Family Caregivers of Older People in Nursing Homes

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Purpose  This paper aims to review literature related to the experiences of family caregivers after institutionalization of their older relatives.

Methods  Thirty-one research-based articles were reviewed for information on the following six dimensions: caregivers’ involvement in care; the effects of institutionalization on mental health of caregivers; predictors of caregivers’ mental health; caregivers’ feelings; caregivers’ difficulties and needs; and interventions for caregivers.

Results  Family caregivers continued their caregiver roles after institutionalization. There was a significant decrease in the caregivers’ burden after institutionalization. Depression in caregivers, however, was not significantly reduced. The predictors of caregivers’ mental health included characteristics of care recipients, caregivers, and institutions as well as interactions. After institutionalization, caregivers experienced positive feelings, negative feelings, and mixed feelings. Caregivers encountered many difficulties related to care recipients’ decreasing cognitive functions, care recipients’ behavioral problems, and institutional problems. Interventions improved caregivers’ outcomes, care recipients’ outcomes, staff members’ outcomes, and the communication/relationships among the three groups.

Conclusion  This review expands existing knowledge and provides valuable information. Nurses and researchers need to conduct more research related to family caregivers’ difficulties and needs. Future studies should develop more effective interventions and test the effects of interventions on family caregivers as well as care recipients and staff members. [Asian Nursing Research 2008;2(4):195–207]

Key Words  aged, caregiver, family, institutionalization

INTRODUCTION

About 1.5 million older people live in nursing homes in the United States of America (U.S. census, 2005). The proportion of institutionalized older people increases with age so that about 22.7% of those aged 75 and over live in nursing homes (U.S. census). As the condition of frail older relatives’ deteriorates over time, they require more care, assistance, and time, many family caregivers are obliged to place their older relatives in institutions (Gold, Reis, Markiewicz, & Andres, 1995; Whitlatch, Feinberg, & Stevens, 1999). There are numerous studies regarding issues of family caregivers; however, most studies focus on family caregivers of community dwelling elders, predictors of institutionalization, and interventions that might delay institutionalization (Banerjee et al., 2003; Bharucha, Pandav, Shen, Dodge, & Ganguli, 2004;...
Because institutionalization is regarded as the end of family caregiving, issues regarding the family caregivers of institutionalized elders have been neglected (Dellasega & Nolan, 1997; Kellett, 1999).

Since the 1990s, many researchers have begun to explore the experiences of family caregivers after institutionalization. Family caregivers were reported to continue their caregiving role after institutionalization (Dellasega & Mastrian, 1995; Stull, Cosbey, Bowman, & McNutt, 1997). Family caregivers were found to show depression, feelings of relief, satisfaction, sadness, loss, and guilt after institutionalization of their frail older relatives (Fink & Picot, 1995; Rosenthal & Dawson, 1991). There has been only one published review article (Davis & Buckwalter, 2001) regarding family caregiver issues after institutionalization and the study focused only on family caregivers’ responses and involvement after institutionalization. Therefore, there is a dearth of literature reviews focusing on the experiences of family caregivers following institutionalization. Nurses in institutions still have difficulties in understanding family caregivers of institutionalized elders and have problems providing appropriate interventions for them. The purpose of this paper is to review literature related to the experiences of family caregivers after institutionalization of their older relatives.

METHODS

An electronic database search of Medical Literature Analysis and Retrieval System online (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and The American Association of Retired Persons (AARP) Ageline was conducted to retrieve studies from 1990–2007 using the following keywords: elderly, elder, older, family, caregiver, carer, transition, nursing home, long-term facility, institution, and institutionalization. The database searches were limited to research-based studies published in English. No limitation was applied to research methods and health conditions of care recipients. Abstracts of 730 potentially relevant studies were reviewed and if there was insufficient information in the abstract, full texts of the articles were retrieved to check eligibility. Articles that explored the experiences of family caregivers who placed elderly relatives in institutions were retrieved. In this review, the institutions included nursing homes, skilled-care nursing homes, and long-term care facilities.

Articles focusing on the following six dimensions were selected for inclusion because most existing studies regarding family caregiving after institutionalization have focused on family caregivers’ involvement, mental health, predictors of mental health, and feelings: family caregivers’ involvement in care after institutionalization; the effects of institutionalization on mental health of family caregivers; predictors of family caregivers’ mental health after institutionalization; family caregivers’ feelings after institutionalization; family caregivers’ difficulties and needs after institutionalization; and interventions for family caregivers of institutionalized elders. A total of 31 research-based articles were included in this review.

RESULTS

Family caregivers’ involvement in care after institutionalization

Three studies reported family caregivers’ continuous involvement in care after institutionalization of their elderly relatives. Two studies used a qualitative research design (Dellasega & Mastrian, 1995; Fink & Picot, 1995) and one used a mixed method (Stull et al., 1997). All three studies were conducted in the USA.

Caregivers reported role redefinition (Dellasega & Mastrian, 1995) and continued their caregiver role (Fink & Picot, 1995) after the institutionalization of their relatives. Dellasega and Mastrian reported that family caregivers had to redefine and change their caregiving roles after nursing home placement. In Fink and Picot’s study, most caregivers reported that after nursing home placement they continued to monitor...
the needs of their relatives and to check whether their relatives’ needs were met. Stull et al. (1997) explored family involvement in care before and after nursing home placement. Three kinds of care tasks (personal care, financial/legal matters, and care of clothing) were examined. In the study, family caregivers had reduced involvement in personal care and care of clothing of their relatives after nursing home placement. However, there was a slight but non-significant increase in family caregivers’ involvement in financial and legal matters. In addition, Stull et al. assessed the percentage of care tasks performed by caregivers before and after nursing home placement in terms of five tasks (walking, reading, using a wheelchair, shopping and eating). After nursing home placement, caregivers provided significantly more assistance with reading, using a wheelchair, and eating and provided significantly less assistance with walking and shopping.

Effect of institutionalization on the mental health of family caregivers

Ten studies explored the effects of institutionalization on the mental health of family caregivers (Table 1). As indicators of mental health, caregivers’ depression (Gaugler, Zarit, & Pearl, 1999; Lieberman & Fisher, 2001; Matsuda, Hasebe, Ikehara, Futatsuya, & Akahane, 1997; Rosenthal & Dawson, 1991; Stephens, Kinney, & Ogrocki, 1991; Stull et al., 1997), burden/strain (Dellasega, 1991; Gold et al., 1995; Riddick, Cohen-Mansfield, Fleschner, & Kraft, 1992; Stull et al.; Yeh, Johnson, & Wang, 2002), anxiety (Lieberman & Fisher), and anxiety-insomnia (Matsuda et al.) were examined.

Eight studies used quantitative methods and two used mixed methods (Dellasega, 1991; Stull et al., 1997). Four were longitudinal studies (Gold et al., 1995; Lieberman & Fisher, 2001; Matsuda et al., 1997; Yeh et al., 2002). Six were conducted in USA, two in Canada (Gold et al.; Rosenthal & Dawson, 1991), one in Japan (Matsuda et al.), and one in Taiwan (Yeh et al.). Five studies explored one caregiver group, four compared nursing home caregivers with home-based caregivers, and one compared three groups (nursing home caregivers, home-based caregivers, and caregivers who placed relatives in a nursing home during the follow-up period).

Six studies explored family caregivers’ depression after institutionalization. Rosenthal and Dawson (1991) examined caregivers’ depression using the Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) in the first month after institutionalization, and reported that 46% of the caregivers in the study showed mild to severe depression. Gaugler et al. (1999) also explored caregivers’ depression using a seven-item scale derived from the Hopkins Symptom Checklist (HSC) (Derogatis, Lipman, Covi, & Rickels, 1971). Consistent with the result of Rosenthal and Dawson, Gaugler et al. found that family caregivers experienced moderate levels of depression during nursing home transition. In addition, four studies reported that institutionalization did not significantly decrease depression/depressive symptoms (Lieberman & Fisher, 2001; Matsuda et al., 1997; Stephens, Kinney, et al., 1991; Stull et al., 1997). Stephens et al. compared two groups of nursing home caregivers and home-caregivers using 13 items from Symptom Checklist-90-R (SCL-90-R) (Derogatis, 1983), and reported that there was no significant difference in depression between the two groups. Lieberman and Fisher also compared two groups of nursing home caregivers and in-home caregivers using a modified HSC (Derogatis, 1974) and reported that there was no significant difference in depression between the two groups. This was consistent with the results of Stephens et al. These results were supported by Matsuda et al.’s study which compared three groups using the depression subscale of the General Health Questionnaire (GHQ) (Nakagawa & Daibo, 1985) and found no significant difference in the level of depression and no significant change in depression over 1 year among the three groups. Using CES-D, Stull et al. also found that there were no significant changes in caregivers’ depression before and after placement of relatives in a nursing home.

Five studies focused on caregivers’ burden or strain. Using the Revised Burden Interview (BI) (Zarit, Reever, & Bach-Peterson, 1980), Dellasega (1991) examined the role and personal strain of caregivers,
Table 1  
*Effect of Institutionalization on Mental Health of Family Caregivers*

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Design, number of group, sample size, country, outcome variable</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Dellasega (1991) | Mixed method  
Two groups  
124, USA  
Burden | Both groups showed moderate to severe caregiving burden (role strain and personal strain). There was no significant difference in the burden between the two groups. |
| Rosenthal & Dawson (1991) | Quantitative method  
One group  
69, Canada  
Depression | In the first month after institutionalization, 46% of the wives reported depression (mild to severe). |
Two groups  
120, USA  
Depressive symptoms | There was no significant difference in depressive symptoms for the two groups. |
| Riddick et al. (1992) | Quantitative method  
One group  
84, USA  
Burden | There was a significant decrease in the burden of care after nursing home placement. |
| Gold et al. (1995) | Quantitative method  
Two groups  
157, Canada  
Burden | While the burden of home-based caregivers increased non-significantly over time, the burden of institutionalized-caregivers was significantly decreased over time. |
| Matsuda et al. (1997) | Quantitative method  
Three groups  
103, Japan  
Anxiety-insomnia, Psychiatric morbidity, Depression | There were significant decreases in anxiety-insomnia and psychiatric morbidity at more than 6 months after placement. There was no significant change in depression among the three groups. |
| Stull et al. (1997) | Mixed method  
One group  
81, USA  
Strain  
Depression | After nursing home placement, there were significant decreases in the five domains of caregivers’ strain (i.e. physical strain, social constraints, time constraints, interpersonal strain, elder manipulates/demands) except one domain (financial strain). There were no significant changes in depression. |
| Gaugler et al. (1999) | Quantitative method  
One group  
162, USA  
Depression | Caregivers showed moderate levels of depression during the nursing home transition. |
| Yeh et al. (2002) | Quantitative method  
One group  
77, Taiwan  
Burden | There were significant decreases in the global burden and perceived burdens (caused by lack of family support, impact of schedule, and impact on health). |
Two groups  
182, USA  
Anxiety, depression | There were no significant differences in anxiety and depression between nursing home placement caregivers and non-nursing home placement caregivers. |
comparing nursing home caregivers and in-home caregivers. In the study, both groups showed moderate to severe role and personal strain. There was no significant differences in role and personal strain between the two groups. In contrast, four other studies reported that there was a significant decrease in caregiver burden after nursing home placement (Gold et al., 1995; Riddick et al., 1992; Stull et al., 1997; Yeh et al., 2002). Riddick et al. compared caregivers’ past burden (before nursing home placement) with present burden (after nursing home placement) using the Burden of Care instrument (Zarit, et al.). In this study, caregivers displayed a significant decrease in the burden after nursing home placement. Gold et al. examined the burdens of two groups (nursing home caregivers and in-home caregivers) using the BI over 2 years. In this study, the burden of nursing home caregivers was significantly decreased over time, while the burden of in-home caregivers increased over time. In addition, using the Caregiver Reaction Assessment (CRA) (Given et al., 1992), Yeh et al. reported that after nursing home placement, caregivers showed significant decreases in perceived burden. Consistent with this result, Stull et al. also reported that there was a significant decrease in caregivers’ strain (i.e., physical strain, social constraints, time constraints, interpersonal strain, elder manipulates/demands) after nursing home placement.

Two studies addressed caregivers’ anxiety or anxiety-insomnia (Lieberman & Fisher, 2001; Matsuda et al., 1997). Using a subscale of GHQ, Matsuda et al. compared three groups: nursing home caregivers, home-based caregivers, and caregivers who placed relatives in a nursing home during the follow-up period. They found that caregivers showed significantly less anxiety-insomnia at more than 6 months after nursing home placement. Contrary to this result, Lieberman and Fisher compared two groups of nursing home caregivers and in-home caregivers using the HSC and reported no significant difference in anxiety between the two groups.

In summary, most studies which focused on depression reported that family caregivers manifested depression after the institutionalization of their relatives and caregivers’ depression was not significantly decreased by institutionalization. In contrast, most studies which focused on burden or strain reported that caregivers’ burden and strain were decreased significantly after institutionalization.

**Predictors of family caregivers’ mental health after institutionalization**

Ten studies explored the factors associated with caregivers’ negative outcomes after institutionalization using a quantitative study method (Table 2): Five examined the predictors of caregivers’ depression (Brody, Dempsey, & Pruchno, 1990; Gaugler et al., 1999; Majerovitz, 2007; Stephens, Kinney, et al., 1991; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001) and four examined the predictors of caregivers’ burden (Majerovitz, 2007; Monahan, 1995; Tornatore & Grant, 2002; Yeh et al., 2002). Three studies explored the predictors of psychological distress (Ducharme, Levesque, & Cossette, 1997), burnout (Almberg, Grafstrom, Kirschbaum, & Winblad, 2000), and anger (Gaugler et al.). Seven studies were conducted in the USA, one in Canada, one in Sweden, and one in Taiwan.

Caregivers’ depression was associated with the following: care recipient’s problematic behaviors; care recipient’s cognitive problems (memory loss and confusion); the extent of care recipient’s demands; time pressure; less help with instrumental activities of daily living (IADLs); caregivers’ age, number of illnesses, lower income, poor health, and adjustment; difficulty with care recipient’s mental and emotional state; increased family conflict; lower social support; negative interactions with care recipients; and negative interactions with other residents’ families (Brody et al., 1990; Gaugler et al., 1999; Majerovitz, 2007; Stephens, Kinney, et al., 1991; Whitlatch et al., 2001).

The predictors of caregivers’ burden included the caregiver’s higher age; non-white race; marital status; higher education; poor health; shorter length of time as a caregiver prior to institutionalization; more involvement with hands-on care; frequent caregiving tasks; lower expectations about nursing home care; dissatisfaction with nursing home care; less participation in support groups/workshops; coping with the
### Table 2

**Predictors of Family Caregivers’ Mental Health After Institutionalization**

<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Sample size, country, outcome variable</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brody et al. (1990)</td>
<td>331 USA Depression</td>
<td>The number of caregivers’ illnesses, less help with IADLs, time pressure, and the extent to which care recipient was demanding were the significant predictors of depression.</td>
</tr>
<tr>
<td>Stephens, Kinney, et al. (1991)</td>
<td>120 USA Depression</td>
<td>Care recipients’ problematic behavior and cognitive problems (memory loss, and confusion) were the best predictors of caregivers’ depression.</td>
</tr>
<tr>
<td>Monahan (1995)</td>
<td>29 USA Burden</td>
<td>The predictors of burden were caregivers’ characteristics (non-white, married, higher education, poor health) and less participation in support groups/workshops.</td>
</tr>
<tr>
<td>Ducharme et al. (1997)</td>
<td>220 Canada Psychological distress, Positive affect</td>
<td>The predictors of psychological distress included appraisal of memory dysfunctional behaviors of the patient, the frequency of depressive dysfunctional behaviors of the patient, a low level of social support, a high level of conflict from the social network, and affective regulation. The predictors of positive affect were informal and formal support from social networks and staff members, and affective regulation.</td>
</tr>
<tr>
<td>Gaugler et al. (1999)</td>
<td>162 USA Anger, Depression</td>
<td>The predictor of anger among husbands was the decrease in socio-emotional support. The predictor of depression among wives was the increase in family conflict.</td>
</tr>
<tr>
<td>Almberg et al. (2000)</td>
<td>37 Sweden Burnout</td>
<td>The predictors of burnout were patient cognitive hassles, behavior hassles, caregiver-staff interaction hassles, patient-staff interaction hassles, and practical/logistical hassles.</td>
</tr>
<tr>
<td>Whitlatch et al. (2001)</td>
<td>133 USA Depression</td>
<td>Caregiver’s age, adjustment, difficulty with care recipient's mental and emotional state, and negative interactions with care recipient or other residents’ families were the predictors of depression.</td>
</tr>
<tr>
<td>Yeh et al. (2002)</td>
<td>77 Taiwan Burden</td>
<td>The predictor of global burden was duration of caregiving prior to institutionalization.</td>
</tr>
<tr>
<td>Tornatore &amp; Grant (2002)</td>
<td>276 USA Burden</td>
<td>The predictors of burden were higher caregiver’s age, shorter length of time in caregiving prior to institutionalization, custodial unit (least geared toward dementia care), more involvement with hands-on care, and lower expectations for care.</td>
</tr>
<tr>
<td>Majerovitz (2007)</td>
<td>103 USA Burden Depression</td>
<td>The predictors of burden included caregiver’s age, caregiver’s health, coping with care recipient’s memory and behavior problems, caregiving tasks, satisfaction with nursing home, and social support. The predictors of depression included caregiver’s health, income, and social support.</td>
</tr>
<tr>
<td>Tornatore &amp; Grant (2004)</td>
<td>285 USA Satisfaction</td>
<td>The predictors of higher satisfaction were earlier stage of dementia, longer time of care prior to institutionalization, frequent visit, less involvement in hands-on care, higher expectations for care, not working full-time, and rural location of nursing home.</td>
</tr>
<tr>
<td>Levy-storms &amp; Miller-Martinez (2005)</td>
<td>145 USA Satisfaction</td>
<td>The caregivers who provided more ADL and IADL assistance at admission were less satisfied with institutional care at admission and became less satisfied during the year after admission of institution.</td>
</tr>
</tbody>
</table>
care recipient’s memory and behavior problems; low level of social support; and custodial unit (least geared toward dementia care) (Majerovitz, 2007; Monahan, 1995; Tornatore & Grant, 2002; Yeh et al., 2002). Caregivers’ psychological distress was associated with the following: appraisal of memory related dysfunctional behaviors of the care recipients; the frequency of depressive dysfunctional behavior of the care recipients; a low level of social support; a high level of conflict from the social network; and affective regulation (coping strategy) (Ducharme et al., 1997). The predictors of caregivers’ burnout were care recipients’ cognitive problems, behavioral problems, caregiver-staff interaction problems, care recipient-staff interaction problems, and practical/logistical problems (Almberg et al., 2000). Caregivers’ anger was associated with decreased socio-emotional support (Gaugler et al., 1999).

Three studies explored the predictors of caregivers’ positive outcomes after institutionalization (Ducharme et al., 1997; Levy-Storms & Miller-Martinez; Tornatore & Grant). Two examined predictors of caregiver satisfaction (Levy-Storms & Miller-Martinez, 2005; Tornatore & Grant, 2004) and one examined predictors of positive affect (Ducharme et al.). Two studies were conducted in the USA and one in Canada. Caregiver satisfaction was associated with less advanced stages of dementia, longer length of time involved in caregiving before institutionalization, frequent visits, less involvement in hands-on care, high expectations for institutional care, not working full-time, and rural location of the nursing home (Levy-Storms & Miller-Martinez, 2005; Tornatore & Grant). Caregivers’ positive affect was associated with informal and formal support from social networks/staff members, and affective regulation (Ducharme et al.).

In summary, characteristics of care recipients, caregivers, and institutions were associated with caregivers’ mental health. In addition, interactions between the caregiver and care recipient/nursing home staff/other residents’ families were reported as predictors of caregivers’ mental health. Caregivers’ negative outcomes were associated with care recipients’ cognitive problems; caregivers’ characteristics; negative interactions; shorter length of caregiving time before institutionalization; a low level of support; and low expectation about nursing home care. Caregivers’ positive outcomes were associated with the following: care recipients’ having a less advanced stage of dementia; rural location of the nursing home; caregivers’ employment status; frequent visits; longer length of caregiving time before institutionalization; less involvement in hands-on care; high expectations of nursing home care; high level of support; and affective regulation.

**Family caregivers’ feelings about institutionalization**

Among nine studies that focused on the feelings of family caregivers after institutionalization (Table 3), five used qualitative methods (Dellasega & Mastrian, 1995; Fink & Picot, 1995; Johnson, Morton, & Knox, 1992; Kellett, 1999; Moyle, Edwards, & Clinton, 2002), three used quantitative methods (Riddick et al., 1992; Stull et al., 1997; Zarit & Whitlatch, 1993), and one used a mixed method (Rosenthal & Dawson, 1991). Six were conducted in the USA, two in Australia, and one in Canada.

Three studies reported that after institutionalization, family caregivers felt less anger/resentment and overload/tension. Stull et al. (1997) examined the feelings of family caregivers before and after nursing home placement. Caregivers reported a significant decrease in their feelings of anger/resentment after nursing home placement. This finding supported the result of Rosenthal and Dawson (1991) that reported anger/resentment was less frequently expressed than other negative feelings. Zarit and Whitlatch (1993) compared home-based caregivers with nursing home caregivers and found that nursing home caregivers showed significantly lower scores in feelings of overload and tension compared with home-based caregivers.

Two studies reported that caregivers simultaneously expressed negative feelings as well as satisfaction after institutionalization (Riddick et al., 1992; Rosenthal & Dawson, 1991). Rosenthal and Dawson reported that 90% of caregivers reported feelings of satisfaction after institutionalization. In the study, however, 84% of caregivers also expressed at least one or more negative feelings, such as sadness and
<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Design, sample size, country</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Rosenthal &amp; Dawson (1991)</td>
<td>Mixed method 69, Canada</td>
<td>In the first month after institutionalization, 90% of the wives reported feelings of satisfaction. However, 84% of the wives expressed at least one or more negative feelings. Sadness (64%) and loneliness (61%) were the most frequently reported feelings. The feelings of guilt (38%), anger (30%) and resentment (28%) were less frequently reported.</td>
</tr>
<tr>
<td>Johnson et al. (1992)</td>
<td>Qualitative method 22, USA</td>
<td>Two major categories (uncertainties and conflicts) were identified. The category of uncertainty was found in relation to the following: progress for the patient either regarding the disease process or the influence of the environment; complexity of the health care system; and lack of information about the patient, the patient's health status, or the events surrounding care. The category of conflict was identified in relation to the following: difficulty reconciling the present with long held personal beliefs/values; disparity between the system of health care represented by the institution and family goals; and disrupted family relationships.</td>
</tr>
<tr>
<td>Riddick et al. (1992)</td>
<td>Quantitative method 84, USA</td>
<td>Caregivers were somewhat satisfied with institutionalization. The most frequent negative emotions were sadness, frustration about the lack of control over care recipient's health, and guilt.</td>
</tr>
<tr>
<td>Dellasega &amp; Mastrian (1995)</td>
<td>Qualitative method 7, USA</td>
<td>Institutionalization conflicted with their view of themselves as an ideal caregiver. Consequences of institutionalization on caregivers included emotional turmoil, ambivalence, and role redefinition.</td>
</tr>
<tr>
<td>Fink &amp; Picot (1995)</td>
<td>Qualitative method 10, USA</td>
<td>Three major themes were identified: relief and re-involvement; regrets and losses; and the continuing caregiver role.</td>
</tr>
<tr>
<td>Stull et al. (1997)</td>
<td>Quantitative method 81, USA</td>
<td>After institutionalization, caregivers showed significantly less anger and resentment compared with before institutionalization. Caregivers reported a slight but non-significant decrease in the feelings of duty/obligation and a slight but non-significant increase in the feelings of guilt.</td>
</tr>
<tr>
<td>Kellett (1999)</td>
<td>Qualitative method 14, Australia</td>
<td>Five shared meanings were identified: loss of control; feeling of being disempowered; feeling of guilt, sadness and relief simultaneously; sense of failure; and having to make a forced and negative choice.</td>
</tr>
<tr>
<td>Moyle et al. (2002)</td>
<td>Qualitative method 15, Australia</td>
<td>Six major themes were identified: relief versus burden of loss; loss from observation of the cognitive decline; loss of companionship; loss creating fears and frustration; loss of personhood; loss related to the anticipation of death.</td>
</tr>
<tr>
<td>Zarit &amp; Whitlatch (1993)</td>
<td>Quantitative method 428, USA</td>
<td>Institutionalized-care caregivers reported significantly lower scores in the feelings of overload and tension after institutionalization, compared with the home-based caregivers.</td>
</tr>
</tbody>
</table>
loneliness. This finding was consistent with the result of Riddick et al.'s study which reported that caregivers felt not only satisfaction but also negative feelings such as sadness, frustration, and guilt.

From the five qualitative studies (Dellasega & Mastrian, 1995; Fink & Picot, 1995; Johnson et al., 1992; Kellett, 1999; Moyle et al., 2002), the following major themes were identified: relief; sadness; loss; simultaneous sadness and relief; simultaneous relief and loss; ambivalence; conflict; emotional turmoil; uncertainty; being disempowered; a sense of failure; guilt; and regret. Fink and Picot reported that caregivers expressed feelings of relief with regard to the post-placement experience. Moyle et al. argued that “institutionalization did not result in an absolute relief of the family caregivers’ burden but also caused further loss” (p. 27). Loss was a frequently reported experience of family caregivers after institutionalization (Fink & Picot; Kellett; Moyle et al.). Loss was expressed by caregivers in terms of several areas: loss of control; loss from observation of cognitive decline; loss of companionship; loss creating fears and frustration; loss of personhood; and loss related to the anticipation of death (Kellett; Moyle et al.).

In summary, most studies included in the review that focused on caregivers’ feelings reported that after institutionalization, caregivers showed less anger/resentment, less overload/tension, more satisfaction, and sadness. The major themes related to caregivers’ feelings were relief; sadness; loss; simultaneous sadness and relief; simultaneous relief and loss; ambivalence; conflict; emotional turmoil; uncertainty; being disempowered; a sense of failure; guilt; and regret.

**Family caregivers’ difficulties and needs after institutionalization**

There were three studies which explored family caregivers’ difficulties and needs after institutionalization (Ejaz, Noelker, Schur, Whitlatch, & Looman, 2002; Friedemann, Montgomery, Maiberger, & Smith, 1997; Stephens, Ogrocki, & Kinney, 1991). All three studies were conducted in the USA. Stephens et al. explored caregivers’ difficulties among 66 caregivers of nursing home residents. At least 50% of the caregivers cited care recipients’ cognitive function and behavior (i.e. confusion, lack of interest in things, forgetfulness, reduced mental function, not recognizing familiar people, and agitation) as stressors (Stephens, Ogrocki, et al.). In addition, about 30% of caregivers reported the following problems relating to the nursing home: traveling to and from the nursing home; giving up other activities to visit the care recipient; extra expense; having to remind nursing home staff to do things for care recipients; and having to tell the staff how to care for care recipients. Friedemann et al. explored the problems of nursing homes with 177 family caregivers. Caregivers cited the following as nursing home problems: lack of patient identity (overlook patients’ special needs); environmental problems (space, appearance, privacy, cleanliness, room assignments, wandering, theft); and communication problems with staff. Ejaz et al. also explored caregivers’ needs with 133 family caregivers. In their study, more than 40% of caregivers reported that improvements were needed in food, laundry, activities, the manner in which complaints/concerns were handled, the quality of care in relation to cost, the amount of care, personalized attention, and nursing assistants.

In summary, after institutionalization, family caregivers encountered difficulties related to care recipients’ decreasing cognitive function and behavioral problems. Caregivers also reported difficulties or needs related to institution factors such as traveling to and from the nursing home; giving up other activities to visit; extra expenses; food; laundry; environmental problems; activities; amount of care; quality of care; nursing assistants; the manner in which complaints/concerns were handled; ignoring of patients’ special needs; personalized attention; having to remind nursing home staff to do things for the care recipient; having to tell staff how to care for the care recipient; and communication with staff.

**Interventions for family caregivers of institutionalized elders**

Three intervention studies were included in this review (Maas et al.; McCallion, Toseland, & Freeman, 1999; Pillemer et al., 2003). All three were conducted...
in the USA. Two of the three studies were randomized clinical trials (McCallion et al.; Pillemer et al.) and one was a quasi-experimental study (Maas et al., 2004). McCallion et al. examined the impact of the Family Visit Education Program (FVEP) on family members, nursing staff, and residents with dementia. The FVEP was designed to educate family members to communicate and interact more effectively with residents with dementia. The FVEP was composed of three areas: verbal communication, nonverbal communication, and the effective structuring of family visits. The FVEP improved the way that families communicated with residents and reduced residents’ problem behaviors and depressive symptoms. Pillemer et al. conducted parallel training sessions on communication/conflict resolution techniques to increase cooperation and effective communication between families and nursing staff members. Pillemer et al. also reported three positive outcomes of the intervention: both the family group and the staff group improved attitudes toward each other; families reported less conflict with staff; and staff reported a lower rate of resignations from work. Maas et al. examined the effects of the Family Involvement in Care (FIC) intervention which consisted of four elements: orientation to facility, education for dementia, negotiation of partnership, and evaluation/renegotiation. They found significant beneficial effects on caregivers’ emotional reactions to the caregiving role, perceptions of relationships with staff, and perceptions of care for their relative.

In summary, although the three intervention research studies varied in the elements of interventions, all of them focused on improving the communication or relationship among family caregivers, care recipients and/or staff members. The three studies reported beneficial effects of the interventions on communications or relationships among the three groups. In addition, the studies showed improvements in caregivers’ outcomes (emotional reactions to their role and perception of care for their relative) as well as care recipients’ outcomes (problem behaviors and depressive symptoms) and staff members’ outcomes (lower rate of resignation from work).

**DISCUSSION AND CONCLUSION**

This review provides a synthesis of the literature regarding family caregivers’ experiences after institutionalization of their elderly relatives in terms of six dimensions: involvement in care; mental health; predictors of mental health; feelings; difficulties/needs; and interventions. Given that there is only one published review article (Davis & Buckwalter, 2001), this review expands existing knowledge and provides valuable information for health care providers. This review, however, has a few limitations: relevant articles published in non-English were not included and most studies included were conducted in the USA. Therefore, the generalization of the results to other family caregiver groups is limited.

This review showed that family caregivers continue their caregiver roles after institutionalization of their relative. Although they provide less care in some care tasks, they still provide care related to reading, using a wheelchair, eating, and care recipients needs even after institutionalization.

In terms of the mental health of family caregivers, there was a significant decrease in caregivers’ burden or strain after institutionalization. Depression among family caregivers, however, was not significantly decreased after institutionalization. There were inconsistent results in caregivers’ anxiety after institutionalization. Future nursing research should continue to explore family caregivers’ depression and anxiety after institutionalization and needs to develop effective interventions for depression and anxiety of caregivers.

This review demonstrated that predictors of caregivers’ mental health (negative and positive outcomes) included characteristics of care recipients, caregivers, and institutions as well as interactions between the caregiver and care recipient/other family members/nursing home staff/other residents’ families. Most studies included in this review focused on non-cultural predictors, rather than cultural predictors of caregivers’ outcomes. Monahan (1995) reported that non-white family caregivers showed significantly higher burden levels than did white caregivers, and addressed ethnicity as a predictor of caregivers’
burden. Waltrowicz, Ames, McKenzie, and Flicker (1996) reported that caregivers from non-English speaking backgrounds manifested more burden than their counterparts in English-speaking nursing homes. Given that ethnic and cultural differences have a great influence on family caregivers’ experiences (Janevic & Connell, 2001), future studies are required to examine cultural predictors as well as non-cultural predictors.

Most studies included in this review that focused on caregivers’ feelings reported that after institutionalization, caregivers experienced positive feelings, negative feelings, and mixed feelings. Nurses in institutions should talk with family caregivers frequently, have a better understanding of their negative and mixed feelings, and be sensitive to their feelings (Kavanaugh, 1997; Ryan, 2002).

Family caregivers reported decreases in care recipients’ cognitive function and behavioral problems were difficulties after institutionalization. They also reported other needs or difficulties related to institution factors such as distance, extra expenses, services, quality of care, and interaction/communication with staff members. There were only three studies which explored family caregivers’ difficulties and needs after institutionalization. The difficulties and needs of family caregivers after institutionalization have been neglected by researchers. Nursing researchers need to give more attention to this area and conduct more research related to family caregivers’ difficulties and needs, focusing on institutional factors. In addition, given that family caregivers of institutionalized elders with dementia have more difficulties than other family caregivers (Levesque, Ducharme, & Lachance, 1999), future intervention research should focus on family caregivers with institutionalized elders suffering from dementia.

There were three studies that addressed the effects of interventions for family caregivers and these aimed to improve communication or relationships among family caregivers, care recipients and staff members. Until the late 1990s, little attention was given to intervention research for family caregivers after institutionalization. Further nursing studies are required to develop effective interventions for family caregivers after institutionalization. In addition, although there are some articles that propose strategies for family caregivers (Kavanaugh, 1997; Ortigara, 2001; Ryan, 2002), these are not research-based intervention studies. Therefore, little is known about the effects of the suggested intervention strategies on family caregivers. Given that interventions that target family caregivers have positive effects on care recipients’ outcomes and staff members’ outcomes, future nursing studies should test the effects of interventions on family caregivers as well as care recipients and staff members.

**References**


