.01	.01	.885, *ns*
Total model: R^2 = .29, $p < .0001$, f^2 = .41				

c)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 2c

	B	LL BCI	UL BCI	p
Functional disability	.05	.02	.09	.004
Perceived burden	.05	-.18	.23	.804, *ns*
Social support	-.09	-.41	.22	.561, *ns*
Burden x social support	.001	-.01	.01	.877, *ns*
Total model: $R^2 = .17$, $p < .0001$, $f^2 = .20$				

d)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 2d

	B	LL BCI	UL BCI	p
Functional disability	.05	.02	.08	.005
Perceived burden	.06	-.08	.21	.376, *ns*
Psychological flexibility	-.05	-.14	.05	.313, *ns*
Burden x psychological flexibility	-.001	-.003	.001	.229, *ns*

Total model: R^2 = .35, p < .0001, f^2 = .54

Key: ⟶ Direct path   ┅┅┅▶ Indirect path   ─ ─ ─▶ moderator

* p < .05 ** p < .01 *** p < .001; BCI = Bootstrapped confidence interval; LL = Lower Limit;

UL = Upper Limit; AC = Avoidant coping; SS = Social support; PF = Psychological flexibility

Figure 3 Conditional Process Analysis Models with Satisfaction of Life as Dependent Variable
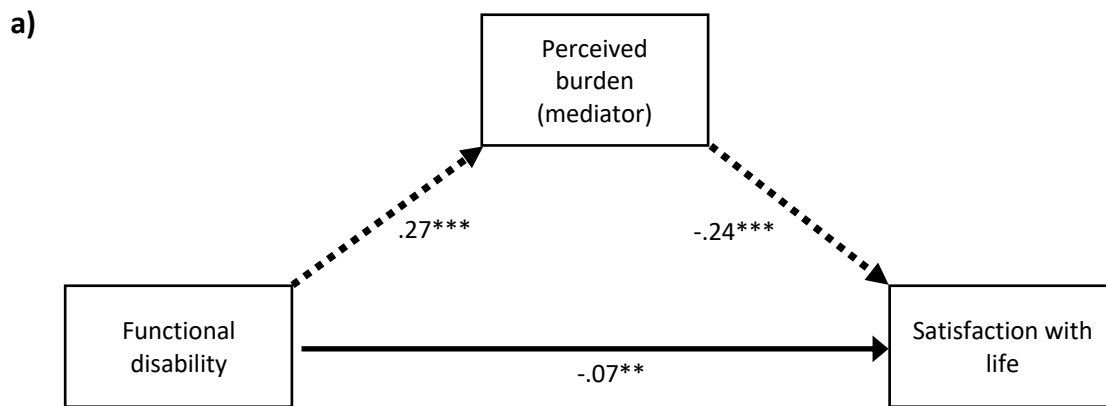
a)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 3a
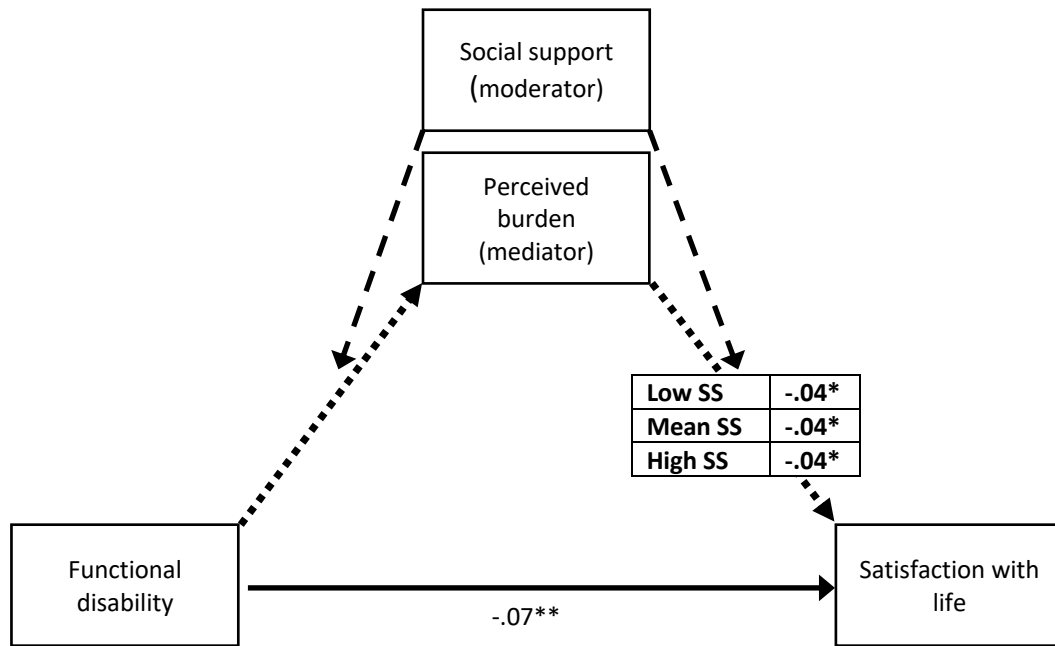
	B	LL BCI	UL BCI	p
Functional disability	-.07	-.11	-.02	.007
Perceived burden	-.24	-.32	-.17	<.001
Age (covariate)	-.12	-.19	-.05	.001
Time caring (covariate)	-2.84	-4.75	-.92	.004
Indirect path via mediator:	-.07	-.10	-.04	<.05

Total model: R^2 = .51, p < .0001, f^2 = 1.04
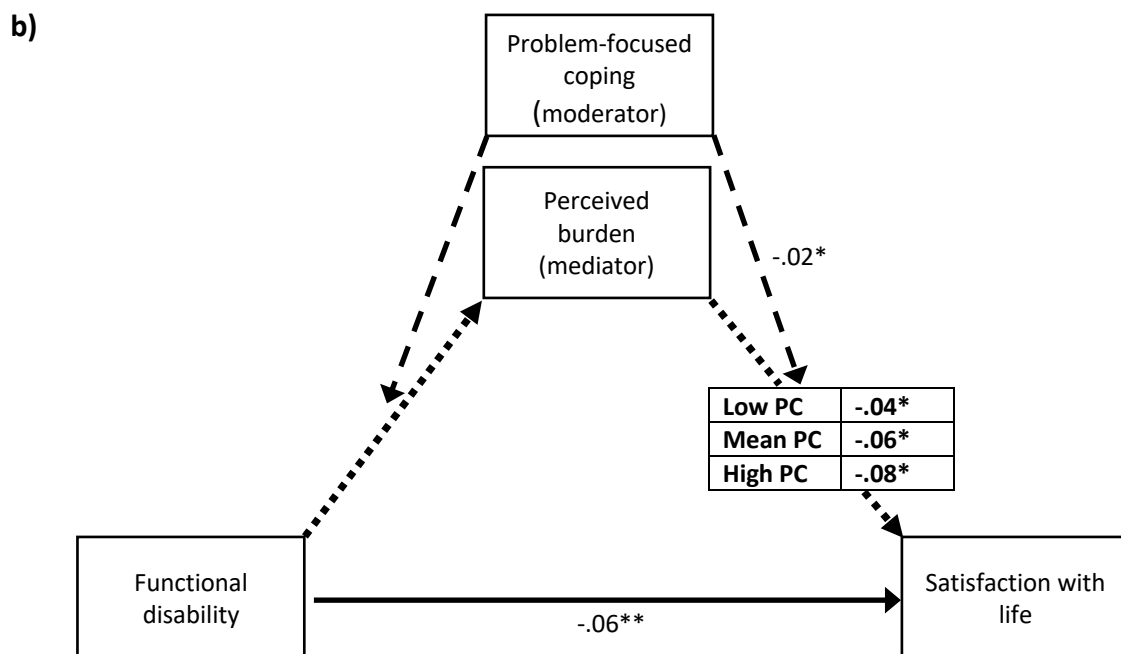
b)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 3b

	B	LL BCI	UL BCI	p
Functional disability	-.06	-.11	-.02	.005
Perceived burden	.11	-.17	.38	.437, *ns*
Problem-focused coping	1.40	.56	2.24	.001
Burden x problem coping	-.02	-.04	-.01	.012
Age (covariate)	-.14	-.20	-.07	<.001
Time caring (covariate)	-3.07	-4.91	-1.24	.001

Total model: R^2 = .56, p < .0001, f^2 = 1.27
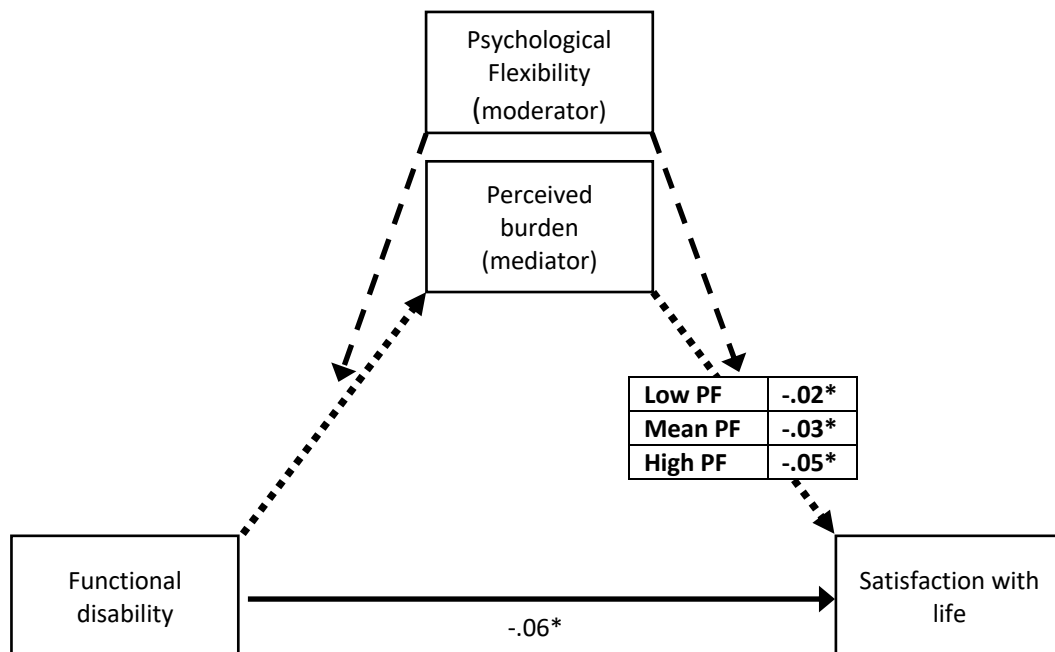
c)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 3c

	B	LL BCI	UL BCI	p
Functional disability	-.07	-.11	-.02	.006
Perceived burden	-.25	-.50	.01	.058, *ns*
Social support	.04	-.36	.43	.854, *ns*
Burden x social support	.001	-.01	.01	.716, *ns*
Age (covariate)	-.12	-.19	-.05	.001
Time caring (covariate)	-2.52	-4.45	-.53	.011

Total model: R^2 = .52, p < .0001, f^2 = 1.08

d)

Unstandardised regression coefficients and bootstrapped confidence intervals for the model in Figure 3d

	B	LL BCI	UL BCI	p
Functional disability	-.06	-.11	-.01	.011

Perceived burden	-.09	-.29	.11	.378, *ns*
Psychological flexibility	.13	-.004	.26	.057, *ns*
Burden x psychological flexibility	-.001	-.004	.001	.255, *ns*
Age (covariate)	-.13	-.20	-.06	<.001
Time caring (covariate)	-3.04	-4.93	-1.16	.002

Total model: R^2 = .53, *p* < .0001, f^2 = 1.13

Key: ──────▶ Direct path ┈┈┈┈▶ Indirect path ─ ─ ─ ▶ moderator

* *p* < .05 ** *p* < .01 *** *p* < .001; BCI = Bootstrapped confidence interval; LL = Lower Limit;

UL = Upper Limit; PC = Problem-focused coping; SS = Social support; PF = Psychological

flexibility