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**Literature search results**

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**Search details**

Bereavement, loss, grief or change, and dementia

**Resources searched**

NHS Evidence; TRIP Database; Cochrane Library; BNI; CINAHL; EMBASE; MEDLINE; PsychINFO; Google Scholar

**Database search terms:** dementia*; exp DEMENTIA; alzheimer*; exp ALZHEIMER’S DISEASE; ALZHEIMER DISEASE; bereave*; BEREAVEMENT; exp GRIEF; grief; grieving; sorrow; loss; PERSONAL LOSS; change*; BEHAVIORAL CHANGES; ATTITUDE TO CHANGE; exp COPING; pre-grie*; pre-grieve*; “anticipatory grie*”; “anticipatory bereave*”; “sense of loss”; “attitude to change”

**Evidence search string(s):** (bereav* OR loss OR grief OR griev* OR chang* OR sorrow*) (dementia* OR alzheimer)

**Google search string(s):** (~bereavement OR ~“sense of loss” OR ~grief OR ~sorrow OR “attitude to change”) (~dementia OR ~alzheimer)

**Summary**

There is some research on grief and bereavement in dementia from the points of view of the patient, the carer and the healthcare professional. By including the keywords ‘change’ and ‘loss’, the number of results runs into the tens of thousands, so I omitted them. However a subsequent search on “sense of loss” and “attitude to change” did not reveal any additional research, so I think you have all the relevant research that has been published since 2012. Pre-grief seems not to return any results, but ‘anticipatory grief’ does; and this may be a recognised synonym.
### Guidelines

**Alzheimer’s Society**

*My life until the end: dying well with dementia*, 2012

**NICE Pathways**

*Dementia* 2012

### Evidence-based reviews

**The Mental Elf**

*Supporting carers with anticipatory grief for a loved one with dementia: systematic review*, 2012

- The prevalence of anticipatory grief is estimated at 47%-71%, although these figures are based on quite poor quality research
- Anticipatory grief is highest in moderate to severe dementia, where the spouse is the carer and the person with dementia is in a care home
- Carers with anticipatory grief often also become clinically depressed
- The strongest predictive factors for grief after the death of a loved one with dementia are being a spouse carer and being depressed

### Published research

1. *Coping and Depression in Old Age: A Literature Review.*

**Author(s)** Bjørklof, Guro Hanevold, Engedal, Knut, Selbæk, Geir, Kouwenhoven, Siren Eriksen, Helvik, Anne-Sofie

**Citation:** Dementia & Geriatric Cognitive Disorders, 01 March 2013, vol./is. 35/3/4(121-154), 14208008

**Publication Date:** 01 March 2013

**Abstract:** Background/Aims: The interest in the relation between coping and depression in older persons is growing, but research on the concepts and instruments of coping in relation to depression among older persons is scarce and systematic reviews are lacking. With this background, we wanted to gain a systematic overview of this field by performing a systematic literature search. Methods: A computer-aided search in MEDLINE, CINAHL, PsycINFO, Embase, PubMed and www.salutogenesis.fi was conducted. We systematically searched for studies including coping and depression among persons 60 years of age and above. The included studies were evaluated according to predefined quality criteria. Results: Seventy-five studies, 38 clinical and 37 community settings, were included. Of these, 44 were evaluated to be of higher quality. Studies recruiting samples of older persons with a major depressive disorder, moderate or severe cognitive impairment or those who were dependent on care were scarce, thus the research is not representative of such samples. We found a huge variety of instruments assessing resources and strategies of coping (55 inventories). Although we found the relation between resources and strategies of coping and depression to be strong in the majority of studies, i.e. a higher sense of control and internal locus of control, more active strategies and positive religious coping were significantly associated with fewer symptoms of depression both in longitudinal and cross-sectional studies in clinical and community settings. Conclusion: Resources and strategies of coping are significantly associated with depressive symptoms in late life, but more research to systematize the field of coping and to validate the instruments of resources and strategies of coping in older populations is required, especially among older persons suffering from major depression and cognitive decline. Copyright © 2013 S. Karger AG, Basel

**Author(s)** Hall, Geri R., Shapira, Jill, Gallagher, Maribeth, Denny, Sharon S.

**Citation:** Journal of Gerontological Nursing, 01 March 2013, vol./is. 39/3(10-14), 00989134

**Publication Date:** 01 March 2013

**Abstract:** Caring for people with non-Alzheimer's dementias is particularly challenging for families and care providers. This is especially true for those with frontotemporal degeneration (FTD) who exhibit profound changes in personality, behavior, language, and movement. Initial symptoms are often misdiagnosed as psychiatric disorders or early-onset Alzheimer's disease, and typically do not respond to pharmacological and nonpharmacological interventions designed for people with other dementias. Using individual examples, this article illustrates common features of two subtypes of FTD: behavioral variant FTD and non-fluent primary progressive aphasia.

**Source:** CINAHL

3. The feeling of 'mattering': the positioning of emotions in dementia care.

**Author(s)** Sheard, David

**Citation:** Journal of Dementia Care, Mar 2013, vol. 21, no. 2, p. 23-27, 1351-8372 (March 2013)

**Publication Date:** March 2013

**Abstract:** Introduces the concept of 'mattering' and argues that to achieve positive culture change in dementia care the primary emphasis of workforce development must be on developing emotional intelligence. [PUBLICATION] 34 references

**Source:** BNI

Available in print at Grantham Hospital Staff Library
Available in print at Pilgrim Hospital Staff Library
Available in print at Lincoln County Hospital Professional Library

4. Grief experiences of 3 caregiving wives of veterans with dementia.

**Author(s)** Ford JL, Linde BD, Gigliotti C, Kim KY

**Citation:** American Journal of Hospice & Palliative Medicine, March 2013, vol./is. 30/2(137-45), 1049-9091;1938-2715 (2013 Mar)

**Publication Date:** March 2013

**Abstract:** Three wives share their experiences of caregiving for husbands with dementia. The 3 husbands, aged 51, 71, and 84, developed dementia following years of devoted military service. To present lived experiences of caregiving wives', meanings attributed to caregiving are investigated, variations in caregiving and grieving experiences are explored, and therapeutic implications are offered. Through case study approach and with issues of caregiver grief considered, we introduce life course and ambiguous loss theoretical perspectives. Emergent qualitative themes and quantitative inventory ratings indicate significant differences in caregiver grief response depend on care-recipient age. Practice implications and directions for future care recipient, age-related research are presented.

**Source:** Medline

5. Anticipatory grief therapy for older persons nearing the end of life

**Author(s)** Cheng J.O., Lo R.S., Woo J.

**Citation:** Aging Health, February 2013, vol./is. 9/1(103-114), 1745-509X;1745-5103
Abstract: Aging brings about multiple and accumulating losses over a long trajectory of illness with deterioration in overall functioning with secondary losses in social and existential domains. The reality of anticipatory grief (AG) in older patients facing the end of life is easily overlooked with little provision of psychosocial support, especially for those aging in institutions without integrated palliative care services. This article discusses the challenges that AG poses for the older patients, as well as the desired therapeutic outcomes through using this approach. The evidence base for AG therapy has been limited. Beneficial therapeutic approaches for AG-related constructs will be reviewed, with recommendations to design interventions that target the AG of older patients facing different advanced conditions. AG interventions successfully implemented in the end-of-life care pathway may ensure optimal palliative care for the family. 2013 Future Medicine Ltd.

Source: EMBASE

6. Anticipatory grief among close relatives of persons with dementia in comparison with close relatives of patients with cancer

Author(s) Johansson, Åsa K., Sundh, Valter, Wijk, Helle, Grimby, Agneta

Citation: American Journal of Hospice and Palliative Medicine, Feb 2013, vol. 30, no. 1, p. 29-34, 1049-9091 (February 2013)

Publication Date: February 2013

Abstract: Close relatives of persons with dementia self-reported reactions on the Anticipatory Grief Scale (AGS), were observed by nurses (Study I), and compared with relatives of cancer patients in a study using the same methodology (Study II). Study I showed an overall stressful situation including feelings of missing and longing, inability to accept the terminal fact, preoccupation with the ill, tearfulness, sleeping problems, anger, loneliness, and a need to talk. The ability to cope was, however, reported high. Self-assessments and nurses’ observations did not always converge, e.g. for the acceptance of the illness. The reactions of the relatives in the dementia and the cancer groups showed more similarities than dissimilarities. However, the higher number of responding spouses in the cancer group may have influenced the outcome. [PUBLICATION] 23 references

Source: BNI

7. Do changes in coping style explain the effectiveness of interventions for psychological morbidity in family carers of people with dementia? A systematic review and meta-analysis.

Author(s) Li R, Cooper C, Austin A, Livingston G

Citation: International Psychogeriatrics, 01 February 2013, vol./is. 25/2(204-214), 10416102

Publication Date: 01 February 2013

Source: CINAHL

8. Personality Traits and Behavioural and Psychological Symptoms in Patients with Mild Cognitive Impairment.

Author(s) Mendez Rubio, Montserrat, Antonietti, J.P., Donati, A., Rossier, J., Von Gunten, A.

Citation: Dementia & Geriatric Cognitive Disorders, 01 February 2013, vol./is. 35/1/2(87-97), 14208008

Publication Date: 01 February 2013

Abstract: Background and Aims: Both personality changes and behavioural and psychological symptoms (BPS) may be associated with mild cognitive impairment (MCI) in later life and help identify incipient dementia. We wished to investigate the links between personality and BPS in MCI. Method: We studied premorbid personality traits as estimated
5 years back and their changes in 83 control subjects and 52 MCI patients using the revised NEO Personality Inventory for the Five-Factor Model completed by a proxy. Information on BPS was obtained using the Neuropsychiatric Inventory (NPI). Analyses were controlled for current depression and anxiety. Results: Premorbid neuroticism and openness to experience were associated with the total NPI score. The changes in neuroticism, extraversion, openness to experiences, and conscientiousness were associated with apathy and affective symptoms. Conclusions: Personality changes and BPS occur in MCI. The occurrence of affective BPS and apathy is associated with both premorbid personality traits and their changes. Copyright © 2013 S. Karger AG, Basel

Source: CINAHL

9. Responding to the death of a resident in aged care facilities: Perspectives of staff and residents.

Author(s) Tan, Heather M., O'Connor, Margaret M., Howard, Teresa, Workman, Barbara, O'Connor, Daniel W.

Citation: Geriatric Nursing, 01 January 2013, vol./is. 34/1(41-46), 01974572

Publication Date: 01 January 2013

Abstract: A qualitative study using individual semistructured interviews was undertaken to explore the perceptions and experiences of 23 aged care residents with mild dementia concerning the deaths of co-residents. The views of 25 facility staff members were also explored. The study was based in 3 aged residential facilities in Victoria, Australia. Interview data indicated that residents and staff had differing views. Residents reported that the impact of the death of a co-resident was much less than staff members thought. Residents generally wanted to be told about the death of someone they knew and considered attempts to hide the death and the removal of the body both unnecessary and disrespectful. Both groups agreed that the celebration of the life of a resident was important, although they differed in their preferences for the way this is done. These findings have implications for staff education and practice.

Source: CINAHL

10. A comparison of psychosocial outcomes in elderly Alzheimer caregivers and noncaregivers

Author(s) Mausbach B.T., Chattillion E.A., Roepke S.K., Patterson T.L., Grant I.

Citation: American Journal of Geriatric Psychiatry, January 2013, vol./is. 21/1(5-13), 1064-7481;1545-7214 (January 2013)

Publication Date: January 2013

Abstract: Objective: To conduct an analysis of the stress, coping, and mood consequences of Alzheimer caregiving. Design: Cross-sectional. Setting: Community-based study. Participants: Sample included 125 Alzheimer caregivers and 60 demographically similar older adults with nondemented spouses (i.e., noncaregivers). Measurements: We compared caregivers and noncaregivers on stress, coping, and mood outcomes. We also examined antidepressant use within the caregiver sample. An emphasis was placed upon effect size differences, including Cohen's d as well as more clinically meaningful effect sizes. Results: Caregivers were significantly more likely to endorse depressive symptoms and to meet clinically significant cutoff for depression (40% for caregivers; 5% for noncaregivers). Approximately 25% of caregivers reported taking antidepressant medication, although 69% of these continued to experience significant symptoms of depression. Caregivers also utilized fewer positive coping and greater negative coping strategies than noncaregivers. Conclusion: The number of caregivers will increase dramatically over the next two decades, and caregivers will likely seek care from primary care providers. We provide an overview of the psychological issues facing caregivers so that effective screening and treatment may be recommended. 2013 American Association for Geriatric Psychiatry.

Source: EMBASE
11. Students anticipating the death of a family member or loved one.

Author(s) Fleischman, Jarena G

Citation: Supporting and educating traumatized students: A guide for school-based professionals., 2013(139-154) (2013)

Publication Date: 2013

Abstract: (from the chapter) Children as well as adults grieve from the death of a loved one in many different ways, and no specific time frame indicates when grieving should end. Nevertheless, some common reactions may be exhibited by children and adolescents who anticipate losing an immediate family member due to a terminal illness or other causes. Educators and the school play an important role in the lives of grieving children by providing emotional support and flexibility and recognizing normal responses to grief at the various stages of death (i.e., anticipatory grief, terminal stage, reconstitution stage) and how to react. The degree to which the child adjusts to the loss of a parent (or sibling) may depend to a large extent on the surviving parent's own distress and adjustment to the death. Bereavement in children and the reconstitution of their lives are largely shaped by the surviving parent(s). The surviving caregiver's ability to understand and respond to the child at different developmental stages can play a significant role in determining the child's ability to grieve and move forward in life. Therefore, educators are encouraged to support the surviving caregivers by being a source of information and staying in frequent contact. If children struggle with the grieving process, then complicated grief could develop along with other mental health concerns. Educators must know their own limits and when collaboration with other professionals in the school building or a referral to mental health professionals is necessary. In times of crisis, school-based professionals must recognize the significance of their role in supporting children and working with surviving family members to help the child through this traumatic time. When the surviving parent isn't able to provide the support needed for the child due to his or her own grief, then the school must be able to recognize this and have a plan in place to give additional support until the surviving parent or other caregiver is able to provide what the child needs. (PsycINFO Database Record (c) 2013 APA, all rights reserved)

Source: PsycINFO


Author(s) Chan, Diana, Livingston, Gill, Jones, Louise, Sampson, Elizabeth L

Citation: International Journal of Geriatric Psychiatry, January 2013, vol./is. 28/1(1-17), 0885-6230;1099-1166 (Jan 2013)

Publication Date: January 2013

Abstract: Objective: Supporting dementia carers is an identified target of the UK government, yet we know little about such family carers' grief before and after the death of the person with dementia for whom they care. We systematically review the existing literature on characteristics, prevalence, predictors and associations of grief in dementia carers before and after death. Methods: We searched electronic databases and found 31 publications meeting predetermined criteria. Results: Grief in dementia carers, which may be normal or complicated, is a complex reaction to losses occurring before and after death. Carers experience anticipatory grief as multiple losses for themselves (companionship, personal freedom and control) and the person with dementia. Anticipation and ambiguity about the future, anger, frustration and guilt are core features. Anticipatory grief is greatest in moderate to severe stage dementia and spouse carers, especially when the person with dementia is institutionalised. There was poor quality evidence about the prevalence of grief; studies reported anticipatory grief between 47% and 71%, and complicated grief after death is estimated around 20%. Carer depression increases with anticipatory grief. Being a spouse carer and being depressed are the strongest predictors of complicated and normal grief after death. Conclusion: Grief in dementia carers can be expected; however, those at risk of distressing anticipatory and complicated grief may be identified and targeted for intervention when necessary. Higher quality research from a wider range of samples and countries is needed to explore this complex and emergent topic. (PsycINFO Database
13. Pre-death grief in Parkinson's caregivers: A pilot survey-based study

Author(s): Carter J.H., Lyons K.S., Lindauer A., Malcom J.

Citation: Parkinsonism and Related Disorders, December 2012, vol./is. 18/SUPPL. 3(S15-S18), 1353-8020;1873-5126 (December 2012)

Publication Date: December 2012

Abstract: Objective: To evaluate the evidence for pre-death grief in caregivers (CGs) of persons with Parkinson's disease (PD) and to compare non-motor PD symptoms (cognitive decline, depression, hallucinations) versus motor symptoms (fluctuations of mobility) for associations with CG grief reactions. Background: Prolonged grief in response to loss has been associated with negative outcomes and decreased well-being in caregivers (i.e. spouse or adult child) of relatives with dementia. In Parkinson's disease (PD) the negative impact of providing care has been referred to as caregiver strain. Grief has not been explored in PD caregivers, and understanding grief may offer new insights for future intervention. Methods: Volunteer caregivers (n = 74) filled out the Marwit and Meuser Caregiver Grief Inventory (MM-CGI-SF) which measures 3 types (i.e. subscales) of grief: Personal Sacrifice and Burden, Heartfelt Sadness and Longing, Worry and Felt Isolation. This scale also provided a total grief score. Volunteer caregivers also responded to self-reported UPDRS questions about the motor and non-motor symptoms of their PD relative (i.e. spouse or parent). T-tests were used to correlate CG subscales of grief with patient variables. A hierarchical regression analysis was used to determine the predictive contribution of motor and nonmotor symptoms to grief. Results: Grief based on the total score was found in 17% of CGs. Grief was significantly higher in CG's whose relative had more severe symptoms. The type of grief experienced was similar across all three subscales. Hierarchical regression analysis revealed that nonmotor symptoms explained slightly more of the variance (14-23%) than motor symptoms (11-17%). Conclusions: This study revealed that pre-death grief is a significant finding in PD caregivers. The severity of symptoms and the presence of nonmotor symptoms, especially cognitive decline, predict caregivers who are at greatest risk of prolonged grief; however it should be kept in mind that motor symptoms also contribute. 2012 Elsevier Ltd.

Source: EMBASE

14. The needs of informal carers for people with dementia.

Author(s) Egdoll, Valerie

Citation: British Journal of Healthcare Management, 01 December 2012, vol./is. 18/12(628-635), 13580574

Publication Date: 01 December 2012

Source: CINAHL

Available in fulltext from British Journal of Healthcare Management at EBSCOhost

15. Observatins and experiences of family members during end-of-life dementia care.

Author(s) Gnaedinger, Nancy, Robinson, Janice, McIvor, Sheilagh, Koebel, Tracy

Citation: Canadian Nursing Home, 01 December 2012, vol./is. 23/4(7-12), 08475520

Publication Date: 01 December 2012

Source: CINAHL

Available in fulltext from Canadian Nursing Home at EBSCOhost

16. Development of an Anticipatory Grief Scale for Family Caregivers of a Person Dying at
Abstract: Purpose: To develop an Anticipatory Grief Scale for Family Caregivers (AGSFC) of a person dying at home and analyze its reliability and validity. Methods: Based on a review of the literature and our previous study, a temporary scale consisting of 51 items was prepared. The scale was conducted on 99 families who were caring for a family member dying at home. As a control group, the scale was also conducted on 68 families who were providing care for a family member with a non-terminal disease. Results: As a result of factor analysis, 4 factors (spiritual pain in preparing for a loss, physical and mental fatigability in daily life, precedent anxiety regarding bereavement, and exhaustion) comprised of 19 items were extracted. The reliability of the scale was confirmed by a Cronbach's alpha internal consistency reliability coefficient of 0.87 (0.70DS0.85 for subscales). The criterion-related validity was confirmed by comparison with the 28-item General Health Questionnaire (GHQ28) scores. Construct validity was confirmed by comparison between families caring for a family member in the terminal stage and families providing care for a family member with a non-terminal disease. Conclusion: The reliability and validity of the AGSFC were confirmed. Therefore, this scale may be suitable for use with family caregivers of a person dying at home. Further, it is necessary to refine this scale.

Source: CINAHL

17. Continuity and loss: The carer's journey through dementia.

Author(s) Gillies, Brenda

Citation: Dementia (14713012), 01 September 2012, vol./is. 11/5(657-676), 14713012

Abstract: This paper looks at the ambiguous journey travelled by family, mainly spouse, carers in Scotland is based on 37 interviews which formed part of a larger study exploring the subjective experience of 20 individuals with dementia. The majority of the interviews were conducted with the carer alone, others with the relative with dementia (RWD) present and some as joint interviews. The carers are found to be recognizing many manifestations of loss in the loved one and, simultaneously in their carer role, striving to maintain continuity of that person through compensatory actions and the provision of a supportive care environment. These experiences are located along a trajectory of continuity and loss. This article provides further insight into the caregiving relationship in dementia and the complexities of maintaining that relationship in the shifting ground of a progressive illness.

Source: CINAHL


Author(s) Frazer, Soraya M., Oyebode, Jan R., Cleary, Adam

Citation: Dementia (14713012), 01 September 2012, vol./is. 11/5(677-693), 14713012

Abstract: This paper investigates the subjective experiences of older women living alone with Alzheimer’s disease, vascular or mixed dementia. Eight women were interviewed to explore how they managed their identities and coped with day-to-day living, in the absence of a significant co-resident other who might reflect them back to themselves. Through interpretative phenomenological analysis themes emerged about loss, embodiment, adapting, awareness, safety, relationships, exclusion and loneliness. Memory loss had the most significant impact through loss of independence. However, the women were actively engaged in re-constructing their sense of self, using a variety of coping strategies. Relationships with friends, neighbours and attendance at memory clubs were important. A
19. I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study.

**Author(s)**: Pipon-Young, Fiona E., Lee, Kristina M., Jones, Fergal, Guss, Reinhard

**Citation**: Dementia (14713012), 01 September 2012, vol./is. 11/5(597-616), 14713012

**Publication Date**: 01 September 2012

**Abstract**: In this study we explored the experiences of younger people with dementia (age 60–67 years) using an action research methodology across three phases. Phase One involved interviews with participants (n = 8). Phases Two (n = 5) and Three (n = 4) consisted of two action research groups. Thematic analysis highlighted few difficulties commonly associated with younger people with dementia (e.g. loss of employment). Participants highlighted a need for social support from a variety of sources as well as the opportunity to develop a shared social identity and a focus on remaining strengths. The ‘action’ (Phase Three) comprised a leaflet written by participants for other people with dementia. The findings suggest there is a need for people with dementia to receive information from people who have experienced dementia and for that information to foster a sense of hope and resilience. Furthermore, the findings support the use of action research methodologies with people with dementia.

**Source**: CINAHL

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20. [Telling the truth to Alzheimer and dementia patients in the early stages of the disease]

**Author(s)**: Ilan S., Glick S., Jotkowitz A.B.

**Citation**: Harefuah, September 2012, vol./is. 151/9(537-540, 555), 0017-7768 (Sep 2012)

**Publication Date**: September 2012

**Abstract**: Disclosing the diagnosis of Alzheimer’s disease to the patient is emotionally difficult and ethically challenging. Arguments against telling the truth include: diagnostic uncertainty, patient’s inability to understand the diagnosis, patient's unwillingness to recognize the diagnosis, potential negative social implications, unpredictable emotional reactions and losing hope. Arguments in favor of truth telling include: patient autonomy, relations with the physician based on trust, emotional adaptation, future planning and support for the patients and their family. Current research in Western countries indicates that most patients of all ages wish to know their diagnosis, whereas many relatives and physicians believe that they should conceal it from the patient. Many physicians experience difficulties in delivering the diagnosis to the patient. Studies show that less than half of them reveal the diagnosis to the patient and rarely discuss the prognosis, even though they convey this information to the relatives. Patients’ reactions to the diagnosis of Alzheimer’s disease is influenced by the way it is delivered, the patients’ emotional vulnerability, coping style and past experience with dementia. Reactions vary from denial, anger, fear, sorrow and depression to positive coping. The proper question is how to disclose the diagnosis and not whether it should be told. Disclosing the diagnosis is a complicated and dynamic process that should begin when there is suspicion of a cognitive decline. It demands physician sensitivity flexibility and discretion. Discussing the diagnosis in time enables the patient to be involved in treatment decisions and planning his or her future.

**Source**: EMBASE

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**Author(s)**: Burack, Orah R., Weiner, Audrey S., Reinhardt, Joann P.

**Citation**: Journal of the American Medical Directors Association, 01 July 2012, vol./is. 13/6(522-528), 15258610
**Abstract:** Abstract: Objectives: Distressing behavioral symptoms often associated with dementia are not uncommon in the long term care setting. Culture change with its “person-centered approach to care” provides a potential nonpharmacological intervention to reduce these symptoms. The purpose of this study was to examine the relationship between a culture change initiative and nursing home elders' behavioral symptoms. Design: Seven long term care communities (nursing units in 3 skilled nursing facilities) participated in a culture change intervention designed to transform the nursing home experience from a traditional hospital-model of care to one that is person-centered. Six comparison communities were matched to the intervention communities and continued to function along the typical nursing home organizational structure. Data were collected at baseline and 2 years later. Methods: Subjects were 101 elders (intervention group n = 50, comparison group n = 51). Each elder’s primary day certified nursing assistant completed the Cohen-Mansfield Agitation Inventory, examining frequency of behavioral symptoms, including verbal and physical agitation as well as more forceful behaviors (eg, hitting, kicking) at both data collection periods. Results: After controlling for functional status and race, a significant condition by time interaction was found for physical agitation and forceful behaviors with the person-centered group maintaining levels of behavioral symptoms as compared with a significant increase over time among the comparison group. A trend with the same pattern was found for verbal agitation. Conclusions: Person-centered care demonstrated potential as a nonpharmacological intervention for distressing behavioral symptoms. The positive impact of culture change appears to extend to elders with cognitive impairment who are less obvious beneficiaries of this model, featuring the central principals of autonomy and person-centered care.

Source: CINAHL

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22. The experience of pre-death grief in Parkinson's caregivers: A pilot study

**Author(s)** Carter J.H., Lyons K.S., Lindauer A., Malcom J.

**Citation:** Movement Disorders, June 2012, vol./is. 27/(S300), 0885–3185 (June 2012)

**Publication Date:** June 2012

**Abstract:** Objective: To evaluate the evidence for pre-death grief in caregivers (CGs) of persons with Parkinson's disease and to compare nonmotor (cognitive decline, depression, hallucinations) versus motor (fluctuations)symptoms in predicting grief. Background: Prolonged grief in response to loss has been associated with negative outcomes and decreased wellbeing in caregivers of relatives with dementia. In Parkinson's disease (PD) the negative impact of providing care has been conceptualized as caregiver strain. Grief has not been explored in PD caregivers and may offer new insights for intervention. Methods: Volunteer caregivers (n=74) filled out the Marwit and Meuser Caregiver Grief Inventory (MM-CGI-SF) which measures 3 types (i.e. subscales) of grief: Personal Sacrifice Burden, Heartfelt Sadness and Longing, and Worry and Felt Isolation plus a total grief score. They also responded to self-report UPDRS questions about the motor and nonmotor symptoms of their PD spouse. T-tests were used to correlate CG subscales of grief with patient variables. Hierarchical regression analysis was used to determine the predictive contribution of motor and nonmotor symptoms. Results: Grief (total score) was found in 17% of CGs. Grief was significantly higher in CG’s whose relative had more severe symptoms. The type of grief experienced was similar across all three subscales. Hierarchical regression analysis revealed that nonmotor symptoms explained more of the variance (14-23%) than motor symptoms (11-17%). Conclusions: This is the first study to show that pre-death grief is a significant finding in PD caregivers. Severity of symptoms and the presence of nonmotor symptoms, especially cognitive decline, predict caregivers who are at greatest risk of prolonged grief.

Source: EMBASE

Available in print at Lincoln County Hospital Professional Library

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23. "I want to find my life again": dementia and grief

**Author(s)** Rev Temple-Jones J.
Abstract: This first-person, qualitative narrative follows the author's encounters with Maureen (M), a resident in a long-term care (LTC) facility whose husband has recently died. The author (C), a Spiritual Care Professional, explores how shifts in identity provoked by dementia impact Maureen's grief. The author focuses on intersections between identity and dimensions of care, as clients with dementia lose the self due to the effects of the disease processes and/or by grief. This article challenges Spiritual Care Professionals to think beyond the neurologically dissipative symptoms of dementia towards reconstructing clients' identities using new feelings and conceptualizations and drawing from memory-based narratives where possible. The author calls for all paid caregivers and Spiritual Care Professionals in particular to consider creatively rethinking their actions and values using the social constructivist model when interacting with clients. Caregivers can encourage the reconstruction of self and identity among clients with dementia by recognizing that clients still feel all emotions even if they are no longer able to express these emotions through words.

Source: EMBASE

24. Living with mild cognitive impairment: The patient's and carer's experience

Author(s) Dean K., Wilcock G.

Citation: International Psychogeriatrics, June 2012, vol./is. 24/6(871-881), 1041-6102;1741-203X (June 2012)

Publication Date: June 2012

Abstract: Background: Mild cognitive impairment (MCI) is a relatively common condition and rates of diagnosis are likely to increase in the near future. Little is known about the experiences of patients with MCI and their carers nor about the most appropriate interventions to support this group. Methods: The existing literature on this topic up to July 2011 was identified via systematic searches of the Embase and Medline databases, the Cochrane Library and relevant sections of the National Electronic Library for Health. The main search term "mild cognitive impairment" was used in combination with other relevant terms. The reference lists of reviewed articles were also examined for any additional papers of significance. Papers identified by this method were examined and those deemed relevant were included in this review. Results: Twenty-one suitable papers were identified for inclusion in this review, a relatively small number. The studies reviewed suggest that patients with MCI and their carers face a variety of practical and emotional challenges. No interventional studies of support have been undertaken, but the authors of relevant observational studies have suggested provision of information, psychosocial support and strategies to enhance patient interaction with carers and social contacts. Conclusions: MCI results in significant challenges for both patients and their carers. Further work is required in order to establish the best way to help patients and carers meet these challenges. 2012 International Psychogeriatric Association.

Source: EMBASE

25. Staff outcomes from the Caring for Aged Dementia Care REsident Study (CADRES): A cluster randomised trial.

Author(s) Jeon, Yun-Hee, Luscombe, Georgina, Chenoweth, Lynn, Stein-Parbury, Jane, Brodaty, Henry, King, Madeleine, Haas, Marion

Citation: International Journal of Nursing Studies, 01 May 2012, vol./is. 49/5(508-518), 00207489

Publication Date: 01 May 2012

Abstract: Abstract: Background: Dementia care mapping and person centred care are well-accepted as processes for improving care and well-being for persons with dementia living in the residential setting. However, the impact of dementia care mapping and person centred care on staff has not been well researched. Objectives: The impact of person
centred care and dementia care mapping compared to each other and to usual dementia care on staff outcomes was examined in terms of staff burnout, general well-being, attitudes and reactions towards resident behavioural disturbances, perceived managerial support, and quality of care interactions. Design: A cluster-randomised, controlled trial. Settings: The study was conducted between 2005 and 2007 in 15 residential aged care sites in the Sydney metropolitan area, Australia, with comparable management structures, staffing mix and ratios, and standards of care. Participants: 194 consenting managers, nurses, therapists and nurse assistants working in the participating sites. Methods: Intervention care sites received training and support in either person centred care (n =5) or dementia care mapping (n =5); control sites continued with usual dementia care (n =5). Staff outcomes of those three groups were assessed before, directly after the four month intervention (post) and after a further four months (follow-up). The primary outcome measures were the Maslach Burnout Inventory-Human Services Survey and the 12-item General Health Questionnaire. Analysis involved repeated measures analyses of variance for each of the outcome measures and adjustment for potential confounders to limit bias. Results: The Maslach Burnout Inventory-Human Services Survey results showed that change over time in emotional exhaustion scores differed between the three groups. Post-hoc analyses for each group separately revealed that the only significant time effect was in the dementia care mapping group (p =0.006), with emotional exhaustion scores declining over time. At baseline, more perceived support from management was associated with less emotional exhaustion (r <sub>s</sub> =0.26, p =0.004, n =122) and less depersonalisation (r <sub>s</sub> =0.21, p =0.023, n =122), but not for any of the other outcome measures. Conclusions: This study has shown that person centred approaches of care, in particular with dementia care mapping, may contribute to reducing staff job related burnout. The findings also highlight a potentially important role of managerial support and a whole of system approach.

Source: CINAHL

26. Spousal relationships in which one partner has early cognitive problems.

Author(s) Prakke, Helena M.

Citation: Dementia (14713012), 01 May 2012, vol./is. 11/2(199-215), 14713012

Publication Date: 01 May 2012

Source: CINAHL


Author(s) von Kutzleben, Milena, Schmid, Wolfgang, Halek, Margareta, Holle, Bernhard, Bartholomeyczik, Sabine

Citation: Aging & Mental Health, 01 April 2012, vol./is. 16/3(378-390), 13607863

Publication Date: 01 April 2012

Abstract: OBJECTIVES: Including the perspectives of persons with dementia (PwD) is essential in order to organize care structures for them. With this systematic review, we set out to screen the existing scientific evidence on self-expressions of community-dwelling individuals with dementia in order to provide a research base for developing an intervention for persons in early stages of the disease. The leading research questions for this review are: What needs do PwD living at home express? What are their subjective demands? What do they do to cope with their situation? METHODS: We performed a systematic literature review of review publications on subjective experiences of PwD. The publications were analysed using MAXQDA 10 to perform a thematic analysis. RESULTS: We identified 41 relevant reviews, of which 6 met our inclusion criteria. PwD experience the whole range of human emotions. Their needs and demands do not differ significantly from those of other groups of patients with chronic conditions. Coming to terms with the disease and maintaining normality appeared to be major themes. With regard to expectations from the side of professional health care, the need for accompanying, continuous support and counselling appeared to be central. Furthermore, disclosure of diagnosis represents a
critical stage for PwD, but our findings indicated that they prefer to be included in this process. CONCLUSIONS: PwD are well able to express their needs. They should be included in research since they can provide valuable findings. Furthermore, those findings should be implemented in applied dementia care.

Source: CINAHL


Author(s) Garand, Linda, Lingler, Jennifer H, Deardorf, Kaitlyn E, DeKosky, Steven T, Schulz, Richard, Reynolds, Charles F, Dew, Mary Amanda

Citation: Alzheimer Disease and Associated Disorders, April 2012, vol./is. 26/2(159-165), 0893-0341 (Apr-Jun 2012)

Publication Date: April 2012

Abstract: Anticipatory grief is the process of experiencing normal phases of bereavement in advance of the loss of a significant person. To date, anticipatory grief has been examined in family caregivers to individuals who have had Alzheimer disease (AD) an average of 3 to 6 years. Whether such grief is manifested early in the disease trajectory (at diagnosis) is unknown. Using a cross-sectional design, we examined differences in the nature and extent of anticipatory grief between family caregivers of persons with a new diagnosis of mild cognitive impairment (MCI, n = 43) or AD (n = 30). We also determined whether anticipatory grief levels were associated with caregiver demographics, caregiving burden, depressive symptoms, and marital quality. The mean anticipatory grief levels were high in the total sample, with AD caregivers endorsing significantly more anticipatory grief than MCI caregivers. In general, AD caregivers endorsed difficulty in functioning, whereas MCI caregivers focused on themes of “missing the person” they once knew. Being a female caregiver, reporting higher levels of objective caregiving burden, and higher depression levels each had independent, statistically significant relationships with anticipatory grief. Given these findings, family caregivers of individuals with mild cognitive deficits or a new AD diagnosis may benefit from interventions specifically addressing anticipatory grief. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO

29. Identifiable Grief Responses in Persons With Alzheimer's Disease

Author(s) Gruetzner H., Ellor J.W., Back N.

Citation: Journal of Social Work in End-of-Life and Palliative Care, April 2012, vol./is. 8/2(151-164), 1552-4256;1552-4264 (April 2012)

Publication Date: April 2012

Abstract: Various dementias alter many aspects of the life and interactions between older adults and their families. This is particularly true even in a context in which the emotion is one that is expected. One such experience is the grief related to the loss of a family member. Physicians, nurses, and family members in long-term care report that they frequently have residents for whom a primary loved one, such as a spouse, has died. Questions quickly surface as to whether or not to tell the senior with dementia, how to tell the person, and how that person's response will impact the family. In two separate focus groups these questions were discussed with a group of family members and an interdisciplinary group of physicians, nurses, nurse aides, and social workers connected to long-term care facilities in one mid-sized community. Three patterns of resident response were identified. "Self-threat" describes situations in which the individual responds to the announcement of the death by questioning who will take care of them now; substitution refers to the individual's inability to remember who has died and substitution with a relative who died years ago; and metaphone, substitution of an object or unrelated item for the loss of a loved one. The authors suggest that persons with dementia should be told in most circumstances that their loved one has died, but that behavioral interventions need to be designed to address the confusion that this announcement can initiate. Families need to be prepared that the senior may not respond in the ways they once would have to this loss.
30. Stress in adult children caring for older parents with Dementia: A pilot study

Author(s) Solberg L.M., Solberg L.B., Peterson E.N.

Citation: Journal of the American Geriatrics Society, April 2012, vol./is. 60/(S239), 0002-8614 (April 2012)

Publication Date: April 2012

Abstract: Background: Adults caring for parents and their own children are the "sandwich generation". Their stress is noted in the behavioral sciences, but largely absent in medical literature. Clinical experiences showed adult children accompanying parents with dementia on clinic visits verbalized distress. The objective of this IRB-approved descriptive survey was to determine among a convenience sample of adult children caring for their parent with dementia the prevalence and severity of emotional and social changes and financial burden since assuming caregiver role. Methods: The study took place at a geriatric private practice. Adult children caregivers completed a 51-item survey (Cronbach's alpha . 80) on impact of the caregiving role on emotion, stress, and finances and coping mechanisms. Of those surveyed 85/95(89%) were returned. 45/85(47%) respondents were primary caregivers of demented elderly parents and 18/45(47%) were of the "sandwich generation. " Descriptive statistics were conducted using SPSS. Results: On average caregivers were 54 years old, 36/45(80%) women, 28/45(62%) were married, 38/45(84%) had children, 18/45(47%) were "sandwich generation. " There was no significant difference in mean caregiver burden between the sandwich generation and non-sandwich generation adult children. Caregivers reported little impact on their professional lives. Over a third reported stress in caring for the older adults' daily needs, felt more irritable, and more feelings of anxiety. 53% reported taking their parent to doctors' appointments was emotionally difficult. Participating in activities of interest/hobbies decreased, but not time spent with friends. Helpful services were seminars on care of demented parents (58%), meetings with social workers for resource availability (63%), and seminars on coping mechanisms (53%). Conclusions: Adult children caring for demented parents experienced stress, anxiety, and sadness. Caregivers' emotions were negatively impacted but not their finances or careers. Emotional stress decreased activities of interests, but not social interactions. Clinicians need to direct attention to the caregivers' emotional well being as part of routine care of the elderly. Helpful coping mechanisms were identified by the respondents. Further program development to support adult children caregivers may be beneficial.

Source: EMBASE

Available in fulltext from Journal of the American Geriatrics Society at EBSCOhost

31. Association between anticipatory grief and social problem solving among caregivers

Author(s) Fowler N.R., Hansen A., Garand L.

Citation: Clinical and Translational Science, April 2012, vol./is. 5/2(158), 1752-8054 (April 2012)

Publication Date: April 2012

Abstract: OBJECTIVES/SPECIFIC AIMS: Caregivers of adults with cognitive impairment (CI) must solve problems and participate in shared decision making for medical decisions. Little is known about the role of anticipatory grief on caregivers' ability to solve problems and participate in medical decisions. Th is study examines the association between anticipatory grief and social problem solving abilities of caregivers for older adults CI. METHODS/STUDY POPULATION: Retrospective analysis of baseline measures from a caregiver self-management intervention clinical trial. Included 73 caregivers of patients with either MCI or dementia from the University of Pittsburgh Alzheimer's Disease Research Center. Primary outcome measure was social problem-solving ability using the Social Problem-Solving Inventory-Revised: Short (SPSI-R:S). Primary independent variable was anticipatory grief using the Anticipatory Grief Scale (AGS). Th e regression model collapsed AGS scores into tertiles. Covariables included two personality traits (openness to
experience and conscientiousness), household income, patient diagnosis, and caregiver role. RESULTS/ANTICIPATED RESULTS: Mean age of caregivers was 64.9 years and 78.1% were female. 75.3% were spouses, 79.5% had some college and 46.5% reported an annual household income of >=$60,000. They endorsed a mean standardized SPSI-R:S score of 110.2 (9.8) and a mean AGS score of 70.1 (14.8). The multivariable model indicates those who had AGS scores in the lowest tertile had significantly higher social problem solving abilities scores (p < 0.05) compared to those with AGS scores in the highest tertile. DISCUSSION/SIGNIFICANCE OF IMPACT: Anticipatory grief may impact problem solving and decision-making abilities. It may be appropriate to develop decision aids for caregivers that explicitly address these emotions.

Source: EMBASE

32. Anticipatory Grief Among Close Relatives of Patients in Hospice and Palliative Wards

Author(s) Johansson A.K., Grimby A.

Citation: American Journal of Hospice and Palliative Medicine, March 2012, vol./is. 29/2(134-138), 1049-9091 (March 2012)

Publication Date: March 2012

Abstract: A Swedish widowhood study revealed that four out of ten widows regarded the pre-loss period more stressful than the post-loss. The present investigation of close relatives to patients dying from cancer (using interviews and the Anticipatory Grief Scale) found that preparatory grief involves much emotional stress, as intense preoccupation with the dying, longing for his/her former personality, loneliness, tearfulness, cognitive dysfunction, irritability, anger and social withdrawal, and a need to talk. Psychological status was bad one by every fifth. However, the relatives mostly stated adjustment and ability to mobilize strength to cope with the situation. The results suggest development of support and guiding programs also for the anticipatory period. SAGE Publications 2012.

Source: EMBASE

33. Coping With Behavior Problems in Patients With Dementia

Author(s) Lippa, Carol F.

Citation: American Journal of Alzheimer's Disease & Other Dementias, 01 March 2012, vol./is. 27/3(149-150), 15333175

Publication Date: 01 March 2012

Source: CINAHL

34. “The Hidden Caregiver”: Kinship Caregivers and Lessons Learned from Dementia Family Caregiving.

Author(s) Lane, Geoffrey Woodward, Podgorski, Carol Ann, Noronha, Delilah Olivia, King, Deborah

Citation: Clinical Gerontologist, 01 March 2012, vol./is. 35/2(195-203), 07317115

Publication Date: 01 March 2012

Abstract: Kinship care is defined as informal custodial care for children (typically grandchildren) due to parental hardship or absence. In contrast, dementia family caregiving refers to care rendered to an impaired, demented adult, typically an older husband or wife. Literature is reviewed and parallel issues relating to stress and coping that impact both caregiver groups are noted. Data are presented from both survey and focus groups conducted with kinship caregivers and their social service caseworkers. In light of previous research conducted with dementia caregivers, practice implications are discussed and several specific recommendations are presented for program development and further research with kinship caregivers.

Source: CINAHL
35. The Leisure Journey for Sandwich Generation Caregivers.

Author(s) Schumacher, Lisa A. P., MacNeil, Richard, Mobily, Kenneth, Teague, Michael, Butcher, Howard

Citation: Therapeutic Recreation Journal, 01 March 2012, vol./is. 46/1(42-59), 00405914

Publication Date: 01 March 2012

Abstract: The purpose of this phenomenological study was to describe the lived experience of leisure for adults in the sandwich generation who care for a parent with dementia and at least one dependent minor child who resides with the caregiver. The findings of this study suggest that leisure is important to sandwich generation caregivers (SGC). However, participants did not understand the significance of leisure to their own health at the beginning stages of their caregiving journey. Therapeutic recreation is a vehicle to introduce the health benefits of leisure to SGC. Six sandwich generation caregivers participated in open-ended in-depth interviews. Six essential themes emerged from the data and were synthesized to form this hermeneutic summary: The leisure journey for SGC was experienced as "reconciling life transitions while succumbing to infinite obligations and managing time shifts to constructing a foundation that enables you to revisit control and embrace the freedom to recreate."

Source: CINAHL

36. Assessment and treatment of behavior problems in dementia in nursing home residents: a comparison of the approaches of physicians, psychologists, and nurse practitioners.

Author(s) Cohen-Mansfield, Jiska, Jensen, Barbara, Resnick, Barbara, Norris, Margaret

Citation: International Journal of Geriatric Psychiatry, Feb 2012, vol. 27, no. 2, p. 135-145, 0885-6230 (February 2012)

Publication Date: February 2012

Abstract: Research in the USA among doctors, psychologists and nurse practitioners to examine approaches to the assessment and treatment of behavioural problems relating to dementia among elderly residents in nursing homes. Responses from an Internet-based survey are described concerning types of challenging behaviour experienced, assessment methods, cause of problems and use of interventions including drug therapy and changes in procedures or activities. Professionals' levels of frustration with interventions used are discussed. [ORIGINAL] 47 references

Source: BNI
Available in fulltext from International Journal of Geriatric Psychiatry at EBSCOhost

37. Anticipatory grief among family caregivers of patients with advanced cancer, congestive heart failure, and chronic obstructive pulmonary disease

Author(s) Sautter J., Steinhauser K., Tulsky J.

Citation: Journal of Pain and Symptom Management, February 2012, vol./is. 43/2(450-451), 0885-3924 (February 2012)

Publication Date: February 2012

Abstract: Overall Objectives 1. Identify risk factors for caregiver anticipatory grief. 2. Become aware of differences in caregiver reactions to advanced chronic illness. Background. Anticipatory grief (AG) is associated with depression and anxiety and may have implications for post-death bereavement. Most AG research has focused on progressive and somewhat predictable diseases such as dementia or cancer, which contrast with the slow decline and unpredictable exacerbations of congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD). Research Objective. Our objective was to examine whether AG is lower among CHF and COPD caregivers compared to cancer caregivers. Method. Data are from a prospective, observational study of 141 patient-caregiver dyads living with advanced cancer, CHF, and COPD. Dyads were
interviewed monthly for up to two years. Measures included the Anticipatory Grief Scale which measures anger, guilt, anxiety, irritability, sadness, feelings of loss, and decreased ability to function at usual tasks. We dichotomized AG scores and used logistic regression to examine differences in likelihood of high AG by diagnosis, patient, and caregiver factors. Aggregate growth curve models examined change over time. Result. At baseline, COPD caregivers were significantly less likely to experience high AG compared to caregivers for cancer (OR = 0.04, 95% CI = 0.003, 0.53). CHF caregivers followed a similar pattern, but the difference was not significant (OR = 0.16, 95% CI = 0.13, 1.05). Anticipatory grief levels remained consistent over time for all diagnostic groups. Nonwhite caregivers were significantly more likely to experience high AG compared to white caregivers (OR = 13.04, 95% CI = 10.34, 124.75); adult child caregivers were less likely to experience high AG compared to spousal caregivers (OR = 0.05, 95% CI = 0.25). Conclusion. Variation in anticipatory grief is a function of disease differences and is not affected by location in the disease trajectory. Implications for Research, Policy, or Practice. Interventions to address caregiver AG should target specific groups that demonstrate higher levels of AG instead of targeting points in the disease course.

Source: EMBASE


Author(s) Mulligan, Elizabeth Anne

Citation: Dissertation Abstracts International: Section B: The Sciences and Engineering, 2012, vol./is. 72/12-B(7693), 0419-4217 (2012)

Publication Date: 2012

Abstract: Research suggests that family caregivers of people with dementia may experience grief prior to the death of their care recipients, in part because of the series of losses they experience and the chronic nature of caregiving. Methods for assessing predeath grief, however, are just beginning to be developed, and basic questions about measurement remain. The purpose of the current study was to identify areas of overlap and disjunction in two self-report measures of predeath grief, one adapted from the postdeath literature (the Prolonged Grief Disorder Inventory) and one designed specifically for use with dementia caregivers (the Marwit-Meuser Caregiver Grief Inventory-Short Form). Results from 202 spousal and adult child caregivers of people with dementia suggest that grief is an important component of the caregiving experience, and that it is related to, but distinct from, depression. Based on their psychometric properties and on confirmatory factor analyses, both measures appear to be appropriate for use with dementia caregivers. There were several areas of overlap between the measures in terms of their relationships with characteristics of caregivers and of the caregiving situation (e.g., spousal versus adult child relationship with the care recipient), although these associations varied somewhat across subscales. One area of discrepancy between the measures was the number of caregivers identified as potentially in need of intervention; the Prolonged Grief Disorder Inventory was a more conservative tool. This dissertation represents an important first step in understanding the grief experienced by dementia caregivers. Future research is needed to determine if predeath grief as measured by each instrument is predictive of long-term distress and dysfunction in the context of longitudinal studies. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

Source: PsycINFO


Author(s) Boss, Pauline

Citation: A psychodynamic understanding of modern medicine: Placing the person at the center of care, 2012(183-193) (2012)

Publication Date: 2012

Abstract: (from the chapter) When illness or injury takes away a family member’s memory or emotions, the incongruence between being here and gone is deeply disturbing. Such ambiguity creates a complicated grief for family caregivers that is in a category of its own. The abnormality that causes so much trouble is the ambiguity—knowing if a person is
here or not here. Ambiguous loss is an unclear loss and thus is without closure. It is caused by an external force (e.g. illness or injury) that prevents clarity about a loved one's status as present or absent. This chapter focuses on the ambiguous loss of psychological absence, specifically as manifested by dementia and the complicated grief it causes for those closely attached to the patient. The premise of ambiguous loss theory is that ambiguity coupled with loss creates a powerful barrier to coping and grieving. There is no validation of loss (as with death) so the mind remains confused about what is happening. The author describes the psychoanalytic roots and treatment implications of ambiguous loss, and concludes that this more relational view of unresolved loss and grief suggests that we pay more attention to caregivers' relational contexts of their loss and the pain that it causes. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

Source: PsycINFO

40. Grief in spousal caregivers of persons with frontotemporal lobar degeneration: Exploring the relationship between challenging behaviors and caregiver grief.

Author(s) Guerrero, Susan

Citation: Dissertation Abstracts International: Section B: The Sciences and Engineering, 2012, vol./is. 72/9-B(5570), 0419-4217 (2012)

Publication Date: 2012

Abstract: Frontotemporal Lobar Degeneration (FTLD) is the second most prevalent dementia after Alzheimer's Disease and is characterized by profound changes in social, interpersonal, and emotional behaviors as well as an emergence of disinhibition or inappropriate behaviors. The devastating emotional effects FTLD has on patients and their families are not well understood. This study investigated the relationship between frontal systems behavioral functioning (i.e., disinhibition, apathy, and executive dysfunction) and the experience of grief and burden on spousal caregivers of persons with FTLD. It was hypothesized that symptom severity would positively correlate with caregiver grief and burden. Seventy-six spousal caregivers of individuals with FTLD completed self-report measures of caregiver grief, caregiver burden, and a measure of frontal systems behavioral functioning in the care recipient, a demographic questionnaire, and one optional open-ended question. Results supported the hypotheses in showing a positive correlation between challenging behaviors in the care recipient and caregiver grief, \( r = .54, p < .001 \), and burden, \( r = .41, p < .001 \). It was further found that caregiver burden significantly predicts levels of caregiver grief, \( r = .73, p < .001 \). Results strongly support managing care recipient challenging behaviors as a way of decreasing caregiver burden along with grief therapy. Caregiver grief is a complex construct and caregivers of persons with FTLD need more support than is currently available. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

Source: PsycINFO

41. Perceived strains and benefits among family caregivers of elderly with Alzheimer's disease

Author(s) Lopes L., Forlenza O., Nunes P., Santos G., Cachioni M.

Citation: Alzheimer's and Dementia, 2012, vol./is. 8/4 SUPPL. 1(P379), 1552-5260 (2012)

Publication Date: 2012

Abstract: Background: Caregiving appraisal is influenced by objective and subjective events and by personal and social resources. Although considered mostly in terms of strain, there is clinical and social interest in identifying its benefits on subjective well-being of family caregivers. Methods: A survey was conducted with 21 family caregivers. They were aged 37 to 77 years (mean 59 years), being 66.7% female and 57.1% spouses of patients with AD, 47.6% had higher education, 61.9% worked outside the home, 66.5% had monthly household income of up to five minimum wages (R$ 3,110.00) and 80% of caregivers lived in the same household as the elderly with AD. The interviews were conducted with caregivers using a sociodemographics form and an Inventory of Perceived Benefits and Strains Concerning Caregiving [yes-not positive (19) and negative (29) items covering physical, social and psychological issues, selected through previous research with
specialists]. Results: Reported benefits were slightly predominant, with superiority of those pertaining to the psychological domain. Among them there were: caring for love (90%); utility (90%); closeness (85.6%); feelings of self-satisfaction (81%); pleasure and satisfaction with care (71%). Social benefits were cited by only 38% of caregivers in relation to family cohesion 28.6% considered example of solidarity and 23.8% reported improvement in family relationships and social value. Negative evaluation in the psychological domain was associated with feelings of sorrow for the irreversibility of their disease (76%); compassion for the elderly (66%); anxiety and sadness (57%). In the social domain the negative evaluations were mentioned: no delegation of care (43%); lack of time for leisure (29%); lack of time for family and friends (19%); and increased family conflicts (19%). The physical strain was reported as: tiredness (52%), insomnia (38%), health deterioration (29%) and lack of time to rest (9.5%). Conclusions: Caring cannot be considered a homogeneous experience. The results suggested that the context of care is complex and involves positive and negative meanings. However, the perceived psychological benefits exceeded the perceived social, physical, psychological strains.

Source: EMBASE

42. Grief and joy: Emotion word comprehension in the dementias

Author(s) Hsieh S., Foxe D., Leslie F., Savage S., Piguet O., Hodges J.R.
Citation: Neuropsychology, 2012, vol./is. 26/5(624-630), 0894-4105;1931-1559 (2012)
Publication Date: 2012
Abstract: Objective: Word comprehension deficits in neurodegenerative conditions are most striking in the syndrome of semantic dementia. Tests of word comprehension typically examine concrete and abstract nonemotion words. Whether or not understanding of words describing emotion concepts (e.g., insulted, fascinated) is also impaired in the dementias has not been systematically investigated. Method: Patients with semantic dementia (SD; n = 8), behavioral-variant frontotemporal dementia (bvFTD; n = 8), Alzheimer's disease (AD; n = 12), as well as healthy controls (n = 15) completed newly designed emotion word comprehension tasks. Participants also undertook the Graded Synonyms Test, an abstract and concrete nonemotion word comprehension measure. Results: Degradation of knowledge about negative and positive emotion words was most impaired in SD. Correlation analyses in the SD group also showed that knowledge of emotion words correlated with the understanding of abstract nonemotion words. The bvFTD group was impaired only when making associations for emotion words. The AD cohort did not differ from controls on any measures of word comprehension. Conclusions: Impairment in word knowledge is greatest in the syndrome of SD, compared with bvFTD and AD, and includes concrete words, abstract words as well as emotion words. Importantly, word comprehension deficits affect positive and negative emotions. 2012 American Psychological Association.

Source: EMBASE

43. Multiple mediators of the relations between caregiving stress and depressive symptoms.

Author(s) Mausbach BT, Roepke SK, Chattillion EA, Harmell AL, Moore R, Romero-Moreno R, Bowie CR, Grant I
Citation: Aging & Mental Health, 01 January 2012, vol./is. 16/1(27-38), 13607863
Publication Date: 01 January 2012
Abstract: Objective: This study tested a model for explaining how stress is associated with depressive symptoms in a sample of spouse caregivers of patients with Alzheimer's disease. It was hypothesized that more depressive symptoms would be significantly correlated with both 'primary' caregiver stressors (i.e., care recipient problem behaviors) and 'secondary' stress (i.e., role overload), but that this relationship would be significantly mediated by four variables: (1) personal mastery, (2) coping self-efficacy, (3) activity restriction, and (4) avoidance coping. Method: We used an asymptotic and resampling strategy for simultaneously testing multiple mediators of the stress-to-depressive symptoms pathway. Results: Greater stress was significantly related to more depressive symptoms.
Increased stress was also associated with reduced personal mastery and self-efficacy, as well as increased activity restriction and avoidance coping. Finally, these four mediators accounted for a significant amount of the relationship between stress and depressive symptoms. Discussion: These results suggest multiple pathways by which both primary and secondary caregiver stresses may be associated with increased depressive symptoms, and may argue for multiple treatment targets for caregiver interventions.

Source: CINAHL

44. Dementia in the family: the caring experiences of grandchild.

Author(s) Philipp-Metzen, Elisabeth

Citation: Journal of Dementia Care, 01 January 2012, vol./is. 20/1(35-37), 13518372

Publication Date: 01 January 2012

Source: CINAHL

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R Madsen, R Birkeland - Journal of Clinical Nursing, 2013 - Wiley Online Library
... Instead, they used words like disappointment, emotional involvement, anger, worry and sorrow. ... Significant similarities about change, grief and personal negative sentiments were identified. ... 2002) Handbook of Bereavement Research. Consequences, Coping and Care, 3rd edn. ...

Continuity and loss: The carer's journey through dementia
B Gillies - Dementia, 2012 - dem.sagepub.com
... and where the wife, in spite of her advancing Alzheimer's disease, confirmed that her husband's growing confidence and expertise... here 'whereby the carers still defined themselves as being in relation with the person with dementia, saw them... Better a dead sorrow than a live one ...
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... Karen stated, “I lost my mother to Alzheimer’s long ago—all I had was memories, but now I don't even have those—it is too painful to even think of her now.” I suggested we use EMDR immediately to de-crease the traumatic memories that were interfering with normal grief ...
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