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**Literature search results**

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<td>Marilyn Shaw</td>
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**Search details**

The impact dementia has on a person’s identity. (Last five years-worth of articles)

**Resources searched**

NHS Evidence; TRIP Database; Cochrane Library; AMED; BNI; CINAHL; EMBASE; HMIC; Health Business Elite; MEDLINE; PsychINFO; Google Scholar; Google Advanced Search

**Database search terms:** Dementia: identity: self-identity: impact

**Evidence search string(s):**

**Google search string(s):** “impact of dementia on identity”

**Summary**

There are a number of articles related to this search and also those dealing with community identity.

**Guidelines and Policy**

CG 123 Common mental health disorders: full guideline


**Evidence-based reviews**

1. The impact of dementia on self and identity: A systematic review.

Author(s) Caddell, Lisa S, Clare, Linda
Abstract: There is much debate in the literature as to the extent to which self and identity persist in people with dementia. The aim of this systematic review was to examine methods currently used to investigate self and identity in people with dementia, and the resulting evidence as to the persistence of self and identity throughout the course of the disease. Thirty-three studies were reviewed, which showed that many approaches have been taken to studying aspects of self and identity in dementia, including both quantitative and qualitative methods. This appears to be partly due to the differing underlying concepts of self that have been used as a basis for these studies. Consequently, results obtained from these studies are somewhat disparate, although it is possible to draw some tentative conclusions from the available evidence. Almost all of the studies suggest that there is at least some evidence for persistence of self in both the mild and moderate to severe stages of the illness, although many studies record some degree of deterioration in aspects of self or identity. Further research is required to clarify existing evidence and to address outstanding questions regarding self and identity in dementia. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO

2. Caddell LS, Clare L

Interventions supporting self and identity in people with dementia: a systematic review

Aging and Mental Health, 2011, 15 (7) p797 -810

There has been an increase in research focusing on how self and identity are affected by the onset and progression of Alzheimer’s disease and other forms of dementia. The purpose of this article is to review the main features of interventions aiming to support self and identity in people with dementia, to draw conclusions regarding the effectiveness of these interventions, and to highlight the implications for future research. Following a comprehensive literature search, 10 studies were selected which met the inclusion criteria. All reported some benefits to participants. There were significant methodological limitations and study quality was generally low. The interventions varied in terms of participant characteristics, content and outcome measures. The article concludes that intervention research in this area is in the preliminary stages, and it is thus difficult to draw any conclusions from the evidence to date. However, the studies do highlight the potential of such interventions to support and improve well-being in people with dementia and suggest that further investigation is warranted.

3. Steeman Els et al

Living with early-stage dementia: a review of qualitative studies


This review covers 33 articles, identified from three bibliographic databases, that focus on the subjective experience of living with early-stage dementia. It describes the process from the stage at which an individual discovers a memory impairment, through the diagnosis of dementia to the attempts made to integrate the impairment into everyday life. In the early stages individuals use self-protecting and self-adjusting strategies to deal with the changes, and with the perceived threats they pose to their feelings of security, autonomy and being a meaningful member of society. However, the memory impairment itself can make it difficult to deal with these changes, causing frustration, uncertainty and fear.

Published research – Databases


Author(s) Daley, Stephanie, Newton, David, Slade, Mike, Murray, Joanna, Banerjee, Sube

Citation: International Journal of Geriatric Psychiatry, May 2013, vol./is. 28/5(522-529), 0885-6230;1099-1166 (May 2013)

Abstract: Objective: To evaluate whether a conceptual framework of recovery developed
for working age adults holds value for users of older people's mental health services, including those with dementia. Method: Thirty-eight qualitative interviews were undertaken with service users and carers from an older people's mental health service in South London and were analyzed using grounded theory methods. Results: Components of recovery, which appear to be meaningful to older people with mental disorder include the following: (i) the impact of illness, (ii) the significance of personal responsibility, and (iii) specific coping strategies. Unlike their younger peers, older people did not aspire to a new and revised sense of identity, nor did they seek peer support from others with lived experience of mental illness. Three components of recovery were identified as being distinct to older people: the significance of an established and enduring sense of identity; coping strategies, which provide continuity and reinforce identity; and the associated impact of physical illness. Finally, two additional components of recovery were identified for people with dementia: (i) the changing experience over time and (ii) support from others. Conclusion: Mental health policy is increasingly framed in terms of 'recovery'. This paper provides empirical evidence of how it applies to users of older people's mental health services. Practice implications include the need to focus on the maintenance of identity, and embed the values of empowerment, agency and self-management within service delivery. (PsycINFO Database Record (c) 2013 APA, all rights reserved) (journal abstract)

Source: PsycINFO

5. Clinical presentation of delusion in dementia disorder.

Author(s) Herlant-Hemar, Kristina, Caron, Rosa

Citation: L'Evolution Psychiatrique, April 2013, vol./is. 78/2(279-289), 0014-3855 (Apr-Jun 2013)

Abstract: Reaching a very elderly age can be a critical experience, involving massive often painful loss. Losing one's physical capacities, loved ones, social status, home, etc. can provoke an identity crisis, potentially leading to a new approach to self, or in certain persons, to psychiatric disorders. As life expectancy, and by consequence the prevalence of age-related morbidity, increases, the human and social impact of psychopathological disorders in the very elderly is becoming a major challenge for scientific research. Based on the clinical case of a 70-year-old nursing home resident, we propose a reflection on persecutory delusions as a mode of deterioration in a context of early-stage dementia. Considering the patient's past history and her own comments on her life experience as an institutional resident, as well as the transfer movements operating during the interviews, we attempt to highlight the way in which delusional construction and reconstruction processes created meaning for her, examining the way delusion can function as a supportive element for a coherent identity. In a determinedly clinical approach, articulating an analytical reading and a phenomenological approach, we shall be interested in her history as well as her current real-life experience in institution such as she delivers it to us during the conversations. By pressing us on the movements in the transfer, we shall try to bring to light the way the delirious construction and the reconstruction can make sense for her, and which functions the delusion can have in the preservation of a shape of identical cohesion. (PsycINFO Database Record (c) 2013 APA, all rights reserved) (journal abstract)

Source: PsycINFO

6. Identity, mood, and quality of life in people with early-stage dementia.

Author(s) Caddell, Lisa S, Clare, Linda

Citation: International Psychogeriatrics, August 2012, vol./is. 24/8(1306-1315), 1041-6102:1741-203X (Aug 2012)

Abstract: Background: There is little empirical research regarding the relationships between identity and well-being in people with dementia. The aim of the study was to explore the relationship of identity with mood and quality of life (QoL) in the people in the early stages of dementia. Method: This was a cross-sectional questionnaire-based study. Fifty people in the early stages of dementia completed measures pertaining to different aspects of identity, mood, and QoL. Multiple regression analyses were carried out to determine whether it was possible to predict any of the variance in mood and QoL from aspects of identity. Results: It was possible to predict 12.8% of the variance in anxiety, 23.4% of the variance in depression, and 25.1% of the variance in QoL from different aspects of identity. Predictors varied for each dependent variable. Conclusions: Aspects of identity predict a modest proportion of the variance in anxiety, depression, and QoL. This suggests that supporting identity in people with dementia who are experiencing difficulties in this regard might have a positive impact on mood and QoL. However, the majority of the variance in mood and QoL must be accounted for by other variables. (PsycINFO Database Record (c) 2013 APA, all rights reserved) (journal abstract)

Source: PsycINFO
7. The importance of remembering and deciding together: Enhancing the health and well-being of older adults in care.

**Author(s)** Haslam, Catherine, Jetten, Jolanda, Haslam, S. Alexander, Knight, Craig P

**Citation:** The social cure: Identity, health and well-being., 2012(297-315) (2012)

**Abstract:** (from the chapter) Despite the claim that the memory loss associated with dementia destroys the person, there are also reports that some elements of self, particularly from the distant past, survive even in advanced stages of the disease (Cohen-Mansfield, Golander, & Arnheim, 2000; Davis, 2004; Kitwood, 1993; Klein, Cosmides, & Costabile, 2003; Sabat & Harre, 1992). Importantly, these remnants can provide a foundation from which the self can, to some extent at least, be reconstructed. However, it is not entirely clear how best to harness these remnants and how to build upon them in order to achieve this outcome. In addition, for many people residing in care, memory loss is not the only threat to self that they confront. For, over time, they often develop an increasing sense of powerlessness, particularly as decisions about care are increasingly made on behalf of residents and hence, are no longer under their control. Unsurprisingly, this too has a major impact on people's sense of who they are and can in turn affect their well-being. In this chapter we argue that group-based interventions that promote a sense of shared social identification and collective empowerment have the potential to reduce the threat to identity that results from increasing loss of memory and diminishing control. To make this case, we focus on findings from two intervention studies that we recently conducted. In the first of these we examined the impact of reminiscence therapy on cognitive performance. In the second, we looked at the impact of empowering residents to make decisions about the decor in their home on cognition and well-being as well as on their use of communal space. As we will see, the reminiscence intervention was effective in bolstering memory only when it was administered to a group. In a similar vein, we show that allowing people to choose their decor collectively had a positive impact on well-being and perceived control. In line with the theoretical principles that informed the design of these studies, we argue that both sets of findings are best understood in terms of a social identity perspective on health and well-being (e.g., see Haslam, Jetten, Postmes, & Haslam, 2009). This points to the benefits that developing a sense of shared group membership can have for a person's quality of life, and suggests that this may be a particularly important pathway for both understanding and improving the lives of people residing in care. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Source:** PsycINFO

8. Preserving the "us identity" through marriage commitment while living with early-stage dementia.

**Author(s)** Davies, Judie C

**Citation:** Dementia: The International Journal of Social Research and Practice, May 2011, vol./is. 10/2(217-234), 1471-3012;1741-2684 (May 2011)

**Abstract:** Recognizing the impact of marriage commitment to living with early-stage dementia has important implications for developing proactive care for individuals with dementia and their families. This mixed method study of six couples experiencing early-stage Alzheimer's dementia explored how married couples experienced the meaning of commitment through memory loss represented by the transitional process of pre-diagnosis, diagnosis, and post-diagnosis. Narrative analysis was used to identify shared themes from couples' accounts through semi-structured interviews and supported by questionnaires related to commitment and marriage satisfaction. Couples' commitment was expressed by four major themes: 'partnership for life', 'reciprocity', 'resilience', and 'forgiveness'. Couples' experienced an undisturbed, enduring commitment to their relationship in spite of the diagnosis of dementia. The 'us identity' of the couple, living-in-relationship, remained intact. Couples considered the challenge of dementia to be a collaborative venture - a journey into the unknown. (PsycINFO Database Record (c) 2012 APA, all rights reserved)

**Source:** PsycINFO

9. What affects pleasure in persons with advanced stage dementia?

**Author(s)** Cohen-Mansfield, Jiska, Marx, Marcia S, Freedman, Laurence S, Murad, Havi, Thein, Khin, Dakheel-Ali, Maha

**Citation:** Journal of Psychiatric Research, March 2012, vol./is. 46/3(402-406), 0022-3956
Abstract: We examined the impact of environmental, person, and stimulus characteristics on pleasure in persons with dementia. Study participants were 193 residents of 7 Maryland nursing homes who were presented with 25 stimuli from these categories: live human social stimuli, live pet social stimuli, simulated social stimuli, inanimate social stimuli, a reading stimulus, manipulative stimuli, a music stimulus, task and work-related stimuli, and two different self-identity stimuli. Systematic observations of pleasure in the natural environment were conducted using Lawton's Modified Behavior Stream. Analysis showed that pleasure is related to stimulus category, personal attributes and environmental conditions. In the multivariate analyses, all types of social stimuli (live and simulated, human and nonhuman), self-identity stimuli, and music were related to significantly higher levels of pleasure than the control condition. Females and persons with higher ADL and communication functional status exhibited more pleasure. Pleasure was most likely to occur in environments with moderate noise levels. These results demonstrate that these nursing home residents are indeed capable of showing pleasure. Caregivers of nursing home residents with dementia should incorporate social, self-identity, and music stimuli into their residents' care plans so that eliciting pleasure from each resident becomes the norm rather than a random occurrence. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)
Phenomenological Analysis to explore participants' perceptions of the impact of dementia on their identity. Participants were ten people with dementia. The four themes emerging from the data represented participants' views on aspects of their current identities, whether they believed that dementia would alter their identities in the future, perceptions of how dementia had affected their lifestyle, and relationships with friends and family. The analysis suggested that for the most part, participants felt that little had changed with respect to their identities as a whole, but most identified features of themselves that were different than they had been prior to the onset of dementia. Thus it appeared that participants were in a state of flux, experiencing both continuity and change in their sense of identity simultaneously. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO

### 13. The social treatment: The benefits of group interventions in residential care settings.

**Author(s)** Haslam, Catherine, Haslam, S. Alexander, Jetten, Jolanda, Bevins, Adam, Ravenscroft, Sophie, Tonks, James

**Citation:** Psychology and Aging, March 2010, vol./is. 25/1(157-167), 0882-7974;1939-1498 (Mar 2010)

**Abstract:** We report findings from an intervention study that investigates the impact of group reminiscence (GR) and individual reminiscence (IR) activities on older adults living in care settings. This research aimed to provide a theory-driven evaluation of reminiscence based on a social identity framework. This framework predicts better health outcomes for group-based interventions as a result of their capacity to create a sense of shared social identification among participants. A total of 73 residents, living in either standard or specialized (i.e., dementia) care units, were randomly assigned to one of three interventions: GR (n = 29), IR (n = 24), and a group control activity (n = 20). The intervention took place over 6 weeks, and cognitive screening and well-being measures were administered both pre- and post-intervention. Results indicated that only the group interventions produced effective outcomes and that these differed as a modality-specific function of condition: Collective recollection of past memories enhanced memory performance, and engaging in a shared social activity enhanced well-being. Theoretically, these findings point to the important role that group membership plays in maintaining and promoting health and well-being. (PsycINFO Database Record (c) 2013 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO


**Author(s)** Jetten, Jolanda, Haslam, Catherine, Pugliese, Cara, Tonks, James, Haslam, S. Alexander

**Citation:** Journal of Clinical and Experimental Neuropsychology, April 2010, vol./is. 32/4(408-416), 1380-3395;1744-411X (Apr 2010)

**Abstract:** We investigated the impact of cognitive deterioration and identity loss on well-being in older adults with dementia. We predicted that in addition to the negative effects that decline in cognitive ability has on dementia sufferers' well-being, there are also independent negative effects of identity loss. Participants (N = 48) were residents receiving standard care with mild dementia, residents receiving specialized care with severe dementia, and an age-matched community comparison group. Predictably, autobiographical memory and cognitive performance decreased linearly as a function of care level. Life satisfaction was lower for the standard care group with mild dementia than for the community sample, but, unexpectedly, life satisfaction was just as high for the severe dementia group receiving specialized care as for the community group. A similar U-shaped pattern was found in ratings of personal identity strength, and this mediated the life satisfaction effect. We conclude that amongst those suffering from dementia, loss of memory serves to compromise well-being primarily because it is associated with loss of identity. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

**Source:** PsycINFO

Available in fulltext from Journal of Clinical & Experimental Neuropsychology at EBSCOhost

### 15. The experience of living with dementia in residential care: An interpretive phenomenological analysis.
Author(s) Clare, Linda, Rowlands, Julia, Bruce, Errollyn, Surr, Claire, Downs, Murna
Citation: The Gerontologist, December 2008, vol./is. 48/6(711-720), 0016-9013;1758-5341 (Dec 2008)
Abstract: Purpose: The subjective psychological experience of people with moderate to severe dementia living in residential care is insufficiently understood. In the present study we aimed to explore the subjective experience of life with dementia in residential care from the perspective of the person with dementia, and to understand the psychological impact of being in this situation. Design and Methods: This was an exploratory qualitative study. Eighty individuals with dementia who were living in residential care homes engaged in unstructured conversations with a researcher. We subjected the transcripts of the resultant 304 conversations to interpretative phenomenological analysis in order to develop a thematic account. Results: The experience of living with dementia in residential care was fundamentally one of experiencing difficult and distressing emotions relating to loss, isolation, uncertainty, fear, and a sense of worthlessness. Participants generally tried to cope by accepting and making the best of things and affirming their past sense of self and identity, but some also expressed frustration and anger. Implications: Participants were able to describe aspects of their situation and their emotional response to it, grounded in a strong retained sense of self and identity. The participants' experience emphasizes the importance of improving the living situation of elders with dementia in residential care settings. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)
Source: PsycINFO

Author(s) Beard, Renee L, Fox, Patrick J
Citation: Social Science & Medicine, April 2008, vol./is. 66/7(1509-1520), 0277-9536;1873-5347 (Apr 2008)
Abstract: Being diagnosed with Alzheimer's disease marks a status passage formally legitimating the incorporation of forgetfulness into daily life. Based on interviews with diagnosed individuals in California, USA, we examine the mechanisms through which an Alzheimer's label is employed to justify forgetfulness, to manage social interactions, and to garner support when deemed necessary, while simultaneously combating the associated demented "master status." For diagnosed individuals, the transition from experience to symptom requires a redefinition of everyday forgetfulness into a medical problem. That is, respondents did not routinely perceive their experiences as pathological but rather were socialised into viewing age-related forgetfulness as symbolic of disease. Support groups sponsored by the Alzheimer's Association and memory clinics have a profound impact not only on the formation of group identity, but also on socialising forgetful individuals into diseased identities. The social disenfranchisement accompanying a diagnosis of dementia transforms forgetful older adults into "Alzheimer's patients," who must manage not only the manifestations of their disease, but also negotiate their interactions and identities. Their adaptation to the "symptoms" of forgetfulness and resultant social relations forms new interactional strategies whereby the diagnosis becomes a resource utilised to get through everyday life. Rather than being passive recipients of a diagnosis, respondents employ the label both as a resource, and as a phenomenon that needs to be incorporated into their self identity. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)
Source: PsycINFO

Author(s) Clare, Linda, Rowlands, Julia M, Quin, Rebecca
Citation: Dementia: The International Journal of Social Research and Practice, February 2008, vol./is. 7/1(9-30), 1471-3012;1741-2684 (Feb 2008)
Abstract: Current theories of social power suggest that development of a shared social identity can create the possibility of bringing about political and attitudinal change as well as benefiting individual psychological well-being. This exploratory, qualitative, internet-based study extending over two years explored the impact of developing a shared social identity among a group of people with early-stage dementia. We investigated the experience of belonging to the self-help network Dementia Advocacy and Support International (DASNI), and its effect on self-concept and adjustment, from the perspective of DASNI members in order to understand more about the factors that promote self-help, and the effects of engaging in self-help, mutual support and advocacy in this context. Seven active members of DASNI with a dementia diagnosis volunteered to participate. Interviews were conducted
via email, and Interpretative Phenomenological Analysis (IPA) was used to develop a thematic account. The challenges engendered by the onset of dementia were reflected in descriptions of loss, struggle and uncertainty. Participating in DASNI, in contrast, engendered a sense of collective strength and having something valuable to contribute, and made it possible to discover that there can be life after diagnosis. Belonging to DASNI helped to counteract the challenges to self and identity posed by developing dementia, thus significantly affecting the experience of living with dementia, and creating the possibility of effecting social change. Gradually, people in the mild to moderate stages of dementia are developing a 'voice' and rejecting the passive patient role. One important element in this process is the way in which people with dementia band together to help themselves and one another, and influence social attitudes, through mutual support and collaborative advocacy. The development of DASNI, consistent with recent theoretical developments in conceptualizing processes of social power and influence, offers significant potential for change. (PsycINFO Database Record (c) 2012 APA, all rights reserved) (journal abstract)

Source: PsycINFO

18. Westius A, Kallenberg K, Norberg A
Views of life and sense of identity in people with Alzheimer's disease
Ageing and Society, 2010, 30 (7) p1257 – 1278
This study aimed to elucidate the role of the view of life of people with Alzheimer’s in framing their sense of identity. ‘View of life’ was interpreted as a vital aspect of sense of identity, understood as the individual's beliefs about their life history and about the attributes that characterised them. Twenty-one people with mild to moderate stages of Alzheimer's disease were interviewed about their life story. The narratives were interpreted using a phenomenological hermeneutic method. By telling their life story, the participants also narrated their view of life, i.e. their conception of reality, their central system of values and their basic emotional attitudes. By their own accounts, the origins of the narrators’ central values and basic emotional attitudes were established in early life. They also expressed a sense of meaningfulness and continuity when looking back on their lives. The results indicated that for a care-giver or confidant, having knowledge of a person with dementia's view of life is valuable when seeking to confirm that person's sense of identity.

19. Duane F, Brasher K, Koch S
Living alone with dementia
Living alone, social isolation and loneliness are terms used interchangeably, although they are really different, but related, concepts. Social isolation of older people who live alone is a major concern for aged care service providers. It is often linked with factors such as physical disability, poor health, loss of a partner and an absence of transport. Cognitive impairment or dementia can exacerbate the situation by curtailing independence and limiting social roles. This paper reports a study undertaken in 2009 with older people who live alone with cognitive impairment or early stage dementia to explore their perspective and experience of living alone. A total of 19 participants were recruited (13 female). The female participants were aged between 79 and 93, and the men between 69 and 91. On average, participants had been living alone for 14 years. Most participants were interviewed two or three times. The following themes were identified: life alone, social contact and support networks, purpose and identity in older age, risk and support strategies. The study findings are discussed through these themes.

20. Twigg J, Buse C
Dress, dementia and the embodiment of identity
The article explores the significance of dress in the embodied experience of dementia, exploring questions of identity, memory and relationship. It suggests that clothing and dress are important in the analysis of the day-to-day experiences of people with dementia, giving access to dimensions of selfhood often ignored in over-cognitive accounts of being. As a result clothing and dress can be significant to the provision of person-centred dementia care. These arguments are explored through ideas of embodied identity, the materialisation of memories, and the maintenance, or otherwise, of appearance in care. The article forms part of the background to an ESRC-funded empirical study exploring the role of clothing and dress in the everyday lives of people with dementia, living at home or in care homes,
and of their relatives.

21. Steeman E et al
Managing identity in early-stage dementia: maintaining a sense of being valued
Ageing and Society, 2013, 33 (2) p216 – 242
This longitudinal study of 17 elderly persons with early-stage dementia followed participants for a period of 10-12 months with the aim of exploring changes in the experience of living with dementia and how this impacted on identity. Participants were recruited from five memory clinics in Flanders, Belgium. Data were collected through open interviews, with interviews lasting on average 60-90 minutes. This paper reports on the third phase of the study, which analysed changes over time by comparing case interviews over time with each person with dementia. The major theme, a struggle to be valued, was clearly present in follow-up interviews. The cases of three participants are used to illustrate how the concept of being valued shifts. This is identified as a shift from ‘being valued for what you do’ toward ‘being valued for who you are’. This progression represents a shift from performance-related core values of identity to those that are existentially related. These findings suggest that the self can be maintained by adjusting to loss.

22. Macrae H
Managing identity while living with Alzheimer’s disease
Abstract Although any illness can negatively affect the self, Alzheimer’s disease poses a special threat. Based on interviews with nine Canadians diagnosed with early-stage Alzheimer’s disease, and adopting a symbolic interactionist perspective, this study examines the impact of the illness on identity. Findings indicate that, given the necessary resources, persons with Alzheimer’s can live meaningful, purposeful lives and creatively manage to protect and preserve identity. In contrast to previous research, participants did not reveal a great deal of concern about potential loss of self.

The following 4 references – no abstracts available - are taken from:
Jetten J, Haslam C, Pugliese C et al
Declining autobiographical memory and the loss of identity: effects on well-being
Jnl Clinical & Experimental Neuropsychology, 2010, 32 (4), p408 – 16

23. Addis DA, Tippett LJ
Memory of myself: autobiographical memory and identity in Alzheimer’s disease
Memory, 2004, 12, p56 – 74

Self identity in older persons suffering from dementia: Preliminary results
Social Science and Medicine, 2000, 51, p381 – 394

25. Sabat SR, Harre R
The construction and deconstruction of self in Alzheimer’s disease
Aging and Society, 1992, 12, p443 – 461

26. Surr CA
Preservation of self in people with dementia living in residential care: A socio-biographical approach
Social Science and Medicine, 2006, 62, p1720 – 1730

27. Frazer SM, Oyebode JR, Cleary A
How older women who live alone with dementia make sense of their experiences: an interpretive phenomenological analysis

The following references are taken from Psychology and Behavioural Science database – all available to download, but let us know if you need us to do them for you:

28. Clare L; Whitaker CJ; Nelis SM
Self-concept in early stage dementia: profile, course, correlates, predictors and implications for quality of life
Abstract: Objective Although it is increasingly accepted that people with dementia retain a sense of self, there is a need for empirical evidence regarding the nature of the self-concept in early stage dementia, how this changes over time and how it relates to quality of life. Methods Self-concept was assessed using the short form of the Tennessee Self-concept Scale in 95 individuals with early stage dementia; 63 were reassessed after 12 months, and 45 were seen again at 20 months. Participants also completed measures of mood, cognitive functioning and quality of life. Caregivers provided proxy ratings of self-concept, completed measures of symptoms and distress at symptoms and rated their own levels of stress and well-being. Results Self-ratings of self-concept were close to the average range for the standardization sample, and the distribution did not differ significantly from expected values. Although caregiver ratings were slightly lower, discrepancies were small. There were no significant changes over time in self-ratings or informant ratings or discrepancies. At Time 1, self-ratings were predicted by anxiety, depression and memory, caregiver ratings were predicted by caregiver distress and by depression in the person with dementia and discrepancies were predicted by caregiver distress. These models remained predictive at later time points. Self-rated self-concept predicted quality of life, with the relationship only partially mediated by depression and anxiety. Conclusions Self-concept appears largely intact in early stage dementia, but in view of the association between self-concept and quality of life, a preventive approach focused on supporting self-concept may offer benefits as dementia progresses.

29. Caddell LS; Clare L
A profile of identity in early-stage dementia and a comparison with healthy older people
Abstract: The aim of the study was to determine whether people in the early stages of dementia experience their sense of identity differently to healthy older people and to examine whether different aspects of identity are related to each other in each group. This was a cross-sectional questionnaire-based study; 50 people with early-stage dementia and 50 age-matched people without dementia completed measures pertaining to different aspects of identity. Measures of mood and self-esteem were also included so that any differences could be taken into account in the analysis. There were very few differences in identity between the groups. After differences in levels of anxiety were accounted for, there were no differences in scores on most measures of identity. However, people in the early stages of dementia scored significantly lower on one subtotal for one measure of identity, whereas healthy older adults reported significantly more identity-related distress than people in the early stages of dementia. For both groups, there were no associations between different aspects of identity. People in the early stages of dementia do not differ much from healthy older adults in terms of their identity. Since healthy older people experience more distress relating to identity, they may be more likely to benefit from some sort of intervention than people in the early stages of dementia. It might be useful to consider identity as consisting of multiple components in future studies, rather than assuming that one aspect of identity represents the overall experience of identity.

30. Hyden L-C; Orulv L
Narrative and identity in Alzheimer’s disease : a case study
Abstract: Abstract: In this case study, focus is on how persons with AD use their remaining linguistic and cognitive resources, together with non-verbal aspects of the storytelling event, as resources in communicating and negotiating their identities in everyday encounters. The results of the analysis, focusing on the telling of the stories, indicate that other aspects than the temporal and referential organization of the narratives has become important resources for the teller in establishing and negotiating identity. The telling of temporally discontinuous narratives does not appear to affect or disrupt the teller’s experience of some sort of a continuous sense of self and identity but are probably more a problem to persons without this kind of diagnosis. Being afflicted by AD most likely leads persons to try to invent and use alternative communicative recourses in order to sustain factors like their senses of self and identities. For researchers this makes it important to try to base their analysis on the actual organization of the talk and to focus on the functions of various responses and utterances in the interaction.

31. Harris PB; Keady J
Selfhood in younger onset dementia: Transitions and testimonies
Abstract: Younger people with dementia and their carers are an overlooked population for research, policy and practice attention. In this study, data were collected from both the United States and the UK in order to explore the meaning and construction of selfhood and identity. The US data collection included in-depth interviews with 23 people diagnosed with younger-onset dementia, while the UK data collection comprised 15 face-to-face interviews with younger carers of younger people with dementia; all carers were/had been caring for a younger person with dementia diagnosed through the DSM-IV-R criteria. A grounded theory analysis of the data resulted in the emergence of five themes to explain the interview data, these were: (1) identity as a worker; (2) identity of abandoned individual; (3) sexual identity; (4) family identity; and (5) identity as an individual engaged in living. Additional research is necessary to further develop the attributes and application of these identity profiles.

32. Hayes J, Boylstein C, Zimmerman MK
Living and loving with dementia: Negotiating spousal and caregiver identity through narrative
Abstract: In this paper, we examine how Alzheimer’s disease and related disorders (ADRD) affect caregivers” perceptions of change in the identity of their afflicted spouse and the ways in which accompanying changes in caregiver identity influence intimate relations. We also explore how gender shapes the ADRD caregiving experience among married couples, specifically, the extent to which intimate relations are also gendered relations. The study group was comprised of spousal caregivers recruited from support groups in the two Midwestern states and from the Alzheimer’s Disease Center (ADC) at a large Midwestern university hospital. In-depth interviews were conducted with 13 men and 15 women whose spouses had ADRD. The intensive interviews confirmed that identity change on the part of sick spouses had important implications for intimacy, although not always in adverse ways. The majority of caregiver husbands and wives reported diminished intimacy as a result of the ADRD. Many men and women believed they would retain feelings of closeness to their afflicted spouses as long as they were alive. Wives were more likely than husbands to report that changes in their spouses” identity altered how they identified themselves within their marriage. This has important implications for intimate relations between people with ADRD and those who care for them. Our findings suggest that caregiving and intimacy are very different experiences for men and women, and point to the need for caregiver education and support.

33. Emilsson UM
Identity and relationships: On understanding social work with older people suffering from dementia
Abstract: Many countries in the Western world are facing great challenges posed by an ageing population. Since cognitive impairments and the prevalence of dementia increases with age, we can expect an increasing number of older people in need of care. However, severe problems with such care are already reported by researchers as well as in the mass media. The aim of this paper is to discuss how the identity confusion among older people suffering from dementia might influence relationships and the staff's behaviour, and in that sense, be part of the care problems reported. Three studies carried out between 1993 and 2003 are introduced aimed at illustrating the severe care problems identified. The interaction between the residents and the staff is focused on and discussed from a psychodynamic viewpoint. Data show that the caregivers also become confused and express a need of affirmation comparable with that of the older people suffering from dementia. That is, even the caregivers' behaviour seems to be influenced by an identity-preserving ambition similar to the one of the dementia sufferers, and this might explain some of the problems in this form of care.

34. Naylor E, Clare L
Awareness of memory functioning, autobiographical memory and identity in early-stage dementia
Abstract: Sense of identity is thought to be closely related to autobiographical memory. Theoretical models of awareness suggest that both may also be related to level of
awareness of memory functioning among people with early-stage dementia. This study explores the relationships between autobiographical memory, identity and awareness in early-stage dementia. Thirty participants with Alzheimer's disease, or vascular or mixed dementia were assessed using the Autobiographical Memory Interview, with an additional section eliciting recall for the mid-life period, the Tennessee Self-Concept Scale, and the Memory Awareness Rating Scale. Lower levels of awareness of memory functioning were associated with poorer autobiographical recall for the mid-life period and with a more positive and definite sense of identity. Reduced awareness may serve a protective function against the threats to self posed by the onset and progression of dementia.

35. Massimi M; Berry E; Browne G et al
An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease
Abstract: One of the most troubling symptoms of Alzheimer's disease is the loss of the patient's sense of identity. This loss complicates relationships, increases apathy, and generally impedes quality of life for the patient. We describe a novel in-home ambient display called Biography Theatre that cycles through music, photographs, movies, and narratives drawn from the patient's past and current life. We conducted an exploratory case study with an 84-year-old male with moderate-stage Alzheimer's disease (Mr H). The study consisted of three phases: a baseline phase, a phase wherein autobiographical materials were collected and discussed, and a phase wherein the display was deployed in the home. The patient demonstrated improvement on standardised tests of apathy and positive self-identity, but did not improve on tests of autobiographical memory, anxiety, depression, and general cognition. We also report on caregiver reactions to the intervention and how the display helped them cope with and reinterpret their loved one's condition. This work suggests that interdisciplinary work involving “off the desktop” computing technologies may be a fruitful way to provide rehabilitative benefit for individuals with Alzheimer's disease.

Published Research - Google Scholar
From 1st fifty results:
G1. Cohen-Mansfield J; Parpura-Gill A; Golander H
Utilization of self-identity roles for designing interventions for persons with dementia
To date, little research has systematically explored the retention of self-identity in dementia and its potential use for the individualization of care. The purpose of this study is to determine the impact of role-identity–based treatment for persons with dementia. We recruited a total of 93 elderly persons with dementia (mean Mini–Mental State Exam score = 10.58) for this study. Experimental (treatment) group participants were engaged in activities designed to correspond to each participant's most salient self-identity. The treatment group showed a significant increase in interest, pleasure, and involvement in activities, fewer agitated behaviors during treatment, and increased orientation in the treatment period. The experimental treatment had effects that were superior to those of the nonexperimental activities. The results highlight the powerful roles that perception of self and fulfillment of self-identity play in overall well–being.

Salience of self-identity roles in persons with dementia: Differences in perceptions among elderly persons, family members and caregivers
Social Science & Medicine, Volume 62, Issue 3, Pages 745-757
In this study, we explored perceptions of the salience of self-identity in persons suffering from dementia as perceived by the participants themselves, by family, and by staff caregivers. Four types of role-identity were explored: professional, family role, hobbies/leisure activities, and personal attributes. Participants were 104 persons with
dementia, 48 of whom attended six adult day care centers while 56 resided in two nursing homes in the Washington, DC metropolitan area. Participants, relatives, and staff members were interviewed to obtain information about past and present self-identity roles of participants and attitudes toward these roles. Findings demonstrate that the importance of role identities decreases over time and with the progression of dementia. The family role was found to be the most important and salient role identity according to all the informant groups. The professional role was the one that showed the steepest decline in importance from past to present. Gender differences were detected for the importance of professional role identity. Participants rated their roles in the past as less important and those in the present as more important compared to family members. Family members reported greater decline in the importance of role identities for those participants with greater cognitive impairment. Participants with moderate cognitive impairment reported greater decline in the importance of role identities than did the participants with severe cognitive impairment. Understanding the past and present self-identities of persons with diminished cognitive abilities is crucial in the effort to provide individualized care and enhance participant experiences.

G3. Clare L, Harman G

**Ilness representations and lived experience in early-stage dementia**

*Qualitative Health Research, 2006, Vol 16, No 4, p484 -502*

The self-regulation model of illness behavior provides a framework for understanding how threats to self from chronic illness can be managed and proposes a significant role for illness representations. This framework can assist in illuminating the experience of developing dementia but has not previously been considered in this context. The authors conducted semistructured interviews with 9 people who had a diagnosis of early-stage dementia to explore illness representations and how these related to daily lived experience, using interpretative phenomenological analysis (IPA). Two overarching themes emerged: It will get worse, reflecting an understanding of dementia; and I want to be me, reflecting a desire to maintain sense of identity. Participants faced a number of personal and interpersonal dilemmas. The authors present a preliminary model of the way in which illness representations contribute to the lived experience of early-stage dementia

G4. Langdon SA; Eagle A; Warner J

**Making sense of dementia in the social world: A qualitative study**

*Social Science and Medicine, 2007, Vol 64, Issue 4, p989 –1000*

The reactions of others can have a significant effect on the lived experience of dementia. Although the literature contains some theories of dementia that take this into account, few studies have asked people with early stage dementia about their experiences of other people's reactions to their changed condition and social status. In the present study, 12 men and women aged 66–87 with early stage dementia, recruited through an Older Adult Mental Health Unit in London, England, were interviewed to elicit their views on others' reactions to them since receiving the diagnosis. They were also asked what they thought others understood by the terms 'dementia' and 'Alzheimer's Disease'. Transcripts were analysed using Interpretative Phenomenological Analysis. Participants displayed somewhat negative reactions to the term dementia, and were concerned others would associate it with being 'demented'. In connection with this, although they were comfortable sharing their diagnosis with those closest to them, they were reluctant to do so beyond this private inner circle. Participants were keen for those who did know about the condition to respond authentically and honestly to them, helping them when necessary but as far as possible carrying on life as normal. A number of the participants seemed to be trying to work out how dementia differed from age-related memory loss and compared themselves with others to aid their understanding of this. The implications of these findings for clinical practice, carers and wider society are discussed.

G5. **Identity loss and maintenance: commonality of experience in cancer and dementia**
This paper examines parallel thematic findings from two qualitative studies exploring the experience of disease as it relates to cancer and dementia. The original studies examined the experiences of 16 individuals with cancer and 20 with dementia, and the impact of these first hand experiences and those of their principal family carers. The paper presents findings linked to the common or shared concepts of identity loss and maintenance as expressed by both the affected individual and the family carer.

G6. Investigating the ways that older people cope with dementia: A qualitative study
Preston L; Marshall A;Bucks RS
Understanding the way that older people cope with dementia has important implications for the enhancement of the psychological well-being and quality of life of this group of people. This qualitative study explored how older people cope with dementia, by engaging 12 people with early-stage dementia in semi-structured interviews. Interpretative phenomenological analysis (IPA) was used to identify the shared themes in participants' accounts. Three major themes emerged: 'managing identity in relation to dementia', 'making sense of dementia', and 'coping strategies and mechanisms' (the latter theme divided into 'everyday, individual strategies', 'coping in relation to others', and 'personal attitude/approach'). There were also two additional themes in relation to process issues: issues of 'conflict and control' which were evident across all other themes, as was individuality and the importance of 'context' in coping with dementia. These findings are discussed in the relation to previous research in this field, and suggestions for further research and clinical practice are outlined.

G7. In their voices: Identity preservation and experiences of Alzheimer's disease
Beard, RL
Although much research pertaining to Alzheimer's disease (AD) explores the impact on caregivers, there is a general paucity of data on experiences of living with the condition. Contemporary medical initiatives to diagnose people earlier in the illness trajectory make it increasingly possible to hear the voice of people with memory loss, which can improve both public perception and policy. This study examined the impact of being diagnosed with early AD on identity construction. Respondents highlighted aspects of being diagnosed that were instrumental in making sense of changes in their lives and identities, including defining moments, to tell or not to tell, and preservation. Findings suggest that understanding how to identify memory deficits, the context of diagnosis, and the techniques employed for managing illness are crucial to subjective experiences. Despite normative expectations and the rhetoric of loss, respondents deliberately manage their interactions to make sense of their lives and preserve themselves.

G8. Awareness of memory functioning, autobiographical memory and identity in early-stage dementia
Sense of identity is thought to be closely related to autobiographical memory. Theoretical models of awareness suggest that both may also be related to level of awareness of memory functioning among people with early-stage dementia. This study explores the relationships between autobiographical memory, identity and awareness in early-stage dementia. Thirty participants with Alzheimer's disease, or vascular or mixed dementia were assessed using the Autobiographical Memory Interview, with an additional section eliciting recall for the mid-life period, the Tennessee Self-Concept Scale, and the Memory Awareness Rating Scale. Lower levels of awareness of memory functioning were associated with poorer autobiographical recall for the mid-life period and with a more positive and definite sense of identity. Reduced awareness may serve a protective function against the threats to self posed by the onset and progression of dementia.

G9. Living with dementia: Curating self-identity
This article describes an ongoing interdisciplinary research study with community-dwelling people living with dementia. The article focuses on one person living with dementia, her family and support group. Seven people were interviewed and their stories woven into one narrative. Our interest is in her self-identity, which we explore through a participatory storytelling approach. In gathering stories with all people who are significant in her life we have observed that what is driving the stories is an ethical imperative that is shared across her social network. We have described this as an imperative to `curate' her self-identity. `Curation' combines telling `about', `for' and potentially `with' the person living with dementia in interactions which reproduce and reconfirm her self-identity. We propose that the notion of curation offers a way in which people, research participants, significant others and health care professionals, can think differently about living with dementia. In particular, we argue that curation enables the person to be acknowledged in interaction as an individual with a coherent, evolving identity which spans past, present and future.