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HEALTH PSYCHOLOGY | RESEARCH ARTICLE

Psychological distress of female caregivers of significant others with cancer

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Abstract: This study explored the role of time since diagnosis and whether the care recipient was a child, a parent, or a spouse, on caregiver's perceptions of the caring role, with a group of 269 female cancer caregivers. Questionnaire measures were used to explore psychological and social resources and psychological distress. Analysis of variance and hierarchical multiple regression were used and identified significant effects of time since diagnosis and care recipient. This study concludes that a more tailored approach to understanding the needs of caregivers is required particularly in terms of time since diagnosis and care recipient, in order to provide more effective support.

Subjects: Health Psychology; Applied Social Psychology; Positive Psychology

Keywords: cancer; caregiver; support; psychological distress

1. Introduction

Changes in health care delivery, along with improved interventions, which bring longer survival among cancer patients have led to an increase in informal caregiving in the home (Cantwell et al., 2000). The economic benefit of informal caregiving to the health care system is probably incalculable, though estimates suggest that there were approximately 38 million adult caregivers in the US in 2006, contributing an average of 1,080 h each per year, saving the economy a conservative estimate of \$354 billion (Gibson & Houser, 2007). The extent and impact of informal caregiving has led some health authorities to attempt to formalize the role of informal caregivers (Weinberg, Lusenhop, Gittel, & Kautz, 2007), and some have advocated the advantages of involving families in developing

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Tony Cassidy and Marian McLaughlin are research psychologists at Ulster University and work with a group of colleagues and PhD students in applied research with a main focus on children and families. The aim of their research is to inform intervention to build positive health with an emphasis on early intervention and prevention.

PUBLIC INTEREST STATEMENT

Family caregivers save the NHS substantial costs through informal caregiving. In this study, caregivers, who were less satisfied with health services, reported more distress. Caregivers of children reported more support from friends and family. Those caring for a parent reported the highest levels of burden. Those caring for a child reported the highest levels of distress. Support from friends and resilience seemed to alleviate the levels of stress and distress. It also appears that the longer they have been engaged in caring, the less stress and distress experienced for those caring for a child or a spouse. However, the reverse was true for those caring for a parent. The findings would suggest that communication and support from health services need to be improved for caregivers and consideration given to identifying and supporting the needs of specific caregivers.

treatment programs (Martire & Schultz, 2007). The quality of care provided by informal caregivers has a significant impact on outcomes for patients, yet the link between statutory bodies and informal caregivers is generally uncoordinated (Silver & Wellman, 2002). In this context, understanding the impact of caring on informal caregivers is imperative in order to provide the support necessary to ensure the care given is effective. A substantial literature now exists attesting to the heightened burden placed on informal caregivers and its impact on both mental and physical health outcomes (Given et al., 1993; Kurtz, Kurtz, Given, & Given, 1995; Nijboer et al., 1998; Stenberg, Ruland, & Miaskowski, 2010).

The experience of cancer patients in regard to psychological distress has been shown to vary across time (Given et al., 2004; Grbich, Parker, & Maddocks, 2001) and it is, therefore, unlikely that carers' experiences would remain stable. While there is some evidence that the impact on carers varies at different stages following initial diagnosis, the developmental process of caring is often neglected. In their recent review, Stenberg et al. (2010) conclude that more research is needed to understand variations in caregiving experience over time. For example, mothers caring for a child with cancer experienced reduced satisfaction with their marriage and increased symptoms of depression, anxiety, and somatization over time (Yeh, 2002), and other studies have shown that unmet needs of carers varies across perceived stage of cancer development (Foot & Sanson-Fisher, 1995; Sharpe, Butow, Smith, McConnell, & Clarke, 2005).

Considering family caregiving as placing additional demands on the caregiver evokes the explanatory mechanisms of the stress-coping model, within which a substantial literature suggests that coping effectiveness is based on the quality of both psychological and social resources (Cassidy, 2011; Lazarus & Folkman, 1984). There is general consensus in the literature that the key psychological resources are self-efficacy, optimism, and resilience (Cassidy, 2011; Karademas, 2006; Luthans, Youssef, & Avolio, 2007). Pinguart and Sorensen (2003), in a meta-analysis of differences between caregivers and non-caregivers in mental and physical health identified self-efficacy as a key factor. Others (e.g. Atienza, Stephens, & Townsend, 2002; Butow et al., 2014) have identified optimism as a buffer against stress in caregiving. These variables tend to be investigated separately in the caregiving literature, while in the more general stress literature, their interactive and combined effect has been demonstrated (Cassidy, 2011). As discussed above, the role of social support in caring is central and it is also identified in an extensive literature as a key variable in mediating or moderating the stress process (Cassidy, 2011). Arguably, the combination of social with psychological resources should provide a mechanism for explaining the impact of caregiving.

Another area that has been widely researched in regard to patients (Davidson & Mills, 2005; Gilbar & Zusman, 2007; Ong, Visser, Lammes, & de Haes, 2000; Fletcher, Dodd, Schumacher, & Miaskowski, 2008), but largely neglected in regard to carers is the relationship with health care professionals; in particular, the level of satisfaction with information and communication with medical personnel. Patients' positive experience of the relationship with health care professionals has been shown to lead to better mental health, quality of life, adherence to medication, and even to faster recovery (Berry, 2007); it seems plausible that caregivers may experience similar outcomes.

Research on caring tends to focus on specific illness (dementia, cancer) or populations (spouse, child). Informal caring, for the most part, occurs in families and one might expect important differences in experience as a function of the family member who is ill. Research on carers of adults with cancer tends to focus on the type of cancer and focuses on the primary caregiver within the family regardless of the relationship with the patient (Nijboer et al., 1998; Stenberg et al., 2010; Fletcher et al., 2008). Where there is differentiation between patient relations (e.g. between spouse and parent), it tends to be in terms of the general impact of the patient's cancer on the family (Carlson, Ottenbreit, Pierre, & Bultz, 2001; Mosher & Danoff-Burg, 2005; Pitceathly & Maguire, 2003; Resendes & McCorkle, 2006). In addition to being faced with a loved one with a life-threatening illness, the carer is faced with the task of caring for them (Dumont et al., 2006).

A separate and growing literature exists on caring for a child with cancer (Dahlquist, Czyzewski, & Jones, 1996; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; McGrath, 2001; Sloper, 2000). These studies show increased levels of psychological distress and stress-related health problems and reduced well-being in both parents of a child with cancer, but interestingly, some of what little longitudinal evidence exists suggests that distress and health problems reduce and well-being increases particularly for mothers (Dahlquist et al., 1996; Hoekstra-Weebers et al., 2001), and that optimism may be the mediator (Fotiadou, Barlow, Powell, & Langton, 2008). Research suggests the development and acceptance of a new reality (Earle, Clarke, Eiser & Sheppard, 2007), though the process of arriving at this new identity is extremely distressing for mothers (Young, Dixon-Woods, Findlay, & Heney, 2002). The outcome may be the development of a closer and special bond between mother and child (Young et al., 2002).

The literature suggesting that there may be benefits as well as costs fits with a growing body of research on positive psychology, traumatic growth, and benefit finding (Linley & Joseph, 2004; Tennen & Affleck, 2002; Windle, 1999). A number of studies have demonstrated this life re-evaluation and finding of positive meaning in patients with cancer (Bishop, Curbow, Springer, Lee, & Wingard, 2011; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Lechner et al., 2003; McGregor et al., 2004; Sears, Stanton, & Danoff-Burg, 2003; Thornton, 2002; Tomich & Helgeson, 2004), but it has not been widely explored in carers (Kim, Schulz, & Carver, 2007). Bishop et al. (2007) did compare spouses or partners with survivors and controls over 6 years after hematopoietic stem-cell transplantation and found that spouses/partners, while slightly better off than controls, reported lower quality of life than controls.

The brief review above suggests some gaps in knowledge regarding the psychosocial impact of caring for a family member with cancer, gaps, which if filled, would usefully inform interventions to help and support carers in carrying out their important and often vital role in health care delivery. The current study proposes to explore the relationship between burden of caring, psychological resources, (resilience, self-efficacy, and optimism), social resources (support from friends and support from family), satisfaction with medical care, time since diagnosis, and psychological distress.

More specifically to;

- (1) Explore the role of time from diagnosis in relation to psychological and social resources, and levels of perceived stress and psychological distress.
- (2) To explore the experience of carers in regard to communication with health care professionals in terms of their levels of perceived stress and psychological distress.
- (3) To explore differences in experiences of carers in relation to whether their care was given to a spouse, a parent, or a child.

2. Method

2.1. Participants and procedure

Participants ($N = 269$) were recruited through Oncology Clinics in two midland cities in the UK and provided with an information form and a self-report questionnaire consisting of the measures described below. Informal comments suggested that most were quite pleased to be asked to participate and found some satisfaction in being the focus of attention. All participants were female, ranged in age from 19 to 74, were the primary caregiver, and had been caring for the care recipient since diagnosis, a range of 2–30 months. In total, 101 cared for a spouse, 81 for a child, and 87 for a parent. Further demographic distribution is shown below (see Table 1).

Ethical approval was received from a University Research Ethics Committee. Permission was obtained from four hospitals in the UK midlands to visit Oncology Departments and leave questionnaires in return envelopes for caregivers using the clinics. A notice concerning the study was

Table 1. Sample demographics

		Relationship of care recipient		
		Spouse	Child	Parent
Time since diagnosis	0–6 months	33	15	19
	7–12 months	13	15	24
	13–24 months	12	17	22
	25 months plus	43	34	22
Age–Mean (SD)		50.3 (11.2)	33.1 (8.6)	36.8 (9.6)

displayed in the waiting room and questionnaire packs were displayed on a table for caregivers to collect if they wished to participate. Questionnaire packs were presented in return envelopes with an information sheet attached to the outside of the envelope. The information sheet explained the purpose of the research and that participation was voluntary and without implication for the caregiver or their patient. It also specified that the research was targeting caregivers and the readers were asked to take and pass on additional questionnaires to anyone they knew who was a caregiver for a patient with cancer. A consent form was attached to the front of the questionnaire and participants were asked to complete a tickbox to indicate their consent. The consent form was returned with the questionnaire in the stamped and addressed envelope provided. Over a period of 10 months, 500 questionnaires were provided and a total of 273 were returned completed. Only four male caregivers responded and these were removed leaving a cohort of 269 females. Since the number of people who attended during the 10 months is not known, an accurate response rate cannot be calculated.

2.2. Measures

The Burden and Perceived Burden Scale: This was a measure based on a list of 19 tasks ranging from physical aid (lifting, helping to walk) through intimate personal care (bathing, washing, toileting) to emotional care (comforting, dealing with emotional outbursts). The list was derived from structured interviews used in other studies and from discussions of caring tasks with carers (Cassidy, 2012). The list was presented with two response sets. Firstly, participants were asked to rate on a three-point scale (never, sometimes always) how often they carried out each task, and secondly, to rate on a four-point scale (not at all to extremely) how stressed they felt when carrying out each task. This allowed two measures to be produced, burden ($\alpha = .78$) and perceived burden ($\alpha = .87$).

The Life Orientation Test (LOT) (Scheier & Carver, 1985) was used to assess both optimism and pessimism. The LOT consists of four positively worded items measuring optimism, four negatively worded items measuring pessimism, and four filler items. The factor-analyzed LOT therefore has two subscales, each measuring a separate factor; optimism, and pessimism, and each four items. The items on the LOT are rated on a five-point fully anchored Likert scale, ranging from 0 (strongly disagree) to 4 (strongly agree). In the current study, reliability coefficients (Cronbach’s α) were .78 for optimism and .72 for pessimism.

The Brief Resilience Scale (BRS) (Smith et al., 2008) is a six-item self-report instrument, which measures the ability to bounce back from stress on a Likert scale from 1 = Strongly Disagree to 5 = Strongly Agree. The BRS is scored, so that a higher score indicates more resilience. It demonstrated good internal consistency and test-retest reliability (Smith et al., 2008) and in this study, internal consistency was $\alpha = .91$.

The Perceived Stress Scale—10 item (Cohen & Williamson, 1988) is a 10-item measure of the degree to which one perceives aspects of one’s life as uncontrollable, unpredictable, and overloading.

It was developed from the Cohen, Kamarck, and Mermelstein (1983) 14-item perceived stress scale (PSS), which was based on Lazarus's theory of stress appraisal (Lazarus & Folkman, 1984). Internal consistency of the items was strong ($\alpha = .86$). The scale is scored on five points from 0 to 4 reflecting categories of never, almost never, sometimes, fairly often, and often.

The Generalized Self-Efficacy Scale (GSES) (Schwarzer, 1992) is a 10-item measure of the self-efficacy concept proposed by Bandura (1977). It reflects an optimistic self-belief in various domains of human functioning. Each item refers to successful coping and implies an internal stable attribution of success. Cronbach α in this study was .87. The scale is scored on four points from 1 to 4 using the categories not at all true, barely true, moderately true, and exactly true.

The Medical Interview Satisfaction Scale (MISS-21) (Meakin & Weinman, 2002) is a 21-item British version of the original scale devised by Wolf, Putnam, James and Stiles (1978) in the USA. The scale was devised for use with patients and items were reworded in this study, so that they were relevant to a carer. It measures four factors in regard to how satisfied the person is with their interactions with health professional. These are distress relief, communication comfort, rapport, and compliance intent. The scale is scored on a five-point Likert scale, from strongly agree to strongly disagree. In this study, the scale produced an overall Cronbach α of .92. Individual factor alphas ranged from .67 to .90.

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

The General Health Questionnaire (GHQ-12: Goldberg, 1972, 1978) is a widely used measure of psychological distress and is comprised of 12 questions, each of which is rated on a four-point scale. At the time of completing the GHQ-12, the participants were asked to consider how they had been feeling over the past month. In terms of scoring the GHQ-12, there are two methods. Likert scoring assigns a score (0-1-2-3) in response to each of the 12 questions, which makes for a maximum total score of 36. The GHQ method or clinical method, which was used in this study, involves allocating scores of 0 and 1. The first two responses indicate the absence of a symptom and are allocated a 0, while the second two answers indicate the presence of a symptom and are allocated a 1, which makes for a maximum total score of 12. A reliability coefficient of .78 was calculated in this study. There have been numerous psychometric studies of the GHQ-12, which show that it measures a number of factors but can equally be used as a unified measure (Campbell, Walker, & Farrell, 2003; Kalliath, O'Driscoll, & Brough, 2004; Shevlin & Adamson, 2005). There have been numerous studies demonstrating the reliability and validity of the GHQ12 in a range of social surveys with different ages and cultural groups (Hardy, Shapiro, Haynes, & Rick, 1999; Henkel et al., 2003; Ip & Martin, 2006; Penninkilampi-Kerola, Miettunen, & Ebeling, 2006; Tait, French, & Hulse, 2003) and all support the construct, discriminant, and predictive validity of the measure. For example, Makowska, Merecz, Moæcicka, and Kolasa (2002) compared the GHQ-12 and the GHQ-28 on five validity indicators: sensitivity, specificity, overall misclassification rate, and positive and negative predictive values. Both versions of the GHQ performed well, but the GHQ-12 performed better on all measures.

3. Results

Using the clinical scoring of the GHQ-12, 64.7% of the total sample was identified as exhibiting symptoms of clinical disorder sufficiently severe to indicate a potential need for intervention, this breaks down to 65% of those caring for a spouse, 66% of those caring for a child, and 43% of those caring for a parent.

Table 2. Correlations and descriptive statistics for study variables (controlling for age)

	Mean (SD)	2	3	4	5	6	7	8	9	10	11
1. Burden of care	3.9 (1.6)	.78**	-.00	-.37**	-.21**	-.16**	-.12	-.32**	.43**	.21**	-.10
2. Perceived burden	4.0 (1.4)		-.10	-.31**	-.31**	-.23**	-.09	-.24**	.54**	.19**	-.09
3. Support from family	17.1(7.2)			.26**	.23**	.12*	.13	.23**	-.10	-.12*	-.11
4. Support from friends	15.7 (5.0)				.20**	.36**	.32*	.71**	-.24**	-.34**	-.16**
5. MISS	4.5 (0.8)					.08	.07	.15*	-.14*	-.23**	.08
6. Self-efficacy	2.5 (0.8)						.31**	.26**	-.26**	-.51**	-.11
7. Resilience	2.9 (0.8)							.25**	-.24**	-.50**	-.10
8. Optimism	11.1 (2.2)								-.12*	-.26**	-.33**
9. Perceived stress	7.6 (2.4)									.37**	-.21**
10. Psychological distress	15.6 (7.9)										-.22**
11. Time since diagnosis (Mths)	22.5 (17.9)										

* $p < .05$ (2-tailed).

** $p < .01$ (2-tailed).

*** $p < .001$ (2-tailed).

Descriptive statistics and correlations between variables were calculated and are shown in Table 2. As those caring for a spouse were older than either of the other groups, age was controlled for in the analysis. Many of the correlations are not surprising and support the transactional model of stress. Perceived stress correlates significantly with psychological distress as measured by the GHQ12, with support from friends but not with support from family, with self-efficacy, with overall satisfaction with health care relations, and with time since diagnosis (using the actual time, rather than the categories). Psychological distress correlates significantly with support from friends and with support from family, with self-efficacy, with medical interview satisfaction (MISS), and with time since diagnosis.

Since one aim was to explore differences in experience in terms of the categories of care recipient, the next analysis involved one-way ANOVAs (see Table 3). Given the number of pairwise comparisons, a Bonferroni correction was used to control for family-wise type-1 errors.

Main effects were observed for the category care recipient on burden of care ($F(2, 266) = 5.06, p < .01$), perceived burden of care ($F(2, 266) = 10.51, p < .001$), MISS ($F(2, 266) = 3.73, p < .05$), support from family ($F(2, 266) = 8.42, p < .001$), support from friends ($F(2, 266) = 4.05, p < .05$), perceived

Table 3. Main effects, effect sizes, and post hoc comparisons from ANOVA

Variables	Spouse	Child	Parent	F-value	Partial n^2	Spouse vs. child	Child vs. parent	Spouse vs. parent
	Mean (SD)	Mean (SD)	Mean (SD)					
Burden of care	3.85 (1.65)	3.64 (1.48)	4.28 (1.63)	5.06**	0.12	ns	**	**
Perceived burden	4.47 (1.40)	3.48 (1.44)	4.23 (1.29)	10.51***	0.17	**	***	ns
Medical interview satisfaction	3.90 (0.79)	5.19 (1.17)	4.05 (0.55)	3.73*	0.09	*	*	ns
Support from family	14.19 (6.01)	18.93 (6.79)	19.18 (7.29)	8.42***	0.18	***	ns	***
Support from friends	14.65 (4.91)	15.98 (5.21)	16.17 (4.74)	4.05*	0.11	*	ns	*
Perceived stress	8.24 (2.37)	7.32 (2.13)	7.22 (2.52)	4.29**	0.10	**	ns	**
Psychological distress	14.32 (4.79)	16.21 (3.83)	14.74 (5.36)	11.15***	0.21	***	***	ns

* $p < .05$.

** $p < .01$.

*** $p < .001$.

ns = not significant.

stress ($F(2, 266) = 4.29, p < .01$), and psychological distress ($F(2, 266) = 11.15, p < .001$). Those caring for a parent scored significantly higher on burden of care than either of the other groups, while those caring for a child scored significantly lower on perceived burden of care than either of the other groups. Those caring for a child reported significantly higher scores on the MISS than either of the other groups. However, the overall mean on the medical interview satisfaction scale (MISS) in this sample ($M = 4.5, SD = 0.5$) was lower than the mean reported by the scale authors [21], which was

Table 4. Hierarchical multiple regression with psychological distress and perceived stress as dependent variables in separate HMRA

Dependent variable = Psychological distress						
Predictor	Parent		Child		Spouse	
	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step 1	.18***		.01		.19***	
Burden		.17		.11		.34***
Perceived burden		.67***		.15		.44***
Step 2	.07***		.12**		.08***	
Support from family		-.11		-.11		-.19*
Support from friends		-.32***		-.32***		-.23**
Step 3	.26***		.20***		.05***	
Resilience		-.53***		-.50***		-.29***
Optimism		-.03		-.01		-.13
Self-efficacy		-.14		-.22*		-.10
Step 4	.02***		.06***		.10***	
MISS		-.21*		-.24*		-.37***
Step 5	.00		.03***		.11***	
Time since diagnosis		-.18*		.37***		.43***
Total R^2	.54***		.42***		.53***	
n	87		81		101	
Dependent variable = Perceived Stress						
Predictor	ΔR^2	β	ΔR^2	β	ΔR^2	β
Step 1	.21***		.03		.25***	
Burden		.23*		.14		.37***
Perceived burden		.47***		.12		.48***
Step 2	.11***		.14**		.06***	
Support from family		-.16		-.18*		-.17*
Support from friends		-.22***		-.36***		-.20**
Step 3	.21***		.18***		.09***	
Resilience		-.46***		-.44***		-.33***
Optimism		-.05		-.18*		-.11
Self-efficacy		-.12		-.20*		-.10
Step 4	.04***		.08***		.10***	
MISS		-.25*		-.29**		-.37***
Step 5	.00		.09***		.09***	
Time since diagnosis		-.19*		.44***		.40***
Total R^2	.57***		.52***		.59***	
n	87		81		101	

* $p < .05$.
 ** $p < .01$.
 *** $p < .001$.

($M = 5.6$, $SD = 0.7$). A one-sample t -test shows that the difference is significant ($t(268) = -34.4$, $p < .001$). Those caring for a spouse reported significantly less support from family and from friends than either of the other groups. Those caring for a spouse exhibited significantly higher levels of perceived stress than either of the other groups, while those caring for a child reported significantly higher levels of psychological distress than either of the other groups.

In order to test the stress model and identify the impact of time since diagnosis and care recipient more clearly, hierarchical multiple regression analysis was used with psychological distress and perceived stress as dependent variables on separate steps and controlling for care recipient by using it as the selection variable. Age of caregiver was also controlled for, but did not have any impact. The results are shown in Table 4.

In the analysis, burden and perceived burden were entered in step 1, as the stress model would suggest there would be a direct relationship between these variables and the outcome measure of psychological distress. Support from friends and family were entered in step 2, as they have been established as mediators in the stress process. The psychological resource factors of resilience, optimism, and self-efficacy were entered in step 3. The role of MISS as a potential mediator was tested by entering it in step 4. Finally, the possible impact of time since diagnosis was tested in step 5.

Between them, these variables accounted for 54% of the variance in psychological distress and 57% of the variance in perceived stress for those caring for a parent, 42% of the variance in psychological distress and 52% of the variance in perceived stress for those caring for a child, and 53% of the variance in psychological distress and 59% of the variance in perceived stress for those caring for a spouse. The amount of variance accounted for varies at each step across those caring for a parent, child, or spouse. The variables accounting for significant portions of the variance in those caring for a parent were; perceived burden, support from friends, MISS, and time since diagnosis. For those caring for a child, the significant variables were support from friends, resilience, self-efficacy, MISS, and time since diagnosis. For those caring for a spouse, the variables were burden, perceived burden, support from family, support from friends, resilience, MISS, and time since diagnosis. Actual burden and support from family only had a significant relationship for those caring for a spouse.

The different patterns of relationship indicated by the beta values provide support for looking at the recipients of care separately. The direction of relationship between the variables and distress was consistent across the three categories of care recipient except for time since diagnosis. The relationship for those caring for a parent was negative, while for the other two groups, it was positive.

4. Discussion

Before discussing the specific findings in relation to the aims and hypothesis, it is important to state that levels of psychological distress in this sample were significantly higher than population norms and a large percentage (64.7%) were exhibiting clinical levels of distress. In addition, the overall mean score on MISS as measured by the MISS was significantly lower in this group than in the normative sample (Wolf et al., 1978), indicating significantly less satisfaction across the current sample of caregivers. MISS measures satisfaction with communication; and interaction with health care professionals and caregivers will have high levels of both. It is not surprising that low levels of dissatisfaction coexist with high levels of psychological distress, and while not possible to test in this data, may very well imply a causal relationship. It is also quite possible that the self-selecting nature of the sample reflects a higher proportion of dissatisfied participants.

The importance of considering who the person is caring for in understanding the impact of caregiving is generally supported by the findings. Highest levels of burden were reported by those caring for a parent, while lowest levels of perceived burden were reported by those caring for a child.

This might be explained in terms of role expectations. A mother expects to care for a child, but is less prepared to care for a parent. In the latter case, role reversal is experienced. Again the lowered levels of support from family and friends, and the higher levels of perceived stress, for those caring for a spouse might also be related to role expectations. A spouse might be the main source of family support and support is a well-established moderator of stress. Those caring for a child reported more satisfaction with medical support although it was still less than one might expect in the general population. Overall, those caring for a child also reported higher levels of psychological distress, which seems to accord with intuition.

The importance of considering time since diagnosis is indicated initially in the correlations with psychological distress, perceived stress, and optimism, suggesting that both distress and stress increase, while optimism decreases with time since diagnosis. However, the correlations with distress and stress are smaller than would be expected, which is probably explained from the HMRA analysis which shows an inverse relationship between distress and time since diagnosis for those caring for a parent. This indicates that while distress does increase for those who have been caring longer for a child or a spouse, it may actually decrease for those caring for a parent. In fact, distress is likely to fluctuate a great deal with time since diagnosis.

The utility of considering the impact of caregiving in terms of a stress model is illustrated from the HMRA, which provides general support for a relationship between caregiving demands (burden and perceived burden), social support, psychological resources (particularly resilience), and psychological distress. In addition, it suggests that satisfaction with medical care and time since diagnosis might usefully be added to the model.

5. Limitations and future directions

The main limitations of the study were (a) it was cross-sectional and (b) it lacked any qualitative data. In future, the inclusion of qualitative interviews either as part of a mixed methods approach or as a separate study would allow more in-depth analysis of the experiences of caregivers. Furthermore, a longitudinal approach would enable more definite conclusions to be drawn than the more tentative ones drawn here in terms of the cohort sequential analysis. The current sample were all female because very few males responded, but there is a need to include males and in the case of children, to include both parents. On the other hand, most carers are female, and as indicated, the stress of caregiving is generally more severe for them. One could argue that understanding the impact and related variables in a female sample will give a better steer to supporting the work they do. However, there is also a comprehensive literature attesting to gender differences in health and health needs, which limits any generalization from these findings to male carers. The sample was self-selecting, in that individuals could choose whether to participate. Information is not available on those who chose not to complete questionnaires, so it is not possible to comment on response rates.

6. Conclusion and recommendations

Given the important role played by caregivers in health care delivery, understanding how best they may be supported is essential. This study indicates that the caring process needs to be considered developmentally, as the changes indicated in outcomes surely belie differential needs that can be the focus of support. In addition, the relationship between the caregiver and care recipient is important in identifying needs and consequences. The study indicates a need to consider the relationship between the caregiver and formal health care, with a particular focus on providing better coordination. It is not possible to make strong recommendations about psychosocial interventions from this study, but what can be said is that any intervention needs to be sensitive to the developmental phase of caregiving over time, to the relationship with the recipient of care, and to consider the interaction between the caregiver and formal health care.

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Competing Interests

The authors declare no competing interest.

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