

Caring for a child with cancer: The role of attachment, self-compassion and social support

Abstract

Background: It is widely accepted that family caregivers are central to the future of cancer care and the impetus is to understand how best to support and empower them.

Aims: The current study explored the role of the relationship between the caregiver and the child, the level of perceived support, and the self-compassion of the caregiver, on distress and wellbeing in mothers who were the primary caregiver for a child with cancer.

Methods: A self-report questionnaire survey of 255 mothers assessed perceived support, attachment to the child, self-compassion and a range of demographic variables including age, education, employment and time since diagnosis.

Results: A model was proposed and explored using Hierarchical Multiple Regression Analysis (HMRA) and tested more fully using Structural Equation Modelling. The results of both analysis support the model and show it to be an excellent fit for the data.

Conclusions: The findings suggest that the quality of the attachment bond with the child along with mother's ability to be self-compassionate, combined with perceived social support may moderate the impact of care burden on perceived distress for mothers caring for a child with cancer.

Key terms: Self compassion; Attachment; Support; Caregiving; Children; Cancer

Introduction

There is an abundance of empirical evidence showing the devastating and distressful impact of a child diagnosed with cancer on the parent or caregiver as well as on the child (Sultan, Leclair, Rondeau, Burns, & Abate, 2016). There is also evidence that a range of factors in the parent or caregiver, the child and the context, can ameliorate this impact (Hildebrand, Alderfer, Deatrick, & Marsac, 2014), with the child and parent having to develop coping strategies to manage the distress over time (Hildenbrand, Clawson, Alderfer, & Marsac, 2011, Pai et al, 2007).

To date, research has generally tended to approach this area from a deficit perspective, with a focus on the negative impact as well as the strategies used to reduce the negative effect. More recently however evidence indicates that both parents and children can demonstrate resilience and find some positive benefit in their experiences (Rosenbery, Scott-Baker, Lyrjala, Back, & Wolfe, 2013). For example, evidence would suggest that there can be a deepening and strengthening of the emotional relationship or attachment bond between parent and child (Campbell-Enns, & Woodgate, 2013). Evidence further indicates that better quality of life in parents of children with cancer is associated with more positive health behaviours (e.g. diet, exercise and sleep), being younger and more affluent, having a longer time since diagnosis, and less intensive treatment for the child (Klassen et al, 2008), which offer potential areas for intervention. The role of attachment is interesting given its central role in child development and maternal caregiving generally (Sullivan, Perry, Sloan, Kleinhaus, & Burtchen, 2011; Walsh, Hepper, & Marshall, 2014). Attachment security fosters empathy and increases the quality of caregiving (Cassidy, Stern, Mikulincer, Martin,

& Shaver, 2018), whereas insecure attachment reduces confidence in caregiving (Fonseca, Nazaré, & Canavarro, 2013). Insecure and disorganised attachment is associated with anxiety and depression in children (Groh, Roisman, van IJzendoorn, Bakermans-Kranenburg, & Fearon, 2012), and with poor and deteriorating mental health in mothers of children with Congenital Heart Disorder (Berant, Mikulincer, & Florian, 2001). In the study by Campbell-Enns and Woodgate, (2013) the key focus of mothers in decision-making was to maintain the attachment bond with their child. The above evidence would suggest that attachment must play a role in the relationship between a mother and child who has been diagnosed with cancer but there has been no empirical investigation.

Guilt is recognised as part of the caregiving experience and is related to increased levels of distress (Losada, Marquez-Gonzalez, Penacoba, & Romero-Moreno, 2010; Roach, Laidlaw, Gillanders, & Quinn, 2013; Spillers, Wellisch, Kim, Matthews, Baker, 2008). Parents receiving a diagnosis of cancer in their child are susceptible to Post Traumatic Stress Disorder (Dunn et al., 2012), and go through a range of emotions similar to that of the grieving process, one of the most damaging and recognised of these is guilt (Stroebe et al, 2014). These authors suggest that guilt is manifest as a dichotomy of self-blame and regret. Despite this evidence, very little research has been done to explicate the effect of guilt. A literature has developed however in the recent past on self-compassion which could be argued to be the antithesis of guilt (Neff & Germer, 2017).

Self-compassion is defined as *“being kind to oneself in times of difficulty, recognizing the shared nature of human suffering, and being mindfully aware of negative thoughts and emotions”* (Neff & Faso, 2014, p.1). Neff and colleagues have applied this three-factor model of self-compassion (self-kindness, mindfulness and common humanity) to a wide range of areas from student mental health to psychopathology (Germer & Neff, 2013; Neff & Davidson, 2016; Neff. & Germer, 2017). Findings demonstrate a positive impact of self-

compassion on wellbeing in parents of children with Autism (Neff and Faso, 2014) however to date it has never been applied widely to the area of caregiver stress and wellbeing. In Neff's model, mindfulness is a dimension of self-compassion. The link between self-compassion and mindfulness is further explicated by Germer (2009) who combined the two variables in clinical practice using mindful self-compassion interventions (Klich, 2016). Self-compassion and mindfulness have been linked in the literature in two ways. Firstly, as a combined effect in interventions (Dudley, Eames, Mulligan, & Fisher, 2018) and secondly as a means of increasing engagement with interventions (Rowe, Shepstone, Carnelley, Cavanagh & Millings, 2016).

Attachment and self-compassion have been shown to be related to each other such that low self-compassion and insecure or avoidant attachment are predictive of psychological distress (Mackintosh, Power, Schwannauer, & Chan, 2018; Wei, Liao, Ku, & Shaffer, 2011). The two constructs have been drawn on to develop a combined Attachment-Based Compassion Therapy (ABCT) which has been shown to be effective in reducing psychological distress (Navarro-Gil, et al., 2018). Given the evidence above it would seem justified to look at both in this study.

The role of social support in relation to caregiver burden appears to be equivocal depending on whether it is received or perceived (del-Pino-Casado, Frías-Osuna, Palomino-Moral, Ruzafa-Martínez, & Ramos-Morcillo, 2018). Interestingly it appears that social support within a secure attachment relationship between the caregiver and the care recipient had the biggest impact in reducing perceived burden (Stensletten, Bruvik, Espehaug, & Drageset, 2016). Nevertheless there is an extensive body of research which has linked physical and mental health with social support among family caregivers (Gouin, da Estrela, Desmarais, & Barker, 2016; Thielemann & Conner, 2009), and interventions using social

support have proved successful in improving the health and wellbeing of caregivers (Roth, Mittelman, Clay, Madan, & Haley, 2005).

It is widely accepted that family caregivers are central to the future of cancer care and recent emphasis has focused on interventions to prepare families for this role (Honea et al, 2008; Sun et al, 2015). Reviews of interventions to prepare family caregivers show that most to date have been based on practical help and information giving (Drummond, Johnston, , & Quinn, 2019). Whilst these have been shown to be somewhat successful in reducing burden and increasing quality of life, it is also recognised that they fall somewhat short in supporting the needs of cancer caregivers (Ferrell & Wittenburg, 2017; Northouse, Katapodi, Song, Zhang& Mood, 2010). That being said, it is also accepted that oncology interventions designed to support the healthcare needs of caregivers, are extremely difficult to translate into practice (Ferrell & Wittenburg, 2017; Northouse, Katapodi, Song, Zhang& Mood, 2010).

Based on the evidence suggesting a link between attachment, self-compassion and social support in ameliorating the impact of psychological distress and mental wellbeing this study seeks to test the model proposed in Figure 1 amongst a sample of mothers caring for a child with cancer. In doing so this study will address current limitations and will offer potential avenues for future interventions for this particularly vulnerable group.

Method

Design: Using a cross-sectional survey design this study explored the relationship between maternal attachment, self-compassion, social support, perceived burden of care and psychological distress / mental wellbeing in a sample of mothers caring for a child with cancer.

Participants: These were 255 mothers who were the primary caregiver for a child with a diagnosis of cancer. Mean age was 36.4 years (SD=6.8) and ranged from 25-50 years old. Of these, 131 were in full time employment and in terms of education 45 had primary level,

110 had GCSE level, 75 had A-level, and 25 had university level education. Time since diagnosis ranged from 2-28 months. All children were being cared for at home. Children ranged in age from 3-9 years old.

Measures: Participants completed a number of demographic questions (age, education, employment, how long since diagnosis) as well as a range of psychometric scales used to assess the study variables. These included:

Burden and Perceived Burden was measured using a list of tasks ranging from physical aid (lifting, helping to walk) through intimate personal care (bathing, washing, toileting) to emotional care (comforting, dealing with emotional outbursts). The list was presented with two response sets. Firstly participants were asked to rate on a three point scale (never, sometimes always) how often they carried out each task, and secondly to rate on a four point scale (not at all to extremely) how stressed they felt when carrying out each task. This allowed two measures to be produced, burden ($\alpha = .78$) and perceived burden ($\alpha = .87$). (Cassidy, Giles, & McLaughlin, 2014).

The Perceived Social Support Scales (PSS-Fr and PSS-Fa Scales: Procidano & Heller, 1983) are two 20-item scales designed to measure perceived levels of social support received from friends and family. Most statements appear on both subscales, but one scale is concerned with family and the other with friends (e.g. 'I rely on my family for emotional support' vs. 'I rely on my friends for emotional support'). The items are rated across a three-point scale 'yes', 'no' and 'don't know'. The measure is comprehensive and designed to reflect a number of forms of support including, emotional, feedback, informational and reciprocity (i.e. provision of support by the individual). In the current study the reliability coefficient values were friends support ($\alpha = .81$), and support from family ($\alpha = .83$).

The Self-compassion Scale (Neff, 2003) Self-compassion is a 26-item self-report inventory and consists of six sub-scales: self-kindness, self-judgment, awareness of common

humanity, isolation, mindfulness, and over-identification. Each item was rated on a 5-point scale (1=*strongly disagree* to 5=*strongly agree*). Cronbach Alpha for the six respective subscales were .94, .94, .87, .89, .92, and .94.

The Child-Parent Relationship Scale (Pianta, 1997; Driscoll & Pianta, 2011) is a modified version of the 15-item Teacher-Child Relationship Scale (Pianta & Harbers, 1996) and measures 2 dimensions of conflicts and closeness (Driscoll & Pianta, 2011). The 8-item conflict subscale measures the degree to which a parent feels that his or her relationship with a particular child is characterized by negativity. The 7-item closeness scale assesses the extent to which a parent feels that the relationship is characterized by warmth, affection, and open communication. The conflict and closeness scales of the CPRS represent two distinct domains of parent-child relationships and for this study the closeness dimension was used as a measure of attachment. Cronbach alpha for the closeness scale was .79 indicating moderate levels of internal consistency.

The General Health Questionnaire (GHQ-12: Goldberg, 1972, 1978) is comprised of 12 questions each of which is rated on a four-point scale. At the time of completing the GHQ-12 the participants were asked to consider how they had been feeling over the past month. To provide an example, headed with the words 'In the last month have you' the participants would answer questions such as 'Been able to concentrate on what you are doing?' by indicating one of the following 'better than usual', 'same as usual', 'less than usual' or 'much less than usual'. In terms of scoring the GHQ-12, there are two methods. Likert scoring assigns a score (0-1-2-3) in response to each of the 12 questions, which makes for a maximum total score of thirty-six. The GHQ method involves allocating scores of 0 and 1. The first two responses indicate the absence of a symptom and are allocated a 0, while the second two answers indicate the presence of a symptom and are allocated a 1, which makes

for a maximum total score of twelve. A reliability coefficient of $\alpha = .78$ was achieved in this study.

Procedure

Following ethical approval for the study contact was made through an Oncology Clinic who agreed to distribute envelopes containing study packs to carers who were attending and who were willing to consider the study. Most carers responded positively and seemed pleased to be involved. The pack contained an information sheet and questionnaires. Participants were requested to return the completed questionnaire and consent form in a prepaid envelope. They were also asked on the information sheet if they knew someone else who was caring for a relative with cancer and if they would be willing to take a pack to pass on to them. At the same time a number of online carer support groups were identified and an online questionnaire with information sheet and consent form was posted. Over a period of 14 months 367 completed responses were received via the packs delivered through the Oncology Clinics and 475 participants responded via the online survey. From the returned measures it was identified that 255 were caring for a child with a diagnosis of cancer. Ethical approval for the study was gained through the researcher's university at the time of the study after rigorous peer review and scrutiny by the university ethics committee (REC/15/0510).

Results

The main aim of the study was to explore the relationship between burden of care, social support, attachment, self-compassion and both psychological distress and mental wellbeing. A model of the proposed relationships based on background literature is shown in Figure 1. The first step in analysis was to calculate bivariate correlations between the variables as shown in Table 1. The pattern of correlations support the proposed relationship between social support, attachment and self-compassion as well as a relationship between this

trio and both psychological distress and mental wellbeing. The findings also indicate a significant relationship between time since diagnosis and each of these variables.

Insert Table 1 about here

Initially to explore the model hierarchical multiple regression analysis (HMRA) was applied to test the potential relationship with wellbeing and psychological distress separately. Firstly, wellbeing was entered as the dependent variable and age, occupation, and education of mother, and time since diagnosis were entered on step one. These variables accounted for 12% of the variance in wellbeing. On step two burden of care and perceived burden of care were added and these increased the variance explained by 15%. Attachment was added on step three and accounted for a further 15% of the variance. On step four support was entered and increased the amount of variance by 3%. Finally, on step five, self-compassion was added to the HMRA model and increased the variance explained by 1%, bringing the total variance explained by the model to 46.3%. This data is shown in Table 2.

HMRA was repeated and wellbeing was replaced by psychological distress as the dependent variable. The model accounted for 53% of the variance in psychological distress. This data is shown in Table 3.

Insert Table 2 & 3 about here

HMRA supports the model proposed in Figure 1 and to test it more robustly structural equation modelling (SEM) with AMOS25 was conducted. The results for psychological distress are shown in Figure 2. This model is a good fit for the data with χ^2 of 8.042, $DF = 3$, $p = .045$. As this is significant the $\chi^2/$ degrees of freedom (CMIN/DF) needs to be less than 5 and in this case is 2.681. The comparative fit index (CFI) is .98, the Incremental Fit Index (IFI) was .98, well above the recommended .9. The Root Mean Square Error of Approximation (RMSEA) was .08 and the probability of a close fit (PCLOSE) was significant (PCLOSE = .173, $p < .001$).

The results of the SEM for mental wellbeing is shown in Figure 3 and again the model is a good fit for the data. The $\chi^2 (3) = 8.232, p=.140$; Comparative Fit Index (CFI) = .98; Incremental Fit Index (IFI) = .98, Root Mean Square Error of Approximation (RMSEA) =.08, p of Close Fit (PCLOSE) = .271, $p<.001$.

Analysis supports the proposed model in Figure 1. The combination of attachment, social support and self-compassion are related to both psychological distress and mental wellbeing and may potentially moderate the effect of care burden and time since diagnosis. Burden of care and time since diagnosis also have direct relationships with distress and wellbeing but their relationship is reduced through attachment, social support and self-compassion.

Discussion

Caring for a child with cancer is an extremely distressing experience for any mother, yet with improved treatments those children can live with the condition for many years with some surviving the illness altogether. Evidence suggests that many mothers develop effective ways of coping whilst many others can be helped through psychosocial interventions. The aim of this study was to explore the potential role of self-compassion, attachment and social support in moderating the psychological distress and increasing mental wellbeing in mothers caring for a child with cancer. The findings support the proposed model and suggest that there is a combined or interactive relationship between attachment, self-compassion and support in relation to reduced distress and increased wellbeing. In essence, caregivers with higher levels of support, who were more self-compassionate, and who had a stronger bond with their child reported lower levels of psychological distress and higher levels of mental wellbeing. It is particularly important to note that this was a cross-sectional study so direction of effect cannot be established. However, the findings emerging from this study alongside evidence from previous research lend additional credence to the contention

that social support, attachment and self-compassion may have a moderating effect on distress and wellbeing (Germer, & Neff, 2013; Gouin, da Estrela, Desmarais, & Barker, 2016; Klich, 2016; Shapiro, Brown, & Biegel, 2007).

It is widely recognised that family caregivers will play a fundamental role in the future of cancer care. Despite this, evidence on how best to support their wellbeing is limited. This study has addressed this research gap and offers potential solutions for the design of future interventions. Self-compassion in particular, has a growing evidence base as an effective intervention in a range of areas including caregiver stress (Germer, & Neff, 2013; Sinclair et al, 2017). In addition, combined with mindfulness it has extensive evidence of effectiveness in improving quality of life and wellbeing in a range of samples (Shapiro et al, 2005; 2007). Navarro-Gil, (2018) describe an attachment-based compassion therapy and discuss its effectiveness in healthy adults. This type of work is in its infancy but could be utilised to support family caregivers.

A robust body of evidence supports the relationship between wellbeing and social support (Gouin, 2016; Roth et al, 2005). The findings from this study strengthens this and signifies the importance of family and friends in supporting the mental health needs of this caregiving group. Any intervention must include mobilisation of social support networks.

To date most of the research which has investigated the impact of caregiving on cancer caregivers has tended to adopt a deficit approach (Sultan et al, 2016) focusing mainly on the negative impact of this role. More recently however a growing body of work has turned its attention to more positive impacts, including the development of resiliency and the deepening of relationships. The findings from this study support this more positive approach as it highlights a significant relationship between attachment and mental wellbeing. This finding supports previous research highlighting that the quality of the attachment bond can mediate the risk of psychological distress and mental ill health for mothers caring for a child with cancer

(Pai et al, 2007). The evidence from the current study supports the development of a positive psychology approach to improve the mental wellbeing of family caregivers.

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Figure 1: Proposed relationships underpinning a path model

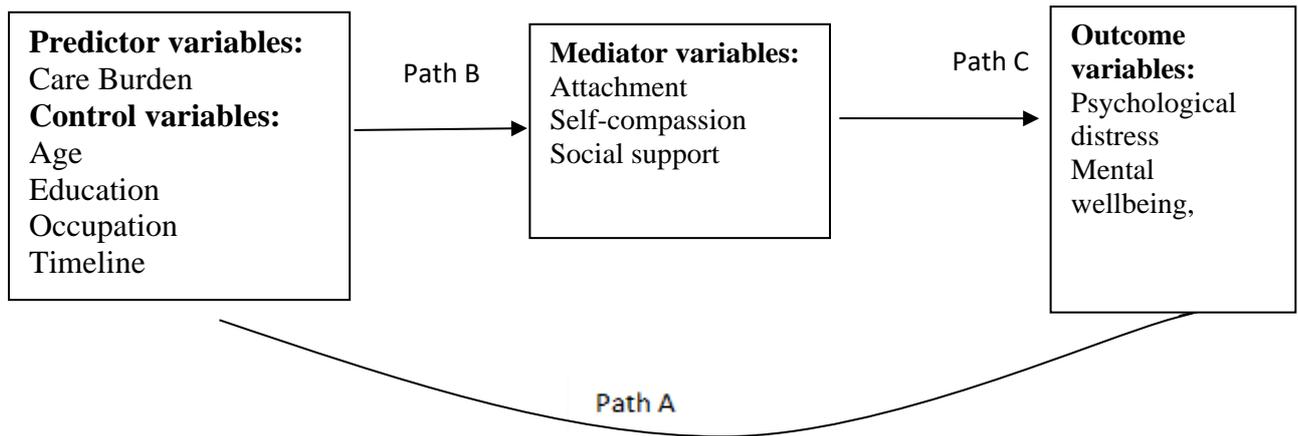


Table 1: Bivariate correlations with distress and wellbeing

	1	2	3	4	5	6	7	8	9
1. age									
2. Time	.19**								
3. Burden	.25**	.08							
4. Perceived burden	.18**	-.01	.07						
5. Friend support	.12	-.06	.03	-.13*					
6. Family support	.07	-.06	-.01	-.14*	.36**				
7. Self-Compassion	-.19**	-.30**	-.19**	-.28**	.22**	.08			
8. Attachment	-.03	-.26**	-.15*	-.28**	.27**	.19**	.52**		
9. Distress	.01	.37**	.05	.39**	-.39**	-.37**	-.48**	-.56**	
10. Wellbeing	-.08	-.25**	.06	-.44**	.33**	.21**	.45**	.53**	-.39**

*P<.05 **P<.01

Table 2: The predictors of wellbeing from hierarchical multiple regression analyses

	B	SE. B	β	p-value
Step 1: $R^2=.12$, $F(4,250)=8.50$, $p<.001$				
Age	-.014	.012	-.077	.240
Education	.046	.095	.032	.631
Occupation	.107	.156	.044	.490
Timeline	-.350	.064	-.336	.001
Step 2: $\Delta R^2=.15$, $F(2,248)=25.95$, $p<.001$				
Age	-.014	.011	-.077	.208
Education	-.129	.090	-.092	.153
Occupation	.041	.143	.017	.775
Timeline	-.280	.059	-.269	.000
Burden	.018	.008	.117	.039
Perceived Burden	-.108	.016	-.410	.000
Step 3: $\Delta R^2=.15$, $F(1,247)=64.65$, $p<.001$				
Age	-.014	.010	-.075	.168
Education	-.065	.081	-.046	.424
Occupation	-.014	.127	-.006	.912
Timeline	-.170	.055	-.163	.002
Burden	.026	.008	.173	.001
Perceived Burden	-.080	.014	-.302	.000
Attachment	.450	.056	.424	.000
Step 4: $\Delta R^2=.03$, $F(1,246)=12.58$, $p<.001$				
Age	-.020	.010	-.110	.042
Education	-.081	.079	-.058	.304
Occupation	-.020	.124	-.008	.875
Timeline	-.140	.054	-.134	.010
Burden	.025	.007	.169	.001
Perceived Burden	-.072	.014	-.271	.000
Attachment	.387	.058	.365	.000
Support	.253	.071	.192	.000
Step 5: $\Delta R^2=.01$, $F(1,246)=12.58$, $p=.02$				
Age	-.015	.010	-.082	.139
Education	-.063	.079	-.045	.426
Occupation	-.040	.124	-.017	.744
Timeline	-.122	.054	-.117	.025
Burden	.027	.007	.179	.000
Perceived Burden	-.069	.014	-.260	.000
Attachment	.335	.061	.316	.000
Support	.215	.073	.163	.003
Self Compassion	.196	.085	.136	.023
Overall: $R^2=.463$, $p<.001$				

Table 3: The predictors of psychological distress from hierarchical multiple regression analyses

	B	SE. B	β	p-value
Step 1: $R^2=.17$, $F(4,250)=13.39$, $p<.001$				
Age	-.027	.012	-.148	.019
Education	-.223	.093	-.156	.017
Occupation	.061	.153	.024	.690
Timeline	.387	.063	.365	.000
Step 2: $\Delta R^2=.11$, $F(2,248)=18.25$, $p<.001$				
Age	-.033	.011	-.181	.003
Education	-.065	.091	-.046	.474
Occupation	.092	.144	.037	.524
Timeline	.316	.060	.298	.000
Burden	.006	.009	.040	.479
Perceived Burden	.095	.016	.353	.000
Step 3: $\Delta R^2=.16$, $F(1,247)=70.94$, $p<.001$				
Age	-.034	.010	-.182	.001
Education	-.133	.081	-.093	.102
Occupation	.149	.127	.060	.242
Timeline	.200	.055	.189	.000
Burden	-.003	.008	-.018	.725
Perceived Burden	.065	.014	.241	.000
Attachment	-.471	.056	-.437	.000
Step 4: $\Delta R^2=.07$, $F(1,246)=34.75$, $p<.001$				
Age	-.023	.009	-.127	.013
Education	-.106	.076	-.075	.163
Occupation	.158	.119	.063	.187
Timeline	.153	.052	.144	.004
Burden	-.002	.007	-.012	.803
Perceived Burden	.052	.014	.192	.000
Attachment	-.370	.055	-.343	.000
Support	-.403	.068	-.301	.000
Step 5: $\Delta R^2=.02$, $F(1,246)=10.47$, $p<.001$				
Age	-.030	.009	-.165	.001
Education	-.131	.075	-.092	.081
Occupation	.186	.118	.075	.115
Timeline	.129	.052	.122	.013
Burden	-.004	.007	-.025	.586
Perceived Burden	.048	.013	.178	.000
Attachment	-.301	.058	-.279	.000
Support	-.352	.069	-.263	.000
Self Compassion	-.262	.081	-.178	.001
Overall: $R^2=.53$, $p<.001$				

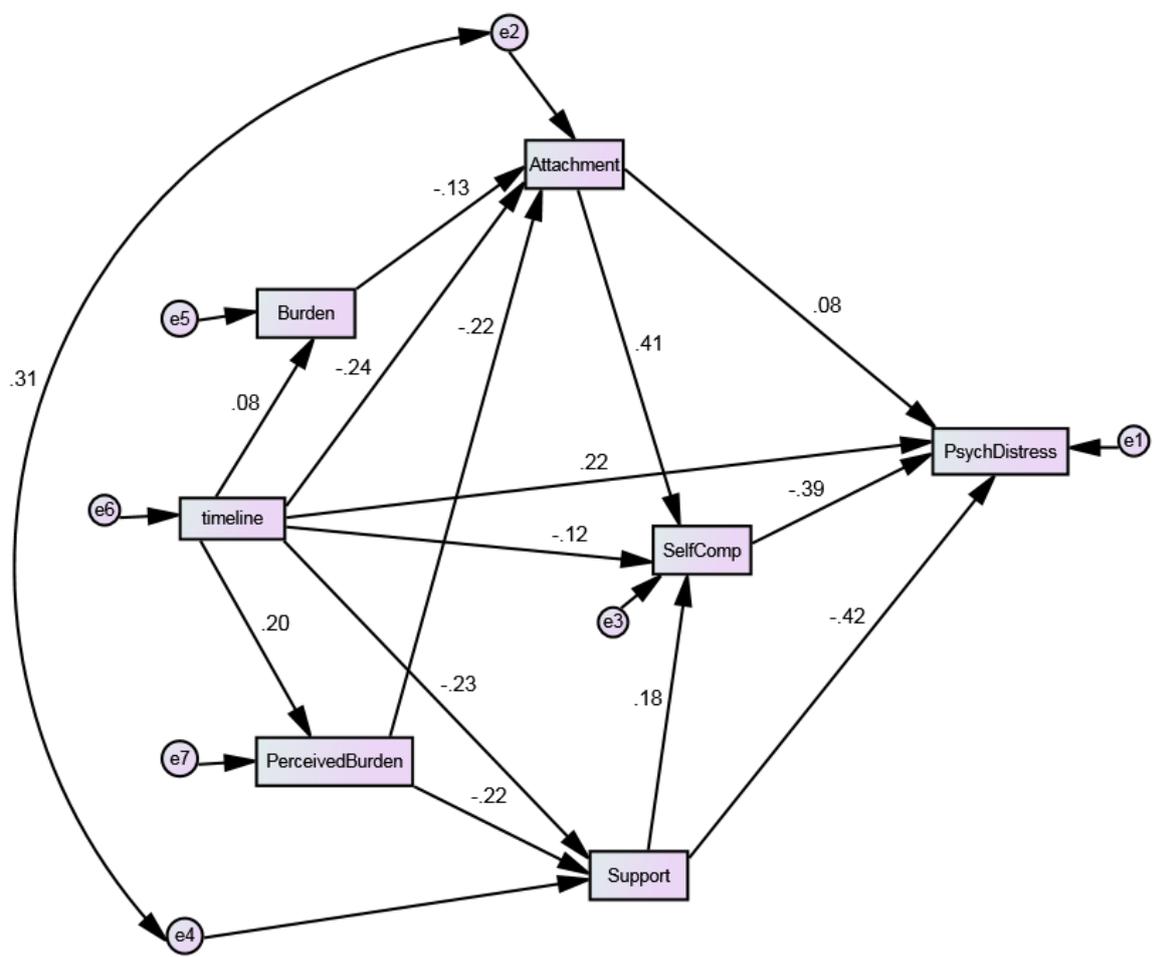


Figure 2: Path model of perceived distress

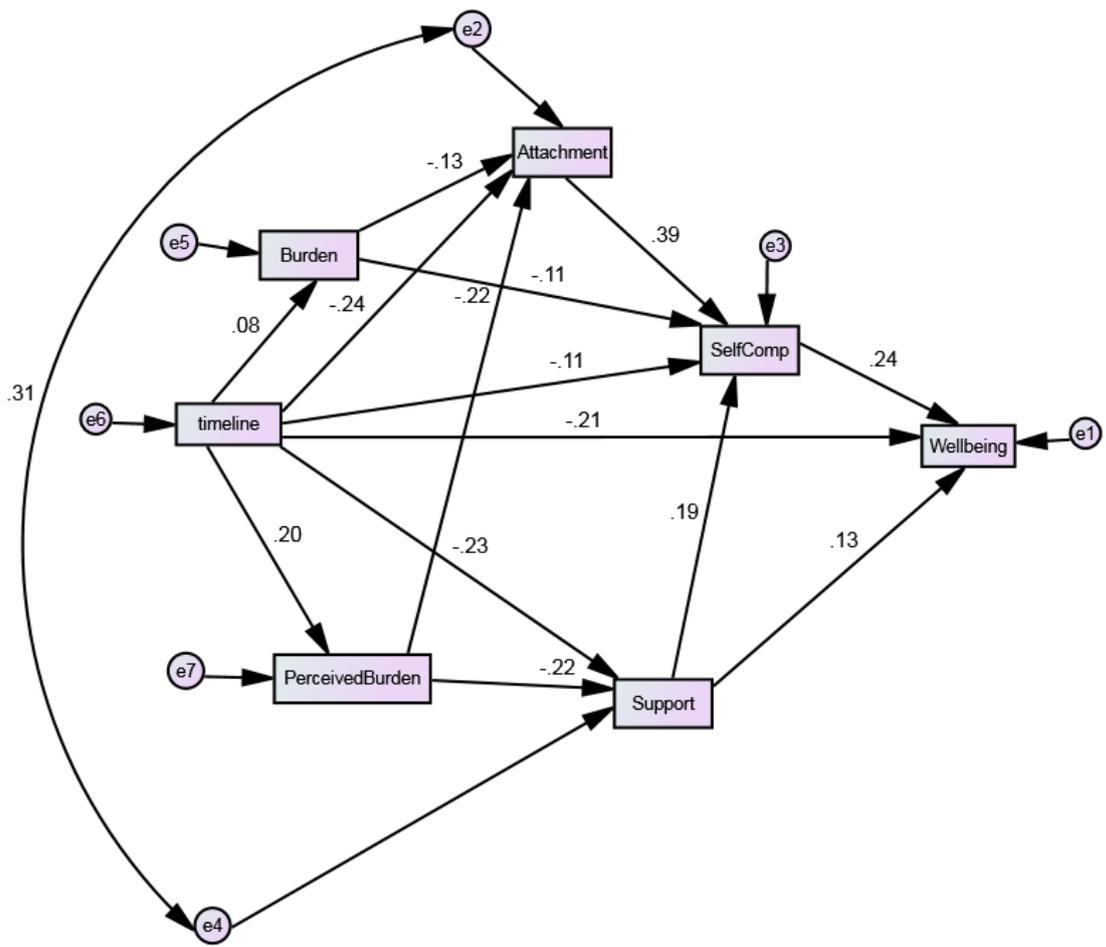


Figure 3: Path model of wellbeing