Problem behaviour, caregiver reactions, and impact among caregivers of persons with Alzheimer’s disease

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Background. Problem behaviours that occur during Alzheimer’s disease (AD) can have major impact on caregivers. How caregivers react to these behaviours may determine the total impact experienced from caregiving.

Purpose. This study examined the relationships between problematic behaviours and caregiving impact in 30 primary caregivers of persons with AD. The first question explored the relationship between frequency of problem behaviour and impact; the second explored the relationship between caregiver reactions to problem behaviours and impact from caregiving.

Methods. The frequency of problem behaviour and the caregiver reaction was measured using The Revised Memory and Behaviour Problem Checklist (Teri et al. 1992). The impact from caregiving was operationalized using the Cost of Care Index developed by Kosberg and Cairl (1986).

Results. Significant associations were found for 11 of the 20 subscales that measured the association between the frequency of problem behaviour in the client and the impact from caregiving experienced by the caregiver. In comparison, the association between caregiver’s reaction to problem behaviours and impact from caregiving was even more significant in value with 15 subscales of 20 being significant. Female caregivers experienced a greater reaction to disruptive and depressive behaviour when compared with male caregivers even though both genders reported similar frequencies of problem behaviours. In regard to findings about the impact from caregiving, four of the six indicators were higher for women than for men.

Conclusions. Caregiver reaction to problem behaviours was more highly associated with impact from caregiving than the actual frequency of the behaviours. These findings have great implications for intervention programs. Caregivers, especially females, need to receive individualized, specific education/training on how to understand and manage disruptive and depressive behaviour in persons with AD.
Keywords: dementia, behaviour problems, interventions, caregiver, reaction, impact, burden, Alzheimer's Disease

Introduction

The incidence of Alzheimer’s disease (AD) has been reported by Evans et al. (1989) to increase as persons age; with 10% of persons aged 65 and approximately 50% of persons over 80 currently thought to have AD. The impact involved in caring for persons with AD has been placed mainly on families (Cornman & Kingson 1996). Snow (1996) reported that seven of 10 persons with AD are cared for at home. Caregiver distress has been well documented in the literature and reviews indicated prolonged consequences of poor physical and emotional health (Schulz et al. 1995, Schulz & Beach 1999).

The study

Purpose

Problem behaviour has been reported to be the most stressful aspect of caregiving (Coen et al. 1997, Payne & Caro 1997) and contributes to increased burden for caregivers. Problem behaviours can have major impact on caregivers. How caregivers react to these behaviours may determine the total impact experienced from caregiving. The purpose of this study was therefore to examine the relationships between specific types of problematic behaviour and the total impact experienced from caregiving. Little is known about the impact of specific problem behaviours on caregivers (Davis et al. 1997).

Literature review

Elders’ problem behaviours have become an important area of study. Research on behavioural problems has taken three directions: (a) Identifying behaviours peculiar to AD (Pruchno & Resch 1989a), (b) Determining how to best manage the problems (Matteson et al. 1996), and (c) Focusing on caregiver reaction to problem behaviour (Dunkin & Anderson-Hanley 1998). Research and practitioners have identified a number of problem behaviours related to AD. These include paranoid and delusional ideation, hallucinations, aggressiveness, affective disorders, and problems with activities of daily living (Pruchno & Resch 1989a). Certain troublesome behaviours are thought to be related to specific stages of AD, for example, wandering is associated with the second stage (Reisberg et al. 1993). After identification of the different types of problem behaviour, the focus of research has turned to how to manage or reduce the frequency of the behaviours. Past management approaches have often followed the medical model of care with the use of physical and chemical restraints. Research on such practices has demonstrated that both types of restraints are associated with increased injuries, falls, agitation, and disorientation (Miles & Irvine 1992, Blazer 1993). While there is much clinical information about symptom management, few controlled studies have tested behavioural interventions (Burgio 1996, Matteson et al. 1996). One exception is the caregiver training intervention designed to increase the caregiving family’s competence in managing troublesome behaviours based on a progressively lowered stress threshold model (PLST). This PLST intervention decreased depression in family caregivers (Gerdner et al. 1996). Other similar intervention studies are needed (Braithwaite 1996).

As frequency of specific problem behaviours is strongly dependent on patient illness factors, frequency of problem behaviour may not be easy to modify. To the extent that caregivers perceive certain behaviours as negative because these behaviours interfere in daily household activities, then behavioural interventions that allow the caregiver to understand and thus master these behaviours are likely to be extremely promising in reducing the perception of negative caregiver impact (Welleford et al. 1995). Thus, caregiver reaction to these problem behaviours is still another interesting area of study. The conceptual framework for the present study comes out of this area of research. Several studies were found that focused on the interaction between the caregiver and person with AD. In a study of 58 memory-impaired individuals observed during caregiving episodes, Burgener et al. (1992) found that several aspects of the person’s behavioural responses, including agitated behaviours and self-care ability, were positively related to a variety of caregiver behavioural approaches, including the caregiver’s calm and person-centred behaviours. Calm, person-centred behaviours of the caregiver decreased agitated behaviours and increased self-care abilities. In another study, the complex nature of feeding a person with AD was explored by Ort and Phillips (1992). Persons with AD judged by caregivers as not able to feed themselves were actually able to do so under the right circumstances. With adequate caregiver support the person revealed a hidden ability previously not realized. This capability indicated it is important that caregivers recognize the difference between partial and total dependence and not create excess disability by doing too much for the person with AD (Osborn & Marshall 1992, 1993). This area of research is of great importance because much difference exists among caregivers in how they adapt to the demands of caregiving.
Recent research suggested that caregiver variables are important determinants of when the person with AD is institutionalized (Cohen et al. 1993). AD persons living with highly distressed caregivers exhibited increased frequency of behavioural problems and agitation when compared with those living with less stressed caregivers. Caregivers’ level of distress was found to have a significant effect on the course and symptoms of dementia (Dunkin & Anderson-Hanley 1998). Caregiver inappropriate reaction to the problem behaviours may increase the frequency and severity of problem behaviours, thus also increasing the impact from caregiving and the ultimate outcome for the person with AD being able to stay out of a nursing home/or institution. Teaching caregivers how their reaction will help to manage/treat problem behaviours has the potential to avert or postpone institutionalization (Payne & Caro 1997).

The literature is confusing with regard to the association between gender and impact from the caregiving experience. Impact is defined as the actual consequences experienced from caring for an impaired person. Female caregivers usually have reported greater caregiving impact than men. Caregiver gender was found to influence strain in family relationships and decline in caregiver health (Barber & Pasley 1995). Similar findings were reported in Sweden (Almberg et al. 1998). Data thought to be important in understanding the caregiver outcome of depression was analysed by Schulz and Williamson (1991) in a 2-year longitudinal study of persons in the mild to moderate stages of AD (n = 174) and their caregivers not residing in an institution. Positive relationships between caregiver depression and the number of patient behavioural problems, negative social support, and financial concerns were found, as well as negative relationships between depression and social support, quality of the prior relationship and satisfaction with social contacts. In regard to gender, female caregivers were significantly more depressed than male caregivers, a finding supported by other researchers (Pruchno & Resch 1989b). In summary, one finding that appears consistently in comparative gender studies is that women caregivers experience worse emotional health outcomes than their male counterparts (Grafstrom et al. 1992, Barber & Pasley 1995, Jansson et al. 1997, Hooker et al. 2000).

The current correlational study of caregivers of persons diagnosed with AD was designed to investigate relationships among the variables of frequency of problem behaviours, caregiver’s reactions to these problem behaviours, impact from caregiving, and gender. In this study problem behaviours were operationalized in terms of memory loss, depressive symptoms, and disruptive behaviours. Each behaviour was scored on both frequency of occurrence and caregiver reaction. Other research measuring problem behaviours in dementia has been criticized (Davis et al. 1997) because studies have most often used composite scores reporting only the sum of two scales (total frequency of behaviour and total reaction to problem behaviour). A strength of the current study is that separate scores for the three frequency and three reaction subscales are reported.

Research questions

This study was designed to answer the following questions:

- What is the relationship between frequency of problem behaviour in the client with AD and impact from caregiving experienced by the caregiver?
- What is the relationship between the caregiver’s reaction to the problem behaviour and impact experienced from caregiving?

Method

Sample

A convenience sample of 30 persons caring for family members diagnosed with Alzheimer’s disease and related dementia (ADRD) was interviewed in their homes. Sociodemographic data (see Table 1) identified that caregivers’ age ranged from 26 to 87 years of age (M = 66.5, SD = 18.1). Most of the caregivers were of Caucasian origin (93.3%), female (76.7%), and wives (56.7%). Their average number of years spent in caregiving was 4 years with a range of 6 months to 15 years (M = 4.17, SD = 2.83). The majority of the caregiver sample was retired or not employed (86.7%). Eighty-six per cent reported their relative’s illness was not placing a financial burden on them. A large percentage had graduated from high school (73.4%), while some had graduated from college (26.7%), and attended graduate school (6.7%). Care recipients’ age ranged from 62 to 96 years (M = 78.5, SD = 7.85). Eighty per cent of persons were reported to be in the middle stage of their disease.

Procedure

Persons caring for a family member diagnosed with AD were recruited through caregiving programmes, chapters of the AD Association, home health agencies, church newsletters, and senior citizens centres surrounding a large metropolitan area in the southern part of the Midwest. Subjects were contacted by phone in order to validate their role as a caregiver for a family member with AD and to invite them to participate in the study. A time was scheduled for an interview in the caregiver’s home with those who volunteered to participate.
Table 1 Characteristics of caregivers and care receivers

<table>
<thead>
<tr>
<th>Sample of characteristics</th>
<th>Number (%)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver’s (CG) age</td>
<td>30</td>
<td>68.9</td>
<td>13.23</td>
</tr>
<tr>
<td>Care receiver’s (CR) age</td>
<td>30</td>
<td>78.5</td>
<td>7.85</td>
</tr>
<tr>
<td>Caregiver’s gender, female</td>
<td>23 (76.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver’s gender, male</td>
<td>7 (23.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship of CG to CR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>6 (20.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>17 (56.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>2 (6.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>4 (13.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter in Law</td>
<td>1 (3.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers employed, Yes</td>
<td>4 (13.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers employed, No</td>
<td>26 (86.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. years CG cared for CR</td>
<td>4.17</td>
<td>2.83</td>
<td></td>
</tr>
<tr>
<td>Financial strain of CG</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>From caring for CR: Yes</td>
<td>4 (13.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>From caring for CR: No</td>
<td>26 (86.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education competed by CG</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 7th grade</td>
<td>1 (3.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Junior high school</td>
<td>1 (3.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eleventh grade or less</td>
<td>3 (10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school graduate</td>
<td>5 (16.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial college</td>
<td>10 (33.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>8 (26.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate school</td>
<td>2 (6.7)</td>
<td></td>
<td></td>
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</tbody>
</table>

Instruments

We were guided in our choice of measures by the model of caregiving dynamics described earlier related to caregiver reaction to problem behaviour (Welleford et al. 1995). In addition to demographic variables of the caregiver, measures were used which represented the frequency of the family member’s problem behaviours, the caregiver’s reaction to problem behaviours, and the impact on the caregiver’s life experienced from the problem behaviours. A total of two instruments were used to measure these variables. The psychometric properties of the measures are described.

Problem behaviour and caregiver reaction

The variables of problem behaviours and caregiver reactions were studied by asking caregivers to respond to The Revised Memory and Behaviour Problem Checklist (RMBPC) developed by Teri et al. (1992). The RMBPC instrument is a 24-item caregiver-report measure of the frequency of and reaction to behavioural problems exhibited by the family member diagnosed with AD or a related disorder. Three subscale scores and one total score are provided for indicators of behaviour problems related to memory loss, depression, and disruption; additionally, corresponding measures are reported for caregiver reaction to these three types of problems.

The RMBPC Likert-type scale allowed the researcher to have caregivers rate their impaired family member’s frequency of behaviour problems as: 0 = never occurs, 1 = occurs frequently, but not in the past week, 2 = occurred 1–2 times in the past week, 3 = occurred 3–6 times in the last week, 4 = occurs daily or more often. Caregiver reaction to care recipient’s behaviour problems were scored by the degree to which the behaviours ‘bothered or upset’ the caregiver: 0 = not at all, 1 = a little, 2 = moderately, 3 = very much, and 4 = extremely.

Overall scale reliability for the RMBPC was reported by Teri et al. (1992), with total alpha scores of 0.84 for frequency of behaviour problems and 0.90 for corresponding caregiver reaction. The authors reported subscale alpha scores ranging from 0.67 to 0.89. Cronbach α scores were reliable for the current study as evidenced by summary alpha scores of 0.81 for frequency of problem behaviours and 0.87 for caregiver reaction to problem behaviours. Subscale α scores ranged from 0.69 to 0.86.

Instrument validity was confirmed via comparison of the RMBPC scores to well-established indices of care recipient depression (the Hamilton Depression Scale, Hamilton 1967), care recipient cognitive functioning (Mini-Mental State Exam, Folstein et al. 1975), caregiver depression (Center for
Epidemiological Studies-Depression Scale, Radloff 1977), and caregiver burden (Caregiver Stress Scale, Deimling & Bass 1984).

Impact from caregiving

The variable of impact from caregiving was operationalized by Kosberg and Cairl (1986). The Cost of Care Index (CCI) was based on a review of the caregiving literature and was designed to assess the potential and actual consequences of caring for elderly impaired persons by informal care providers. Five dimensions of impact were identified involving: caregiver’s perceived value of providing care to an impaired family member, caregiver’s personal and social restrictions, caregiver’s physical and emotional health, characteristics of the impaired care recipient that may provoke the caregiver, and economic costs involved in caregiving. The CCI was developed from these operational definitions.

Caregivers were asked to respond to 20 questions on the CCI instrument by choosing one of four responses that had corresponding numerical values of one to four: Strongly Disagree (1), Disagree (2), Agree (3), and Strongly Agree (4). Low scores of 20 were considered ‘low impact’, while the closer the score came to 80 the ‘higher the impact’ from caring, as conceptually applied in this study.

Kosberg and Cairl (1986), calculated a coefficient of 0.91 for the CCI, which was the same total α score (0.91) found for the tool in the current study. Subscale α scores ranged from 0.69 to 0.87 for the five subscales. The CCI instrument was found to have high internal consistency.

Data analysis

Pearson product moment correlations and Spearman rank-order correlational coefficients were performed to test the research questions. In order to determine whether differences existed in the variables according to gender, individual t-tests were conducted. In order to answer the first research question, frequency of problem behaviours was correlated with impact from caregiving; for the second question, caregiver reaction to problem behaviours was correlated with impact from caregiving. Results of total impact scores are presented along with subscales to provide a complete summary of all the data.

Power analysis

The determination of the appropriate sample size for this study anticipated that the correlations found in Research Questions 1 and 2 in the present study would be comparable with the correlation found between reaction and caregiver burden in Teri et al. (1992). A sample size of 28 caregivers would yield 80% power for detecting a correlation as large as 0.50 using the 0.05 level of significance (Cohen 1988).

Ethical considerations

The study was approved by the human subjects committee. All caregivers signed consent forms informing them they were participating in research.

Findings

Description of characteristics related to variables

The general characteristics of the main variables of interest are first described (Table 2) followed by the findings related to gender. The results from the research questions are presented last (Tables 3 and 4).

<table>
<thead>
<tr>
<th>Table 2 Description of variables</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Variable</strong></td>
</tr>
<tr>
<td>Care recipient</td>
</tr>
<tr>
<td>Impairment</td>
</tr>
<tr>
<td></td>
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<tr>
<td></td>
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<tr>
<td>Caregiver reactions</td>
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<tr>
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<td></td>
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<tr>
<td>Impact of caregiving</td>
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</tbody>
</table>
Table 3  Correlation matrix: frequency of problem behaviours and impact from caregiving

<table>
<thead>
<tr>
<th>Variables from impact</th>
<th>Dependent variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total impact</td>
</tr>
<tr>
<td><strong>Independent variables</strong></td>
<td></td>
</tr>
<tr>
<td>Patients' frequency of problem behaviours</td>
<td></td>
</tr>
<tr>
<td>Frequency memory loss</td>
<td>0.46*</td>
</tr>
<tr>
<td>Frequency depression</td>
<td>0.45*</td>
</tr>
<tr>
<td>Frequency disruption</td>
<td>0.41*</td>
</tr>
<tr>
<td>Total frequency</td>
<td>0.63**</td>
</tr>
</tbody>
</table>

*P < 0.05; **P < 0.01.

Table 4  Correlation matrix: reaction to problem behaviours and impact from caregiving

<table>
<thead>
<tr>
<th>Variables from impact</th>
<th>Dependent variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total impact</td>
</tr>
<tr>
<td><strong>Independent variables</strong></td>
<td></td>
</tr>
<tr>
<td>Caregiver’s reaction problem behaviours</td>
<td></td>
</tr>
<tr>
<td>Reaction memory loss</td>
<td>0.64**</td>
</tr>
<tr>
<td>Reaction depression</td>
<td>0.56*</td>
</tr>
<tr>
<td>Reaction disruption</td>
<td>0.57*</td>
</tr>
<tr>
<td>Total reactions</td>
<td>0.74**</td>
</tr>
</tbody>
</table>

*P < 0.05; **P < 0.01.

Frequency of problem behaviours

Scores, as measured by The Revised Memory and Behaviour Problem Checklist (RMBPC) (Teri et al. 1992), ranged from 2 to 66 for the total frequency of problems identified by caregivers. The mean score was 41.46 and standard deviation 15.39 for the total sample. The problem behaviour was frequency of memory problems (M = 21.7). The least frequent problem behaviour was depression (M = 11.34). Thus, frequency of depression and disruption problems produced the lowest scores, memory problems produced the highest scores. These results are presented in Table 2.

Caregiver reaction

Scores corresponding to the frequency of problem behaviours on the RMBPC, ranged from 5 to 73 for the total caregiver reaction to problem behaviours. The mean score was 26.29 and the standard deviation (SD) 15.27 for the total sample. The category of problem behaviour resulting in the most negative caregiver reaction was disruptive behaviours (M = 10.4). The recipient behaviour that caused the least reaction was memory problems (M = 8.17). Thus, reaction to memory and depression problems produced the lowest scores, reaction to disruption produced the highest score. This descriptive data is also provided in Table 2.

Impact of caregiving

Scores identified by the CCI (Kosberg & Cairl 1986), ranged from 23 to 65 for the Total CCI score, with a mean of 41.63 and a SD of 10.86. The component with the greatest impact was caregiver restrictions (M = 12.5). The valuing of caregiving (M = 5.32) resulted in the smallest impact. See Table 2 for results of caregiving impact according to the other components.

Results

Demographic variables of gender

Independent t-tests and the Mann–Whitney U-test were used to determine whether a difference existed between male and female caregiver reports of frequency of problem behaviours, reaction to problem behaviour, and impact from caregiving.
As the two groups were unequal, the assumption of equal variances was tested using Levine’s technique, as suggested by Hulk et al. (1974). Data analysis identified female caregivers as having a greater reaction to disruptive behaviour than male caregivers, even though both sexes reported similar frequencies of problem behaviours (females: M = 11·65, SD = 6·61; males: M = 5·20, SD = 2·28; F = 5·701, P = 0·02). Similar findings concerning gender were also found with the caregiver reaction to depression related behaviours (females: M = 9·7, males: M = 4·6, P = 0·01). In regard to the impact of caregiving, four of the six indicators were higher for women than for men. These indicators included: restrictions in activities (females: M = 14, men: M = 10, P = 0·01); decline in caregiver physical health (females: M = 11, males: M = 8·0, P = 0·01); provoking nature of the care recipient (females: M = 7·0, male: M = 4·00, P = 0·01); and total impact of care (females: M = 45, men: M = 33, P = 0·01).

First research question

The first research question explored the association between frequency of problem behaviour and impact of caregiving. The total frequency of problem behaviour was significantly correlated with 4 of the 5 subscales. The only nonsignificant association related to the impact of caregiving was for value of the caregiving relationship which was also the lowest correlation (r = 0·33). The strongest association was found between total frequency of problem behaviour and restrictions on caregiver activities (r = 0·64). (Refer to Table 3). The single component of impact from caregiving that had the strongest correlation with all four frequency of problem behaviour scales was the component of caregiver impact titled ‘personal and social restrictions’. A second caregiving impact indicator ‘provoking nature of the care recipient’ also had significant moderate associations with all four frequency of problem behaviour indicators. Overall, significant associations were found for 11 of the 20 subscales that measured the association between frequency of problem behaviour and impact of caregiving.

Second research question

The second research question explored the association between caregivers’ reaction to problem behaviours and their impact from caregiving. Results from the data analysis are provided in Table 4. Significant associations were found for 15 of the 20 subscales that measured the association between reaction to problem behaviour and impact from caregiving. Specifically, the caregiving impact indicators ‘provoking nature of care recipient’ and ‘caregiver restrictions’ had the highest associations with the caregiver reaction to problem behaviour total score (r = 0·74 and 0·73, respectively, P = 0·000) (Refer to Table 4). Generally, the reaction to problem behaviour followed the same pattern of correlations as was found with frequency of problem behaviour, but in all cases the correlations were of much greater strength. Additionally, four of the caregiver reaction correlations became significant for the first time: reaction to memory loss and health (r = 0·73), reaction to disruption and health (r = 0·47) reaction to memory loss and economics (r = 0·51), and reaction to depression and economics (r = 0·48).

Discussion

The study of the association between frequency of problem behaviour and impact from caregiving is important as researchers seek to understand the consequences of problem behaviours and overall impact on caregiving. This study found the strongest association for total frequency of problem behaviour was on personal and social restrictions in the caregiver’s life. Additionally, a significant correlation was identified among the total frequency of problem behaviour and an increase in the provoking nature of the care recipient. Other studies have also found that behavioural problems exert greatest impact on restrictions in the caregiver’s life. Behavioural problems appear to have far greater impact than do cognitive or functional impairment (Coen et al. 1997).

Related to the second research question, it is important to note that the caregiver reaction was more highly associated with caregiving impact than the actual frequency of behaviour. The level of upset reaction to the care recipients’ total, memory, disruption, and depression related behaviour had even higher significant correlations with five of the six indicators for caregiving impact. These five indicators included: increased restrictions on caregivers activities, decline in physical and emotional health, increased economic costs, provoking nature of the care recipient, and the total impact score. Thus, the caregiver perception of the severity of the person’s behaviour is more important than the actual ‘objective’ frequency of impairment. This finding may have great implications for intervention programs. Caregivers must learn to understand depression and disruption in terms of symptoms of memory loss and gain knowledge about how to manage the behaviour. Interventions designed for caregivers might include educational programmes with content on knowledge about AD, understanding problem behaviours in terms of memory loss, and content on anger and frustration management (Gallagher-Thompson & DeVries 1994).
Interventions designed for persons with AD would increase pleasurable and meaningful activities, and support previous skills and positive behaviours (Burgener et al. 1993). Thus, positive patient outcomes could be experienced with a decreased prevalence of depressive and disruptive symptoms. After caregiver education about management of the problem behaviours, possibly the reaction scores may decrease even through actual frequency of behaviours is expected to remain the same due to the progressive nature of the disease. Our findings support other research reports that some problem behaviours provoke greater caregiver reaction and impact than others (Pallett 1990, Miller et al. 1991). Numerous studies carried out over the past decade have addressed the impact on the health and well-being of the caregiver. In a review of the dementia caregiving literature, recipient behaviour problems overwhelmingly predicted caregiver depression (Schulz et al. 1995; Schulz & Quittner 1998). Findings of this study suggest an explanation for these findings, as separate types of problem behaviour was found to impact different aspects of the caregivers life (Davis et al. 1997). Perhaps dementia caregivers experience higher levels of strain because they have to more often cope with problem behaviours such as wandering, screaming, or destroying property.

Related to the demographic characteristic of gender, female caregivers experienced greater reaction to two problem behaviours (depression and disruptive behaviour) when compared with male caregivers even though both genders reported similar frequencies of these behaviours. Examples of the depression behaviours included: appearing sad or depressed, crying, making comments about hopelessness, loneliness, death, being a burden, a failure, or threatening suicide. The other type of behaviour that was most upsetting was disruptive behaviour. Examples of disruption related behaviours include: arguing, talking loudly or rapidly, waking the caregiver up, verbal aggression, embarrassing behaviour, dangerous behaviour to self or others, and destroying property. These types of behaviours were associated with the most upset reaction in female caregivers. It is not surprising that these types of behaviours may be the most threatening. The female caregiver probably is concerned about her own safety or that of others and her ability to control the disruptive behaviour. Thus caregiver knowledge and understanding about anger and frustration management may be important interventions for women.

Certain personal characteristics of the caregiver have been thought to contribute to the impact of family caregiving. Our findings are supportive of other research that suggests female caregivers experience a greater impact from caregiving. Females also had higher impact from caregiving in four of the six indicators when compared with men (restricted activity, decline in health, provoking nature of the care recipient, and total impact of care). The finding that women report a higher level of impact from caregiving than male caregivers do (Miller & Cafasso 1992) was interpreted in many ways, including the possibility that women assist in more personal aspects of caregiving such as toileting and bathing. Another interpretation was that females have more stress from multiple social roles than male caregivers do. Our findings add still another interpretation for increased impact: women may react more to depressed and disruptive care recipient behaviours, thus experiencing more negative consequences. Women’s reaction to depressed and disruptive behaviours is an additional variable to be added to the study of gender differences that determine caregiving outcomes. Future interventions are also needed that promote a positive attitude toward use of respite and other community resources to decrease personal and social restrictions experienced by women caregivers (Robinson & Yates 1994).

Study limitations

The generalizability of this study is limited because of possible self-selection bias that is inherent in any study that uses volunteers. Caregivers who volunteered to participate in this study may have been more aware of the possible impact of problem behaviours of the AD patient on caregiver well-being than the ‘average’ caregiver. In addition, information bias is likely to be found in this study. All of the data collection instruments are based on self-report and none of the reported AD patient behaviours, caregiver reactions, or impacts on the caregivers were verified objectively. A third limitation is the possibility that the correlation between frequency of problem behaviour and impact from caregiving (Table 3) and between reaction to problem behaviours and impact from caregiving in (Table 4) may be artificially inflated due to correlation of each of these variables with an unmeasured variable such as overall caregiver burden. Partial correlation analysis could be used to determine the effect of such variables in future studies of problem behaviour and caregiver impact if these studies also include other measures like overall burden.

Conclusions

Findings from this study indicated that caregiver’s reactions to depressive and disruptive behaviours may put them at risk for problems of declining physical and emotional health, and loss of economic resources. More studies are needed to
determine how the response to problem behaviour changes over the course of illness as the disease progresses. Many caregivers would reply that this problem behaviour was stressful at first but over time they have learned to accept it. The reasons for how and why some caregivers adapt over time whereas others do not is one of the least understood yet most important research questions deserving of further attention (Dunkin & Anderson-Haney 1998). More intervention research is needed to determine how to best support caregivers in management of problem behaviours for each stage of the disease. Replication of studies with larger randomized samples, studied over extended periods of time, are needed to validate instruments and avoid contradictory evidence.

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References


