

The Wellbeing of Carers of People with Severe and Enduring Eating Disorders (SEED).



Stephen Linacre – DClInPsychol Trainee
 Professor Andrew Hill – Thesis Supervisor

Dr Suzanne Heywood-Everett – Field Supervisor



1 Introduction

Health services are urged to consider the impact on informal carers and family members more and more. Recent national publications continue to highlight this as a priority. For example, “No Health without Mental Health” (DoH, 2011) states that services should “put them, and their families and carers, at the centre of their care” (p16). Few studies have looked at carers of people with eating disorders (ED). One such study suggested that a significant portion of carers of people with ED experience their own mental health difficulties (Whitney, Haigh, Weinman, & Treasure, 2007). Kyriacou, Treasure and Schmidt (2008b) have suggested that over 50% of their carer sample of people with ED scored at, or above the clinical threshold for anxiety. Severe and enduring eating disorders (SEED) is a contemporary term used in clinical and research settings to identify people with ED who experience the condition in a severe and enduring form. According to Steinhausen (2002), 20% of people presenting with anorexia nervosa (AN) can go on to develop this into a chronic debilitating form. There has been no quantitative research conducted on carers of people with SEED thus far (Robinson, 2009).

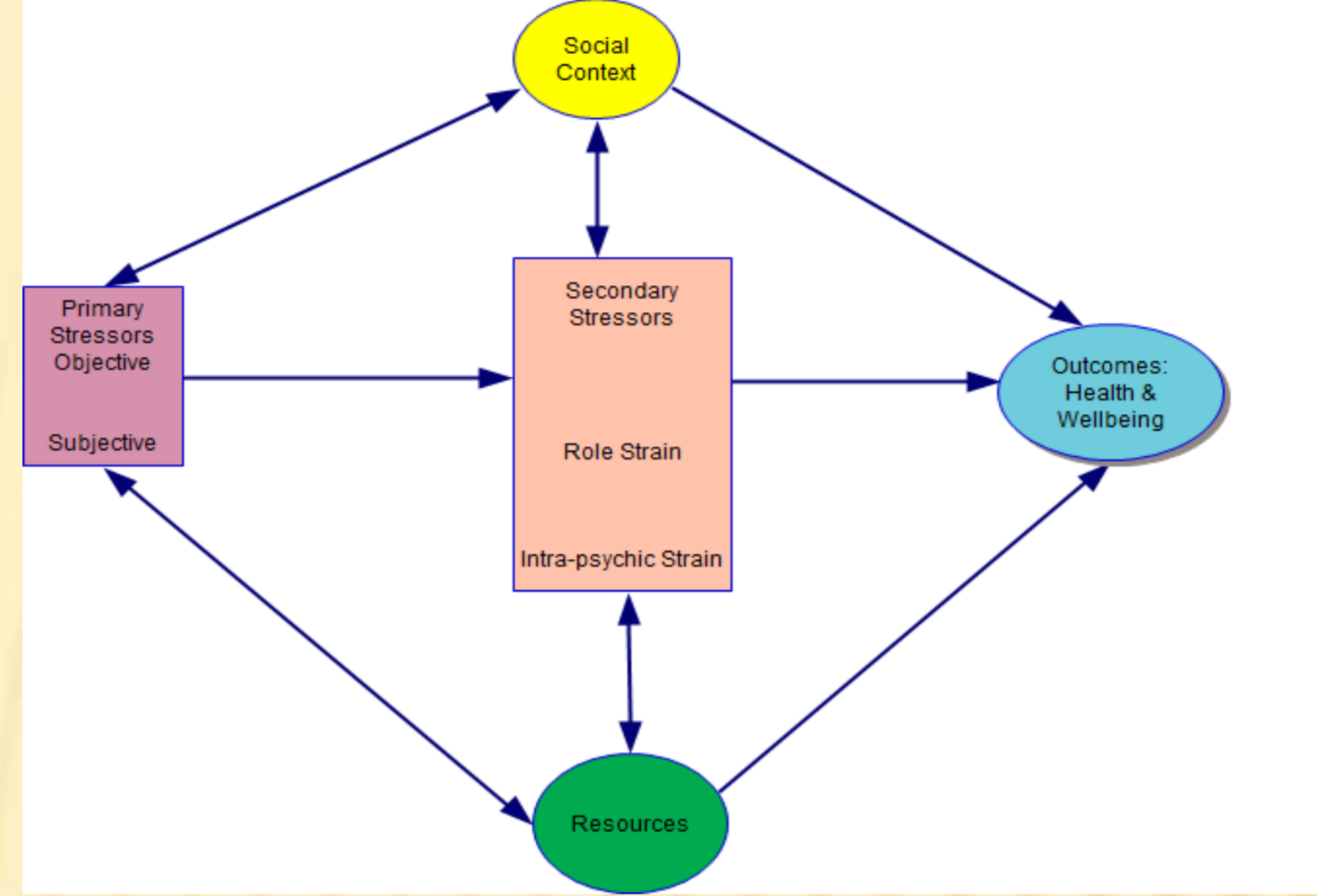
2 Aims

The primary aim of this study was to investigate the psychological wellbeing of carers of people with SEED. A further sub-aim was to compare the existing data on carer wellbeing from studies investigating carers of people living with other long-term health conditions. It was expected that carers of people with SEED would have poorer wellbeing when compared to carers of other patient groups. The study used the Stress Process Model (SPM; Pearlin, Mullan, Semple, & Skaff, 1990) (see 4) to better understand determinants and predictors of carer wellbeing. Previous research on carers has suggested that all “resources” identified in the SPM might be associated with carer wellbeing in a positive way. The current research was specifically interested in carers’ sense of mastery and self rated caregiver competence as this could have implications for services.

3 Hypotheses

1. That self reported wellbeing in carers of people with ED would be poorer than community norms.
2. That female carers would have significantly poorer wellbeing than male carers.
3. That carers of people with SEED would have significantly poorer wellbeing when compared to existing data on wellbeing of carers of other patient groups.
4. That variables representing domains in the SPM would be associated with carer wellbeing. Specifically, it was hypothesised that variables relating to “resources”, particularly “personal sense of mastery” and “self competence in caregiving” would be significant predictors of carer wellbeing.

4 Stress Process Model



5 Method

Carers (28 male, 76 female) were recruited from ED carer support groups across England. Carers were stratified using duration (since diagnosis) of their recipient’s ED (0-2 years, 2-6 years, over 6 years). The “over 6 years” category was classified as SEED. Over 6 has been the minimum number of years that researchers have classified as SEED (Wentz et al., 2009). Comparison data were drawn from carers of people with dementia, brain injury, ED and psychosis. Standardised questionnaires measured wellbeing (SF-36) (Ware, Snow, Kosinski, & Gandek, 1993), experiences of caregiving (ECI), perceived caregiver competence (MoCC), sense of personal mastery (MoPM) and expressive support (MoES). Through power analysis calculations approximately 120 carers of people with SEED will be needed.



The analysis involved comparison of carer wellbeing in the obtained data with selected comparison carer group outcomes in published studies. The second part of the analysis involved correlational analysis to identify what variables in the SPM were associated with carer wellbeing. Regression analysis was then performed to identify which of these variables of the SPM had the largest influence on carer wellbeing.

6 Results

In regards to the first hypothesis, the current sample of carers of people with ED reported significantly poorer wellbeing than community norms. When carer wellbeing was analysed by length of care, no significant differences were found between the groups. In regards to the second hypothesis, there was no significant effect of carer gender on reported wellbeing. This may have been affected by the number of male carers available as participants. In regards to the third hypothesis, carers of people with ED reported significantly poorer social functioning than carers of people with dementia. When the reported wellbeing of carers was compared to carers of people with brain injury, carers of people with ED reported significantly poorer wellbeing on several psychologically orientated subscales. Again social functioning was an area that was significantly poorer in carers of people with ED. When the wellbeing of carers in the current sample were compared to carers of people with ED from a previous study (De La Rie et al., 2005), the findings were generally comparable. The fourth hypothesis was tested by conducting correlational analyses and multiple regression. Mental wellbeing scores significantly correlated with the ECI negative total scores and the MoPM total scores. When the ECI negative total scores were broken down, “Dependency” scores significantly correlated with mental wellbeing scores. Dependency, carer gender and a sense of personal mastery accounted for 29% of the variance in mental wellbeing scores. Further research is needed to look at “resources “ of the SPM on how they can help carers.

7 Clinical Implications

- These are available on a takeaway handout alongside the references used. Essentially services should consider ways:
- *to help carers develop their social functioning
 - *to promote positive experiences of caregiving
 - *to develop more skill based workshops to help carers communicate better with their care recipient
 - *to teach cognitive skills to reduce beliefs around responsibility and dependency.
- More research is needed on carers of people with SEED as although this research found little difference in wellbeing between the length of care, differences were found in the reported experiences. Longitudinal studies may be the next step in understanding carer’s needs.