

VOLUME I: RESEARCH COMPONENT

**THE PERSONAL EXPERIENCE OF CARERS OF INDIVIDUALS WITH
MOTOR NEURONE DISEASE (MND) AND THEIR EXPERIENCES OF
SERVICES**

By

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DOCTORATE IN CLINICAL PSYCHOLOGY

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OVERVIEW

This thesis consists of research and clinical components and is submitted as partial fulfilment of a doctorate degree in Clinical Psychology. Volume 1, the research component, comprises of a literature review, an empirical paper and a public domain paper. The systematic literature review looks at evidence linking attachment and caregiving in adult couples. The empirical paper explores the experiences of individuals with a partners diagnosed with Motor Neurone Disease (MND). Lastly, a public domain provides a summary of the empirical paper.

Volume II, the clinical component, contains clinical practice reports conducted within placements from adult, child, learning disability older adult specialities. The first report contains a behavioural and systemic formulation of a 3 year-old who was referred as her mother was having difficulties managing her behaviour. The second report describes an evaluation of the Experiences of practitioners interpreting and delivering Triple P (Positive Parenting Programme) groups in South Asian Community languages. The third report presents a single case experimental design concerning a behavioural approach to challenging behaviour displayed by a 7-year old boy with learning disabilities and autism. The fourth report is a case study of a Cognitive Behavioural approach used with a man diagnosed with Persistent Paranoid Delusional Disorder. Finally, the fifth report is an abstract of an oral case presentation of a small-scale service related project around a multiple family therapy group for adolescents with anorexia nervosa.

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LITERATURE REVIEW

Title: Caregiving in couples: does attachment style influence ability to provide care to a partner?

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ABSTRACT

In this review, the role of attachment in relation to caregiving within couples is investigated. A brief overview of Attachment Theory and its links to caregiving will be outlined prior to conceptualising how the studies examine attachment style of spousal caregivers in relation to the quality of their caregiving. A systematic search of electronic databases PSYCINFO, MEDLINE, CINAHL was carried out. The results suggest an association between attachment style and ability to provide care to a partner. However it is difficult to measure attachment style over time, and half of the studies reviewed relied on self-report measures administered as a single point in time. All of the studies were correlational, and cannot be used to draw conclusions about causal effects of attachment style on caregiving. The findings of the studies included in this review indicate that secure individuals are likely to provide the most effective care to their partners, in comparison to insecure individuals. Those with avoidant-attachments tend to be less responsive caregivers, and attachment anxiety was related to caregiving difficulties, although this finding is less consistent

Keywords: Attachment Theory, Attachment security, Attachment style, Caregiving, Care, Support, Couple, Spouse, Marital relations, Partner

INTRODUCTION

Family members often assume the role of primary caregivers of individuals with ill health, and this may be most challenging for spouses, since the spouse is typically a primary attachment figure as well as a caregiver (Nijboer et al., 2000). The nature of the relationship between caregivers and care recipients can affect how well care is provided. Attachment theory is a useful framework to conceptualise relationships and appears to shed light on how individuals regulate their emotions and use different coping styles to deal with stressful situations. However, this is an evolving area, and comparability and synthesis across the literature is difficult due to lack of consensus across constructs and measures.

Attachment in childhood

Attachment theory was initially developed to understand the nature of the infant-caregiver relationship (Bowlby, 1969, 1973, 1980). Bowlby hypothesises that individuals are born with a behavioural attachment system that is activated when they are distressed and that serves a major evolutionary function of protection and survival (Bowlby 1969; Bretherton 1987). Bowlby describes the attachment system as a safety-regulating system that strengthens long-term emotional bonds between individuals that contribute to reproductive success. Individual differences in attachment patterns develop as a result of caregivers' varied responses in times of need (Ainsworth et al. 1978; Bowlby, 1969, 1982). From the work carried out by Ainsworth et al. (1978) three main patterns of attachment were identified. *Secure* attachment is associated with responsive caregiving, and helps the growing child to develop the ability to be close to and rely on others. The attachment object is seen as a safe haven from threats and a secure base from which to explore. *Anxious-avoidant* attachment is thought to arise when caregivers are constantly emotionally distant and unresponsive, and children who experience this are usually independent and distant from others, with a discomfort with closeness. *Anxious-ambivalent*

attachment has been linked with caregivers being unpredictable in their responses. Individuals usually display an obsessive desire for closeness to their caregiver, and hypervigilance around signs of abandonment.

Attachment in adulthood

Hazan and Shaver (1987) were among the first researchers to describe how attachment processes may play out in adulthood. They suggested that: “The emotional and behavioural dynamics of infant-caregiver relationships and adult romantic relationships are governed by the same biological system”. Although there are normative developmental changes in the manifestation of attachment behaviours across the lifespan, the basic function of the attachment system remains constant (Hazan & Zeifman 1999). Adult attachment literature usually refers to four attachment styles: *Secure*, *Preoccupied*, *Dismissive*, and *Fearful Avoidant* (Bartholomew & Horowitz, 1991; Johnson, Makinen, & Millikin, 2001). These ways of relating may be also considered in terms of patterns of expectations or strategies that have developed as a result of past relationships (Simpson, Rholes, & Nelligan, 1992).

Attachment styles, are believed to include two working models, one of self-worth and one of the accessibility and responsiveness of others in times of need. These function as inner filters through which individuals organize their experiences and behave to meet situational demands. Secure attachment has been found to function like an “inner resource” (Mikulincer & Florian, 1998) that enables the individual to cope adaptively in the face of stress, thereby optimizing adaptation. Interpersonally, individuals with secure attachment styles are able to adaptively seek support provided from significant others, who through past experience have demonstrated their accessibility and responsiveness particularly in times of distress (Bartholomew & Horowitz, 1991; Shaver & Hazen, 1993). An individual with a secure attachment style typically engages in information search, possesses high tolerance for

unpredictability, disorder, and ambiguity, is reluctant to endorse rigid beliefs, is able to integrate new pieces of information into memory and appraisal systems, and able to revise schemata. Conversely, individuals with insecure attachment styles (preoccupied, fearful, and dismissive) tend to be characterized by unstable and less adequate strategies of affect regulation (Bowlby, 1973; Shaver & Hazen, 1993). The relative lack of inner resources, inherent in those individuals with insecure attachment styles, predisposes them toward exaggerating the magnitude of threat and uncontrollability imposed by a stressful event.

The link between attachment and caregiving in adulthood

Attachment theory stipulates that the caregiving system is another normative, safety-regulating system that is intended to reduce the risk of a close other coming to harm (Bowlby 1969/1982, 1988). Bowlby (1982) suggested that attachment security gives people a sense of security, which allows them to provide more responsive caregiving. Hazan and Shaver (1987) suggested that romantic love involves the combination of three behavioural systems: attachment, caregiving and sex. For the purpose of this review, the focus will be around the attachment and caregiving systems.

When an individual is feeling distressed, sick, or threatened, it makes sense that their partner may be used as a source of safety, comfort, and protection (Fraley & Shaver, 2000). In adult romantic relationships, *caregiving* refers to a broad array of behaviors that complement a partner's attachment behavior, and may include help or assistance, comfort and reassurance, and support of a partner's autonomous activities and personal growth (Collins & Feeney, 2000; Kuncle & Shaver 1994). Responsive caregiving in situations of distress restores feelings of security and has been defined as: “Being sensitive to a partner’s signals, providing the type and amount of support in a manner that promotes the partner’s well-being and protects (rather than diminishes) his or her self-confidence and self-esteem”(Collins, Guichard, Ford, &

Feeney, 2006) Kuncie and Shaver (1994) were the first to explore the link between adult attachment styles and caregiving. They found that reported ability to provide responsive care was related to attachment style. It has been suggested that attachment styles developed in childhood might shape caregiving behaviour in adulthood (Heard and Lake, 1997). Unlike parent-child relationships, which have clearly defined caregiving and care-seeking roles, adult intimate relationships are reciprocal and mutual. Therefore, in well-functioning attachment bonds, adult partners should be able to comfortably rely on one another in times of need, sometimes as care-seekers and sometimes as caregivers (Collins and Feeney, 2000). More recently, adult attachment researchers have moved towards seeing attachment as having two continuous dimensions, anxiety and avoidance, rather than being categorically fixed (Fraley & Waller, 1998).

Aim of Review

This review draws together research on attachment and quality of caregiving. Although caregiving is a dyadic process that involves the interplay of both the attachment (support seeking) and caregiving systems (Feeney et al. 2001), the purpose of this review was to focus on the caregiver. The aims are to explore how attachment styles affect the ability of individuals to care for their partner in times of need.

METHOD

Search Strategy

Database searches of PsycINFO, MEDLINE, and CINAHL, between the years 1987 and 2009 were conducted to identify published research papers. For the sake of comparability and quality, it was decided to review only empirical journal papers. Keyword searches were carried out using the following terms; “attachment”, “attachment ADJ security”, attachment ADJ style”. Boolean operator “AND” with the following terms; “caregiving”, OR “support” “spous*”, OR “couple*”, OR “partner*” were used to reduce the search. The * represents the inclusion of any word that begins with the prefix. The terms “attachment”, “couple” and “caregiver” were exploded to include some related words (please see Appendix 1 for a full description). This search produced 838 papers, and initially the abstracts of each of these papers were read to identify those of relevance.

Papers were included in the review if they met the following criteria:

- The sample included adults (over 16 years)
- The sample included spousal relationships or dating couples
- Attachment theory was used as an explicatory framework
- The investigation included impact on ability to provide support

Only 13 of the identified papers met the inclusion criteria. The remaining papers investigated different relationship dyads e.g. parent-child, focused on general relationship quality, on the individual receiving care, or simply described measures of attachment. One further paper was identified from searching relevant journal indices and reference sections of papers, giving a total of 14 papers for this review.

Summary of Papers

Author (Year) Origin	Study Aim	Design/ Method	Sample	Recruitment Information	Attachment Measure	Caregiving & other outcome measure (s)	Findings
Carnelley et al. (1996) UK	To examine the links between attachment, caregiving, and relationship functioning in dating & married couples	Cross sectional Self-report	Study 1 - N = 52 couples Study 2- N = 36 married couples	Study 1– 1 partner enrolled Psychology course (Uni of Massachusetts) Study 2- 16 from study (Carnelley et al. 1994) 20 through hospital newsletter.	MFP - Carnelley & Janoff-Bulman, (1992), FBS (Latty- Mann & Davis, 1989), Parental Bonding Instrument (PBI), Attachment Measure (Carnelley et al. 1994)	Caregiving & Relationship Quality measures developed for this study	Caregiving learned in childhood attachment relationships may be carried into adult romantic relationships, especially woman's attachment to their mothers
Collins & Feeney (2000) America	To use an attachment theoretical framework to investigate support- seeking and caregiving processes in intimate relationships.	Cross sectional Self-report & Experimental	N = 93 dating couples	Undergraduate participant pool (State University of New York at Buffalo)	Revised version of Adult Attachment Scale (AAS) & ratings using Bartholomew & Horowitz (1991) four attachment prototypes	Relationship quality, perceived stressfulness of the problem, & mood measures	Avoidant attachment predicted ineffective support seeking, and anxious attachment predicted poor caregiving.
Crowell et al. (2002) America	To explore adult secure base behaviour in couples in relation to representations of attachment	Cross sectional Self-report & Experimental	N =157 engaged couples	Recruited from newspaper advertisements & a wedding fair	Adult Attachment Interview (AAI)	Family Behaviour Survey (FBS), Hemmon-Nelson Test of Mental Ability, Secure Base Scoring System (SBSS)	The association between mental representations of attachment & the secure base behaviour of adults is of critical importance.
Davila & Kashy (2009) America	To examine secure base functioning in couples by studying associations between daily social support experiences &	Cross sectional Self-report	N = 114 dating couples	Recruited from Stony Brook University, New York (from a larger study), via email & mail	Revised Adult Attachment Scale (Collins & Read, 1990)	Life event measures used in other studies (e.g. Murray et al. 2003), Perceived Relationship Quality	Secure individuals provided more support to partners & partners sought more support, suggesting that security

	attachment security			solicitations – targets were asked to invite their partner		Components Inventory (Fletcher et al. 2000)	allows people to see partners' needs and respond to them.
Feeney (1996) Australia	To assess the association between attachment and caregiving styles and the implications of these variables for marital satisfaction	Cross sectional Self-reports	N = 229 married couples	Recruited by 3 rd year Psychology students (University of Queensland) from range of sources (family, friends, colleagues etc.)	Parental Bonding Instrument (PBI), & ratings using Bartholomew & Horowitz (1991) four attachment prototypes	Caregiving Questionnaire (Kunce & Shaver, 1994), & Quality Marriage Index (Norton, 1983)	Secure attachment (high Comfort with closeness, low Anxiety over relationships) was associated with beneficial caregiving to the spouse
Feeney & Collins (2001) America	To explore personal & relationship mechanisms that lead people with different attachment styles to be effective or ineffective caregivers	Cross sectional Self-report & Experimental	N = 194 romantic couples	One member of each couple was recruited from Introductory Psychology at State University of New York & University of California	Brennan et al. (1998) Self-report measurement of adult attachment & ratings using Bartholomew & Horowitz (1991) four attachment prototypes	Caregiving Questionnaire (Kunce & Shaver, 1994), Empathy, Social Support, chronic self-focus & various relationship measures	Attachment style is significant predictor of social support & caregiving behaviour in adult intimate relationships
Feeney & Hohaus (2001) Australia	To investigate link between attachment style & spousal patterns of caregiving	Cross sectional Self-reports	N = 362 married couples	44 couples had 1 spouse enrolled in psychology courses (Uni of Queensland), remaining couples recruited by students on these courses	2 measures of attachment style (Griffin & Bartholomew, 1994) Relationship Scales Questionnaire	Caregiving Questionnaire (Kunce & Shaver, modified WHOTO (Hazan & Zeifman, 1994), 2 caregiving measures (Wells & Over, 1994)	Insecure attachment and low levels of responsive care are linked to lower quality of past (or ongoing) care, and also to less willingness to provide care in the future.
Fraley & Shaver (1998) America	To investigate how attachment behaviour is manifested during a stressful situation between couples & how attachment style, partner availability &	Cross sectional Self-reports & observations	N = 99 couples, age range 16-68, 47% married, 43% dating, &	A female member of the research team approached couples waiting in airport gate lobbies	Questionnaire designed for this study & Relationship Styles Questionnaire (RSQ) (Griffin & Bartholomew, 1994a)	Behavioural observations were recorded around couples' interactions	Secure women freely expressed caregiving behaviours & anxious & avoidant women avoided contact with their partners. The data for men was not as

	relationship length influences this.		10% engaged				clear.
Kane et al. (2007) America	To explore the association between one partner's attachment style and the other partner's relationship experiences, mediated by perceived caregiving.	Cross sectional Self-reports	N = 305 dating couples	Combined samples from 2 other studies from Uni of California, Santa Barbara (UCSB) campus & campus of SUNY Buffalo.	Experiences in Close Relationships Scale (Brennan et al. 1998)	Quality of Relationships Inventory (Pierce et al. 1991), Negative support (Rini et al. 2006, Investment Model Scale (Rusbult et al. 1998)	Secure individuals had higher levels of relationship satisfaction compared to insecure individuals, mediated by perceptions of their partners as better caregivers.
Kim & Carver (2007) America	To find out if attachment orientation or gender affect how well care is provided and how much burden is experienced providing it.	Cross sectional Self-report	N = 400 spousal caregivers	Nominated by participants from the Study of Cancer Survivors, identified by state cancer registries in US.	Measure of Attachment Quality (MAQ) (Carver, 1997)	17-item scale developed for this study to measure frequency of caregiver tasks & difficulty providing them	People more likely to be ineffective caregivers can be identified by attachment orientation.
Kim et al. (2008)	To examine prediction of caregiver well-being from relationship qualities specified by attachment theory & from motives specified by self-determination theory.	Cross sectional Self-reports	Husband (n = 154) and wife (n = 160) caregivers	Participants nominated by cancer survivors who completed survey for Study of Cancer survivors (Smith et al. 2007)	Modified version of MAQ (Carver, 1997)	Reasons for Providing Care (RPC) developed for this study, Benefit Finding (Antoni et al. 2001), Satisfaction with Life Scale (Diener et al. 1985), CES-D (Radloff, 1977)	Variations in attachment orientations and in reasons for providing care are important elements in understanding the psychological well-being of cancer caregivers
Rholes et al. (1999) America	To investigate the relationship between attachment orientations & expression of anger between couples in a	Cross sectional Self-report & Experimental	N = 83 college students and their dating	At least one partner was enrolled in Introductory Psychology at Texas A & M University	Adult Attachment Interview (AAI) & Rubin's (1970) Love Scale	Behavioural reactions of women & men were rated during a stress & recovery period	More avoidant men & women displayed greater anger during the stress period

	stressful situation		partners			(focus on anger & negativity)	
Simpson et al. (2002) America	To examine how working models of attachment to parents and romantic partners predicted spontaneous caregiving and care seeking in a stressful situation.	Cross sectional Self-report & Experimental	N = 99 dating couples	At least one member was enrolled in introductory psychology at Texas A&M University	Adult Attachment Interview (AAI) & AAQ (Simpson et al. 1996)	Big Five personality traits (Goldberg, 1990), Relationship Satisfaction Scale (Hendrick, 1988) & rated behavioural observations	Women with secure representations of parents provided more support, & women avoidantly attached to romantic partners provided less support
Simpson et al. (1992) America	Examined how adult attachment styles moderate spontaneous behaviour between dating couples when 1 member of the dyad is confronted with an anxiety-provoking situation.	Cross sectional Self-report & Experimental	N = 83 dating couples	At least one member was enrolled in introductory psychology at Texas A&M University	Modified version of Hazan & Shaver's (1987) measure	Love Scale (Rubin, 1970), Relationship Closeness Inventory (Berscheid et al. 1989) & & rated behavioural observations	Individuals with more secure attachment styles behaved differently than those with more avoidant styles in terms of physical contact, supportive comments, and efforts to seek and give emotional support.

RESULTS

Summary of Papers

The majority of studies were completed within America and focus on student populations. Four of the studies used spouses, seven studies used dating couples, one study used engaged couples and two studies used a mixture. Half of the papers used self-report methods to gather data around attachment and caregiving. The other half used observational and experimental methods to study caregiving behaviours in stressful situations, when the attachment system is activated.

Due to being cross-sectional in nature, all of the papers are intrinsically limited in terms of their lack of explanatory power. Most of the studies measured behaviour over a short period, and it is likely that support-giving behaviors may change over time. Only one of the papers (Davila and Kashy, 2009) gathered data over a two-week period. However, this does not mean that the studies are intrinsically poor, and good studies can be distinguished from poor studies by certain qualities. For example, cross-sectional studies must be done on representative samples of the population if generalizations from the findings are to have any validity. Six of the papers had a sample size of less than a hundred participants, and most of these did not discuss power analysis to show that these sample sizes were good enough to detect meaningful effect. Ten of the studies used relatively homogenous samples of dating college students, so results cannot necessarily be generalized to older more established relationships or across social class and culture.

The quality of the measures used to gather data should also be considered in order to identify a good study. There is no single, “gold-standard” measure of attachment (Crowell et al., 1999; Hesse, 1999). Two reviews (Crowell et al., 1999; Garbarino, 1998) have raised concerns about the validity of adult attachment self-report measures, due to the retrospective nature of the instruments and the complexity of adapting attachment theory to the evaluation of

adult attachment (e.g. romantic relationships, peer relationships, and parent relationships). Relying on self-reports of attachment style in current relationships may also lead to socially desirable responses, as people may find it difficult to admit not being securely attached to their partner. Comparing attachment retrospectively with attachment in current relationship, as well as assessing attachment style of both members of the couple may improve quality. Five of the studies employed this method (Crowell et al., 2002; Feeney, 1996; Feeney & Hohaus, 2001; Carnelley et al. 1996; Simpson et al., 2002).

In terms of outcomes, several of the studies use the Caregiving Questionnaire developed by Kuncze & Shaver (1994). Some studies developed their own measures of caregiving (Carnelley et al. 1996; Kim & Carver, 2007). In addition, a variety of relationship quality measures were used, and seven of the studies observed the couples and rated their interactions. The reliability and validity of these measures are varied.

The main findings of the studies support the hypothesis that securely attached individuals provide more support to partners, suggesting that security allows people to see partners' needs and respond to them. There were mixed outcomes around caregiving behaviours of insecurely attached individuals, with some studies reporting differences between avoidant and anxious carers and others not distinguishing between the two. In fact, very few studies described the four attachment styles, and tended to use just three. Some studies controlled for other variables that may influence caregiving behaviors in couples e.g. gender, and behaviours of the partner requiring support. Again, mixed results were reported.

The following review will critically examine the papers individually, comparing and contrasting study designs, strengths and weaknesses and outcomes. There was no particular pattern across the results, and therefore it made sense to structure the review according to the type of methodology used. Firstly, papers using self-report measures will be reviewed,

followed by an observational study using a natural context, and finally studies using experimental methods in laboratory situations.

Studies using self-report measures

Seven papers used self-report measures alone to explore the relationship between attachment and caregiving behaviours. Carnelley et al. (1996) carried out two studies. In the first study, participants were recruited from a sample used for a larger research project (Carnelley, Pietromonaco, & Jaffe, 1994), and were selected as psychology undergraduates who scored in the mildly depressed or not depressed ranges after completing the Beck Depression Inventory (BDI) (Beck, 1967). In the second study, participants were selected from the same sample, sixteen of whom had recently recovered from major depression, and twenty whom had never experienced clinical depression. However, for both studies, depression status was included in the analysis as a control variable and produced similar results.

Participants rated the caregiving received by their parents, which was measured using items from the Mother, Father, Peer Scale (MFP), (Carnelley & Janoff-Bulman, 1992). Additional information about the predictions of current attachment and caregiving styles could have been gathered by assessing separate dimensions of parental care and overprotection (Parker, 1983; Parker, Tupling & Brown, 1979; Wilhelm & Parker, 1990). Therefore, information was limited by only using a single index of parental caregiving. However, the Family Background Scale (FBS) (Latty-Mann & Davis, 1989), the Parental Bonding Instrument (PBI) (Parker, Tupling, & Brown, 1979), and other items developed by the first two authors (see Carnelley et al., 1994) were also completed by participants. Attachment was assessed using the Revised Inventory of Parental Attachment (R-IPA) (see Carnelley et al. 1994), which is a 48-item multi-dimensional measure. This measure was devised based on a sample of depressed and “normal” women, amongst whom there were few with a dismissive-

avoidant attachment style. It is therefore important to replicate these findings with a wider range of attachment styles to further validate this measure. Current caregiving was assessed using a measure constructed for this study, which tapped into 1) *reciprocal caregiving*, 2) *engagement in caregiving* and 3) *neglectful caregiving*. Again, the use of a single composite measure is limiting, and Kunce and Shaver (1994) suggested, in addition to the 3 aspects assessed here, the importance of assessing Compulsive care.

The results indicated that women who had positive experiences with their mothers during childhood were better caregivers in their romantic relationships. There were no significant associations between women's caregiving and their experiences with their father, or between men's caregiving and their experiences with either parent. Individuals with fearful-avoidant attachments reported less caregiving activity, but no association was found between preoccupied individuals and caregiving activities. This is consistent with Kunce and Shaver's (1994) findings that attachment and caregiving are related constructs, and further suggests that caregiving is associated with early experiences with parents. However, the results should be considered with caution, as the small sample size prohibits assessment of interactional effects.

Feeney (1996) also used the Parental Bonding Instrument (PBI), and attachment style was assessed by asking participants to choose one of the four attachment descriptions (secure, preoccupied, dismissing, fearful) developed by Bartholomew and Horowitz (1991). In addition, participants completed a 15-item measure consisting of two major dimensions underlying attachment style: Comfort with Closeness and Anxiety over relationships (Feeney et al. 1994). Style of caregiving in relation to spouse was assessed using Kunce and Shaver's (1994) 32-item measure. The results indicate associations between attachment and caregiving dimensions. Secure participants reported the most effective caregiving style (high responsiveness and lack of compulsive caregiving), whereas fearful individuals reported the least effective style (low responsiveness and more controlling). Parental bonding variables predicted current attachment

and caregiving styles, except for husbands' anxiety. Responsive caregiving was predicted by reports of both maternal and paternal care, and husbands' compulsive caregiving was predicted by maternal overprotection. These results do not support Carnelley et al.'s (1996) finding that caregiving with a current partner is linked specifically with early caregiving experiences with the same sex parent. However, these findings relied on participants providing retrospective accounts of parenting behaviours, which may be prone to memory bias.

Feeney and Hohaus (2001) used two measurements of attachment style (see Griffin & Bartholomew, 1994); caregiving style was measured with Kuncle and Shaver's (1994) caregiving questionnaire; and attachment to spouse was measured using a modified version of the WHOTO (Hazan & Zeifman, 1994). "Anticipated burden and willingness to care for spouse" was measured using scales developed by Wells and Over (1994), and participants also answered semi-structured questions around actual experiences of caring for their spouse.

The results imply that attachment style and strength influence spousal caregiving. Preoccupied wives reported more negative feelings about the care they provided, and fearful spouses (both husbands and wives) used less problem-focused coping and reported that caregiving caused ongoing relationship problems. These findings linking fearful attachment with less effective caregiving are consistent with Feeney's (1996) findings. Dismissive wives were also unlikely to provide effective care, suggesting that this style of attachment is potentially more problematic for women who are required to take on a caregiving role. Comfort with closeness was associated with higher levels of responsive care. In contrast, anxiety over relationships was linked to lower levels of responsive care, less problem-focused coping and more escape-avoidance (wives), and less acceptance of spouse's need (both genders). Partner attachment dimensions also appeared to impact on the ability to provide effective caregiving, highlighting the need to study adult attachment and caregiving as a dyadic process.

One of the strengths of this study was the large sample of participants, who also varied widely in age, education, and occupation, improving the generalisability of findings. Another strength of this study is that it measured strength of attachment in addition to attachment style and combined measures of past, current, and future caregiving (using qualitative and quantitative measures). In comparison to other studies, which measure caregiving behaviours in general, more realistic descriptions were obtained by asking participants about actual experiences of providing additional support or care for their spouse. However, this relied partly on retrospective information and, when participants were asked to imagine a caregiving situation in the future, they may have found it difficult to assess how they may respond and report honestly. It should also be considered that these descriptions might still not inform us about an individual's ability to provide care to a partner who is chronically ill for example. Pearlin, Mullan, Semple, & Skaff, (1990) point out that caregiving is intrinsic to any close relationship where people attempt to protect each other's well-being, but when caring for a partner with a chronic health condition, this can become the dominant, overriding component of the relationship, and the difference should be considered.

Kim and Carver (2007) used spousal caregivers nominated by cancer survivors, who completed a Measure of Attachment Quality (MAQ) (Carver, 1997) and a 17-item caregiving measure developed for this study. Variations in attachment style were almost unrelated to reports of frequency of emotional, instrumental, tangible, and medical aspects of caregiving, but gender appeared to have an impact. For husbands only, avoidant attachment was associated with less frequent emotional care, and anxious attachment was associated with less frequent medical care. However, attachment security related negatively to difficulty providing care for all types of tasks (emotional, instrumental, tangible, and medical), attachment avoidance related positively to difficulty in providing care for three of tasks (emotional, instrumental, and tangible), and attachment anxiety did not predict difficulty providing any of the care tasks.

However, variables such as responsive or over-controlling caregiving were not measured, which is a criticism of this study.

Another weakness of this study is the fact that caregivers' attachment style was assessed, but not the spouses' attachment style. As Feeney and Hohaus (2001) pointed out, it is better to include both partners in order to understand attachment dynamics, and information from care-receivers will add to the accuracy of caregiving reports. Duration and amount of care provided are additional important variables that were not included in this study. Although a large sample was used, generalisability of the findings may be limited due to the lack of variation in ethnicity and economic status, and the fact that participants were all caregivers to individuals with cancer.

Kane et al. (2007) asked their participants to complete Brennan et al.'s (1998) Experiences in Close Relationships Scale, a widely used measure of adult attachment style. The perceived social support subscale from the Quality of Relationships Inventory (QRI: Pierce, Sarason, & Sarason, 1991) was also completed to assess perceived support during times of stress. Six items were created to measure the degree to which the partner is perceived to be a responsive and sensitive caregiver, and a 6-item scale was used to measure negative support responses (Rini et al. 2006). Relationship satisfaction was measured using a 6-item subscale from the Investment Model Scale (IMS: Rusbult et al. 1998).

The findings suggested that one partner's attachment style was associated with the other partner's relationship satisfaction and perceptions of that partner's caregiving behaviour. Both men and women perceived avoidant partners to be less caring and supportive. Men were less satisfied with highly anxious partners, which was partially mediated by their perceptions of them as poor caregivers. Women were less satisfied with highly-avoidant partners, which was completely mediated by their perceptions of their partners as poor caregivers. The same findings did not arise for men with avoidant female partners. These gender differences are

consistent with findings from several other studies (e.g. Kim & Carver, 2007). Although prior studies have shown that insecurely attached individuals are less effective caregivers, this is the first study to show that *partners* of insecurely attached individuals feel less supported and cared for. Although a large sample size was used, it consisted mainly of young college students, so generalisability is limited.

Kim et al. (2008) used female spouses caring for an individual with cancer. The sample consisted of mostly white, relatively educated and affluent caregivers, so generalisability of the findings may be limited. Caregivers' attachment to spouse was measured using a modified version of the Measure of Attachment Qualities (MAQ; Carver, 1997) and caregiving motives were measured using a brief scale developed for this study, Reasons for Providing Care (RPC). Caregiver's psychological adjustment was measured using a modified version of Benefit Finding (Antoni et al. 2001), the Satisfaction With Life Scale (Diener et al. 1985), and the Center for Epidemiologic Studies Depression Index (CES-D; Radloff, 1977). The validity of some of these measures is questionable, as the internal consistency of the measures for attachment avoidance and caregiving motives were at the lower end of the usual acceptable range.

The results implied that attachment security with respect to spouse was related to autonomous reasons for providing care, finding more benefit in caregiving, and greater life satisfaction. Attachment anxiety was related to introjected motives for caregiving, and to greater depression. Among wives, anxious attachment was significantly related to lower life satisfaction and avoidance related to lack of autonomous reasons for caregiving. Among husbands, avoidance was significantly related to less life satisfaction and more depression. These findings further support evidence that anxious attachment involves hyperactivation of the attachment system and avoidant attachment involves deactivation of the attachment system in the spousal relationship. Kim et al (2008) add to these findings by suggesting that

hyperactivation of the attachment system may lead to controlling caregiving. They also found that attachment style was associated with well-being among female carers, whereas the relationship between attachment and motives for caregiving played a larger role among males.

Davila and Kashy (2009) examined secure base functioning naturalistically by studying associations between daily social support experiences and attachment security. Rather than exploring attachment security individually in attachment-based models of support process, studies such as this one explore it as a dyadic process. In this study, the secure-base process is viewed as a distressed person's ability to adaptively turn to their partner for support, alongside their partner's ability to recognize the distress and be available to provide comfort and support (Crowell et al., 2002; Waters & Waters, 2006).

Participants were asked to complete several measures at the end of each day for a 14-day period. Daily attachment security to partner was measured using the 18-item Revised Adult Attachment Scale (Collins and Read, 1990), modified to assess current romantic relationship. Daily social support experiences were assessed using life event measures used in other studies (e.g. Murray et al. 2003) and daily relationship satisfaction was measured using the three-item satisfaction subscale from the Perceived Relationship Quality Components Inventory (Fletcher, Simpson, & Thomas, 2000).

Secure individuals reported that they provided more support and their partners sought more support. In contrast to Carnelley et al. (1996), no unique associations were found between comfort with intimacy and support provision. In addition, no unique associations were found between dismissive attachment and support. However, anxious attachment was associated with difficulties around support provision. More specifically, on days when partners reported seeking more support, anxious individuals provided less. The lack of associations found between attachment styles and support behaviours may have been due to the fact that the data was not collected around specific stressful experiences. This may be a weakness of the study,

as Bowlby (1969, 1973) suggests that attachment processes are activated most during times of stress. However, generalizability is questionable due to the participants mainly consisting of young, college students. Overall, the use of self-report or interview methods to assess attachment styles has been criticized in the attachment literature (Bartholomew & Shaver, 1998). Using observational methods alongside this method would have improved the validity of these findings.

Observational study

One paper used self-report measures and behavioural observations in a natural environment to explore the relationship between attachment orientation and support behaviours. Fraley and Shaver (1998) investigated how attachment and support behaviour is manifested during a stressful situation between couples and how attachment style, partner availability and relationship length influences this. Couples waiting in airport gate lobbies were approached and asked to complete a questionnaire, which included 18 items from Griffin and Bartholomew's (1994) Relationship Styles Questionnaire to measure attachment style. As soon as the couple completed their questionnaires, another researcher unobtrusively observed their interactions until both members of the couple left the gate area and then completed a standardized behavioural coding form.

The findings showed that *secure* women freely expressed attachment and caregiving behaviours. *Preoccupied* women (highly anxious and low in avoidance) expressed high levels of attachment behaviour, which is associated with unresponsive caregiving. *Fearful* women (highly anxious and avoidant) and *dismissive women* (low on anxiety and highly avoidant) tended to avoid contact with their partners, which also suggests they may have difficulties giving support. The findings for men were not as clear and any trends were relatively weak. One of the difficulties in carrying out naturalistic observations of adult attachment relationships

is trying to find situations that are stressful enough to activate the attachment system where it is possible to carry out unobtrusive observations. However, it could be suggested that the every day stressors of living with a long-term illness probably activate attachment and caregiving systems on a regular basis and this set of circumstances could provide an opportunity for carrying out this sort of observational research. A limitation of this study is that carrying out observations in an airport setting may be restrictive in the behaviours that people display. Another limitation is the small number of variables assessed, as other factors such as fear of flying, length of separation, distance of destination may have influenced attachment behaviour. Finally, these attachment and support behaviours may be specific to this particular context, and may not be generalisable to situations requiring caregiving behaviours. However, the sample was diverse in age and relationship factors, and praise should be given for creativity!

Experimental studies

Six papers used self-reports and experimental laboratory conditions to observe attachment and caregiving behaviours. Simpson, Rholes, and Nelligan (1992) had two phases to their study. In phase one, participants completed a modified version of Hazan and Shaver's (1987) measure of attachment styles (Simpson, 1990). This choice in measure limits the investigation to current attachment, which may not reflect attachment styles that were developed in childhood. Rubin's (1970) Love Scale, and the Relationship Closeness Inventory (RCI; Berscheid et al., 1989) were also completed. In phase two, couples were unobtrusively observed after the woman had been told she was going to be exposed to an anxiety-provoking activity. The purpose of this statement was to increase stress levels in order to activate the attachment process. Independent observers then rated the behaviour of both members of each couple from the videotapes. *Global adjective ratings* were evaluated for men and women,

based on descriptions found in theory (Bowlby, 1973) and research (Ainsworth et al., 1978) on attachment. Specific verbal content of conversations and physical behaviours were also rated.

The findings showed that more securely attached men provided better support as their partners' level of anxiety increased and more avoidant men provided less support as their partner's anxiety increased. Similarly, more secure women sought more support as their anxiety increased and more avoidant women sought less support. Some of the limitations of this study are the relatively small sample size used, and the fact that only men were given the opportunity to provide support, reducing the generalisability of the findings.

Rholes, Simpson, and Orina (1999) investigated the relationship between attachment orientations and expression of anger between couples in a stressful situation. According to Bowlby (1979), highly avoidant individuals would be expected to become angry when their partners turn to them for support, as they resent being forced into the role of the caregiver. In contrast, highly ambivalent individuals would be expected to be happy to care for their partners, so they can be close to them. The first two phases of this study were the same as that in the previous study (Simpson, Rholes, & Nelligan, 1992). However, a third phase was added to this experiment, which involved informing participants that the anxiety provoking activity would not be taking place due to "malfunctioning equipment", and each couple was unobtrusively videotaped again for five minutes during this *recovery period*. The amount of anger individuals displayed toward their partner was rated during the stress period, and behaviour was also rated in the recovery period.

The results showed that highly avoidant men displayed greater anger if their partners were more distressed, but this was not found in relation to the level of partners' support seeking and therefore may not apply in a caregiving situation. This anger is likely to prevent partners meeting each other's needs. In contrast, secure and ambivalent men displayed comparatively less anger. Bowlby (1973) implied that anger plays an important role in attachment

relationships, and makes the distinction between functional anger (anger of hope) and dysfunctional anger (anger of despair). One of the criticisms of this study is the lack of distinction between functional and dysfunctional anger due to observations being limited to a short, single interaction. Again, as this study used a relatively small sample size consisting of college students, the findings cannot easily be generalised to older couples, or other long-term romantic relationships.

Collins and Feeney (2000) used a revised version of the Adult Attachment Scale (AAS; Collins & Read, 1990). Participants also rated their attachment styles in relation to romantic relationships using Bartholomew & Horowitz's (1991) four attachment prototypes. Couples were videotaped while one member of the couple disclosed a personal problem to his or her partner and interactions were coded for support-seeking and caregiving behaviours with a modified version of Barbee and Cunningham's (1995) coding scheme. They found that anxiously-attached partners were poorer caregivers, providing less instrumental support, being less responsive, and displaying more negative support behaviours. These findings provide the first behavioural evidence for this implication, which is consistent with prior self-report studies (Carnelley et al., 1996; Feeney, 1996). Collins and Feeney (2000) suggest that anxious adults may find it hard to set aside their own attachment needs in order to provide the consistent, sensitive support required to be a responsive caregiver. Contrary to findings from prior observational research (Fraley & Shaver, 1998; Simpson et al., 1992), caregivers' avoidance did not relate to caregiving behaviour.

However, the laboratory conditions may have influenced the results, as avoidant individuals may have been able to provide short-term support but this may have been different with more emotional demands. The results also may have been influenced by the lack of distinction between different forms of avoidant attachment. Due to the fact that participants were aware of being videotaped, this may have led to socially desirable responses.

Feeney and Collins (2001) asked participants to complete two attachment measures, Brennan et al.'s (1998) 36-item attachment scale, and Bartholomew and Horowitz's (1991) four attachment prototypes. Several measures around empathy, social support, self-focus, and relationship quality were completed. A measure of relationship-specific motivations for caring was designed for this study, in addition to Kuncie and Shaver's (1994) caregiving questionnaire and relevant items from the Quality of Relationships Inventory (Pierce, Sarason, & Sarason, 1991). Secure attachment was associated with more effective caregiving, attachment-related avoidance was associated with unresponsive and controlling caregiving, and anxiety was related to overinvolved, intrusive, and controlling caregiving. Responsive caregiving was assessed behaviourally by exposing one member of the couple to a stressful laboratory situation and experimentally manipulating their need for support. Once again, attachment security was associated with more effective caregiving. Avoidant individuals were less supportive when partners required more support; although they were actively supportive in the low need condition. This pattern of results suggests that avoidant individuals have difficulty providing emotional care, and is consistent with findings of prior studies (Kim & Carver, 2007; Fraley & Shaver, 1998; Simpson et al., 1992). In contrast, anxious caregivers were unable to provide responsive support in relation to their partner's level of distress, which is a similar pattern to that found by Davila and Kashy (2009). However, compulsive and controlling caregiving was not coded, which is a limitation of this study. This study can also be criticized for not including the support-seekers' ability to communicate their needs as an influence on effective caregiving.

Crowell et al. (2002) explored secure base behaviour in relation to representations of attachment. The Adult Attachment Interview (AAI; George et al., 1985) was used to assess representation regarding attachment. The Family Behaviour Survey (FBS; Posada & Waters, 1988) was used to assess relationship functioning, and intelligence was measured with the

Hemmon-Nelson Test of Mental Ability (Lamke & Nelson, 1973). Participants were videotaped in an interaction task discussing a problem in the relationship, and were assessed using the Secure Base Scoring System (SBSS), a system based on Ainsworth's analyses of infant-parent secure base use and support.

Secure men and women were more effective in secure base use and support. Among women, no differences were found between dismissing and preoccupied groups. However, preoccupied men were more able to use and provide secure base support in comparison to dismissive men. Attachment representations were not the only influences on participants' behaviour, as romantic relationship experiences and current partner were also influential. However, these findings may have been influenced by the fact that all of the participants were engaged to be married, which may have led to socially desirable responses as they discussed their relationship problem. It was also assumed that discussing a relationship problem would be stressful enough to activate the attachment process. Couples may be more effective in secure base use and support in this context, but this may not be generalisable to a more demanding caregiving situation.

Simpson et al. (2002) administered the Adult Attachment Interview (AAI; Main & Goldwyn, 1994) to each partner. Participants also completed a survey consisting of a measure of the Big Five personality traits (Goldberg, 1990), the Relationship Satisfaction Scale (Hendrick, 1988), and the Adult Attachment Questionnaire (AAQ; Simpson et al., 1996). The couples were then videotaped while one partner (the male) waited to do a stressful task. Observers rated each woman's support giving and each man's support seeking. The findings suggest that working models of attachment to parents predict the amount of support women give to their distressed romantic partners. Securely attached women provided responsive support and more avoidant women were less supportive, which is consistent with previous studies (Carnelley et al. 1996; Fraley & Shaver, 1998; Simpson et al., 1992).

One of the criticisms of this study is that behavioural ratings were global, summary measures and did not examine how support behaviours may have changed at different points of the couples' interactions. In addition, observations only took place over a five-minute period, which may have not been sufficient time to capture the support process fully. Finally, a limitation of this study, and experimental studies in general, is the lack of time and relaxed atmosphere, which are conditions necessary to provide sensitive and attentive care (Bowlby, 1988)

DISCUSSION

The existing literature is limited in both scope and methodology. Many of the studies have relied on self-reports of attachment and caregiving behaviours. All of the findings are correlational in nature, and therefore no causal conclusions can be made.

However, the findings of the studies included in this review indicate that secure individuals are likely to provide the most effective care to their partners, in comparison to insecure individuals. The results also suggest that individuals who are not comfortable with intimacy, otherwise known as having avoidant-attachments, tend to be less responsive caregivers (Carnelley et al. 2006; Feeney, 1996; Feeney & Collins, 2001; Fraley & Shaver, 1998; Rholes et al. 1999; Simpson et al., 1992; Simpson et al., 2002). Attachment anxiety was also related to caregiving difficulties, although this finding is less consistent. Some studies reported that anxious individuals provided more controlling caregiving (Feeney, 1996; Feeney & Hohaus, 2001; Kim et al. 2008), and others implied that anxious individuals provide less caregiving (Carnelley et al. 1996). Collins and Feeney (2000) suggest that people with anxious-attachments provide less support, are less responsive, and show more negative caregiving behaviours. Experimental studies, such as Feeney and Collins (2001), imply that anxious caregivers provide support to their partner, but have less capacity to respond in a well-attuned,

synchronised manner. More in-depth examination of observed caregiving behaviour of anxious individuals is required, over longer periods of time and in different contexts.

Future studies need to control for other possible influential variables such as romantic relationship experience, gender, length and type of relationship. In addition to attachment orientation, these variables may impact on an individual's caregiving behaviour to their current partner. Gender differences may reflect the fact that, although more males are taking on caregiving roles, caregiving is traditionally expected of women in most cultures (Harris & Long, 1999; Siriopoulos et al. 1999). Studies using samples of married couples may have different findings, as experiences and expectations of caregiving are likely to be more influential in comparison to dating couples. In addition, a majority of the studies use student populations and very few look at caregiving against a backdrop of the lack of reciprocity that comes when one partner has a chronic illness.

Individuals may find it difficult to be honest about their attachment security to partners and their abilities to provide care, so future research should control for socially desirable response styles. It is important to note that attachment relationships are dynamic in nature. Although they build continuously upon prior attachment history, they can be influenced by changes in support and life circumstances (Bowlby, 1988). So future studies should consider early attachment development as well as attachment to current partner. Longitudinal designs, using multiple methodologies are required to further test the proposed causal relations between attachment and long-term support and caregiving processes.

Clinical Implications

Professionals who work with carers and care-receivers may find it helpful to consider the impact of individual differences in attachment and caregiving styles. As the papers in this review imply, reasons for providing care (identified by attachment style) and attachment

orientations are likely to impact on caregivers' ability to provide responsive care, and may have a negative impact on their well-being. Davila & Kushy (2009) suggest that attachment security can change in response to changes in the interpersonal environment, which implies that these processes are open to change.

The findings in this review have indicated that some caregivers may struggle to adjust to their role, and this can be identified by their attachment orientation. Hence, it may be important to be aware of attachment style of caregivers, in particular avoidant and anxious individuals who may need additional support. Programmes for caregivers should be developed to help these individuals learn how to be more aware of their partners' needs and to respond sensitively and responsively, whilst incorporating the value of the caregiver role.

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EMPIRICAL PAPER

TITLE: The personal experience of carers of individuals with Motor Neurone Disease (MND) and their experiences of services

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ABSTRACT

Carers play an essential role in the lives of people suffering from chronic health problems. Understanding the concepts related to caregiving experiences and the relationships among them can enable us to better address the needs of caregivers. Motor Neurone Disease (MND) raises many of the issues relevant to caring for people with chronic disabling conditions, and yet there is a lack of research exploring the experiences of those assisting someone with MND. The findings of the limited number of studies to date are diverse and sometimes contradictory. This study explored eight individuals' experiences of having a partner with MND, their experiences of services, and the meanings they gave to these experiences. Semi-structured interviews were carried out and transcripts were analysed from an Interpretative Phenomenological perspective.

The main themes are 1) *Impact on life*, which is broken down into: trying to be strong, having concern for partner's safety, loss of intimacy with partner, struggling with anger and frustration, being continually tired, having social restrictions, and uncertainty around the future, and 2) *Adjusting to the situation*, which includes: varied experience of services, adopting a problem-solving approach to practical difficulties, living day-to day, adapting to sudden lifestyle changes, and trying to remain positive.

Although the participants described similarities in their experiences of having a partner with MND, there were also some significant differences. These differences were explained using attachment theory and Pearlin's (1990) caregiver stress-process model as frameworks. Recommendations for services are discussed.

Key words: Motor Neurone Disease; chronic illness; caregiving; spousal carer; couples; and interpretive phenomenology

INTRODUCTION

Family carers can be a major source of help and assistance to the people for whom they provide care. They are also major contributors to the welfare system, balancing the national health care expenditure. The importance of informal caregiving has been given increasing consideration, in research as well as government policy. In relation to this study, the care of people with long-term conditions has recently become a focus of health care policy in the UK and several policy documents recognize the needs of carers e.g. the National Service Framework (NSF) for Long Term Conditions (Department of Health, 2005). A review of the literature on carers' experience of providing care to people with long-term conditions stated that all services and Motor Neurone Disease (MND) charities need to consider the impact of MND on the carer as well as the patient (Department of Health, 2005). The report highlights that services provided at the time of diagnosis are important to carers, many of whom feel that they have to fight for services and that they receive too little too late.

Evidence suggests that there is substantial variation in how caregivers adapt to their care giving demands. Many studies have attempted to understand the relationship between care giving and health outcomes of the caregivers. Much of the literature focuses on stress related to direct provision of care, however, as Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) suggest, it is important to recognize stress occurring in the wider social context in order to gain a complete understanding of its impact. Contextual factors such as severity of poor health, internal factors such as mastery and self-esteem, coping strategies and social support have all been linked with psychological and/or physical effects on caregivers. Understanding the concepts related to caregiving experiences and the relationships among them may allow us to better tackle the needs of caregivers. The aims of this study are to identify useful

concepts for research and practice with people providing care to a partner with Motor Neurone Disease (MND).

MND is a progressive neurodegenerative disorder that affects over 350,000 of the world's population at any one time. There is a considerable variability between patients with regard to early symptoms, rate and pattern of progression, and survival time (Small & Rhodes, 2000) with the average survival about 3.5 years from onset (Leigh et al., 2003). However, people with MND may become severely disabled and dependent within months, posing challenges for both them and their carers, who are most often spouses (DeLisa et al. 2004). MND therefore raises many of the issues relevant to caring for people with chronic disabling conditions.

Cross sectional questionnaire based studies have begun to explore the psychological impact of providing care for people with MND (Goldstein, et al., 1998, 2000; Rabkin, Wagner, & Del Bene, 2000; Hecht et al., 2003; Chio, Gauthier, Calvo, Ghiglione & Mutani, 2005). Carers have been reported as experiencing anxiety and depression; carer strain has been related to loss of perceived marital intimacy, and the impact of the illness on different areas of carers' lives, including their social life. Caregiver burden has been related to carers' depression, fatigue, and impaired quality of life. Goldstein, Atkins, Landau, Brown & Leigh (2006) carried out a longitudinal study using questionnaires to measure the psychological impact on carers over time. They reported that carers' psychological distress increased significantly over time, and that in the face of the significant physical impairment associated with MND, psychosocial factors seemed to greatly influence well-being. Mockford, Jenkinson, & Fitzpatrick (2006) carried out a review on literature from 1994 to 2004 of informal carers' experiences of living with someone diagnosed with MND and their experience

of services, highlighting the lack of written documentation on the experience of assisting someone with MND, and the diverse and sometimes contradictory outcomes.

The management of MND has progressed rapidly over the last two decades and treatments and interventions have been developed to prolong survival. These treatments do not, however, stop progression or reverse weakness. Love, Street, Harris, & Lowe (2005) suggest that prolonged caring for individuals with MND has significant costs for the carer such as loss of social support, which impacts on their well-being and eventually on those with MND.

Although several surveys have been carried out with carers for people with MND (Goldstein et al. 2006; Love et al. 2005), there is a lack of qualitative research exploring carers' experiences in-depth, including their experiences of services. Caregivers have reported that good professional support is helpful to their caregiver role (Pierce & Salter, 1988; Williams, Oberst, Bjorklund, & Hughes, 1996). If caregivers' well-being deteriorates, their ability to be an effective caregiver for a person with MND declines too. Therefore a deeper understanding of the way in which spouses experience and respond to the development of MND in their partner, and the way in which they themselves understand and make sense of the changes they are observing, should enable the development of more sensitive and supportive clinical services.

Research Aims and Questions

This study aimed to find out what it is like to experience having a partner with MND, how services are experienced, and the meanings people give to these experiences. The goal was to achieve these aims through understanding, interpreting and contextualising detailed accounts of individual carers. It is hoped that dissemination of the knowledge gained from this study can be used to improve the

provision of services provided to individuals with MND and their carers, and enhance the general body of research on carers and their needs.

METHOD

Design

Interpretive Phenomenological Analysis (IPA) (Smith & Osborn, 2003) was adopted due to the complexity and sensitivity of the subject area, and the requirement to gain detailed views of the informants to supplement the existing body of questionnaire based research. The question of the meaning that partners of people with MND gave to their experiences was of prime importance and IPA is a method for exploring how participants make sense of their own experiences.

Procedure

Sampling method

A “purposive” sampling method was used to identify participants who could offer a meaningful perspective on having a partner with MND. Names and contact details of carers were obtained through the clinic records held at a major regional MND clinic in a teaching hospital. Participants were recruited via an invitation letter, which contained an information sheet outlining the study. Criteria for inclusion in the study were individuals who were currently providing care for a family member with a diagnosis of MND.

Data collection

Participants were individually interviewed, using a semi-structured interview process (adapted from Smith, 1995). An attempt was made to establish rapport with the participants by meeting with them once before the interview to explain the process and by being sensitive to their reactions throughout the interview. A “funnel”

interview style was used, starting with some broad questions inviting the participants to describe what happened when their partner was first diagnosed with MND and their experiences of the services. The remaining areas of focus were more specific to their own roles in providing support to their partner, their relationship with them and with services and how these things had impacted upon them and changed over time.

Coverage of all these areas took prominence over order of topics discussed. (See Appendix 7 for Interview guide). The interviews did not exceed 90 minutes and were undertaken at the participants' place of choice (all chose to be interviewed in their own homes) and they were only interviewed on one occasion. They were tape-recorded and recordings were transcribed verbatim, though with changes to identifying details such as names.

Participants

Eight individuals responded to the invitation to participate, six of whom were female and two male, with ages ranging from mid forties to early seventies. Seven of the participants were married, and one was a long-term partner. Their partners were at varying stages of MND, and time since diagnosis varied from 6 months to six years. Despite some variation in gender, relationship status, age, and stage of partner's MND, it was felt that these eight individuals were able to offer insights from a position of shared expertise.

Table 1: Summary of Participants' situation at time of interview

Name	Age	Summary of Context
Anne	50's	Has Multiple Sclerosis (MS), husband always cared for her. Married to husband 14 years. Has two friends and one daughter-in-law who offer support and live nearby. Husband diagnosed 5 years, has significant cognitive deficits, uses Percutaneous Endoscopic Gastrostomy tube (PEG) to feed, but still able to walk.

Frank	40's	Still works, has a teenaged son and a supportive network of family and friends. Wife's two brothers, father, uncle, and grandfather died of Motor Neurone Disease. Wife diagnosed 6 years, and wheelchair bound. Were practicing Roman Catholics, but had "crisis of faith" associated with wife's MND.
Maria	60's	Retired and in recovery from cancer. Have large supportive network of family and friends, of whom many are professionals. Describes being privileged economically and with professional knowledge. Husband diagnosed 5 years, uses PEG to feed and talking machine to communicate, struggling with mobility but reluctant to use wheelchair.
Jim	60's	Retired and in recovery from cancer. Have two children and two grandchildren nearby. Has no support with wife's care, apart from wife's cousin to sit with her one night a week, so he can go out. Wife diagnosed 5 years, now wheelchair bound.
Emily	50's	Still works, but considering early retirement. Daughter lives abroad and has no other support network. Has experience of progressive illness, as father had MS and helped her mother care for him in her childhood. Husband diagnosed 3 years, now wheelchair bound.
Sue	70's	Retired, has no children but large support network of friends. Husband diagnosed 2 years, fed through PEG but still mobile
Catherine	60's	Semi-retired to spend time with husband. Has 3 children, 2 live in different parts of country, one was living abroad but moved back after father's diagnosis. Husband diagnosed 6 months, has moderate cognitive deficits, difficulties with balance, still mobile. Feels privileged economically, and shared "wonderful" life together from young age.
Helen	50's	Jointly ran own business, but wound this up to spend time together. Has two children, both left home and own mother in a nursing home. Has large supportive friendship network. Husband diagnosed one year, losing use in one hand and wears a soft leg brace on one leg.

Reflections around own preconceptions

In order to engage with other people's experience, as researchers, we need to be able to identify and reflect upon our own experiences, preconceptions and assumptions. I have carried out several research studies prior to this one around family caregiver perspectives, and since pursuing my career in Clinical Psychology, I have had a wish to give carers a voice by telling their stories. Whilst reflecting on my own personal history, I realised that my mother has been a "carer" for others all of her life and has emphasised the importance of this role to me by framing her experiences in a positive light and encouraging me to care for others. This experience has led to my association of the caring role predominantly with females. During my professional

experience, carrying out my clinical work with different populations and across a variety of settings, the family members of my clients appeared to vary dramatically in their ability to adapt to the role of caregiving and how they experienced ill health within the family. From the stories I have heard, I also hold the preconception that services for carers are patchy and often unable to meet their individual needs. It is with these experiences and assumptions in mind that I carried out my research.

Data Analysis

As its name implies, Interpretive Phenomenological Analysis (IPA) (Smith & Osborn, 2003) combines two traditions in qualitative research. It is phenomenological – it attempts to obtain a detailed story of the participant's own experience, rather than an objective account. It assumes that participants are experts in their own experiences and can offer researchers an understanding of their feelings, intentions, motivations, and attitudes. It is also interpretative – the researchers enter into the process of interpretation, bringing their own expertise to bear on the reflective process of achieving meaning. The interpretations can be drawn from a range of theoretical positions but they should emerge as interpretations of the participant's account, rather than emerging from prior hypotheses.

The first case was analyzed in detail before moving on to similarly detailed analysis of the other cases. The transcript was read and re-read and any observations about the data were noted. The next stage was to identify and label themes that characterized each section and capture the essence of what was found in the text. The final stage involved constructing a conceptual framework that related the themes back to theory, and to the literature, which was represented in tables. (See appendix 8 for example of an analysis table.) Then a narrative story was created to explain the themes, illustrated with verbatim extracts from the transcripts.

The process of “triangulation” was used to check credibility of interpretation of the data. This was done in several ways; supervision was used to gain an expert perspective around interpretations, and an “analysis group” was set up with peers to compare agreement around themes and interpretations. The reports were also shown to participants for feedback on the appropriateness of representation.

Ethical issues

Ethical approval was sought and obtained from an NHS Research Ethics Committee. I obtained informed, written consent after the participants had read and fully understood the information sheet. Participants were informed that they were free to withdraw from the study at any time up to two weeks after their interview.

The issue of caring for somebody with a diagnosis of MND can be a sensitive area to discuss. Interviews were conducted with this in mind. The interviewer remained aware of this at all time and received supervision from a Clinical Psychologist for all the interviews conducted. If people became distressed during the interview, they were offered time to debrief. Finally, participants were told that all the information used for the study would be kept anonymous¹.

RESULTS

The analysis focuses on the participants’ experiences since their partner received a diagnosis of MND, but it is important to set the scene by placing these experiences within the context of receiving the diagnosis. All of the participants talked about the initial uncertainty around the diagnosis and how they received the news in a very “matter of fact” manner. Jim and Emily described how no formal diagnosis was

¹ All names have been changed to protect participant anonymity

given. Jim explained, “It was really odd in some ways because nobody said you have got Motor Neurone”. Those who were given a formal diagnosis described feeling in shock after receiving the diagnosis, and being left with a lack of information, and instructions to come back in six months time. Jim explained how his wife did not want to talk about the MND with him after the diagnosis. He acknowledged that MND affects people in different ways, but that he would have found it helpful to talk to someone else and to be given some general information about what he may expect:

“As far as carers are, when you get something like this the main difficulties are not having somewhere people in my situation can go to get some answers like; What do I need to look for? What do I need to know? Because you come out and they say okay you’ve got Motor Neurone, we’ll see you in another six months take these tablets sort of thing and you think what the hell am I dealing with here. You can’t see it, you can’t feel it you don’t know haven’t got a clue (...) Well we do now because I’ve done some research to find out, but there was nothing there at the start.”

In contrast, Catherine was the only participant who experienced the diagnostic process as positive and helpful, appreciating the “matter of fact” way in which it was delivered. Her experience appeared to be different from the others, in the way that she felt they were given time to process the news and were helped to draw out the positives:

“He just told us in a very quiet and matter of fact way and allowed it to sink in slowly and asking questions. He didn’t give false hope, but he helped us draw out the positives by saying you know that it wouldn’t be painful and that it does mean that you have time to do the things that you want to do. So yes so he was very helpful.”

These narratives were dominated by a sense of confusion and feelings of abandonment. There were inconsistencies in experiences of initial help, as some couples were offered support and referred to the specialist MND Clinic straight away, whilst others actively sought out and approached services themselves. Seven out of the eight participants described their initial experience as unhelpful, although all of them articulated their felt support and reassurance once in contact with the specialist MND Clinic. This is discussed in more detail within the sub theme: varied experiences of services

In the following sections, I will describe my participants' claims and concerns about their experiences after their partner was diagnosed with MND. I have divided these into two main themes: 1) Impact on life, which has seven sub-themes: trying to be strong for partner; having concern for partner's safety; loss of intimacy with partner; struggling with anger and frustration; being continually tired; having social restrictions; and uncertainty around the future; and 2) Adjusting to the situation, which has five sub-themes: varied experience of services; adopting a problem-solving approach to practical difficulties; living day-to day; adapting to sudden lifestyle changes; and trying to remain positive.

Impact on Life

There was a clear sense of the great impact having a partner with MND had on these participants' lives. They felt the need to be strong and protect their partners in many ways and showed concerns around their partners' safety. The impact on relationships with their partner was stressed, in addition to their feelings of anger and frustration, physical tiredness around the provision of care, social restrictions, and uncertainty around the future.

Trying to be strong for partner

The need to be mentally strong for their partner was expressed by all. Frank showed his fear of things falling apart if he showed “weakness” by expressing his own struggle with the situation, “You have to remain mentally strong if you can for both really because if we both fell into the same pit at the same time we could be in problems”. In their effort to be strong and not burden their partners further, all participants felt it difficult to express any “negative” feelings in relation to their situation. This was particularly apparent in Emily’s account: “I’ve become very protective about ensuring that he doesn’t see me in an upset state”. This sense of not wanting to burden others also applied to other relationships as participants described their reluctance to share feelings with family and friends. This was particularly clear in Catherine’s account:

“My dad’s been very good, but I wouldn’t burden him with how I feel really. I’ve got brothers who have been very good but I don’t really talk openly to them. I suppose it’s mainly the children. I’ve got a few friends, but you tend to put on a brave face with them and most of the time I’m fine.”

Having concern for partner’s safety

Due to the physical disabilities caused by MND, the safety of their partner was a concern expressed by most. This was particularly apparent around situations that involved leaving their partners at home and worrying about any harm that may come to them. This was evident from Anne’s statement, “When I go out for a few of hours or something he’s always in the back of my head; what if something might happen? (...) He might fall or he might burn himself or he might have an accident”. Many of

the participants described “watching” over their partners when they are with them, suggesting an associated sense of vulnerability with their partners’ physical symptoms of MND. This does not appear to be linked with the stage of MND, as Helen describes feeling the need to watch her partner even though his MND has not progressed much: “It’s being there and watching him, I do find that causes my anxiety (...) He’s fallen a few times and straight away I think *oh my god that’s because of the MND*”

Loss of intimacy with partner

It was evident that most of the participants experienced a loss of intimacy with their partners in varying ways. Catherine described Tim’s sensitivity around receiving physical affection since having MND. She hints at trying to understand his struggle, but finds it hard to get used to being less spontaneous and more careful when showing physical affection:

“He gets very tired and erm and his balance is a bit dodgy erm I suppose one thing that’s hard is that he doesn’t like being touched so much. So whereas you really want to hold him, he says ‘no, just hold me there’ you know he says that he can’t explain it but he says that he feels it does something to his balance or breathing, makes him feel more vulnerable, but I understand that... It’s not that you can’t touch him, but you just have to treat him as if he's very fragile”

Both Anne and Catherine give the sense of their relationship as having more of a child-parent dynamic. Anne appeared to identify with Simon in this way due to his complete dependency on her for survival, “He’s more like a child now. You know well I mean looking after, I mean he can’t do, I mean he’s fed over night but he couldn’t set that up on his own.” and Catherine described the impact on her

relationship since simplifying her communication due to their partners' cognitive deficits:

"I think that about two years ago I started simplifying the way I said things because I found he wasn't understanding some vocabulary and so our relationship's faltered slightly in that way. Not that we've become more distant from each other, but it's almost as if you're talking with a much younger person and that you take things slower. So it's not just been a physical change with him"

Maria's husband relied on a machine to communicate with her due to his loss of speech, but his MND had not impacted on his cognitive abilities. In contrast to Anne and Catherine, Maria made it clear in her account that she identified with her husband in the same way as before he had MND and seemed to maintain the intimacy in their relationship by treating him the same in as many ways as she could:

"What irritates me are the things that have always irritated me about him (*laughs*) and with MND he doesn't seem to have changed personality so the things untidiness erm losing things you know not being very attentive sometimes. I mean they are the things that have always irritated me. So they're not nothing's sort have gone away really"

Some explained how taking on the caregiver role "changes the dynamics of the relationship". Many participants expressed their reluctance to take on the identity of being a "carer", but Helen expressed the idea of not being able to avoid it, "I mean I don't really like the label of carer really, but then what else can you call yourself?" Frank provided a detailed account of the importance for him to make a distinction between providing physical care for Vicky and relating to her as a romantic partner:

"There's a very very thin line that you try to stay away from, well me personally, because you can overlap into being more of a carer than you can a partner and all

those emotions that go with being a partner can be blurred into this person who's just helping you get off the toilet or get into the bath and you do have to work at it."

When asked if she considered herself a carer, despite carrying out all of Phillip's physical care, Maria claimed that she did not view herself as a carer and experienced caregiving as a mutual process in their relationship that Philip was still actively involved in, "He's never been the most active person in the house in that way, but he's always been somebody who would support you and care for you and he hasn't changed".

Struggling with anger and frustration

Feelings of frustration and anger seemed to dominate five of the accounts, although the underlying reasons the people gave varied. Anne described her frustration around coping with Simon's cognitive deficits in the context of her own struggle with physical symptoms of MS:

"It's really frustrating and he drives me mad because he can't remember anything so we have lists everywhere. I have to write everything down for him. Erm but even if I say to him can you go and get something and then I'll wait and I'll think he doesn't know what he's gone for and I'll go and find him, or he comes back without it, or he comes back with something totally different."

Frank and Jim both express their frustration around not having the time to pursue their own interests due to their partners' care always taking priority. Again, Frank feels "selfish" when expressing his frustration:

"It doesn't just affect Vicky it affects everybody that's around her er myself yeah sometimes I have to pull myself up sometimes because sometimes I do feel selfish

thinking bloody hell I would have loved to have done that but I can't and er like I used to go running quite a lot but I don't and it's not resentment against Vicky, it's resentment against the disease"

When asked what kind of feelings it brings up when thinking about their partner's MND, Anne described feeling angry around having her husband taken away from her, "Anger. I feel cheated" and Helen expressed her anger around the loss of future that she planned, "You feel like your future's been taken away from you."

Being continually tired

Participants with partners at later stages of MND described their experience of being physically tired most of the time. Emily described her lack of energy due to the physical nature of moving John around in order to care for him, "Physical energy I just run out of because I get to the point when actually trying to move him, physically trying to move him is an enormous task". Several people mentioned their disrupted sleep due to having to turn their partners over in the night. Frank gave an example of this, "She has certain problems in literally turning onto the side when she's changing position so obviously if she needs to do that obviously I have to wake and then help her with that". In addition, Frank explained how Vicky's breathing and swallowing had been affected by the MND and hinted around his fear of her dying in the night, which was also impacting on his ability to sleep:

"She's having some problems with her throat and her swallowing. Not greatly with the swallowing but obviously that's a real hit home you know you think my god you know this is the vitals that it's affecting here. But as I say people can live their lives without legs and without arms but not without breath. You don't realise it but there's an undercurrent of constant watch and your sleeping patterns are obviously disrupted"

Anne shared her experience of the Percutaneous Endoscopic Gastrostomy (PEG) feeds disrupting Simon's sleep and therefore disturbing her, and how their tiredness had a negative impact on their quality of life: "If he has a restless night then so do I and I get really tired and he's really tired as well so there aren't any happy times."

Having social restrictions

Most of the accounts described how having a partner with disabilities due to MND restricted their lives, impacting it on many levels. This is demonstrated by Jim's claims:

"It does have this effect on every aspect of your life. You can't go out when you want to go out you can't go where you wish to go or you used to be able to go.

You can't do the things that you normally did"

Others shared their experiences of struggling with being restricted socially due to the lack of facilities to accommodate their partners' disabilities in places such as their friends' homes and public areas. For Anne, Sue, and Maria, whose partners all had swallowing difficulties due to their MND and were being fed through a PEG tube, eating meals together at home and out socially was proving difficult. Anne described how they had stopped eating out, "We used to go to lots and lots of places so obviously we don't go there anymore. We don't go out for meals anymore because he can't eat."

For those with partners in the later stages of MND, the importance of having breaks for themselves was expressed. However, there was a sense of guilt expressed by some in relation to their need to spend time away from their partner. Emily was worried that her partner may feel abandoned, "You sort of you feel guilty. I know I can do that, I know I should be able to do that erm and I don't want him to feel abandoned".

Uncertainty around the future

Due to the variation around how individuals are affected by MND and how long they will survive with it, participants described their uncertainty around their partner's future. This was evident in Frank's account,

"You read into it and then you see the life expectancy and so that's the problem. So every Christmas you think is this the last Christmas or you know was that the last birthday? You don't know, although her disease pattern seems quite slow, it doesn't matter how slow it is once it starts hitting the vitals it doesn't matter does it?"

Helen expressed her general lack of knowledge around MND and the paradox she faced due to being in denial about her partners' diagnosis and not wanting to have more information, and yet feeling anxious around the uncertainty of not knowing:

"I imagine that he'll lose the use of his hands, so that'll be one, well that'll be the first disability I imagine and then it'll be the arm and perhaps the leg. I mean this is how I see it I mean I don't know as I say I don't really know that much about it and how it does affect people."

However, some of the participants found a positive side to the uncertainty of the disease by using it as hope for slow deterioration and a possibility that it may not affect *their* partner in such an awful way as they have witnessed or read about. This was evident in Helen's claim, "In the back of our minds we know basically what's going to go on, but I think you just sort of tell yourself well everybody's different and we try and get through it that way."

This sense of fear around associating MND with an awful death was hinted at in most of the accounts, but some expressed this more openly than others. Those who

talked about their partner's death explicitly had partners at a later stage of the disease, and it was clear that this was on Anne's mind at the time of being interviewed, "It's a cruel disease. And the fact that it's so erm progressive (*becomes tearful*) you know he's not going to die very nicely is he?"

Adjusting to the situation

People's ability to adjust to having a partner with MND varied greatly. However, some common themes that appeared to influence their ability to adjust to their situation were: how participants experienced services; their ability to adopt a problem-solving approach to practical difficulties; live from day-to day; adjust to life-style change; and remain positive.

Varied experience of Services

Participants shared their different experiences of services, some were offered help and others had to find services and chase the support themselves. Sue experienced services as positive and found that help was offered to her from the start, "It was there and it was offered to me you see. I didn't have to go chasing it, if I wanted anything it was offered you know". Several participants also described how they felt services had made themselves available and Anne described how having phone numbers to contact professionals as and when she needed them gave her a sense of reassurance:

"They're very good I mean if I've got any problems I only have to phone them, all of them have said if you've got any problems what so ever you only have to ring I mean I've got hundreds of phone numbers new phone numbers and things"

In contrast, Emily gave the sense of needing to "fight" for services for her partner:

“I’m very determined and I don’t take no for an answer and it’s really easy for me to fight for him, you know I can do that easily and if they’re not doing their job I just get persistent and insistent and I get what he needs”

All of the participants experienced the specialist MND clinic as supportive and containing. Helen claimed how she found it helpful to visit the MND Consultant, as she was able to give her information about MND in a sensitive way, “She has to tell you the facts but she just in a more sympathetic way and I actually like feel you know I quite like going to see her”. Frank commented on the reassurance he gained from having access to expert knowledge around MND, “They couldn’t understand why it was a chest infection and it was closing the throat and whereas [the MND Consultant] said ‘No Vicky, it’s nothing to do with the chest infection it’s the Motor Neurone Disease’”. In context of the associated lack of hope around the terminal nature of MND, several participants commented on the hope they experienced from their relationship with the MND Clinic. Maria linked this feeling of hope with knowing about (the MND Consultant’s) involvement with the latest research:

“She’s very you don’t give up hope with her. The other one was you’ve got it and that’s it you know. She doesn’t make you feel like that, she’s chasing all the new knowledge so she’ll be the first to know if anything good comes along won’t she.”

Adopting a problem-solving approach to practical difficulties

Most participants mentioned that the most helpful aspect of their relationship with professionals was their problem-solving approach and practical support they provided. This was evident in Maria’s account:

“It’s having at their finger tips all the practical advice so it’s the way they handle it, yes you know that is a problem but we’ll look at how we might problem-solve

it. So a problem-solving approach and then knowing what the problem will be and knowing what you're likely to face."

The majority of the accounts gave the sense of using a problem-solving approach and focusing on practical ways of helping their partners as their MND progressed. Emily and Catherine both described their focus on making practical adaptations to their homes to accommodate their partners' physical needs, claiming that this gave them a sense of control and helped them to cope with the emotional impact of their partners' deterioration. Catherine stated:

"There are things that you can do to make you feel that you're ahead of it somehow and you're prepared and taking control in a way... you feel you're actually doing something positive and practical, which takes your mind off the emotional side of it"

However, Frank reflects on his practical approach to the situation as Vicky gradually lost the use of parts of her body in the earlier stages of her MND, but now that it is damaging her "vital" organs the reality of her survival being at risk and being unable to "do" anything means that he could no longer avoid facing the emotional impact:

"It's er er more so a physical thing I think erm at the early stages of Motor Neurone Disease with Vicky it was affecting, it started in her big toe and has worked though the non vitals if you will. In hindsight I think you learn to adapt to losing the legs and to losing the tummy and the left side and the feet and to a certain extent the arms. She's losing some strength in her arms but she er now it's gone to the vitals and that really really does bring it all right to a head. You know she's having some problems with er her throat and her swallowing (...) obviously that's a real hit home you know you think my god you know this is the vitals that

it's affecting here. But as I say people can live their lives without legs and without arms but not without breath."

Living day-to day

Most accounts gave the sense of living from day-to-day in order to cope with their situation. Catherine described this as a change in her view of life, "Your whole view of life changes and your priorities change and you don't look too far ahead. You just get on with each day and try and get the best out of it". Emily also claimed that coping on a day-to-day basis was required in order to cope with the emotional impact of her partner's deterioration:

"You just cope on a day to day basis and periodically there were shocks along the way because although you know the process and the progress really if you've read about it or whatever you know about it erm but sometimes there are particularly difficult emotional hills to get over but you just get over it really you have to do that and you have to take it day to day"

However, these individuals appeared to be facing a paradox, as they also wanted to make the most of life with their partners. Maria stated, "I think that we've just sort of decided to enjoy life". Helen hints at the difficulty she had around learning to live from day to day and attempts to make sense of it by reflecting on the fact that we can only live in the present as none of us know what life will bring:

"We just try and, as I say, live day to day but it's very hard you know living day to day I mean I know we all we only have like this moment in time don't we really, we do only have day to day because none of us know what's around the corner. Erm but it's just a different way of coping with your life I think and it's learning to manage that"

Adapting to sudden lifestyle changes

Several participants talked about the sudden change in lifestyle they had to adapt to, which is evident in Emily's claim, "I had lots of things organised to do and erm you know suddenly it all changed." This appeared to be easier for some than others, Helen's account in particular was dominated by her struggle to adapt to the lifestyle change:

"Personally I'm having problems with or it's the whole lifestyle change because of the MND. Because we had a business and we employed like thirty people, a local business which was after thirty years, which has obviously been our life, we've lived and breathed it and you know the ultimate outcome of the business was to retire fairly early and sort of get on and enjoy life and that's all stopped now you know."

Catherine also articulates having to manage the sudden change in lifestyle, as Tim took an early retirement and she reduced her working hours to spend more time with him at home, "Normal is quite different because we're suddenly getting, I mean when you retire they say it's quite traumatic anyway so life is very different anyway just by virtue of him being retired so ..."

Many participants adapted to the lifestyle change by socializing more with friends, and this appeared to give them a sense of normalizing their situation. Maria made these claims:

"I don't know really I don't know what it is, it's just friendship, companionship, things to do that normalise life, they make it normal. You know, they don't make the fact that I've got problems abnormal. You know they take us out, but they

don't worry about Phillip you know he's still Phillip. So it's normalising things, it's not making you sick"

Ability to remain positive

Most participants described MND as a "cruel" disease for varying reasons and Emily shared her experience of "trying to be very positive and say it's not the fact that we can't do it anymore it's about what we can do and what we're still able to do."

Some talked about the cruelty of MND in the way that it has left their partner incapacitated and Frank also expresses his view of the cruelty around the lack of treatment and related lack of hope:

"I think cruel because it's so debilitating (...) and cruel in the aspect that one is there's no known cure and two what it does to people you know they can't do anything."

In contrast, both Catherine and Maria's accounts gave a sense of feeling privileged in various ways in comparison to others, which appeared to help them to remain positive about their situation. Catherine claimed, "We're both fortunate that we've got a nice house and we can afford to get it adapted". She was also able to find positive sides to her partners' diagnosis, which appeared to be influenced by her constructive experience of being helped to find the positives when the diagnosis was given. She valued the progressive nature of MND in that the knowledge of her partner's death has allowed her to spend with him that she may not have otherwise spent, "You just have to get on with things and in a way you feel quite privileged, you've got the time to make some decisions and have time together". She also described her preference around being able to see the visible signs of MND, which appeared to give her a sense of control in comparison to the "hidden" nature of other diseases such as cancer, "The

gradual nature of it seems kinder in a way than some diseases and also you're not imagining a cancer inside that's eating."

Despite Sue's description of MND as an "awful disease" due to the debilitating and restrictive nature, her experience was dominated by the importance of remaining positive in order to support her husband, due to her belief that her husband's frame of mind had a strong influence on his rate of deterioration, "The doctor said to us that William's got the right frame of mind and that's what's kept him going you know." Finally, I will leave you with a quote from Catherine's account that shows how her philosophical position about life allows her to face her situation with humour, and how wider social values around life, illness, and death may impact on people's ability to adapt to a situation such as having a partner with MND.

"There's no point pretending it's not going to happen, but you can have a laugh about it and it's just part of life isn't it? I think nowadays we have such comparatively healthy lives that people don't tend to think about death and things, but it's no surprise is it that there's a death and illness and someone has to get it don't they?"

DISCUSSION

It is clear that, while these eight participants have much in common, there are also some significant differences. Consistent with findings from previous questionnaire based studies (Goldstein et al, 2006) the psychosocial consequences of MND appeared significant in the experience of all participants. However, this study has given us a deeper understanding of the way in which spouses experience and respond to the development of MND in their partner. From their claims and concerns, the need to be strong for their partner is evident, as well as their worry for partner's safety.

This suggests how they view their partners as “vulnerable” due to their physical weakness as a result of their condition. Physical tiredness as a result of caring for their partners and uncertainty around the future were also themes in all accounts. However, struggles with anger and frustration were clear in some of the descriptions, but not all.

Some of the participants described the loss of intimacy they were experiencing with their partners, and anxiety around degeneration was touched upon by most. However, explicit conversations around changes to sexual relationships and fear around death of partners were mainly avoided, and participants were evasive or became distressed when questioned further around these subjects. This process highlighted the fact that these sensitive topics are likely to have been important aspects of the participants’ experiences, and may have been discussed more readily with time to build on the researcher-participant relationship. Although more difficult to interpret, process information suggesting avoidance of sensitive but significant issues may alert us to areas for further exploration in future research. It appears that impact on sexual relationship and fear of death may have been areas of concern for these participants, despite their absence in the dialogue.

Experiences of services were varied, although most people described negative experiences around receiving the diagnosis and subsequently felt well-supported by the professionals at the Specialist MND Clinic. A problem-solving approach to practical difficulties appeared to help in coping with the emotional impact around their partners’ deterioration, as well as living from day-to-day. Living from day-to-day as a way of coping with unpredictability and fear of future events has also been evident in other recent research (Allen, Oyebode, & Allen, In press). However, this study highlighted the paradox that people may face when in a situation such as this

one, trying to live from day-to-day at the same time as wanting to make the most of life with their partner.

Participants varied in their ability to adapt to lifestyle changes, and in their ability to remain positive in the face of this challenging life experience. These differences can be understood using Pearlin's caregiver stress model as a framework (Pearlin, Mullan, Semple, & Skaff, 1990). The model describes caregiver stress as a process of interrelated conditions, including the socioeconomic characteristics and resources of caregivers and the primary and secondary stressors to which they are exposed.

Primary stressors are described as problems related directly to caregiving, such as constant tiredness, concerns around safety, and loss of intimacy. Secondary stressors are divided into two categories: the strains experienced in roles and activities outside of caregiving e.g. restricted social life, and intrapsychic strains, involving the weakening of self-concepts. It was evident from some accounts that participants did not wish to identify with being a caregiver. Pearlin et al (1990) describe *role captivity* as an intrapsychic strain that refers to being an unwilling, involuntary incumbent of a caregiver role. They suggest that coping and social support can also influence the stress process at different levels. In summary, although many psychosocial factors seemed to have an important impact on the lives of partners of individuals with MND, it is evident from the findings that a positive experience of receiving the diagnosis may have a great impact on the overall experience. This echoes Pearlin's claims that;

“It is useful to think of Caregiver stress not as an event or as a unitary phenomenon. It is, instead, a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers' health and behavior. The mix is not stable; a

change in one of its components can result in the change of others.” (Pearlin, 1990, pp.9)

Reflections

As Larkin & Griffiths (2004) point out in their study, using Smith’s (1996) IPA framework allowed me to identify the experiential, affective, cognitive, narrative, and discursive fundamentals of the data, whilst exploring the individual experiences of the participants. However, this method also has limitations. Although the results were grounded in the participants’ claims and concerns, the extent to which we can bracket off our own assumptions as a researcher has been a subject of much recent debate. The process of interviewing, analysing and writing up data within an IPA framework should be viewed as a collaborative process with the outcome of a co-constructed narrative around the participants’ experience.

I also want to mention my emotional journey in this research process, which has also been highlighted by others (Lewis, 2008; Hoffman, 2007; Mark, 2005; Gilbert, 2001) as important, due to the influence of emotion when interviewing, analyzing, and theorizing about phenomena and experiences. During each interview, I shared some emotional moments with my participants as they shared their experiences of having a partner with MND. They described their shock around the diagnosis, sadness around loss of intimacy with their partner, frustration around restricted social lives, and fear around deterioration and an awful death. These descriptions stirred up similar emotions in me, which helped me to empathize and connect with the participants, but also may have encouraged me to collude with them in not probing further around defended areas such as their feelings around their partner’s pending death. As McAdams (1998) suggested, participants may use denial, projection,

intellectualization, and other strategies outside their awareness in order to keep anxiety at bay and enhance esteem whilst responding to research questions. As a consequence, it has been highlighted by some that we need to balance our accounts of ‘what informants are saying about the meaning of their experiences’ with ‘interpretations that may or may not conform to what informants have told us.’ (Kidder & Fine, 1998, pp. 48–49).

It should also be noted that the previous conclusions were made based on a relatively brief relationship with the participants involved. Through a process of intersubjective meaning making, the narrative revealed something about how these eight individuals related to having a partner with MND at that particular time, and within the context of the interview process. This study could have been improved by interviewing participants twice, and using data from different sources, e.g. diaries, to further validate their stories. However, the results were shown to participants for feedback on the appropriateness of representation. Overall, participants were happy with the report, and slight adjustments were made to meanings given to a couple of quotations based on their comments.

Clinical Implications

This study has illuminated some important aspects of partners’ perspectives, in relation to caring for an individual with MND. It was also evident that partners of individuals with MND could have very different support needs, despite commonalities in their overall experience. Individual assessment of the needs of those caring for a partner with MND may be vital in order to offer the necessary support and guidance.

From the experiences of most of these individuals, it may be helpful to consider the way in which the diagnosis of MND is delivered, giving people more time to process the news, with more information provision and guidance towards appropriate services. It is also apparent from these accounts that respite is valued by those who are caring for a partner in later stages of MND. I hope that my discussion here will encourage services around people with MND to review the support offered to carers, in particular partners who feel it is their duty to provide care, but struggle to take on the caregiver role.

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APPENDIX 1

Search Strategy

“Attachment ADJ behaviour” OR “attachment ADJ disorders” OR “attachment theory” OR “attachment ADJ security” OR “attachment ADJ style*” (Including studies with keyword being “attachment”)

AND

“Caregivers” OR “Caregiving” OR “carer*” OR “support”

AND

“Couple*” OR “Marital ADJ relations” OR “Partner*” OR “Spous”

Limits:

Articles related to Adults (18 yrs+) and Peer reviewed journal articles

Databases

PsycINFO (1987 – April 2009) – Retrieved a total of 858 papers, and after the limits were added 285 articles were identified, of which 12 were included in the review. References were searched and 1 further paper was identified as relevant and included in the review.

MEDLINE (1996 – April 2009) – Retrieved a total of 1196 papers, and after the limits were added 351 articles were identified. All relevant articles were duplicates from other databases except 1 paper was included in the review. References were searched, but no further papers were identified.

CINAHL (1989 – 2009) - Retrieved a total of 243 and after the limits were added 202 articles were identified. All relevant articles were duplicates from other databases, and no further papers were identified.

Thus a total of (285 + 351 + 202) 838 papers were retrieved, 13 successfully met the criteria for inclusion.

Appendix 2

[Not available in the digital copy of this thesis]

Appendix 3

[Not available in the digital copy of this thesis]

APPENDIX 4: Letter of Invitation

Private and Confidential

(date)

(address)

Dear (name),

Re: The personal experience of carers of individuals with Motor Neurone Disease (MND) and their experiences of services

At your last visit to the MND clinic at the QE hospital, I told you about our research and you mentioned that you might like to take part. The research is about people's experiences of caring for someone with Motor Neuron Disease (MND) and their experiences of services. Please find enclosed an information sheet that explains the study in more detail.

If you would like to take part, please complete the slip at the bottom of this letter and return it to me in the enclosed prepaid envelope. Alternatively I will ring you in two weeks' time to see if you have decided if you would like to take part.

Thank you for your time.

Yours sincerely,

Hayley Smith
Trainee Clinical Psychologist

Yes, I would like to take part in the study to discuss my experiences of caring for somebody with Motor Neuron Disease (MND)

Name: _____

Address: _____

Telephone number: _____



APPENDIX 5

Participant Information Sheet

Study title: The personal experience of carers of individuals with Motor Neurone Disease (MND) and their experiences of services

You are invited to take part in a piece of research investigating experiences of carers of individuals who have received a diagnosis of MND. Before you decide whether you would like to take part it is important that you understand what the research will involve and why it is being conducted. Please take time to read the following information sheet carefully before you make your decision.

What is the purpose of the study?

The purpose of this study is to explore carers' experiences of providing care for an individual with MND. The findings of this study will be published so that they are available to carers of people with MND. The project aims to help health professionals and voluntary services find out more about how to best support carers of people with a diagnosis of MND. This piece of research is part of a doctorate in clinical psychology, undertaken by a post-graduate student at the University of Birmingham.

Why have I been chosen?

This study is investigating the carers' experiences of providing care for individuals with MND and their experiences of services. You have been contacted through the MND clinic at the Queen Elizabeth Hospital because they have identified you as a carer of an individual with a diagnosis of MND.

Do I have to take part?

No, you do not have to take part in this research. If you choose to take part, you will be given a copy of this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time up to two weeks after your interview with the researcher, and you do not have to give a reason. Should you wish to withdraw from the study; any interview data will be destroyed.

What will happen to me if I take part?

You will be interviewed about your experiences by Hayley Smith, Trainee Clinical Psychologist. This interview will be audio-taped, and then transcribed by the researcher, Hayley Smith. Some direct quotes that are pertinent to the study will be included within the final thesis and publication. As a result, for your anonymity, you will be asked to choose a pseudonym. This will ensure that you are not identifiable. The researcher will need to keep a record of your contact details, in order to remain in contact with you throughout the study. These details will only be held by the researcher.

What do I have to do?

You will be required to take part in one interview, lasting approximately one and a half hours, during which you will be asked about your experiences of providing care for your relative and your experiences of services.

What are the possible disadvantages and risks of taking part?

During this interview, you will be asked questions that may prompt emotional memories of a difficult time. This may cause you to feel distressed. If at any point you feel distressed then it is possible to pause or terminate the interview.

What are the possible benefits of taking part?

Talking about potentially distressing events can have a positive effect as it may provide an opportunity to talk about your experiences; something that you may not often have had the opportunity to do.

In addition, you may experience positive feelings from contributing to research that has the potential to provide useful information to others going through a similar experience.

What happens when the research study stops?

Once the interview has been conducted, it will be transcribed by the researcher, and analysed using a process called Interpretive Phenomenological Analysis. This will highlight any themes occurring amongst the interviews. You will be sent a summary of the findings of the study, and will have access to the final publication.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have any complaints, please contact Professor G W Humphreys, Head of School of Psychology, University of Birmingham, Edgbaston, B15 2TT; phone: 0121 414-4931

Will my taking part in the study be kept confidential?

Yes, all the information about your participation in the study will be kept confidential. If you decide to take part, a letter will be sent to your GP to inform him, along with an information sheet about the study. In the case of serious risk to yourself or others, I would need to break confidentiality and contact your GP. All data from the study will be kept for 15 years. Electronic copies of the data will be held by Hayley Smith and Jan Oyeboode at the University of Birmingham. Data files on the computer will be anonymised and password protected. Upon completion of the research, the information will be kept by Jan Oyeboode at the University of Birmingham. Paper records will be destroyed one year after completion of the research.

To obtain independent information or advice about your rights as a research subject or about being involved in this study, please contact, MND Association helpline (known as MND Connect) tel: 08457 626262 or email: mndconnect@mndassociation.org

Contact Details:

Hayley Smith
School of Psychology
Edgbaston
Birmingham B15 2TT
Telephone number 0121-414-4904

Supervisor:

Jan R Oyeboode
Same address University of Birmingham



APPENDIX 6

Consent Form

Title of Project: The personal experience of carers of individuals with Motor Neurone Disease (MND) and their experiences of services

Name of Researcher: Hayley Smith

Please read the following statements and place your initials in each box to say that you understand about the content of the information sheet, your involvement, and that you agree to take part in the above named study.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree for my interview to be audio taped.
4. I agree for verbatim quotations from my interviews to be used in the above study.
5. I agree that my GP will be informed of my participation in the study
6. I agree to take part in the above study.

☐
☐
☐
☐
☐
☐

Name _____ Signature _____ Date _____
 Researcher _____ Signature _____ Date _____
 Name of Person
 taking consent _____ Signature _____ Date _____
 (if different from researcher)



APPENDIX 7

Interview Guide

Study title: The personal experience of carers of individuals with Motor Neurone Disease (MND) and their experiences of services

The interview will be structured around “themes” rather than specific questions

- 1. Coping in general and the forms this takes and changes over time, in relation to relationship with person with MND**
Probes: what were your initial reactions, intensity of loss change/stay the same, life changes and reclaiming, ways to cope helpful/unhelpful, people involved (ie. Resources drawn upon/wish could have drawn upon)
- 2. Family & Social support**
Probes: Details of children and where they live, amount of contact, extended family, friends, leisure activities, religion/spirituality (Intrinsic/extrinsic)
- 3. Diagnosis**
Probes: How do you describe your spouse/partner’s condition? Stage they are at now? Length of time since diagnosis? How did you feel at time? And now?
- 3. Relationship**
Probes: closeness, warmth, examples of this, type of relationship
- 4. Understanding how roles around caring have facilitated/inhibited the relationship with the person with MND**
Probes: determinants of what roles have been taken on, changes in the relationship and feelings towards the person, label of carer (how much of your role do you think is of a carer or something else?)
- 5. Effects on life**
Probes: views about/ ways of coping with caring/ effects of MND, happiest times/most stressful times
- 6. Services**
probes: what has been helpful/unhelpful, recommended changes for ideal service

General Prompt: Can you tell me about a time that this happened? How did that feel?

APPENDIX 8: Example section of transcript

Interview 7

1. I: I'd just like to start by asking you how you cope in general since your
2. husband's diagnosis? *expected worse.*
3. P: A lot better than I expected to, "you just have to get on with things" and in a
low expectations
Bit sadistic /
rich??
looking on the
the side
4. way "you feel quite privileged, you've got the time to make some decisions and
the side of things.
5. have time together" — *privileged*
6. I: Right okay so how long ago was your husband diagnosed?
7. P: In March
8. I: In March this year?
9. P: So it's just six months *← Looking ahead.*
10. I: Six months okay. So you said that you feel you have more time to think
suggests a
long journey
ahead
11. about what you'd like to do with your life? — *control over death*
Assuming
correctly placed
up
12. P: Well yes because if he'd been run over by a bus or something you'd have to
preparation
13. cope with all the trauma, well you wouldn't have had the knowledge. Well it's
knowledge =
paver
time to prepare
& reflect
14. "a gift" really having the time together *→ +ve side again.*
15. I: So how has it been for you since?
16. P: Well quite a roller coaster I suppose because there's so much, "your whole
living in the
here & now
17. view of life changes and your priorities change and you don't look too far
Paradox
able to plan ahead
but (time day
to day)
(change from
planning to
spontaneity?)
18. ahead. You just get on with each day and try and get the best out of it" *→ +ve*
19. I: Mmm and how has your husband been effected by the Motor Neurone?
20. P: Well he's gone swimming today so he's still active. He was very shocked.
less loss
(then expected?)
21. Before he was diagnosed I realised that something wasn't right, but he was
Trying to
support I care,
but hard
Minimising (G77)
know something
not right.
'intuition?'
22. quite sure that it wasn't something serious, so when we heard it really came
overwhelming
23. out of the blue But all things considering he's coped very well because he
Shock of
diagnosis
→
THEME:
Ability to see
positive side
of things.
24. only heard on the Wednesday that he had the disease and he finished work on

25. the Friday, so his whole life completely changed within a few days *change.*
26. I: Was he already planning to finish work?
27. P: Er no do you mean before he heard?
28. I: before he found out yeah
29. P: Er no he would have carried on working for about four more years probably *Impact on their life - having him at home*
30. and when he heard, he thought he'd carry on for a few more months until he'd *Loss?*
31. finished the project that he was on er but he found that he just couldn't
32. concentrate so he was encouraged to go off sick and then he took early
33. medical retirement
34. I: Okay and what does that mean for you?
35. P: Erm well it's changed my life too because whereas before he was never *early retirement for both*
36. here and I was working and now he's here all the time and I've cut back my *THEME: life style changes*
37. work quite a lot to be well not that I need to care for him because he's not at *future prep.*
38. that stage at the moment, but just to be together and support each other and do *Still reciprocal?*
39. the things we would have done normally in our retirement *normal stuff (ive)?*
40. I: Okay so you're feeling like your life hasn't been affected too much in a *normalising*
41. negative way?
42. P: Er well I suppose impact felt negative but then you manage to turn around *focus on the.*
43. your view of things because "you can't wake up every day thinking oh he's
44. going to die soon" and I don't know you just sort of manage to turn the *depersonalised.*
45. (negative into positive) somehow. I think (the human spirit must be quite strong)
46. in the way it manages to deal with things in a different way than you would
47. expect, because I was expecting to be much more tearful or whatever. But no
48. it's difficult to explain, it's almost as if it's happening to somebody else and
49. you're dealing with it in a more (matter of fact) way than you expect
- Pragmatic*
- hiding from the day again*
- "The human spirit" - it's not my husband, it's a higher being*
- emotional distancing*
- "Thank God it's not me"*
- was expecting not to cope*

APPENDIX 9: Example of analysis table

Superordinate theme:	Participants contribution to this theme	Subthemes	Participants contribution to this sub-theme	Key Cross References	Indicative Quotes	Notes
1. Uncertainty around the future	All participants	Unknown life expectancy	Anne, Frank, Emily, Catherine, & Helen	Anne (L10), Frank (L113, 118, 401), Emily (L240), Catherine (L43), Helen, (L91, 132, 323)	“You read into it and then you see the life expectancy and so that’s the problem. So every Christmas you think is this the last Christmas or you know was that the last birthday? You don’t know, although her disease pattern seems quite slow, it doesn’t matter how slow it is once it starts hitting the vitals it doesn’t matter does it?” (Frank)	Maria, Jim and Emily did not talk about their partners’ life expectancy or anything else around the subject of their pending death.
		Uncertainty around how partner will deteriorate and ability to cope	All participants	Anne (L69), Frank (L50), Maria (L180), Jim (L671), Emily (L64, 251, 350), Sue (L25, 380, 476), Catherine (L303), Helen, (L43, 60, 72, 125, 261, 267, 277, 312, 338, 367, 432, 491)	“I imagine that he’ll lose the use of his hands, so that’ll be one, well that’ll be the first disability I imagine and then it’ll be the arm and perhaps the leg. I mean this is how I see it I mean I don’t know as I say I don’t really know that much about it and how it does affect people” (Helen)	This theme was evident in all accounts due to the unpredictable nature of MND. Some participants appeared to find this easier to cope with than others. Sue & Helen showed the most fear.
		Hope for partner being different	Sue and Helen	Sue (L454), Helen (L136, 157, 328, 336)	“In the back of our minds we know basically what’s going to go on, but I think you just sort of tell yourself well everybody’s different and we try and get through it that way” (Helen)	Sue and Helen may have expressed this hope due to their partners being in the early stages of MND.
		Fear of an awful death	Anne, Frank, and Helen	Anne (L146, L375), Frank (L100), Helen (L470)	“It’s a cruel disease. And the fact that it’s so erm progressive (<i>becomes tearful</i>) you know he’s not going to die very nicely is he?” (Anne)	Although the other participants didn’t mention this explicitly, avoidance may have been used as a defence against any difficult emotions this may have evoked.

Appendix 10

[Not available in the digital copy of this thesis]