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The participative arts for people living with a dementia: a critical review

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Abstract

In the last decade, interest has increased in the role of the participative arts for people who are living with a dementia. The flourishing of this area can be partly understood because of an awareness of the potential for art to deliver health care outcomes. In addition, there is widespread agreement that non-pharmacological interventions are important for people living with a dementia. Therefore, participative arts activities have attracted attention as representing beneficial interventions. This critical review which involved the careful mining of academic and grey literature using replicable search strategies contextualises the participatory arts for people living with a dementia and provides an overview of some of the art forms that are most widely used. The review also highlights some of the extant gaps in the knowledge base. The focus is on the UK context but the role of the participative arts for those with a dementia is equally relevant to practitioners in Europe and the US, and therefore some attention was also given to international literature.

Keywords: participatory arts, dementia, intervention, health, well-being, quality of life.

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Introduction

Dementia is a broad term and relates to a group of syndromes rather than one single disease entity. To date, more than 200 subtypes of dementia have been defined and each one has a different pathway or process (Stephan & Brayne 2010). However, in general terms the dementia syndrome is characterised by progressive decline in cognition of sufficient severity to interfere with activities of daily living (Knopman et al. 2001). The main subtypes include Alzheimer's disease (AD), vascular dementia, dementia with Lewy Bodies, frontal lobe dementia, Pick's disease, and alcohol related dementia (Stephan & Brayne 2010).

''Dementia'' is therefore a syndrome that defies any simple definition; it has become a fear-laden term that encapsulates society's worst terrors (Zeilig 2014a). Despite the general lack of consensus about what dementia is in neurological terms, there is agreement that dementia is a long-term medical disability. To this end, there are regular reports in the media and elsewhere concerning the prevalence of the condition both in Europe and globally. The recent G8 summit (December 2013, London) highlighted the importance of countries working together to find a cure: http://dementiachallenge.dh.gov.uk/category/g8-dementia-summit/

However, at the present time, finding a cure or even effective drug treatments is proving elusive. Thus a growing body of research and work has steadily focussed on improving quality of life (QOL)[1] for people living with a dementia (PWD) (Gross et al. 2013). The importance of reducing the use of antipsychotics for PWD and therefore investigating ''non-pharmacologic tools'' has also been widely embraced across the US (Kaldy 2013). In the absence of appropriate pharmacological interventions the social conditions in which those with a dementia live also need urgent attention. Pioneering work by researchers and practitioners has contributed to the understanding that although Alzheimer's and other dementias may be incurable at present, they are conditions that can be treated and

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[1] There are debates and disagreements in the research literature concerning 1) how to measure QOL and 2) what QOL actually refers to. The lack of consensus about this contributes to a lack of reliable assessments of projects. It is not within the scope of this review to address these controversies.

that treatment always includes more than drugs (Killick 2013; Kitwood 1997; Sabat 2001; Zeisel 2009).

Interest in the social conditions that affect dementia is part of the socio-political context that has led to a burgeoning of arts and cultural initiatives for PWD. These initiatives are diverse and reflect an increasingly prevalent assumption that the arts and culture play an intrinsically positive role in health and well-being. However, there has been very little critical evaluation or review of these initiatives and interventions. Indeed, there are gaps in the evidence base relating to the real and measurable benefits from cultural activities for people with a dementia. This is largely because the field is still in its infancy.

The overall aim of the following review is to strengthen the knowledge base concerning the efficacy of arts based approaches for PWD and to investigate the question: *What is the value of arts and culture for people living with a dementia?* The broad question being explored here is in contrast to previous reviews, which have tended to focus on the specific impact of particular arts interventions on PWD for purposes of evaluation or in order to measure particular variables such as episodic memory or aesthetic stability.

The review is a comprehensive analytical and rigorous discussion. However, it is not systematic as it is not an exhaustive summary, did not use meta-analysis, and although selection bias was minimised by ensuring that colleagues used the same search terms and databases, it was solely the Principal investigator (PI) that was responsible for synthesising the data.

Key databases were searched using the following terms:

(dementia* OR alzheimers OR vascular OR multi-infarct*)
AND
(cultural OR portraiture OR film* OR television OR tv OR memoir* OR novel*
OR poe* OR theatre OR performance OR art* OR storytelling OR stories OR music
OR sing* OR danc* OR galler* OR archive* OR museum OR ''creative writing'' OR
fashion OR drawing OR paint* OR craft* OR choral OR choir OR panto* OR
collage OR design)
AND
UK OR ''united kingdom'' OR engl* OR welsh OR wales OR Scot* OR Irish or
Ireland

The databases that were used include:

Scopus
Web of Knowledge
Social Policy and Practice
Applied Social Sciences Index and Abstracts
British Humanities Index
British Nursing Index
International Bibliography of the Social Sciences
Social Services Abstracts
Sociological Abstracts
Global Health
Health Management Information Consortium
PsycINO
Medline
Cochrane

An endnote library was created of 222 references. Of these the articles that were targeted were those including:

- Explicit reference to creative activities that involved older PWD,
- The role of museums and/or art galleries for PWD,
- Participatory arts activities that aim to enhance well-being or QOL for PWD,
- Participatory arts activities that focussed on aesthetic appreciation for PWD,
- Activities that did not include therapies of any kind,[2]
- Systematic data/meta-analyses about the value of the arts for older people, including one Cochrane Review on music therapy for PWD.

A total of 63 articles form the basis for the ensuing examination of the role of the arts for PWD, however the preceding contextual background on the relationship of the arts to health, includes additional references and is provided as an essential framework for the review.

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[2] The focus was on the participatory arts and not therapies (art, music, or drama); however, several articles exploring music as a therapeutic intervention were reviewed where these included relevant methodological information.

The evidence pertaining to the role of particular arts activities is then discussed in some detail.

Context: The Arts and Health

> In order to correctly define art, it is necessary, first of all, to cease to consider it as a means to pleasure, and to consider it as one of the conditions of human life. (from: "What Is Art?" by Leo Tolstoy)

Debates concerning the relationship of the arts to society can be traced back to Plato and Aristotle and continue to vex contemporary commentators. Tolstoy's conception of art as integral to human life is an argument that has some contemporary resonance. In the twenty-first century in the United Kingdom as beleaguered arts and cultural organisations are facing significant economic challenges (Clift et al. 2009; Mowlah et al. 2014) there is an increasing urge to articulate the pivotal role that the arts and culture play in all aspects of our lives, including centrally to our health and well-being. The need to raise awareness concerning the role of the arts as a "strategic national resource" is explicitly stated in a recent report by Arts Council England (Mowlah et al. 2014) and similarly underlies the report by Renshaw (2013). Thus the sociopolitical context in the UK for investigating the value of the participative arts for PWD has also been conditioned by the need for arts organisations to respond to major political changes and funding constraints. This has resulted in an awareness that arts organisations need to actively engage with a more diverse population and a growing appreciation that participatory work/practice that is socially engaged is inherently valuable (Parkinson et al. 2013; Renshaw 2013).

Beyond the important contextual background is the growing body of scientific evidence in support of the value of the arts for health (Clift et al. 2009). Research has evidenced that a higher frequency of engagement with arts and culture is associated with a higher level of subjective well-being (Mowlah et al. 2014) and also that there are instrumental benefits from the arts that can positively affect physical health (Clift 2012). To this end, it has been argued that by supplementing medicine and social care, participation

in the arts and access to a range of arts opportunities can dramatically improve QOL (Burnham et al. 2007; Cayton 2007; Owen 1999; Staricoff 2006). In connection with this, there has been a growing awareness that health may involve more than simply the absence of disease and that art and aesthetics have an important role to play in delivering health care (Moss & O'Neill 2014) as well as a reappraisal of the associations between the arts and society in general.

Indeed, the role of the arts for addressing health issues and as a mode for the delivery of social care has been a recurrent topic this century both in Europe and the US (Buttrick et al. 2013; Cohen et al. 2006, 2007; Hanna & Perlstein 2008; Ramsey 2013). This interest is fuelled by an expanding body of research into the links between culture and flourishing (2013). In addition, there has been explicit interest in the possibility that the arts represent a relatively cost-effective way of alleviating health issues (Ramsey 2013). Work by Cohen (2009) convincingly reports on the cost effectiveness of art programmes in relation to medication usage and visits to the doctor amongst a sample of older people in the US. Of course, successful participatory arts projects are of much greater value to the individuals that take part than the economic benefits they may represent for health or other agencies.

However, it should also be noted that the arts in health movement has not been without its critics. As Clift et al. (2009) have highlighted, a collection of essays by the Mirza (2006) challenged the evidence base for claims concerning the personal and social benefits of the arts. More recently the "fulsome" language and "somewhat uncritical stance" of "evangelists of the arts and health movement" has been criticised:

> Equally, reviews of the efficacy of arts in health care … rarely stand up to sustained academic scrutiny, with a tendency to mould weak data and speculative associations into an often less than convincing polemic. (Moss & O'Neill 2014: 1032)

It is hoped that as Moss and O'Neill propose, this article will help to contribute to the development of a more reflective and critical line of reasoning concerning the role and value of the arts in particular for PWD.

The Participative Arts for PWD

Here, the participative arts refer to professional artists that conduct creative or performing arts projects in community settings with PWD and their carers. The purpose of these projects is predominantly to promote health and well-being and is therefore therapeutic. However, it should be noted that in some cases the use of the arts with PWD might also be primarily for aesthetic purposes – in order to create a high quality work of art. Clearly, the therapeutic and aesthetic objectives of a project may overlap and complement one another.

This is distinct from the work of art therapists who typically work in clinical settings (hospitals or hospices) and are usually health care professionals who aim to ameliorate specific conditions (Castora-Binkley et al. 2010). In addition, therapists (whether these are dance/movement, music, drama, or art therapists) tend to focus on the condition (whether this is a dementia, a psychological, or physical problem for instance) and how this can be "treated." For therapists, the arts (whether these are music, painting, theatre) are used as tools to achieve measurable ends. Although this is a valuable approach, the focus of this review is on the arts as a possible means of engaging PWD rather than ways of treating the symptoms or aetiology of the illness itself.

The growth in understanding about residual creative ability that exists in PWD has added to interest in researching and initiating arts projects for PWD (Moriarty 2003; McFadden et al. 2008). Indeed, some practitioners argue that "the peculiar circumstances" of dementia might even release an innate creativity that is connected with an inventive immediacy (Craig & Killick 2011). Whether or not creativity is augmented by dementia (and at the present time there is scant research on this issue), it is widely appreciated that there is a need to find meaningful and engaging interventions for people who live with a dementia, whether they are living in the community or in care homes, and that the participative arts can improve PWD's moods, enhance their relationships, reduce social isolation, and provide sensory stimulation (Guzmán-García et al. 2013). Moreover, the participative arts may provide unique access to the emotional and physical memories of people who live with a dementia even while their cognitive capacities are diminishing (Eekelaar et al. 2012; McLean 2011; Smith et al. 2012).

In the past decade there has been an increasing number of arts and cultural initiatives for people who live with a dementia both in the UK and the US (Killick 2012; Roe et al. 2014; Zeilig 2014b; Zeisel 2009). These initiatives are diverse and include music and drama groups, creative writing programmes, dance groups, puppetry, painting classes, and visits to art galleries. Many projects use a range of arts activities to engage participants with a dementia. In the UK there are also a number of organisations that have emerged in the past decade that have a specific focus on using the arts with PWD. In recent years, a growing body of evidence has been compiled exploring the potential of the arts to have an impact on the health and well-being of PWD (Basting 2009; Camic et al. 2013b; Fritsch et al. 2009; Ledger & Edwards 2011). However, this field is nascent – and consolidating evidence about the varied and often small scale, short-term projects, is problematic.

As is cogently noted by McLean (2011) in her evidence review of the impact of the participatory arts on older people, this is a new and emerging research field, with little available high quality research. This is echoed by Roe and colleagues (2014) in their discussion of the "creative arts" for PWD:

> A strong evidence base to inform such creative arts activities is lacking … Rigorous evaluation and research evidence is required to support their continuing development. (4)

Similarly, there has been scant work exploring the views of PWD concerning their perceptions of the value of arts and culturally based activities.

Singing and Music Groups

The only Cochrane review of the arts for PWD that has been located examines the evidence relating to music therapy (Vink et al. 2006) (updated in 2010) and is therefore not directly relevant here. However it is significant that of all possible art practices it is music that has been examined in a Cochrane review. This perhaps indicates that questions regarding the therapeutic value of music for PWD have a particular interest for investigators and practitioners alike. The specific focus of this

review was to assess whether music therapy can diminish behavioural and cognitive problems or improve social and emotional functioning. Ten studies were included that used a range of behavioural and psychological tools as outcome measures. However, the overall conclusion by Vink et al. (2006) was that the methodological quality and the reporting of the included studies were too poor to draw any useful conclusions. Sherratt et al. (2004) similarly highlight the limitations of research studies in this area.

Weaknesses in methods and questions about the reliability of data are equally pertinent when considering the role of other participative arts considered in this review. Many studies are beset with methodological difficulties and are unable to formulate robust conclusions. Nevertheless, there have been several convincing and methodologically stringent RCTs[3] investigating the role of music and singing for PWD (Cooke et al. 2010; Harrison et al. 2010; Särkämö et al. 2014). These studies indicate the benefits of music and singing for PWD; albeit with varying emphases.

Harrison et al. (2010) and Cooke et al. (2010) report on different aspects of the same randomised controlled trial using a cross-over design – with a music intervention and a reading control group. This RCT studied the effects of a live music programme on agitation, emotion, and QOL for PWD. Standardised, quantitative measures were used including the Dementia Quality of Life and Geriatric Depression Scales. Qualitative data was also gathered but solely from the musicians involved in the programme. Although the reflective data from the musicians indicated that the intervention protocol was successful in terms of promoting improvements in mood, memory, general well-being, and QOL for PWD; the standardised measures used with PWD did not provide evidence that the therapeutic use of live music was more effective than a group reading activity. However, results did suggest that both the music and reading activities offered

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[3] RCT refers to a randomised controlled trial. This is the method used in evidence based clinical trials whereby a group of patients is randomised into an experimental group and a control group. Using randomisation is one way in which any possibility of selection bias in a trial is minimised.

opportunities to improve sense of belonging, self-esteem, and depressive symptoms in some PWD.

Särkämö et al. (2014) similarly explored QOL for PWD. This study adopted a single blind RCT approach to determine the long-term efficacy of a novel dyadic music intervention on PWD. A comprehensive neuropsychological testing battery was used to evaluate cognitive domains (Särkämö et al. 2014) and standardised scales including the Cornell–Brown Scale for QOL were used to evaluate mood. This careful systematic approach to the possible effects of music on cognitive, emotional, and social aspects of life for a group of PWD with mild/moderate dementia and their family members demonstrates that everyday musical leisure activities can have an important role in maintaining cognitive ability, enhancing mood and QOL, and promoting the well-being of family members. The study also indicates the potential for using RCT designs when investigating longer-term effects of arts activities.

Definitions of music vary (Spiro 2010) and may include "active" improvised musical activities or activities that include music but do not necessarily have it as a main focus. Music listening amongst PWD has also been investigated. This is primarily a receptive activity and represents a passive form of musical interaction. The effects of playing customised music on the levels of agitation and depression amongst PWD was studied by Janata (2012). The study was designed as a controlled, randomised, single-site trial lasting 16 weeks. Weekly data samples were collected for the Neuropsychiatric Inventory, the Cohen–Mansfield Agitation Inventory, and the Cornell Scale for Depression in Dementia (Janata 2012).

This study was inconclusive and it is hypothesised that this is because of the particular assessments used in this study (Janata 2012). The authors conclude that more detailed examination of the interaction between music, specific agitation behaviours, dementia severity, and time of day is warranted.

Thus there is a developing literature on the benefits of music for PWD in relation to the behavioural symptoms of dementia and sense of well-being (Gerdner 2000; Hara 2011; Rose 2008; van der Geer et al. 2009). In addition, the specific ability of music to allay cognitive decline based on under-standings generated by the neuroscience of music has also been studied (Särkämö et al. 2012, 2014). These latter studies indicate that music may be

able to reduce emotional and behavioural disturbances and have positive effects on cognitive functioning. Yet, methodological "pitfalls" (Särkämö et al. 2012) mean that conclusions about the long-term benefits and practical applicability of music interventions remain tenuous.

The value of singing in dementia care has also been widely noted (Götell et al. 2009). This has been reinforced by the "Singing for the Brain" model and Silver Song Club Project (Skingley & Vella-Burrows 2010). The evaluation by Bannan and Montgomery-Smith (2008) demonstrated that singing was an enjoyable activity for PWD and also had the potential to enhance QOL and well-being for their carers. The role of singing for improving health has been established for other cohorts in wide ranging studies (Cohen et al. 2006, 2007; Clift et al. 2009).

Camic et al. also observe the intense enjoyment for PWD derived from singing (Camic et al. 2013b). This was a small scale but thorough study (10 PWD and carers over a 10-week period) (Camic et al. 2013b) that used quantitative and qualitative evaluative measures. The objective of the study was to assess whether engagement in singing groups positively affected PWD. Standardised measures included assessing the PWD's cognitive abilities at baseline with the Addenbrooke Cognitive Examination and subsequently at post-group and 10-week follow up. Their mood was assessed with the Geriatric Depression Scale and QOL with the Dementia Quality of Life (Dem-QOL-proxy), behavioural and psychological problems with the Neuropsychiatric Inventory and activities of daily living with the Bristol Activities of Daily Living Scale (Camic et al. 2013b). In addition to these standardised measures, levels of engagement and participation were measured using a "specially constructed" observational scale (Camic et al. 2013b). The qualitative data provided a different perspective than the quantitative data; whilst the former demonstrated the enthusiasm with which PWD participated, the standardised measures were inconclusive. Indeed, the benefit of using qualitative data with statistical analysis is also appreciated in the RCT study of a music intervention for PWD (Harrison et al. 2010).

The study by Camic et al. did not support the commonly held belief that PWD are not interested or capable of taking on new activities (Camic et al. 2013b). Singing and music have also been used with people who are in more advanced stages of dementia and have lost all verbal skills or who

are completely bedridden (Povey 2011), however more rigorous studies about the role of music and singing for PWD who are in more advanced stages of the illness are required.

Art Groups: Drawing, Making and Painting

Although there may be numerous projects that use art with PWD, research into art-making activities for PWD is sparse (Eekelaar et al. 2012). However, despite small samples there is evidence that those with a dementia who engage in arts activities experience improvements in social and psychological well-being. For example, Kinney and Rentz (2005) used a careful method of evaluation to compare the effectiveness of a drawing and painting programme (Memories in the Making) led by an artist facilitator with participation in a structured activity on the well-being of twelve adults with a dementia at 2 day centres. Well-being was assessed using an outcomes-based observation tool designed specifically for this study and that focussed on seven domains of well-being. This study reported that participants demonstrated increased sustained attention, engagement, and communication. However, these findings are tentative because of the small sample size and certain aspects of the observation tool developed (Kinney & Rentz 2005).

The work of the Magic Me group (http://www.magicme.co.uk) has also been successful at engaging PWD with the creation of artworks (Gilfoy & Knocker 2009) as has the small scale "Lighting Up" project (Sherratt 2010). However, both accounts of artists working with PWD would benefit from both a theoretical framework and from longer-term evaluation that assesses the duration of the benefits experienced by PWD who participate. As noted by Salisbury et al. (2011), partial explanation for the benefits of arts interventions for PWD comes from neurological findings that demonstrate how drawing therapeutically affects the brain. Future research in this area might benefit from incorporating and investigating these findings.

Evidence from recent studies on aesthetic perception amongst those living with a dementia as noted by Graham et al. (2013), suggests that interactions with art can lessen the severity of AD symptoms. The interesting results of Graham et al.'s work (2013) indicate that:

> ... people with AD do possess aesthetic perception much like that of healthy adults, we must explain how this is possible given that brain areas that seem to underlie normal aesthetic perception appear to be damaged in AD. (6)

The authors speculate that apparent damage may not be so severe and that sub-cortical systems could help individuals compensate. If aesthetic judgments remain stable then the value of interventions involving art viewing are evident. This is a finding that is echoed in earlier studies (Halpern et al. 2008). Clearly a deeper understanding about the role of visual information may also lead to the development of novel therapies and programmes. It may even be that other areas of aesthetic judgment also remain stable.

Eekelaar et al. (2012) in a project that gathered data in novel ways including audio recordings investigated the association between visual arts based interventions (in the context of an art gallery) and cognitive stimulation for PWD (Eekelaar et al. 2012). The study design involved measuring cognitive responses to a semi-structured interview by PWD and audio recording these, as an alternative to standardised questionnaires, which have proved problematic in research with PWD. Because of the research focus that was on PWD's episodic memory and verbal fluency, questions about the gallery's artwork were used to elicit verbal responses (Eekelaar et al. 2012). The study procedure (once consent had been obtained) was for the PWD and carer to attend three 90-minute gallery sessions over 3 weeks. The final hour of the session was spent in an art-making session. Four weeks post intervention, participants were interviewed again, shown reproductions of the art they had viewed, and asked for feedback about the group. This study, although limited in scope and scale – six PWD participated and the study took place over 7 weeks without a control group – indicated that episodic memory and verbal fluency could be enhanced both by art viewing and art-making. This is a finding that deserves further investigation.

Ullán et al. (2013) designed a monochrome photographic procedure for people living with a "mild or moderate" form of dementia. Above all, this project demonstrates that the PWD who participated were able to use new technologies and learn new skills. Participants also enjoyed the activity. However, this study was highly selective (those with more advanced forms

of dementia were not included) and only provides information about the process of the workshops rather than their longer-term impact.

Dance Projects

Since the beginning of the twenty-first century there has been a marked escalation in projects and approaches using dance with PWD. In the UK the work of Richard Coaten has been central to fostering understanding about the intrinsic value of movement, dance, and the imagination for PWD (Coaten 2002).

Dancing with PWD has been explored in hospital settings and day centres and positive effects have been noted. These include a decrease in challenging behaviour and the promotion of person-centred care (Coaten et al. 2013). In addition, there has been increasing recognition of the benefits of non-verbal, body-oriented focus for PWD and the embodied nature of the illness, in contrast to the predominant emphasis in western culture on verbal, cognitively-based activities (Coaten & Newman-Bluestein 2013; Kontos 2005). Dance projects can increase movement range and mobility in PWD and therefore nurture remaining capacities (Coaten et al. 2013; Smith et al. 2012). Dance is inherently interactive and playful and these are important qualities that dance projects can offer PWD, their carers, and the staff of day centres/care homes (Coaten & Newman-Bluestein 2013; Smith et al. 2012). However, a recent systematic review of dance as a psychosocial intervention in care homes (Guzmán-García et al. 2013) highlights that evidence on the efficacy of dancing in care homes is limited because of the methodological challenges facing this research.

The "Moving Memories" project (Coaten et al. 2013) was relatively long term (36 weeks) and involved a group of 10–14 PWD as well as care workers, a researcher, and the dance artist who led the activity. The project explored the role that movement can play in the lives of those who live with a dementia and also for care staff within a day centre. The report stresses the value of having an independent researcher who was able to use ethnographic processes (such as diaries) to capture the spirit of dance. Similarly, the pilot project, led by Smith et al. (2012), used qualitative methods to gather data about the dance intervention. However, in their reflective report, Smith et al. (2012) comment upon the limitations of relying upon feedback interviews with participants and the need for future

evaluations to include film and visual mechanisms especially in dance projects.

Theatre and Storytelling

A primary benefit of drama-based projects is the opportunity to express emotions and thus cope with the condition of living with a dementia (Harries et al. 2013). After all, telling stories and acting these out is a fundamental human experience and remains a key method for sharing experiences.

Participatory theatre activities that include creative storytelling for PWD have been pioneered in the US by Anne Basting in her innovative *Time Slips* project (2001). Basting's "Finding Penelope" project (a site specific performance based in a Milwaukee care home; Mello & Voights 2012) has demonstrated that PWD are able to learn new skills and actively take part, even co-direct a theatrical production. The evaluation of "Finding Penelope" was qualitative and drew on a wide variety of sources including: video recordings of meetings, in-depth interviews, and photographs amongst other data (Mello & Voights 2012). The goal of this project was to *transform long-term care through creative engagement* ... and also to *change the conditions of care for persons with dementia.* As eloquently noted by Zeisel (2009) the dramatic ambience itself conveys feelings and ideas and thus drama provides a powerful mode of communication for PWD. This was evidenced by Basting's project, which was also important in generating a sense of belonging amongst participants (Zeisel 2012). The evaluation of "Finding Penelope" whilst arguably limited (it was written by a member of the project team) found that the theatrical project had made a positive difference in the quality of residents' and staff lives.

Basting's work is important in encouraging creative work that does not rely on memory. The Storybox project (a UK theatre based project) similarly emphasises creating rather than reminiscing, this is associated with a failure-free atmosphere (Harries et al. 2013). In addition, improvisation is often central to participatory theatre. Improvisation allows PWD to dare, to play, and to create, and is a process that many find liberating (Basting 2001). Improvisation also facilitates inclusion by fostering collaboration, fun, and experimentation (Harries et al. 2013). The model of interactive theatre that has been used with PWD by the group "Ladder

to the Moon'' (Zeisel 2009) similarly encourages co-creation and experimentation as a means of involving as many PWD as possible.

The dramatic staging and performing of the stories of PWD is an important means of combatting prejudice and stigma about dementia (Zeisel 2009). Even within care homes, theatrical performances have had demonstrably positive effects on the attitudes of staff – as outlined in the evaluative report of the ''Ladder to the Moon'' residency (Parsons 2009). However, whether altered attitudes are evidenced in changed caring practices is less apparent (Parsons 2009).

Poetry and Writing

Poetry appeals to similar parts of the brain as song (Zeisel 2009). The need for rhythm and rhyme is innately human and it is posited that this is one of the reasons that working with PWD to create poetry is so appropriate. In the UK John Killick has pioneered ways of working with PWD to co-write poetry. This work and the poems produced (Killick 1997, 2007, 2008) have contributed to insights into the worlds of some individuals living with a dementia.

In addition, Killick's work has persistently emphasised the existence of selfhood, the ability to communicate in language, and to exercise creative choice even at relatively late stages of a dementia. The importance of the collective creation in creating poetry with PWD is also highlighted in other studies (Aadlandsvik 2008). Participants might not be able to write any longer but can direct the poet (who acts as an amanuensis for the PWD) and this allows PWD some degree of control and autonomy. The one-to-one interactions of a poet with a PWD and the personal nature of the activity may be a major factor contributing to the success of these interventions (Gregory 2011).

Poetry is also used with PWD as something to recite together or to read with PWD and has been found to be a means of releasing an individual's personality (Glazner 2006). Creating poetry as a means of encouraging reminiscence was the focus of the ''Try to Remember'' project (2011); however the views and benefits for PWD were not the explicit focus of this study. A study of a literature-based intervention for PWD (Billington et al. 2013) that addressed the impact and effect of shared reading on PWD found that there was a significant reduction in dementia symptom

severity but similarly failed to investigate the views or opinions of PWD in any detail.

Despite the anecdotal evidence that many projects use poetry and creative writing with PWD, studies evaluating the efficacy of these interventions (especially from the point of view of the PWD) are scant and work examining the applications of poetry using rigorous, robust methodologies is rather sparse.

The Role of Museums and Art Galleries

Museums are public places that are non-stigmatising and that have websites that extend beyond the boundaries of the physical place (Camic & Chatterjee 2013). However, despite the increase in understanding about the possible cognitive and psychological benefits of arts and health interventions in museums, research is still at an early stage (Camic & Chatterjee 2013).

Art galleries as a "normal," intellectually stimulating location for social interaction have great potential for engaging PWD especially given the possibilities that aesthetic perception remains relatively stable for PWD (Graham et al. 2013). Art galleries can use their resources to devise projects that engage PWD quite easily (Camic & Chatterjee 2013; Camic 2013a; MacPherson et al. 2009; Rosenberg et al. 2009; Zeisel 2009). Participatory projects in art galleries can use a variety of methods for engagement, including structured discussions of actual artworks followed by opportunities for art-making (Camic et al. 2013a; Roe et al. 2014). Indeed the controversial area of new learning for PWD has been confronted by Camic both in the context of a singing group (2013), and within a gallery setting (2013a). In both instances, the research team found that PWD were able to undertake new learning.

Traditional art gallery settings have been the focus for most studies exploring the influence of the location of participatory arts projects for PWD (Camic & Chatterjee 2013; Camic et al. 2013a; Eekelaar et al. 2012; MacPherson et al. 2009; Rosenberg et al. 2009). This area could be expanded by exploring the effects of similar projects at different, less conventional types of galleries and museums (as noted by Camic et al. 2013a).

Memories that are visually encoded are vivid and can be easily stimulated; this explains the powerful nature of visual stimulation in art

galleries, as noted by Rosenberg et al. (2009). Similarly, Zeisel (2009) makes numerous observations about the possibilities that PWD have for aesthetic appreciation of art that are based on his experience of museum tours with his "Artists for Alzheimer's" programme.

Issues of Evaluation

The thorny issue of adequately evaluating complex interventions such as participative arts projects: that involve interrelated variables, confounding factors, and a range of possible outcomes, was a recurring theme in the literature reviewed. Some of the main concerns relate to the use of inappropriate outcome measures; for example, Camic et al. (2013b) highlight the inadequacy of standardised QOL measures for people with a dementia. In addition, overtly clinical approaches to evaluating the participative arts – for example, investigating cognitive effects or the impact of "doses" of music – has also been queried (Harries et al. 2013; de Medeiros & Basting 2014).

However, it is important to note that it is not solely the participative arts for PWD that are difficult to evaluate. In their general guidance on the evaluation of complex interventions, the Medical Research Council notes that whilst there are some aspects of good practice that are evident:

> ... on many important issues there is no consensus yet on what is best practice. (Craig et al. 2008: 6)

In large part, this is because of the methodological and practical constraints that affect the evaluation of complex interventions.

Discussion

According to the literature reviewed, the participative arts are able to contribute positively to the lives of those living with a dementia in manifold ways. These include: aiding communication; encouraging residual creative abilities; promoting new learning; enhancing cognitive function; increasing confidence, self-esteem, and social participation; and generating a sense of freedom – among other documented benefits. In addition, the arts are effective at alleviating boundaries between service providers and people with dementia and in providing new insights for the dementia workforce and family members. The arts have a unique application for uncovering

and communicating the interior worlds of those living with a dementia (Gjengedal et al. 2014; Ryan et al. 2009). The spate of recent theatre productions, memoirs, and films exploring various aspects of living with a dementia indicate that there is a receptive and wide audience for artistic contemplations of this condition.

Yet the complex role of the participative arts for PWD is a field that is in its infancy. Moreover, because of methodological challenges, and a dearth of theoretically informed work, most conclusions are tentative rather than confident, particularly concerning the long-term impact of arts projects. However, recent studies using RCT designs to investigate singing and music for PWD (Harrison et al. 2010; Särkämö et al. 2014) reflect the growing interest in systematic research in this area. As noted elsewhere:

> The basic research has begun, and the field is now ready for a deeper exploration . . . .
> (Spiro 2010: 897)

In concurrence, this review indicates that the evidence base can certainly be strengthened. In particular, studies that take place over longer time periods with more diverse groups of PWD and that use a variety of evaluative methods (several studies have demonstrated the efficacy of combining qualitative with quantitative measures) are needed.

As Hara points out, in particular relation to research on the effects of music on PWD Hara (2011), the neuroscientific approach tends to examine music as an isolated phenomenon (separate from the social context) and to examine it solely in terms of its ability to effect change. Thus the effect of music is measured in a specific and predefined way, much like a pharmaceutical drug. This aptly highlights a key difficulty in evaluating the role of the participative arts for PWD – the number of external, confounding factors, and the importance of appreciating the whole context. Studies that explore the underlying cognitive, neurological, and emotional mechanisms that may be affected are required. In addition, studies that draw on appropriate theoretical models and that consciously integrate the views of participants living with a dementia should be conducted in order to make reliable conclusions that are generally applicable and have practical relevance for PWD. Furthermore, economic analysis should be included in studies of the participatory arts for PWD so that commissioning agencies can make decisions regarding the relative expense of these

groups (Camic et al. 2013b) in comparison with other therapeutic or pharmacological interventions.

Despite the need for further stringent evaluative research, the work that has already been conducted indicates that the participative arts will continue to develop and respond to the needs of PWD in uniquely valuable ways. In particular, recent work in the UK (Zeilig et al. 2014), indicates that feelings of peace may be generated for PWD by music making, and that arts projects can produce internal connections and also friendships. In addition, arts projects can create a space that is outside the demands of daily life and the ability for PWD to engage reciprocally. Whilst it is difficult to establish whether these effects are intrinsically associated with the arts activity as opposed to any other form of social participation; the inherent emphasis of most arts projects is on group creation and playfulness. The focus on play and creation privileges the present moment and is particularly valuable for PWD.

After all, the emphasis of the arts is on experience, feeling, imagination, and meanings that lie to the side of our vision, meanings that may be masked and cannot easily be measured. The emphasis on emotions that is integral to the arts is of particular relevance for PWD and their carers. Moreover, if health is more than the absence of disease and is primarily about adaptation, understanding, and acceptance (Davies et al. 2014) then the arts may indeed be more powerful for those living with a dementia than anything medicine has to offer.

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The level of development of nursing assistants' value system predicts their views on paternalistic care and personal autonomy

By Sofia Kjellström[1] & Per Sjölander[2]

Abstract

The quality of care is substantially influenced by the staff's value priorities. The purpose of this study was to identify and characterize value systems among nursing assistants and nurses' aides, and to assess relations between their value systems and views on good care. A cross-sectional, quantitative study in a Swedish municipality was performed (N = 226). Three distinct value systems were identified, and they corresponded to early (n = 121), middle (n = 88), and late (n = 17) conventional stages of ego development. Early conventional value systems emphasized strict rules, routines and working conditions of staff, while middle and, in particularly, late conventional value systems stressed individualization and autonomy of older people. Assessment of value system, socio-demographic, and occupational variables showed that the value systems had a stronger predictive impact on views on care ethics, participation, and autonomy. The results indicate that staff with late conventional value systems prioritized older persons' exercise of autonomy, while paternalism held priority in staff with early conventional value systems.

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Introduction

The quality of care provided to older adults in nursing homes and through home care is, to a large extent, determined by educational, organizational and personality characteristics of the staff (Chung 2013; Sheridan et al. 1992). Personality characteristics such as one's value system, cognitive and social abilities, especially nursing assistants and nurses' aide obviously have an important impact on the daily care provided to the older people (Bowers & Becker 1992). Value priorities have been shown to play an important role in even seemingly trivial activities like getting a person dressed, which can be done with different degrees of participation from the older person depending on the staff's respect for integrity and autonomy (Dauwerse et al. 2012; Eyers et al. 2012; Persson & Wästerfors 2009).

In Sweden, a platform of fundamental values for elderly care was amended to the Social Service Act on the 1st of January 2011 Social Services Act (SFS, 2001: 453). The Act states that elderly persons should, to the extent possible, be able to choose how and when they receive support, be involved in the decision-making processes, and have their autonomy respected. Thus, central values should be privacy, integrity, autonomy, participation and individualization of care.

In Sweden, the care for older people is provided by trained and qualified staff (Trydegård 2012), mainly by nursing assistants with a three year high school education specific for this profession. A small and decreasing fraction of the staff is nurses' aides who typically have little formal education but extensive experience from working in care organizations. The nursing assistants and nurses' aides are organized in rather independent teams with delegated responsibility for the daily care. A university educated nurse is often in charge of several teams, implying relatively infrequent interactions and meetings for instructions (usually restricted to communication on demand and weekly routine meetings). The terms "nursing assistant" and "nurses' aides" are used somewhat differently internationally, but generally, and in Sweden, the nursing assistants have more formal

education than the nurses' aides. However, the extent and quality of their education could differ widely between different countries.

Nursing assistants with poor education have been reported to focus on paternal, concrete and physical aspects of caring, being less capable of solving abstract problems, and to show negative attitudes towards changes (Dauwerse et al. 2012). In a Swedish study, it was found that nursing assistants supported the older persons' preferences to a higher extent than nurses' aides (Mattiasson & Andersson 1995). This is in conformity with results showing that the level of professional training predicts the extent of autonomy given to the patients (Leibovich et al. 2011).

Among nursing assistants, two mental models have been suggested to guide their caring approach (Anderson et al. 2005). "The Golden Rule" where the key question is "what would I want to be done for me?," and the staff imagines herself in the resident's situation and treats the older person according to what would be her own preferences as an aged person. In the other mental model, "Mother Wit," analogies are made between caring for children and caring for older persons, implying that the older person was treated like a child, which run the risk of inappropriate care (i.e. infantilization) or barriers to appropriate care. These ways of relating to older persons appear to be insufficient in order to provide individualized and person-centered care (Anderson et al. 2005).

Interpersonal cognitive complexity, i.e. the ability to perceive others in complex and personalized ways, has been shown to be an important factor among gerontological caregivers (Medvene et al. 2006). People with more developed abilities for interpersonal cognitive complexity show enhanced understanding of others' perspectives, demonstrated more authentic empathy, and related to older persons in more individualized ways (Grosch et al. 2011). This is in accordance with Gilligan's suggestion of a developmental pathway for care reasoning moving from primarily a self-concern approach, to an other-concern focus, and finally to a balance between other and self (Gilligan 1982; Pratt et al. 1991; Skoe et al. 1996; Skoe & von der Lippe 2002). In this way the care reasoning involves an increasingly more complex understanding of human relationships, a more thorough understanding of autonomy, and a more differentiated view on the appropriateness of various caring approaches and measures for different individuals (Juujärvi et al. 2012).

Theoretical Frameworks

Adult development theory. In developmental psychology, the subfield of adult development stems from Piaget's theories and research on psychological development of children (1954). Consequently, this subfield embraces several theories on personality development after the adolescence, and over the last decades, empirical evidence has piled up in support for these theories (Cook-Greuter 1999; Kegan 1994; Kohlberg 1971, 1981; Labouvie-Vief et al. 1987; Loevinger & Blasi 1976; Loevinger & Hy 1996; Manners & Durkin 2001; Pfaffenberger 2005; Pratt et al. 1991; Sinnottt 2003; Torbert 2004; Westenberg et al. 1998). Development in this context refers to growth in complexity of meaning-making and world views as the individual matures. The degree of development has been found to have strong predictive validity in relation to competence at work and leadership agility (Joiner & Josephs 2006; Torbert & Rooke 2005), personal autonomy and integrity (Loevinger & Blasi 1976), and views and attitudes on care, responsibility, tolerance and discrimination (Kjellström & Ross, 2011; Sjölander et al. 2014; Juujärvi et al. 2012).

According to the stage theory of ego development, personality characteristics develop in a sequential process from pre-conventional stages, via conventional to post-conventional stages (for review, see e.g. Commons 1989, Commons 1990; Cook-Greuter 1999; Manners & Durkin 2001). In large adult samples, only a small percent demonstrate pre-conventional personality characteristics. The large majority of adults show characteristics typical for conventional stages of development ($\sim$ 75%) (Torbert 2004).

At the early conventional stage of development, the *diplomat* or *conformist stage* (in $\sim$ 10% of an adult population), the meaning-making structure is typically based on conformity with social rules and norms (Loevinger & Blasi 1976; Torbert 2004; Westenberg & Block 1993). The world view is constructed on absolutism, polarities and dualistic relations, i.e. a distinct good and bad, right and wrong, etc. (Torbert 2004). Knowledge is assumed to be absolute in the sense that there is only one single correct answer to a given issue. Things can be known with absolute certainty, and experts know the answers. Judgements of other people are normally founded on one's own reactions and beliefs, i.e. the perspective taking ability is self-centred (Cook-Greuter 1999).

The middle conventional stage, called the *self-aware* or *expert stage* (in ∼35% of an adult population), is characterized by a mindset that are focused on self-satisfaction and social acceptance through occupational skills and achievements (Torbert 2004). Although understanding the perspectives of other people is based on self-centeredness, there is an increasing understanding of specificity and uniqueness. Abstract concepts and phenomena, such as reality, can be explained in scientific terms and thereby be understood the same way by all people (Cook-Greuter 1999; Loevinger & Blasi 1976; Torbert 2004).

At the late conventional stage of development, the *conscientious* or *achiever stage* (in ∼30% of an adult population), most people show recognition of multiple sources of knowledge, and that different perspectives on an issue are natural. This stage is also characterized by a pronounced self-responsibility, goal-directedness and conscientiousness. The ability to understand other people's perspectives is highly developed, as well as the necessity of critical assessment as a means to develop both individuals and the society (Cook-Greuter 1999; Loevinger & Blasi 1976; Torbert 2004).

Less than 20% of an average adult population holds a post-conventional meaning-making structure, which is characterised by an understanding of the relativity of reality and that our construction of meaning is inherently linked to social structures, history, future, and personality characteristics. Individuality and the uniqueness of situations, phenomena and persons are recognized, as well as the awareness of paradoxes and self-constructed identities (Cook-Greuter 1999; Loevinger & Blasi 1976; Torbert 2004).

Developmental mechanisms. Differentiation and integration are fundamental mechanisms in all developmental processes where there is a progression from lower to higher forms. Differentiation is mostly defined as an increasing complexity of, and specialization and interdependence of elements, whereas integration is viewed as a congruent organization of the elements. These evolutionary mechanisms emanate from the ideas of Greek philosophers and have since then been supported by an abundance of empirical evidence in a variety of scientific disciplines, e.g. ontology, epistemology, cosmology, embryology, physiology, psychology and sociology (for references, see e.g. Akrivou 2008; Johnson 2000; Kolb 1984). In developmental psychology, the concepts of differentiation and integration are fundamental for theories of psychoanalysis (e.g. Adler 1964; Mahler

et al. 2008), of self-psychology on identity, development and adjustment (Blasi & Glodis 1995; Erikson 1968), and of adult ego development (Blasi & Glodis 1995; Cook-Greuter 1999; Kegan 1994; Loevinger & Blasi 1976; Piaget 1954). Increasing differentiation of the meaning-making structure is characteristic of conventional stages of ego development (e.g. right vs. wrong), while increasing integration is the dominating trait in post-conventional stages of development (Cook-Greuter 1999; Loevinger 1979).

Value system. A value system is a complex set of values with different priorities held by an individual or a society (see e.g. Rokeach 1973; Schwartz 1992). In general, a value system can be either idealized or realized. The idealized value system is a group of differently prioritized individual values determining what is right and wrong, the realized value system is the one people actually use in everyday life. Thus, the idealized and realized value systems might be identical, but for most people the realized value system deviates by situational exceptions.

A person's value system is shaped by several factors. For most people, their idealized value system is a reflection of norms and values of their society, i.e. the cultural value system, which is the set of values considered desirable or undesirable in the group of people to which the person belongs. However, the value system held by individuals within a seemingly homogenous culture might be quite different due to specific value priorities retained in sub-cultures developed in families, workplaces, religious communities, and/or political organizations.

Another factor that forms and modifies a person's value system is the situational context and cognitive capacity to reflect on the relative importance of values, how different values relate to each other, and the implications of different value priorities. One's stage of ego development has been found to be of importance for how people prioritize various values (Cook-Greuter 1999; Kohlberg 1971; Loevinger & Blasi 1976; Loevinger & Hy 1996). For instance, at the early conventional stage of ego development, highly prioritized values are conformity, friendliness, pleasing behaviors, social stability and security (Westenberg & Block 1993). At the late conventional and early post-conventional stages, the value system is characterized by an open-minded and less dogmatic relation to values, beliefs and behaviors of others, implying higher priority to values such as tolerance, autonomy, relativity and individuality (Helson &

Roberts 1994; McCrae & Costa 1980; Pals & John 1998; White 1985). The correspondence between one's value system and stage of ego development makes it possible to estimate the stage of ego development based on one's articulation of their value system (Sjölander et al. 2014).

Aims and Hypotheses

The aims of the present study were to identify and characterize common value systems among nursing assistants and nurses' aides employed in Swedish old age care, and to assess the relations between value systems and views on good care.

The following hypotheses were tested:

- It is possible to identify distinct value systems among nursing assistants and nurses' aides, and to determine the relationship of these value systems to the relative levels of ego development.
- Less developed value systems are related to a more paternalistic view on good care, whereas more developed value systems are characterized by higher priority to dialogue, autonomy, and preferences expressed by the older persons.
- Value system is a good predictor of individual nursing assistants' and nurses' aides' views on good care for older persons.

Methods

Design and Setting

The study was designed as a cross-sectional, randomized, and quantitative investigation of nursing assistants and nurses' aides working in Sweden. The participants were employed in old age care as nurse assistants or nurses' aides and worked in nursing homes or home care in a Swedish municipality with approximately 100,000 inhabitants.

Procedure

In November 2012, a total of 1715 nurse assistants or nurses' aides worked at the municipality at 33 nursing homes and 30 home care units.

The participating nursing home units (n = 13) and home care units (n = 8) were randomly selected. Within each unit all staff working day-time were invited (334 out of 457) and (123 out of 147), resulting in a sample of 457. Of these, 87% (397) agreed to participate. The questionnaire was administered at staff meetings by the head of each unit after providing oral and written information about the study. Of these, 58% (n = 229) answered the questionnaire. Three were excluded since their answers were incomplete, resulting in a final study group of 226.

Measures

A questionnaire was constructed to cover three different areas: one on socio-demographic and occupational variables, i.e. gender, age, education, employment position, work experience, and working location (see Table 2), one on value priorities (i.e. value system), and one about views on good care.

Value system. The staff's value systems were assessed through six questions covering different themes: education, criticism, important values, knowledge, conflicts, and children. For each question the respondent was asked to rate the relative importance of five answers or statements (see Table 1). Thus, 30 separate variables were included in the analysis of value system. The rating was done on a five-point ordinal scale, ranging from unimportant to most important. The statistical reliability was sufficient to disclose three categories in the data set, i.e. the Cronbach's α coefficient = 0.81. The scores on a slightly different questionnaire have been shown to be significantly correlated to the individual's stage of ego development ($r = 0.536$; $p = 0.015$) (Sjölander et al. 2014).

Characteristics of good care. Nineteen statements on care ethics and the role, participation and autonomy of the older person in the care practices, were included in the questionnaire (see Tables 3–5). All statements were rated on a five point ordinal scale ranging from disagree completely to agree completely.

Data Analyses

Value system. Distinct value systems, i.e. common patterns of value priorities, were identified using principal component-based pattern recognition

statistics, i.e. Partial Least Squares Regression to Latent Structures (Wold et al. 2001). Categorization of the individuals' value system was based on a probabilistic algorithm. The pattern recognition method and the categorization algorithm have been described in detail elsewhere (Sjölander et al. 2014).

Differentiation of value priorities. The extent of differentiation between groups of related values was quantified and used as an indicator of development. A factor analysis, with orthogonally rotated factors (Varimax rotation), on the 30 value variables was conducted to identify clusters of related variables (see Table 1). For each individual, the average rating was calculated for the variables with the largest loading on a given factor (variable loading > 0.5), generating rating averages for clusters of related variables. In this way an average rating score was calculated for each significant factor, defined as the factors with a cumulative eigenvalue larger than 1.0. The value clusters were arranged according to their relative importance, i.e. from lowest to highest rated, generating a profile of value priorities for each individual (Figure 1). By a simple regression model, a straight line was fitted to the profile and the slope of the line was used as a quantitative measure of the degree of differentiation between different value priorities. A steeper slope indicated a more differentiated, and hence developed, value system.

Prediction of views on good care. Binary logistic regression models were done to evaluate main effects of the value system, socio-demographic, and occupational variables on views on good care. Nineteen models were calculated, one for each statement on care ethics and the participation and autonomy of the older persons in the care process. The dependent variables, i.e. the 19 statements on good care, were dichotomized to predict the probability of low and high outcomes. The dichotomizations were based on median scores. The predictive impact of the value systems and the socio-demographic variables were expressed as odds ratios (OR) with 95% confidence intervals (95% CIs).

Statistics

The statistical package SPSS (version 11.5, SPSS Inc, USA) was used for descriptive statistics, calculations of averages, standard deviations and

statistical comparisons, including the binary logistic regression analyses and the factor analysis. The multivariate pattern identification analysis was done with SIMCA-P+ (version 11, Umetrics, Sweden).

Research Ethics

All participants engaged in an informed consent process, emphasizing that participation was voluntary, with the right to withdraw from answering the questionnaire at any time. The main results of the study has been presented to, and discussed with, the participants and executives within the care organization.

Results

Value Systems among Nursing Assistants and Nurses 'Aides

The pattern recognition analysis revealed three significant principal components, indicating three distinct value systems. Together, the three principal components explained 40% of the variance in the data set.

By probability calculations, individuals' value profiles were classified into one of the three distinct value systems. A total of 88 individuals showed a values profile that was most similar to value system 1, i.e. the value pattern disclosed by the first principal component. All together 121 individuals demonstrated a profile with the highest correspondence to value system 2 (the pattern disclosed by the second principal component), and 17 individuals had a profile most similar to value system 3 (the pattern disclosed by the third principal component).

Hierarchical Arrangement of Value Systems

The hierarchical arrangement of the three value systems was based on a factor analysis, using orthogonal rotation of the factors to maximize variance between the variables. A factor analysis groups variables according to their pattern of correlation, implying that related variables load highly on the same factor. The factor analysis resulted in a total of 9 factors accounting for 66.6% of the variance. The rotated component matrix, including tentative factor names, is presented in Table 1.

Table 1. Component matrix (varimax rotation) for the 30 value variables

	Factors								
Variables	1. Social conformity	2. Epistemological relativism	3. Over-confidence in education	4. Conflicts for improvement	5. Independence and creativity	6. Conflict avoidance	7. Obedience and hard work	8. Critique is insulting	9. Expert knowledge
What characterize good education?									
It improves my chances to get a safe and secure employment	0.092	0.007	**0.775**	0.053	− 0.041	− 0.059	0.116	0.235	0.103
It is important for developing autonomous individuals and a society where all people are of equal value	0.192	− 0.217	**0.639**	0.362	0.151	− 0.114	0.055	0.089	0.145
It improves my possibility to understand myself and the world	0.183	0.290	**0.680**	0.022	0.150	− 0.077	0.125	− 0.166	0.099
It is important for my personal goals and future achievements	0.218	0.115	**0.658**	0.027	0.065	0.352	− 0.102	0.043	− 0.137
It improves our rationality and the functions of the society	0.356	0.136	**0.534**	− 0.184	0.279	0.316	0.039	− 0.019	− 0.177
What are your views on criticism?									
Positive and negative views are a natural part in all healthy relations	0.396	**0.554**	0.094	0.026	0.216	− 0.240	− 0.061	− 0.240	0.034
I appreciate critics that reveals my hidden motives and behaviors	**0.537**	0.197	0.093	0.048	0.230	0.036	− 0.082	− 0.438	0.311
I am insulted by critique from people who do not know what they are talking about	0.118	− 0.073	0.185	0.004	− 0.069	0.036	0.006	**0.719**	0.165
I accept constructive critique that might be beneficial for the development of myself and the society	**0.771**	0.153	0.100	0.055	0.198	− 0.055	− 0.006	− 0.099	0.174
I regard critique as a reminder of societal norms and regulations	**0.575**	− 0.104	0.122	− 0.030	0.274	0.194	0.216	0.229	0.171

Table 1 (*Continued*)

	Factors								
Variables	1. Social conformity	2. Epistemological relativism	3. Over-confidence in education	4. Conflicts for improvement	5. Independence and creativity	6. Conflict avoidance	7. Obedience and hard work	8. Critique is insulting	9. Expert knowledge
What is most important for you?									
To develop my ability to scrutinize myself and the world I am part of[a]	0.357	0.059	0.220	0.387	0.163	0.370	0.041	− 0.295	0.032
That my surroundings value my expert competencies and occupational skills	**0.750**	0.233	0.149	0.118	− 0.002	− 0.021	− 0.003	0.142	− 0.175
To contribute to a positive development of other people	**0.613**	0.022	0.265	0.360	− 0.011	0.182	− 0.008	− 0.187	− 0.013
That the society provides security by accepting and appreciating me	**0.697**	0.126	0.234	0.201	− 0.065	0.108	0.068	0.203	− 0.181
That my surroundings satisfy my needs[a]	0.504	− 0.091	0.067	0.189	− 0.204	0.469	0.176	0.159	− 0.120
What are your views on knowledge?									
We know some things. We also know things that we do not know, and other things are we unaware of that we do not know	− 0.032	**0.576**	0.118	0.139	0.065	0.208	0.224	− 0.045	− 0.239
The feeling often determines what is right or wrong[a]	0.088	0.476	− 0.011	0.038	0.296	0.268	− 0.168	0.332	0.205
Experts and specialists have the best knowledge	− 0.037	0.082	0.085	0.021	− 0.025	0.038	0.106	0.149	**0.820**
There are both things we definitively know and things that we do not yet understand	− 0.007	**0.654**	0.108	0.164	0.057	− 0.333	0.059	0.066	0.016
Different views on knowledge are reasonable since phenomenon can be interpreted in different ways	0.232	**0.717**	0.008	0.096	− 0.001	0.040	− 0.016	− 0.101	0.224

Table 1 (*Continued*)

| Variables	Factors								
	1. Social conformity	2. Epistemological relativism	3. Over-confidence in education	4. Conflicts for improvement	5. Independence and creativity	6. Conflict avoidance	7. Obedience and hard work	8. Critique is insulting	9. Expert knowledge
What are your views on conflicts among friends and family?									
Conflicts are often caused by people with wrong ideas	0.067	− 0.133	0.042	0.028	− 0.065	**0.807**	0.150	− 0.045	0.041
Conflicts are interesting since they expose different views	0.090	0.204	0.133	**0.789**	− 0.079	− 0.015	− 0.139	0.032	0.025
I tolerate conflicts since they may lead to improvements	0.194	0.151	− 0.012	**0.861**	0.121	− 0.021	− 0.024	− 0.031	0.005
I avoid conflicts since they disturb the social atmosphere	0.044	0.116	− 0.039	− 0.246	0.148	**0.572**	0.222	0.402	0.075
Conflicts are a natural part of human relations[a]	0.185	0.549	− 0.014	0.514	0.139	− 0.050	0.039	− 0.022	− 0.050
How important are the following child qualities?									
Tolerance	0.032	0.113	0.069	0.027	0.469	− 0.107	**0.620**	0.178	− 0.085
Independence	0.096	0.091	0.086	0.051	**0.836**	− 0.025	0.136	− 0.006	0.089
Creativity	0.083	0.116	0.118	0.055	**0.765**	0.022	0.123	− 0.119	− 0.098
Obedience	0.089	− 0.022	0.062	− 0.083	− 0.005	0.099	**0.834**	0.045	0.085
Hard work	0.003	0.084	0.059	− 0.068	0.189	0.308	**0.749**	− 0.121	0.069

[a]These four variables did not load uniquely high on any of the factors.

The variables are in bold that loaded highly on a specific factor.

For each individual, an average rating score was calculated for those variables loading strongly on the 9 factors, thus generating average ratings for 9 value clusters. By arranging these rating scores hierarchically, from lowest to highest, the slope of a straight line fitted to the individual's profile was calculated (Figure 1). The slope was used as a quantitative measure of differentiation between value clusters with different priority. For the 88 individuals with value system 1 the mean slope was 0.32 (SD, 0.11), while the 121 individuals with value system 2 showed a mean slope of 0.24 (SD, 0.11), and the 17 individuals with value system 3, a mean slope of 0.41 (SD, 0.12). An ANOVA was conducted on the average slope values, showing significant differences between the sub-groups ($F(2, 223) = 24.8$, $p < 0.0001$). The post-hoc tests revealed significant differences between value systems 1 and 2 ($p < 0.0001$), value systems 1 and 3 ($p < 0.01$), and value systems 2 and 3 ($p < 0.0001$). Thus, the degree of differentiation between the value clusters was highest for the sub-group with value system 3, second highest for the sub-group with value system 1, and lowest for the sub-group with value system 2.

Characterization of the Value Systems and Their Relation to Development Stages

To characterize the content of value priorities in the three value systems, and to evaluate their level of development on the early, middle and late conventional scale, the mean rating for each of the nine value clusters was calculated separately for the three value systems (Figure 2). A MANOVA was carried out on the nine value clusters showing a significant main effect for value system (Wilks' Lambda $F(18,324) = 23.7$, $p < 0.0001$). The patterns of value priorities indicate that the sub-group with value system 2, the least differentiated system, was dominated by individuals with an early conventional world view, emphasizing a society that provides stability, harmony, conformity and collective belonging (Sjölander et al. 2014; Loevinger & Blasi 1976). In comparison to the other two value systems they scored highest on "conflict avoidance," lowest on "epistemological relativism" and "independence and creativity," and together with the sub-group with value system 1 they scored high on "critique is insulting."

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Figure 1. Individual examples of slope (*k*) calculated by simple linear regression to fit the mean rating of 9 value clusters identified in the factor analysis and arranged according to priority.
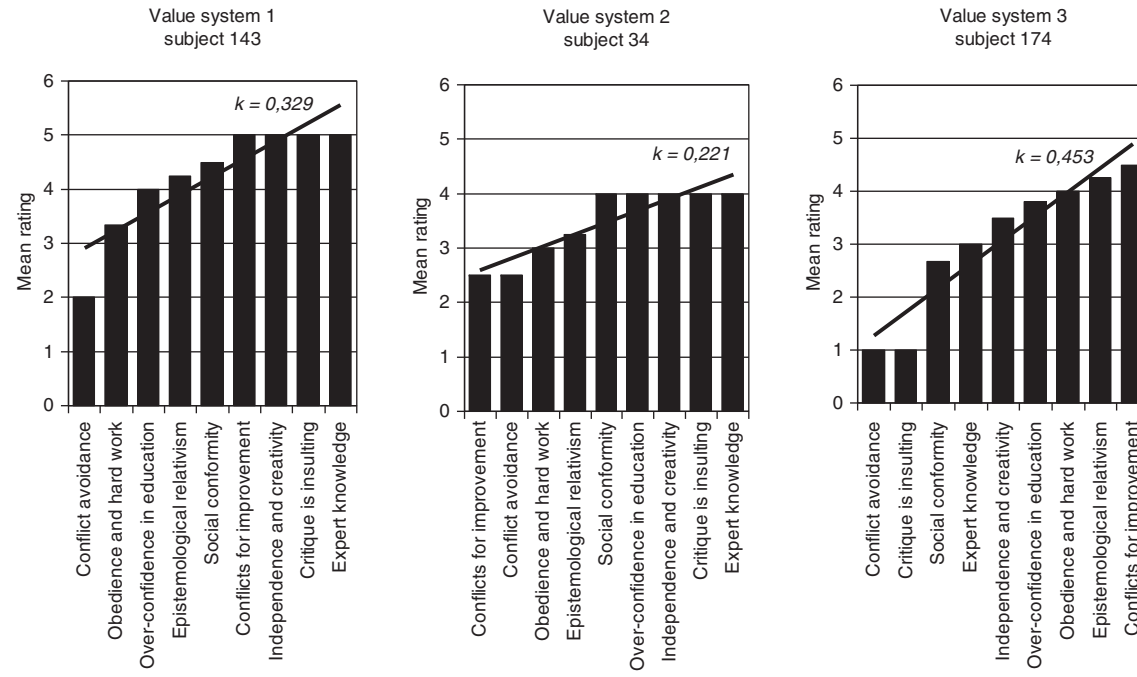
The sub-group with value system 1 put particularly high value on conformity, education, achievement, and expertise, which are cardinal characteristics of middle conventional meaning making structures (Sjölander et al. 2014; Loevinger & Blasi 1976). Thus, they scored highest on "social conformity," "over-confidence in education," "conflicts for improvement," *and* "expert knowledge" (Figure 2).

In comparison to the other two value systems, the sub-group with value system 3 scored highest on "independence and creativity" and lowest on "social conformity," "over-confidence in education," "expert knowledge," "conflict avoidance" and "critique is insulting." Taken together, the pattern of value priorities of the sub-group with value system 3 indicates a late conventional meaning-making structure where social conventions and cultural values are beginning to be questioned, and where independence and individual development gain in importance (Sjölander et al. 2014; Loevinger & Blasi 1976). Thus, the hierarchical arrangement of the three value systems corresponds nicely to value priorities typically found among people with early, middle and late conventional meaning-making structures.

Prediction of Views on Good Care

In order to evaluate the predictive impact of nursing assistants' and nurses' aides' value system on their views on good care for older persons, regression models were calculated where main effects of value system type, socio-demographic, and occupational variables were compared. Socio-demographic and occupational characteristics of the three sub-groups with different value systems are given in Table 2. There were no statistically significant differences between the sub-populations, with the exception for the relative frequency of staff work at nursing homes and home care. Among those with a late conventional value system, it was significantly more common to work at a nursing home and less common to work in home care in comparison to the sub-group with a middle conventional value system.

The regression analyses revealed that the level of value system was significantly related to the outcomes of 10 of the 19 statements, workplace site to 6 of the statements, age to three, level of education to three, work

Figure 2. Characteristics of the early, middle and late conventional value systems expressed as mean rating and SD of the 9 variables identified by the factor analysis. Statistical comparisons by Benferroni adjusted post-hoc tests and level of significance indicated by stars (*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$).
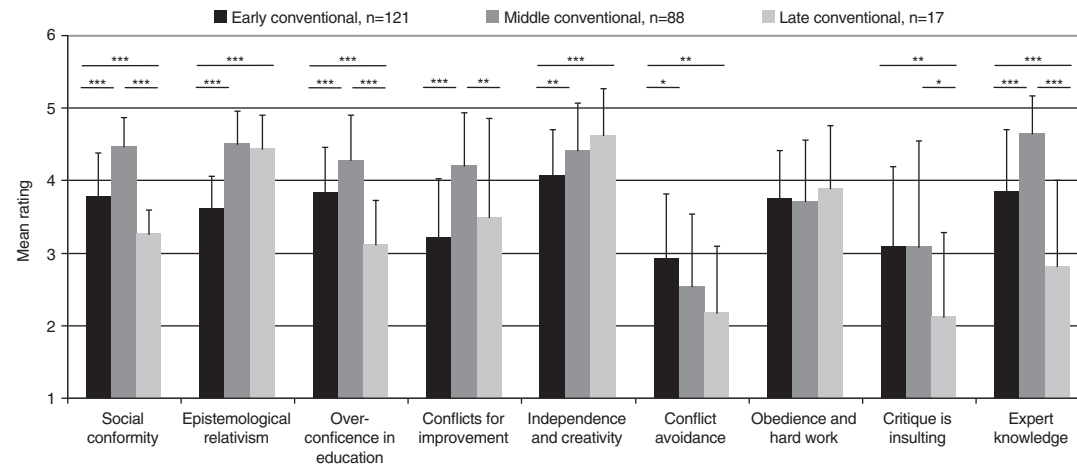
Table 2. Socio-demographic and occupational characteristics of the three sub-groups with different value systems

	Early conventional, n = 121	Middle conventional, n = 88	Late conventional, n = 17	p
Gender distribution (women/men)	114/7	81/7	17/0	n.s.[a]
Age (mean ± SD)	44 ± 12	42 ± 13	49 ± 12	n.s.[b]
Education, highest level				
Compulsory, 6–9 years (%)	15	12	6	n.s.[a]
High School, 10–12 years (%)	78	80	88	
University, ≥ 13 years (%)	7	8	6	
Occupation				
Nursing assistant (%)	82	82	94	n.s.[a]
Nurses' aide (%)	18	18	6	
Work place				
Nursing home (%)	60	48	82	< 0.05[b]
Home care (%)	40	52	18	
Employment years in old age care (mean ± SD)	17 ± 10	14 ± 11	19 ± 12	n.s.[c]

[a]Kruskal Wallis Test.
[b]One-way ANOVA.
[c]Significant difference between middle and late conventional ($p < 0.01$, Mann-Whitney U-test).
n.s. = $p > 0.05$.

experience to three, gender to one, and occupation to one of the care statements.

The outcome of the 6 regression models on ethical issues is presented in Table 3. In comparison to the sub-group with an early conventional value system, the sub-groups with middle and late conventional value systems were more likely to be in favor of an individualized approach in the old age care and to have an enhanced awareness of possible conflicts between ethical issues, but were less likely to advocate ethical standards without exceptions. To adopt ethical standards without exceptions was more agreeable among staff with high school education in comparison with staff with compulsory school as their highest level of education. Those working

Table 3. Binary logistic regression models for predicting nursing assistants' and nurses' aides' views on care ethics

| | OR (95% CI) | | | | | | | | | | | | | | | | |
| | Value system | | | Gender | | Age (years) | | | Education (years) | | | Occupation | | Work place | | Work experience (years) | | |
Statement	Early conventional	Middle conventional	Late conventional	Men	Women	20–30	31–50	> 51	6–9	10–12	≥ 13	Nurses' aid	Nursing assistant	Home care	Nursing home	< 5	5–10	> 10
Ethics is best learned from experts																		
	1	1.1 (0.5–2.5)	0.4 (0.0–3.5)	1	0.3 (0.1–1.3)	1	2.4 (0.6–9.1)	**5.6 (1.3–23.4)**	1	2.2 (0.6–8.2)	**6.6 (1.1–38.8)**	1	1.1 (0.4–3.4)	1	**0.3 (0.1–0.7)**	1	0.5 (0.1–1.7)	0.3 (0.1–1.1)
Ethics is about addressing the elderly based on their individual conditions and needs																		
	1	**3.8 (1.9–7.7)**	**4.5 (1.2–16.3)**	1	1.0 (0.3–3.9)	1	1.7 (0.6–4.9)	1.8 (0.5–5.7)	1	0.4 (0.1–1.2)	0.9 (0.2–4.4)	1	0.5 (0.2–1.5)	1	1.1 (0.5–2.1)	1	0.7 (0.2–2.3)	0.7 (0.2–2.0)
There is always one approach or action that is the most ethically correct																		
	1	1.6 (0.8–3.1)	0.4 (0.1–1.8)	1	1.5 (0.4–5.8)	1	**2.7 (1.0–7.6)**	**3.2 (1.0–10.1)**	1	1.5 (0.5–4.3)	2.6 (0.6–12.5)	1	1.0 (0.4–2.8)	1	1.0 (0.5–1.9)	1	0.6 (0.2–1.7)	**0.3 (0.1–0.9)**
Occasionally the most ethical action implies that one has to violate regulations or laws																		
	1	0.8 (0.4–1.8)	0.4 (0.1–1.5)	1	2.4 (0.5–11.9)	1	0.8 (0.2–3.2)	1.5 (0.3–6.7)	1	2.5 (0.8–7.7)	1.6 (0.3–8.2)	1	2.3 (0.8–7.1)	1	1.1 (0.5–2.4)	1	**0.1 (0.0–0.9)**	**0.1 (0.0–0.6)**
One has to learn the current ethical standards and adopt them without exceptions																		
	1	**0.2 (0.1–0.6)**	**0.1 (0.0–0.5)**	1	0.5 (0.0–5.1)	1	0.6 (0.1–3.1)	1.3 (0.2–7.6)	1	**7.1 (1.8–27.5)**	0.8 (0.1–4.9)	1	1.6 (0.4–6.0)	1	**0.3 (0.1–0.9)**	1	1.6 (0.3–9.6)	0.7 (0.2–3.7)
To act ethically correct towards a person may imply that you act unethically towards someone else																		
	1	**11.9 (4.4–32.2)**	**5.5 (1.2–26.2)**	1	3.0 (0.3–29.4)	1	1.0 (0.2–3.7)	2.1 (0.5–9.5)	1	0.6 (0.2–2.5)	0.4 (0.1–5.2)	1	0.6 (0.2–2.1)	1	1.2 (0.4–3.3)	1	0.4 (0.1–1.7)	0.4 (0.1–1.6)

One model for each statement, and each model containing the same potential determinants.

Relations expressed as odds ratios (OR) with 95% confidence intervals (95% CI).

Statistically significant relations are marked by bold numbers.

Level of development of nursing assistants' value system

in nursing homes were less likely to agree on this ethical approach compared to staff working in home care.

Older staff members and those with university education were more likely to believe in experts as teachers in ethics, compared to young staff members and those with compulsory school as their highest level of education. Staff at nursing homes were less likely to believe that ethics is best learned from experts, as compared to the home care staff.

Old and middle-aged staffs were more likely, as compared to young staff members, to think that a particular ethical approach always is the most correct. Interestingly, staff who had worked in old age care for more than 10 years was less in favor of this statement in comparison with those with less than 5 years of experience. The more experienced staff was also less in support of the statement implying that good ethics may be inconsistent with current laws and regulations.

Table 4 shows that the relations between value systems and issues on participatory care were particularly strong. In comparison to those with an early conventional value system, staff with a late conventional value system were less in favor of a care structure where the staff tell the older persons how and why things should be done, and less in support of a caring approach that is based on the staffs' own preferences on how they would have been liked to be treated. Staff with middle and, in particular, late conventional value systems were more likely to support a participatory approach where the elderly are appreciated as unique individuals and their participation is based on agreements between the older people and the staff. Participation that is decided by the older person based on advice from the staff was more agreeable to those with middle conventional value systems as compared to those with an early conventional value system.

Women, as compared to men, were more in support of a participatory approach that is based on the staff's own preferences on how they would prefer to be treated as old. Nursing assistants, however, were less in favor of this approach in comparison with nurses' aides.

As compared with staff working in home care, the staff in nursing homes was less likely to advocate a participatory setting where the older people are appreciated as unique individuals, and where their participation is based on agreements between the older person and the staff.

Table 4. Binary logistic regression models for predicting nursing assistants' and nurses' aides' views on participatory care

Statement	Value system			Gender		Age (years)			Education (years)			Occupation		Work place		Work experience (years)		
	Early conventional	Middle conventional	Late conventional	Men	Women	20–30	31–50	> 51	6–9	10–12	≥ 13	Nurses' aid	Nursing assistant	Home care	Nursing home	< 5	5–10	> 10
Participatory care means that the staff tell the elderly how and why they should be treated in a particular way																		
	1	0.6	**0.2**	1	0.9	1	1.0	3.3	1	1.8	0.8	1	1.6	1	1.5	1	0.5	0.5
		(0.3–1.4)	**(0.1–0.9)**		(0.2–4.6)		(0.3–3.3)	(0.8–13.0)		(0.5–6.3)	(0.2–4.5)		(0.5–4.4)		(0.7–3.2)		(0.1–1.8)	(0.1–1.8)
Participatory care implies that the staff get information from the elderly about their needs and wishes																		
	1	0.6	0.6	1	2.5	1	0.9	1.4	1	1.5	1.5	1	0.8	1	1.0	1	0.5	0.5
		(0.3–1.2)	(0.2–2.2)		(0.6–10.8)		(0.3–2.6)	(0.5–4.3)		(0.5–4.5)	(0.3–7.1)		(0.3–1.9)		(0.5–1.9)		(0.2–1.4)	(0.2–1.3)
Participatory care means that the staff together with the elderly agree on how to organize the care																		
	1	**5.5**	**10.0**	1	0.2	1	1.3	1.0	1	0.8	0.9	1	1.3	1	**0.5**	1	0.4	0.6
		(2.6–11.5)	**(2.0–50.4)**		(0.0–1.4)		(0.4–3.8)	(0.3–3.4)		(0.3–2.4)	(0.2–4.4)		(0.5–3.4)		**(0.2–0.9)**		(0.1–1.5)	(0.2–2.0)
Participatory care implies that the staff provide advises to the elderly who makes the decisions																		
	1	**2.2**	0.5	1	1.7	1	0.5	0.8	1	1.4	2.8	1	1.4	1	0.5	1	0.5	0.7
		(1.1–4.5)	(0.2–1.9)		(0.4–6.8)		(0.2–1.7)	(0.2–2.9)		(0.5–4.1)	(0.5–14.8)		(0.5–3.6)		(0.3–1.1)		(0.2–1.8)	(0.2–2.1)
Participatory care means that the staff organize the care based how they themselves would have been preferred to be treated																		
	1	0.6	**0.1**	1	**4.5**	1	0.5	0.6	1	1.8	1.9	1	**0.3**	1	2.0	1	1.8	1.8
		(0.3–1.2)	**(0.0–0.4)**		**(1.1–18.4)**		(0.1–1.6)	(0.2–2.5)		(0.6–5.8)	(0.3–10.7)		**(0.1–0.9)**		(0.9–4.1)		(0.5–6.6)	(0.6–6.1)
Participatory care is all about considering the elderly as unique individuals																		
	1	**3.3**	**4.1**	1	1.3	1	0.8	1.0	1	0.5	0.3	1	1.6	1	**0.3**	1	0.6	1.3
		(1.5–7.2)	**(1.1–22.8)**		(0.3–5.3)		(0.3–2.3)	(0.3–3.3)		(0.1–1.8)	(0.1–1.9)		(0.6–4.6)		**(0.2–0.8)**		(0.2–1.9)	(0.4–3.9)

One model for each statement, and each model containing the same potential determinants.
Relations expressed as odds ratios (OR) with 95% confidence intervals (95% CI).
Statistically significant relations are marked by bold numbers.

Level of development of nursing assistants' value system

Table 5. Binary logistic regression models for predicting nursing assistants' and nurses' aides' views on autonomy of the older persons

| | OR (95% CI) | | | | | | | | | | | | | | | | | |
| | Value system | | | Gender | | Age (years) | | | Education (years) | | | Occupation | | Work place | | Work experience (years) | | |
Statement	Early conven-tional	Middle conven-tional	Late conven-tional	Men	Women	20–30	31–50	>51	6–9	10–12	≥13	Nurses' aid	Nursing assistant	Home care	Nursing home	<5	5–10	>10
Self-determination implies that the elderly can do whatever they like																		
	1	0.8	2.8	1	0.4	1	**0.2**	**0.1**	1	2.5	3.0	1	0.6	1	**0.4**	1	**0.2**	0.4
		(0.4–1.6)	(0.7–10.8)		(0.1–1.9)		**(0.0–0.6)**	**(0.0–0.4)**		(0.8–7.8)	(0.6–15.2)		(0.2–1.7)		**(0.2–0.9)**		**(0.0–0.8)**	(0.1–1.4)
To support the self-determination of the elderly means that the staff have to reflect on how they themselves would prefer to be treated when they get old																		
	1	1.3	0.6	1	1.1	1	0.6	1.0	1	0.7	1.3	1	0.6	1	0.6	1	1.0	1.3
		(0.7–2.5)	(0.2–2.1)		(0.3–3.9)		(0.2–1.7)	(0.3–2.8)		(0.3–2.1)	(0.3–5.9)		(0.2–1.5)		(0.3–1.1)		(0.3–3.2)	(0.5–3.7)
Self-determination means that the needs of both the staff and the elderly have to be taken into account																		
	1	0.9	0.5	1	1.0	1	0.5	0.8	1	**3.2**	**5.1**	1	0.5	1	0.9	1	1.6	1.7
		(0.5–1.7)	(0.1–1.8)		(0.3–3.7)		(0.2–1.4)	(0.3–2.3)		**(1.0–10.1)**	**(1.1–24.7)**		(0.2–1.2)		(0.5–1.7)		(0.5–4.8)	(0.6–4.8)
The limitations of the self-determination is decided by the commanding officers and managers																		
	1	1.0	0.9	1	2.3	1	0.6	0.6	1	1.4	2.6	1	0.4	1	0.6	1	0.3	0.6
		(0.5–2.2)	(0.2–4.8)		(0.4–13.1)		(0.2–1.7)	(0.2–2.1)		(0.4–5.0)	(0.5–15.2)		(0.2–1.1)		(0.3–1.4)		(0.1–1.2)	(0.2–1.7)
The staff and the elderly should have a continuous dialogue regarding the desire for self-determination among the elderly																		
	1	2.2	1.7	1	0.7	1	3.1	1.4	1	1.5	1.4	1	0.9	1	**0.3**	1	0.7	1.1
		(0.8–5.5)	(0.3–9.4)		(0.1–4.5)		(0.9–11.0)	(0.4–5.4)		(0.4–5.6)	(0.2–10.3)		(0.3–3.1)		**(0.1–0.8)**		(0.2–3.0)	(0.3–4.3)
It is important that the working conditions of the staff is taken into consideration when decisions are made about self-determination of the elderly																		
	1	1.3	**0.1**	1	0.9	1	1.1	0.4	1	3.0	5.7	1	0.4	1	0.5	1	1.2	0.6
		(0.5–3.6)	**(0.0–0.4)**		(0.2–5.3)		(0.3–3.9)	(0.1–2.2)		(0.3–28.7)	(0.4–79.9)		(0.1–1.3)		(0.2–1.3)		(0.3–5.0)	(0.2–2.7)
To support self-determination is a matter of getting to know the specific needs and desires of the individual elderly																		
	1	**4.7**	**16.1**	1	0.5	1	1.6	2.6	1	0.8	0.6	1	1.3	1	0.5	1	0.3	0.6
		(2.3–9.9)	**(1.9–98.3)**		(0.5–2.3)		(0.5–4.7)	(0.8–8.6)		(0.2–2.3)	(0.1–3.0)		(0.5–3.6)		(0.3–1.1)		(0.1–1.1)	(0.2–1.9)

One model for each statement, and each model containing the same potential determinants.
Relations expressed as odds ratios (OR) with 95% confidence intervals (95% CI).
Statistically significant relations are marked by bold numbers.

The results of the 7 regression models on opinions on autonomy of the older person are shown in Table 5. In particular, staff with a late conventional value system, but also those with middle conventional value systems, agreed more strongly than staff with early conventional value systems to the statement implying that autonomy should be founded on the specific needs and desires of the individual elderly. The late conventional value system was significantly related to a reluctance of letting the staff's working conditions influence decisions about the self-determination of the older persons.

To allow the older person to do whatever they like was less supported among middle and older staff (compared to younger staff), among staff working in nursing homes (compared to those working in home care), and among staff with 5–10 years of working experience (compared to those with less than 5 years of experience).

Staff with high school or university education, in comparison to those with elementary school only, was more likely to think that issues of autonomy must take into consideration the needs of both the staff and the elderly. A dialogue between the older person and the staff in matters regarding self-determination was less supported by staff working in nursing homes than among those working in home care.

Discussion

Three distinct value systems were identified in the study sample. The relative degree of differentiation between value clusters suggested that these value systems were characteristic for individuals at early, middle and late conventional stages of ego development. More than half of the study sample had a predominantly early conventional value system, while less than 10% showed a late conventional value system. Compared to socio-demographic and occupational factors, the value systems had stronger predictive impact on the staff's views on care ethics and on participation and autonomy of the elderly. The views among staff with early conventional value system were to a large extent related to strict rules, routines, their own working conditions, and how they would like to be cared for as old, while the views among those with middle, and, in particularly, late conventional value systems were more based on collaboration between

the older person and the staff, on individualization and the needs and preferences of the elderly. It is concluded that staff at late conventional stages of ego development show value priorities that are most in accordance with the aim of optimizing the older persons' exercise of autonomy and minimizing the exercise of paternalism, which is stated in the Swedish Health and Medical Services Act (SFS, 1982: 763).

Methods and Analyses

The identification of value systems and the classification of the individual's value system were accomplished by pattern recognition statistics and probability calculations, and the hierarchical arrangement of the value systems was based on quantification of the ability to differentiate between value clusters. This analytical approach was chosen rather than to construct content-based qualitative classification criteria that are bound to be more or less subjective due to semantic ambiguities, intra-disciplinary prejudices and/or cultural biases. Most other methods applied in studies of adult development focus on one or a few qualitative features characteristic at different stages of development. By grouping the individuals according to the statistical probability of belonging to identified response patterns, the categorization procedure is less affected by interpretation biases.

A limitation of this analytical approach is that it might be considered as imperviously complicated with several steps of multivariate statistics and coordination of different systems, i.e. one identification system, one classification system, one hierarchical arrangement system and one "good care" system. However, the analytical design seems justified since multivariate statistics are the most appropriate tools when investigating multivariate issues where a number of variables might interact in complex manners.

The response rate was 58% in the present study. This has at least two implications for the interpretations of the result. First, the number of distinct value systems among nursing assistants and nurses' aides might have been underestimated. Secondly, the relative frequency of individuals with early, middle and late conventional value systems might be biased. Since pre-conventional individuals are the least likely to participate in any kind of voluntary survey (Loevinger 1998), one might speculate that a higher response rate could have revealed also a pre-conventional value

system. People with late conventional value systems are known for their conscientiousness and are probably the sub-group in which the response rate is the highest (Sjölander et al. 2014; Loevinger 1998), implying that the frequency of individuals with such value systems might be overestimated in relation to the size of the sub-groups with early and middle conventional value systems.

Hierarchical Arrangement of Value Systems, and Their Relation to Stages of Ego Development

In a previous study, using a similar test of value systems, it was found that the identified value systems were significantly correlated to stage of ego development (Sjölander et al. 2014). This is in agreement with observations of others demonstrating significant association between stages of ego development and value systems (Helson & Wink 1987; Loevinger & Blasi 1976; Torbert 2004; Westenberg et al. 1998). Although the value systems identified in the present study were not explicitly validated according to ego development measures, such as The Washington University Sentence Completion Test (Loevinger & Hy 1996), the hierarchically arranged sequence of value systems conforms to general developmental principles and was supported by value priorities characteristic at different stages of ego development (Cook-Greuter 1999; Loevinger & Blasi 1976; Loevinger & Hy 1996; Torbert 2004; Westenberg et al. 1998). Thus, the hypothesis that nursing assistants and nurses' aides show differently developed value systems was supported by the present results.

Determinants of ''Good Care''

The ethical principal of equality is the fundament on which the Swedish health care system has been constructed. With respect to the equal value of all people it should provide the citizens with the best possible care and treatment based on each individual's dignity and needs (SFS, 1982: 763). Over the last couple of decades there has been an increasing ambition to meet the individuals' desire to take an active part in treatment decisions and the care giving processes. This has necessitated modifications of how the equality principle is interpreted and concretized. A system based on fixed routines where general treatment and care programs were exclusively

decide and delivered by health care professionals has gradually been forced to change in order to meet the citizens' demand for participation and individualization.

There are obviously a large number of factors of importance for the quality of care provided through the health care system, e.g. economic conditions, housing facilities, access to technical aids, ambitions in guidelines and legislations, and level/quality of education. One factor that has become more important, concomitantly with the citizens' increasing demand for participation in, and individualization of, the treatment and caring processes, is the personality characteristics of those working in the health care system. For instance, staff with more developed interpersonal cognitive complexity, i.e. ability to perceive others in complex and personalized ways, are more empathic and have an improved capacity to understand the perspectives of others and to relate to a care taker in a more person-centered way (Grosch et al. 2011; Juujärvi et al. 2012; Medvene et al. 2006).

The finding of the present study support these results since staff with more developed value systems were more likely to appreciate the preferences for autonomy and participation among the older persons, and to put priority to dialogue and collaboration with the older person in the decision making process. In addition, our results indicate that there is a challenging discrepancy between the value system of staff with early conventional meaning-making structures, who were in majority in the present study population, and the demand for participation and individualization among older people and policy makers. Taken together, the present data corroborate the hypothesis that less developed value systems are related to a more paternalistic view on good care, whereas more developed value systems are characterized by higher priority to dialogue, autonomy, and preferences expressed by the older persons.

There is no doubt that education is an important determinant of professionalism among health care staff. But that does not necessarily imply that the education provides health care professionals with competencies that fully match the demands of the care takers. The present results indicate that the level of education was unrelated to individualization and appreciation of the preferences of the older people in the care process. Instead, staff with high school education, which is the most common

level of education among Swedish nursing assistants, were in favor of standardization of routines that should be applied without exceptions. These findings raise questions about the focus and the content of the Swedish educational curriculum for nursing assistants.

To what extent may the individual's value system be developed through education? Research in adult development clearly show that it is possible to improve one's ability to understand others' perspectives and to get a more complex understanding of oneself, and the reality and the world we are a part of. However, there is still weak evidence that such development is substantially bolstered by educational programs (Manners et al. 2004; Pfaffenberger 2005). Thus, for most of us it seems that our stage of personal development remains rather stable after we have passed early adulthood (Grosch et al. 2011), which does not of course means that it would be impossible to influence meaning-making systems in a systematic way by future innovations in e.g. educational science.

Predictive Validity of Value Systems

One of the main findings of the present study is that the value systems, in comparison to socio-demographic and occupational factors, showed a stronger relationship with the staff's views on care ethics, participatory care and autonomy of the older person. Thus, the hypothesis that the value systems of nursing assistants' and nurses' aides' is a good predictor of their view on good care for older persons is supported by the present study. This result is in conformity with previous research demonstrating significant predictive validity of individual's values system. In the study by Sjölander et al. (2014), value systems were significantly more related than gender, age, level of education and occupation, to people's attitudes towards refugees and views on discrimination and integration.

Thus, although the predictive validity of the value systems seem to be convincing, it has still to be investigated to what extent the idealized value systems, investigated in the present study, relate to differences in actual behavior. One's stage of ego development, however, has been demonstrated to predict behaviors and actions related to helping, responsibility, and conformity (Loevinger 1979; Torbert 2004), and since ego development and value systems are correlated, one would expect significant relations also between value systems and behaviors. Yet, since the extent to which

an idealized value system translates into behavior is influenced by circumstances such as social context, organization and leadership. Future studies aimed at clarifying the relation between idealized and realized value systems should include the effects of situational and environmental factors.

Cultural Value System and Leadership

A significant feature among people at early conventional stages of development is that they internalize collective conventions, norms and values without much consideration (Cook-Greuter 1999; Loevinger & Blasi 1976; Loevinger & Hy 1996; Torbert 2004; Westenberg et al. 1998). Their value system is largely a mirror image of the value system of the group to whom they belong, and their action logic is focused on social relations, stability and harmony within the in-group, e.g. the staff or the working group. For example, as shown in the present study, staff with early conventional value systems find it important to strongly consider the working conditions of the staff in issues concerning the autonomy of the older person. This is related to a dualistic world view where firm distinctions are made between ''we'' and ''them,'' staff and patients, women and men, etc. (Cook-Greuter 1999; Loevinger & Blasi 1976; Loevinger & Hy 1996; Torbert 2004; Westenberg et al. 1998).

In the early conventional mind frame, leadership has a prioritized position, and a respected leadership should be authoritative, concrete and rule-based (Loevinger & Blasi 1976; Torbert 2004). Thus, a suitably adapted leadership is crucial in an organization dominated by individuals with early conventional value systems. In the old age care organization studied in the present investigation, a leadership that would be respected, needs to promote social relations and provide concrete guidance in the daily care (Torbert 2004). In most Swedish old age care organizations the interaction between the nurse in charge and the staff is infrequent and often restricted to communication on demand and on weekly meetings. This is consistent with a large survey showing that a majority of staff working in old age care lacked perceived support from their managers (Trydegård 2012).

To obtain improved emphases on the needs and conditions of the older person it seems important to create a local environment where the staff and the elderly are included in the same collective structure, i.e. to expand

the in-group affinity of the early conventional staff to embrace also the older people (cf. Torbert 2004). This might be achieved by applying rules and routines that promote a person-centred way of providing care, and to arrange activities where the staff and the older person may participate on equal terms. Admittedly, it is a delicate matter to establish routines which does not act as a straightjacket on staff with late conventional value systems that have more developed perceptions of person-centred and individualized care. A successful leadership in the care organization studied in the present investigation should identify staff with more diversified and developed value systems, and to recruit them to key positions where they may have a substantial impact on the cultural value system that is guiding their working groups.

Acknowledgements

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Looking "out of place": analysing the spatial and symbolic meanings of dementia care settings through dress

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Abstract

The article explores how clothing exposes – and troubles – the ambiguous location of care homes on the boundaries of public/private, home/institutional space. It deploys a material analysis of the symbolic uses and meanings of dress, extending the remit of the new cultural gerontology to encompass the "fourth age," and the lives of older people with dementia. The article draws on an ESRC-funded study "Dementia and Dress," conducted in the United Kingdom (UK), which explored everyday experiences of clothing for people with dementia, carers and careworkers, using ethnographic and qualitative methods. Careworkers and managers were keen to emphasise the "homely" nature of care homes, yet this was sometimes at odds with the desire to maintain presentable and orderly bodies, and with institutional routines of bodywork. Residents' use of clothing could disrupt boundaries of public/private space, materialising a sense of not being "at home," and a desire to return there.

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Introduction

Dress mediates our material and embodied relationships to space and place. It is shaped by the meanings and conventions of particular social spaces, but also has transformative qualities (Hockey et al. 2013), materialising transitions across spatial boundaries. In this article, we use dress as a "material lens" (Chapman 2006) for understanding the meanings and social relations of one particular space – the dementia care home. Care homes occupy a particularly ambiguous position at the boundaries of public/ private space, home/not home. We explore how dress illuminates the contested meanings of this space for residents with dementia and for staff, and materialises a "desire to be elsewhere" (Potvin 2009).

   The article begins by briefly summarising sociological and anthropological literature on changing meanings and the representations of "the care home," and their relation to ideals of home and hospitality. It then goes on to review research on dress, space and place. These issues are then further explored in relation to the findings of the ESRC-funded "Dementia and Dress" study. Several key themes are drawn out. Firstly, the article explores the role of clothing in defining public/private boundaries within the care home, and how residents with dementia negotiate – and subvert – these boundaries. Following this, we examine the meaning of "dressing up and going out" as a dress practice which often diminishes following transitions to care, but is re-appropriated in the context of the "care home party." The final theme explores the role of clothing in challenging the meaning of care settings as "home," and expressing residents' desire to return home at an embodied level. The concluding discussion draws together implications for understandings of dress and its relation to space and place, as well as wider implications for cultural understandings of ageing and the "fourth age."

Conceptualising the Care "Home": Changing Meanings of Space and Place

Glenda Laws (1997) states that: "age relations are constituted in, mediated by, and constrained by space" (98). She argues for a "spatiality of age

relations" which recognises the mutual constitution of age, space and place that is both material and symbolic. Spaces are "age graded" and access to and mobility across spaces shifts throughout the life-course, with old age marginalised into "discrete spaces" (91). This is particularly apparent with age-segregated spaces such as the care home. The care home has its roots in the poorhouses of the 19th century. The ending of the Poor Law in 1948 in England saw the emergence of specialist care homes for older people (Bland 1999; Peace et al. 1997). Since then, institutional care provision has shifted, moving from the domain of local authorities to the private and voluntary sectors.

The dominant discursive construction of care homes in the post-war era in the UK has been in terms of home. Care providers have deployed both the physical features and symbolic ideals of "home" to make care homes more appealing – representing them as "homely" and as a "home away from home" (Hockey 1989). Home represents both a physical space and a "state of being" – a sense of "being at home in the world" (Jackson 1995), and of belonging (Mallet 2004). Western concepts of the ideal home focus on freedom, security and privacy, constructing the home as a haven (Chapman & Hockey 1999), which can shut out the outside world (Allan & Crow 1989), in which individuals can express their identities, their memories and biographies, through the symbolic use of material objects (Blunt & Dowling 2006).

However, despite the use of the term "home," it is argued that these spaces in fact have little in common with the private domestic world (Hockey 1999). The lack of autonomy and privacy often experienced in care settings is incompatible with the ideal of home, as routines of bodywork, and the co-presence of other residents and staff mean that these spaces are never wholly private (Higgins 1989). Furthermore, loss of material possessions during the transition to care disrupts embodied connections to memories and identity (Fairhurst 1999; Mountain & Bowie 1992). Reflecting this, care and nursing homes have been described as liminal spaces or "non-places" associated with dislocation and transience, devoid of meaning and connection (Reed-Danahey 2001). In terms of the meaning of care homes to residents, qualitative research indicates mixed findings. Whilst sometimes likened them to their home (Higgs et al. 1998: 202), more often residents have described care homes as "homey" but

"it ain't home" (Wiersma & Dupuis 2010: 281), sometimes as akin to a "hotel" (Gubrium 1995: 35), or even a "prison" (Gubrium 1993: 146).

The design of spaces for old age is changing, however, reflecting changing concepts of ageing and the life-course, and the growing emphasis on older people as healthy and active consumers (Laws 1997). A recent UK government commission called for a reinvention of the care home model to create "places of laughter and light" which are more appealing to the "rock and roll generation" of baby boomers (Bingham 2013). As in the healthcare sector more generally (Bromley 2012), the design of care homes is increasingly drawing inspiration from the commercial and hospitality sectors, and the "hotel model." This model of care may be a more positive one, since it emphasises the rights, choices and privacy of older residents as active consumers, rather than passive recipients of care (Bland 1999). However, it has been suggested that smaller, more "homely" care units may be better suited to the care of people with dementia (Verbeek et al. 2009), with new initiatives like the "Green House Project" aiming to provide an environment which is not merely "home-like," but offers a "real home," one that emphasises privacy, autonomy and intimacy in design and organisational practice (Scher 2013).

Clothing and Spatial Divisions

Dress is "situated bodily practice," inscribed by the norms of particular social spaces, and boundaries between public and private spheres (Entwistle 2001). In turn, dress is part of the material and cultural practices which help produce particular social spaces, and "define the space as public or private" (Appleford 2015: 1). Dress lies at the interface between our intimate experience of our bodies and the public realm (Entwistle 2000). It is part of the "front" we put on and the public self we present (Goffman 1969). Making everyday decisions about dress involves consideration of the context we are dressing for, and how we would like to be perceived by a particular audience (Banim et al. 2001). Dress is also part of the micro order of social spaces, and dressing inappropriately for a particular space can incur moral judgements and sanctions (Entwistle 2000).

In contrast, private spaces such as the home are described as "safe spaces," free from the scrutiny of the public gaze, where one might express private aspects of the self through dress (Banim et al. 2001). Norms of dress are more relaxed in this sphere, emphasising comfort, ease and softness, reflected in particular forms of dress such as slippers, dressing gowns and casual wear (Twigg 2000). Rituals of changing clothes are part of the "boundary work" which marks transitions between home/work, public/private spheres; and shedding work clothing embodies a sense of "coming home" (Nippert-Eng 1996).

These public/private distinctions of dress are both classed and gendered. There is a long history of research exploring the use of fashion – particularly women's dress – to convey class and status within the public realm (e.g. Simmel 1904/1974; Tönnies 1887/2004; Veblen 1899/1994). In contemporary Britain, spatial demarcations of dress continue to constitute class and gender distinctions (Appleford 2013). For instance, in recent media coverage, working class women were derided for wearing pyjamas in public space, breaking codes of formal/informal, public/private dress (Appleford 2015). Women's bodies and dress are particularly visible – coded in terms of display, as objects "to be looked at"; and women experience greater body consciousness in public spaces (Entwistle 2000). The desire to stand out and the pleasure of "dressing up" are always in tension with a sense of vulnerability, the fear of "giving out the wrong signals" (Tseëlon 1995: 31). This is heightened in particular spatial contexts, for instance whilst walking in urban spaces at night, where women often deploy strategies of dress to manage their bodies in such a way that they do not attract attention (Entwistle 2001).

Research on the interrelation of ageing, dress and spatiality is more limited. However, studies of older women, clothing and embodiment highlight changing meanings of visibility in later life. The older female body is described as both invisible and hyper-visible (Woodward 1999, 2006). Older women incur sanctions for wearing outfits judged "too young," too revealing or sexualised (Hurd Clarke 2011; Twigg 2013). At the same time, older women frequently describe themselves as becoming "invisible" in public space – for some this is experienced negatively in terms of loss of attractiveness, while for others, invisibility represents freedom from the public gaze. However, this marginalisation may be resisted, for instance,

women in the "red hat society" challenge invisibility by dressing up in brightly coloured, eye-catching attire (Yarnal et al. 2011).

These discussions of the possibilities of dress for resisting invisibility and renegotiating public space tend to focus on the "young old." However, dress takes on particular significance in relation to the cultural imaginary of the "fourth age," which is associated with vulnerability, loss of agency and "feared old age," intertwined with cultural meanings of dementia and frailty (Gilleard & Higgs 2010, 2014). Public "slippages of dress" such as tears, stains or drooping hems take on new significance in this context, suggesting mental or moral failure (Twigg 2013). Policing one's dress becomes a means of staving off the threat of dereliction, and with it exclusion from public life. This becomes increasingly challenging in the case of dementia, where the ability to maintain appearance and dress can be diminished as the condition progresses (Baldelli et al. 2007; Beck et al. 1991). Keady and Keady (2005) relate how memory problems can lead to embarrassing public failures of dress, which incur particular sanctions in light of the stigma associated with the condition, invoking images of "dementia patient" (Twigg 2010: 228). Nonetheless, we suggest that people with dementia can still renegotiate spatial meanings and boundaries through dress, exploring this through our analysis of dress practice in the care home.

Methodology

The article draws on an ESRC-funded UK study, Dementia and Dress, which explored the significance of clothing and dress in the daily lives of people with dementia, their carers and careworkers using ethnographic and qualitative approaches. The research was conducted across three care homes in Kent, and with people with dementia and family carers living in their own homes. The sample included 32 case studies of people with dementia: 15 living in their own homes and 17 in the care home settings, selected purposively to incorporate variation in terms of socio-economic background, and stage of dementia (from mild to severe). In terms of gender, nine men and 23 women with dementia took part in the study. There were particular challenges recruiting men in the care home settings – only four care home participants were male – which reflects the lower

proportion of male care home residents nationally (ONS 2014), and also the challenges of recruiting men to a study about dress (Lomas 2000). While the sample roughly corresponds to proportions among the general population, with around two-thirds women to one-third men with dementia (Alzheimer's Society 2014), it means that our analysis of men's dress in the care home context is more limited.

The study also included interviews and observations with family carers and relatives of participants with dementia (29 in total). In addition, 28 members of care home staff were interviewed; careworkers (generally the person's keyworker or someone regularly involved with their care), managers, activities workers and laundry workers. Interviews and observations were also conducted with two clothing companies. While around half family carers interviewed were male, only two careworkers in the sample were male, reflecting the gendered nature of the caring profession.

The three care homes were selected to encompass variation in ownership, design and practice, and were also spatially distinct. The first was a spacious, purpose built care home for people with dementia, run by a voluntary sector organisation. The second was a small converted detached house, run by a small business, specialising in the care of older people with dementia. The third was a nursing home run by a private health care organisation, situated within a converted stately home, with a separate dementia unit. In the UK, care homes may be "voluntary" (run by charitable non-profit organisations), "private": (run by private organisations, small businesses or individuals for profit); or "local authority" (run by the social services department), although this is now less common (Age UK 2014). Within these different types of care home, care may be self-funded, funded by the local authority or National Health Service (NHS) "Continuing Care." Residents at the first two care homes (which were priced at around the national average) were mainly local authority funded, while at the third – more expensive – nursing home, many residents were self-funded. This has implications in terms of class; and the third care home had a more middle class profile, while the other two care homes had a larger proportion of participants from working class and lower middle class backgrounds.

Data were gathered using ethnographic and qualitative methods, including innovative visual and sensory approaches involving "wardrobe

interviews'' (Banim & Guy 2001: 218) with people with dementia, using the clothing in their wardrobes to prompt discussion. A range of clothes, fabrics, images and photographs were used as visual and sensory prompts in interviews and reminiscence groups (Bartlett & O'Connor 2010). We also conducted observations, which facilitated the inclusion of people with more advanced dementia, who found verbal communication challenging (Hubbard et al. 2003). Observations were qualitative and unstructured, taking place in the public areas of the care homes, and included observing: informal discussions of dress among careworkers and residents; non-verbal responses to clothing and interactions with dress; assistance with dress; the location of dress within care routines at different times of day.

Data were analysed using thematic analysis. Initial analysis took place as part of the writing up of field-notes after each research visit, identifying possible themes and "puzzles." Formal analysis began with a careful reading and re-reading of transcripts and fieldnotes, noting down emergent themes and concepts. A list of themes was then developed collaboratively by the research team, and used to code transcripts and fieldnotes, assisted by NVivo qualitative software.

Dress and the Boundaries of Public/Private Space

Care homes are complex spaces, ambiguously positioned in terms of public/private boundaries (McColgan 2005; Nord 2011). These ambiguities are reflected in and exposed by dress, for example, in the simultaneous presence of both slippers and handbags that we observed in care home lounges (Buse & Twigg 2014): slippers signify ease, comfort and being "at home"; while carrying a handbag is a practice associated with public space. There are also internal gradations of public/private space within care home settings, which are marked by dress (Appleford 2015). The lounge and dining areas represent the public "front" of the care home (Goffman 1969), shared with other residents and staff, and open to visitors. Within these spaces, residents were generally presented to "lounge standard" (Lee Treweek 1997) – fully dressed and groomed. However, emphasis on maintaining a publically presentable appearance in these areas was sometimes at odds with the rhetoric that care settings should represent "home":

... how often on your day off do you knock about in your nighty all morning? [...] And it's like why shouldn't they and then there's this great big hoo-ha if we get inspected by the CQC, if someone's sitting in the front room in their pyjamas and that. Well it's their front room, they wanted to – I know there's other people here but they're fine with it and that's what they wanted to do! [Anita, care home manager]

This quotation reveals the contradiction between the idea that wearing pyjamas or a nightie is appropriate within the care home lounge because it represents "home" to residents, and the fact that it is still a public space, inhabited by other residents and visitors. Whilst pyjamas are perfectly acceptable within the private space of the home, wearing them in public is seen as breaking codes of public dress, and therefore incurs moral judgements (Appleford 2015). As the above quotation also illustrates, staff fear that moral sanctions will be directed at *them*, as a visible indicator of poor quality care (Ward et al. 2008), which "looks like we haven't bothered." Reflecting this, careworkers would sometimes "advise" or "guide" residents towards particular clothing choices which looked "nice" or "dignified," and discourage outfits which were loud, "clashing," or bizarre. As one careworker, Sharon, said: "I want people to look as if they look kept" and "make them look nice. I would feel terrible if somebody went out of here and said they looked awful." These ambiguities are further complicated in relation to dementia, because of issues around mental capacity and imputed wishes (Twigg 2010).

There was a gendered and classed dimension to this – an untidy appearance was sometimes seen as more acceptable in the case of working class men, interpreted as a reflection of masculine lack of interest in fashion (Kaiser 2012), and biographies of manual labour, for which everyday dress constituted overalls or casual attire rather than "proper, dressed up clothes." As care home manager Anita reflected regarding one particular resident, Bobby: "he's working class, salt of the earth, he's not over fussed, just as long as he's covered up ...," while his daughter felt that a "casual" or even "scruffy" appearance was acceptable "because it's him" – the way he had "always been."

Maintaining the public "front" of the care home also involves containing the "disruptive body of dementia" (Stirling 1995: 147), which disturbs boundaries of public and private space. This is illustrated by the case of public undressing. In Western culture, nakedness is generally confined to

private spaces and encounters; and undressed bodies outside the norms of public space are "disturbing, disruptive and potentially subversive" (Entwistle 2000: 7). However, dementia can lower social inhibitions. This was particularly seen as problematic in times and spaces where visitors were expected, as careworker Helen said: "we just have to go round and say," "Come on, put a jumper on quickly. Hurry up," you know, "we've got visitors coming." Therefore, the undressed body had to be contained within private space, and care workers would sequester the person with dementia to a bedroom or bathroom, or hide them quickly with clothing or a blanket. Careworkers also attempted to re-establish the boundaries of private/public space, reminding residents: "you're in the lounge, everybody's looking" or "there's lots of other people in here."

In the more private or "backstage" areas of the care home, norms of dress were more relaxed, and there was less emphasis on maintaining orderly bodies (Chatterji 2006). This spatial and symbolic categorisation was given additional expression in the third, more exclusive care home, which was located in a large Victorian country house where the hall, drawing rooms and winter garden provided high ceilinged, formal spaces in which residents enacted their role as "lounge standard residents" (Lee-Treweek 1997). This contrasted with the specialist dementia unit for more severely affected residents. This was located at the back of and below the main house, in the old kitchen offices. Here the spaces were smaller and lower. The regime was warmer, less formal, with a more homely atmosphere in which there was greater emphasis on "being" than "appearing" (Appleford 2015), and where inappropriate undressing would be less noticeable:

> Downstairs [in the dementia unit] it wouldn't not be appropriate because people wouldn't look [...] it's expected. Do you understand? It's more tolerant [...] it's more acceptable. But up here, it's ... they stand out and unfortunately, it's sad for them [...] because they look ... you know, they look out of place, don't they? [Sharon, careworker]

This reflects the different perceptions of visibility and the public gaze in these spaces, and different constructions of "normality" (Goffman 1969). In the dementia unit no-one would look at unusual dress practice, it is regarded as "normal"; whilst in the nursing home it is subject to the stigmatising gaze of residents and visitors, and "looks out of place."

Inappropriate undressing was not only regarded as symptomatic of dementia, but was seen as pointing up the ambiguous spatial meaning of care homes. One careworker, Michael suggested: "maybe it's something you do indoors … I suppose that's part of it; they're in their home. They do what they would do at home." Similarly careworker Helen stated: "they might think they're in their own home doing it. Which they might just walk around with just their knickers on or their vest on." Inappropriate undressing was thus felt to reflect the re-enactment of embodied practices of being "at home," and was to some extent normalised in these accounts. On the other hand, such behaviour was judged to be misplaced within the more public context of the care home, reflecting disorientation and confusion. The fact that such behaviour was considered appropriate "at home" but not "here" exposes the embodied limits of interpreting care settings as home.

Whilst some areas of the care home offer a greater degree of privacy, there is still a lack of *truly* private space (Nord 2011). Even bedrooms are compromised by routines of care, disrupting "space privacy" and "body privacy" (Wiersma & Dupuis 2010). This has implications for dress, since clothes enable us to manage the public front we present to the world, concealing bodily flaws or frailty (Twigg 2000). However, in institutional contexts, the ability to maintain a public "front" is diminished (Goffman 1961). One family carer described how, as a result of impaired hearing, her Nan could not hear careworkers knocking, and "doesn't like the fact that they just open the door," and "she might be in the middle of getting dressed or something." The degree of privacy available to residents varies according to mental and physical frailty, with those who are "aide-dependent" (Gubrium 1997) accorded the least "body privacy."

Nonetheless, as found in previous studies, some residents with dementia deployed bodily strategies to re-create a private space for themselves (McColgan 2005). Such privacy is difficult to attain when the majority of the day is spent in the care home lounge (Barnes 2006). Strategies for creating privacy included utilising items of clothing and dress to redefine spatial boundaries. For instance, women with dementia would use their handbags (Buse & Twigg 2014) or other items of dress as "territorial markers" (Harris & Lipman 1980) to mark out "their seat," or "their space:

> Sadie entered the lounge […] she went to sit down next to me, but then she saw Lillian's cardigan on the chair and said 'I suppose it doesn't matter where I sit' […]

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> She sat down on the other side of the room, adjusted the buttons on her cardigan and looked in her handbag. It reminded me of the gestures people make when they are out on their own in public, and want to appear 'occupied'. When Lillian returned, assisted by a female care worker, she was extremely annoyed to find that Colin had fallen asleep on her cardigan – she said 'how dare you fall asleep on my pillow' and yanked it out from under him. [Fieldnotes care home 2, visit 4]

This illustrates how clothing was used to mark out private "territories," and as a "prop" – a means of looking busy or purposeful when sitting alone in a public space, disguising a sense of vulnerability (Henderson 1975). We observed women with dementia who would spend hours rummaging through their handbag in the care home lounge, which provided a way to avoid talking to other residents, and a "defence against being looked at," resembling practice in public space (Tallack 2002). Men similarly used their pockets to carry reading material or photographs, which could provide a distraction from talking to other residents, and used props such as a walking stick or a newspaper to mark out "their space."

Such actions illustrate the limitations of privacy in care settings, but also suggest how dress may be used by people with dementia to enact agency at an embodied level (Hockey et al. 2013; Kontos 2004), creating a "micro-spatiality of privacy" around themselves, remaking personal space in public (Nord 2011: 948). These practices not only occurred in the public areas of the care home, but also extended to the bedroom. Like handbags, wardrobes represent a private, enclosed space (Woodward 2007), which may be utilised to reclaim privacy which is compromised by the public life of the care home. For example, some residents would use their wardrobes to hide jewellery and special possessions or outfits, concealed within handbags, boxes, or garment bags, as care home resident Marie described:

> Oh we have to keep them in the bag so they don't pull them all out because some people sometimes think they can just raid the wardrobes, see, and you get a bit annoyed if it's all stuff you've bought [...] We've had a few rows going on about clothes!

Women with dementia were often particularly resistant to the idea of someone else doing their laundry, reflecting a reluctance to relinquish domestic roles (Hockey 1989), but also a dislike of the privacy of their wardrobes being "raided," as described above. The wardrobe could also

become a site for defending "body privacy," and careworkers described residents with dementia – both men and women – trying to conceal soiled undergarments in their wardrobes, in an effort to avoid the shame and stigma associated with "leaky bodies" (Lawton 1998).

All Dressed Up and Nowhere to Go?

"Dressing up" is a particular form of dress practice, located within public spaces such as bars, restaurants or parties, and signifying "special occasions" (Appleford 2015; Tseëlon 1995). To an extent, the practice of dressing up is inevitably diminished on admission to care, reflecting the "desegregation" of the spheres of home/work/leisure that characterises institutional life (Goffman 1961: 17, 42). Care home residents generally wore the same outfit all day, except if their clothing was dirty or soiled. As one careworker, Yvonne, said: "in general, they usually remain in what they've chosen for the day [...] as you wouldn't get changed yourself if you were just sitting around indoors." Therefore changes of dress which mark "punctuations in the flow of everyday life" (Stov 2011: 6) are diminished, reflecting a loss of transition between different spatial contexts and identities. The person with dementia generally has one ongoing role throughout the day – that of the care home resident.

The loss of gradations of dress reflects a reduction in public life outside the care home, which becomes increasingly marked as dementia progresses. In the advanced stages of the condition, relatives and careworkers discouraged trips outside the care home, as they were felt to increase distress and disorientation. The loss of mobility and access to outdoor spaces (Laws 1997) was reflected in changes in the wardrobes of care home residents – specifically a reduction in "outdoor" or "dressed up" clothing and shoes. For instance, Mable, a woman with advanced dementia, had just one pair of sandals in addition to her slippers. Her son reflected that there was no need for additional footwear because: "I don't think she goes out that much anyway" as the more she is "out of this home, the more agitated she became." Many care home residents similarly owned just one pair of outdoor shoes, and often these were not stored in the wardrobe, reflecting their infrequent use. This loss of "going out" shoes reflected the transition to care, but also changes in the body – with spreading or swelling feet limiting possibilities for footwear.

This illustrates the interrelations between the bodies, space and dress, and their implications for constraining as well as enabling possibilities (Hockey et al. 2013).

Some residents with milder dementia, however, still went on excursions outside the care home – a transition marked by donning "outdoor" and "best" clothing. As careworker Yvonne reflected, when they go out residents should be: "dressed to go out; they've got to go out looking presentable" and "it's a special occasion for them so they want to be dressed nicely." It was often families who emphasised the importance of "dressing up" to go out; and they were understandably upset if their relative was not presented appropriately. Melissa was "hurt" and "upset" when she found her Dad in "screwed up clothing" because he had "always been smart," and felt this was particularly unacceptable "if I did want to take him out for a meal or something." This again reflects concerns about appearance as a visible indicator of the quality of care (Ward et al. 2008), but also about "the gaze" in public space. Slippages of dress which are ignored in the context of care can incur stigma and moral judgements in public. For instance, Denise complained that when she came to take her friend Lillian out from the care home, she always wore the same old "tatty" clothing, and she worried that "people seemed to look" at her pityingly. Denise said: "when you go out you want to make an effort – there's a difference between what you would wear for lounging at home and going out – but she doesn't seem to worry." Therefore, a decline in gradations of dress not only reflected a characteristic of institutional life, but also of dementia. Families of people with dementia frequently reported that they had lost the ability to dress appropriately for the occasion, failing to demarcate between indoor/outdoor and informal/formal dress.

Despite diminished involvement in public life, dressing up takes on new meaning in the context of the care home, in relation to "institutional ceremonies" (Goffman 1961) such as the care home party. In these instances, dressing up was re-appropriated by care staff to signify a sense of occasion, and reconnect with times and spaces beyond the care home. Changing clothes not only engenders physical transformation, but also mental transformation – shedding or putting on clothes involves putting on, or taking off, particular roles and aspects of the self (Nippert-Eng 1996). Because of the sameness of everyday dress in care settings, dressing up

conveyed a clear departure from the normal order, signifying "special occasions" such as birthdays, and calendric events such Easter, Halloween and particularly Christmas:

> ... I went down Christmas day and Easter day and they'd made sure she looked extra smart kind of thing, you know, which is really nice because that's what mum would like. You know, because she always dressed for special events [...] she doesn't always remember what the special event is these days [laughing] unfortunately but, you know, she knows it's something so that's really good. [Deidre, family carer]

Maintaining these rituals helps maintain a sense of normality and continuity with the outside world. As Deirdre says, dressing for the occasion is something her mother "would like" and "always did." Similarly, Melissa talked about how her dad, Harry, used to dress smartly at Christmas: "he would always dress up in a shirt and tie and a nice posh pair of trousers. Always make an effort." As a careworker, Sharon tried to help residents maintain these rituals, saying: "We all dress up Christmas morning. That's the first thing you put on, is your new clothes, isn't it?" Dressing up therefore provided a way of maintaining wider social rituals within the context of care, and conveying meaning to the person with dementia at an embodied level. Deirdre's mother is not always aware "what the special event is" but dressing up gives a sense that "it's *something*."

At one level, this dressing up practice was conducted for the benefit of residents; breaking up the monotony of institutional time, as well as evoking memories and reminiscence. Residents expressed enjoyment in doing, and wearing, "something different." On the other hand, dressing up for the occasion was also about "institutional display" (Goffman 1961: 96). Visitors were more likely to attend care homes on these occasions and were sometimes specifically invited. Therefore it was particularly important to present a "dressed up view" of the home to visitors, which demonstrates that "natural" and normal things happen there (Goffman 1961: 100):

> ... when Betty was [...] a hundred, her daughter brought in like a two-piece suit for her. And I hung it on the wardrobe [...] I made sure that lady had a bath the day before, her hair was done and everything [...] I wanted her to look nice. [...] I think it reflects on the home as well, doesn't it? [Sharon, careworker]

Therefore "dressing up" for special occasions was not only about how the person with dementia felt, but also about maintaining visible continuity for relatives, and the public front of the home.

Dressing up practice was also used to recreate a sense of place. For instance, in one home, both staff and residents dressed up for a seaside themed day – residents wore straw hats, while staff wore t-shirts, shorts or other casual apparel. Along with material props like sand, deckchairs and shells, dress was used to recreate the atmosphere of the seaside. On another occasion, careworkers wore white lace aprons to serve food to residents for a Valentine's Day dinner. The fact that staff, as well as residents, dressed up is significant here – conveying a sense that things were "different" from the normal order. As one careworker, Jo, said: "it makes the staff feel different as well. They reacted totally differently when they were wearing those." Uniforms signify institutional care and clear role distinctions between staff and residents, whilst dressing up created temporary "role release" (Goffman 1961: 90). Staff changing their dress could help transform the meaning of the space, for instance, Jo described how wearing white lace aprons evoked memories of "tea rooms when they always used to wear things like that," transporting residents – and staff – to other times and places (Potvin 2009).

Escaping the Care Home through Dress

In the examples above, attempts to transform the temporal and spatial boundaries of the care home through "dressing up" were mainly orchestrated by staff. However, dress was also utilised by residents with dementia as part of expressing their "desire to be elsewhere" (Potvin 2009). This involved expressing a longing to "get on the outside" (Goffman 1961: 23), but also a desire to go *home* – a metaphysical place associated with comfort, familiarity and belonging (Higgins 1989). We frequently observed exchanges in which people with dementia would state that they had to get out of "this place" and "go home," which were sometimes accompanied by adjustments of dress, such as putting on a coat:

> ... one of the clients had [the coat] on walking around the lounge because it was hanging up along the corridor [...] she had one of those days, she didn't want to be here with these mad people. 'Will you tell me where I am?' I said, 'Well you're in a

nursing home.' 'Well yes, they have told me that but I don't want to be here ...'
[Hannah, laundry worker]

Therefore, putting on a coat was this residents' way of conveying that she "didn't want to be here," signifying her intention to leave at a material and embodied level. One male resident would often put on his coat in the evening and start gathering up various items from around the care home lounge, putting them in his pockets or up his jumper, as though packing up to "go home."

This desire to "go home" seemed more prominent among women during our observations, perhaps reflecting their greater identification with the domestic sphere. When talking about "going home" women re-enacted gendered rituals of getting ready, asking for a comb or putting on lipstick. These rituals sometimes involved trying to adjust dress to make oneself "presentable," as the following discussion between Florence and fellow resident Mavis illustrates:

> Florence started rolling up her night dress up and saying 'I'll have to do something with myself' and 'if I just do that and smarten myself up I can go'. She then held up her feet and looked at them and said 'I have been trying to put the things on so I can go. I've, I put this coat on' [indicating to a fleece jacket, worn on top of her nightdress]. Mavis said to her 'I'd zip it up, it's cold outside'. [Fieldnotes, care home 3, visit 9]

As discussed earlier, getting dressed is part of preparing the public "face" we present to the outside world, marking the transitions between public/private, indoor/outdoor space – something which is of particular significance to women. Florence is attempting to re-enact these embodied rituals by making herself presentable enough to start her journey home. While she was not in fact wearing the correct attire, her actions clearly expressed meaning and intentionality at an embodied level (Kontos 2004). These attempts to "go home" were more frequent in the evening and were sometimes explained by careworkers in terms of "sun-downing." Sun-downing is defined as: "an acute increase in disorientation or deterioration in cognition, with a sudden onset of restlessness and confusion, in the late afternoon into the early evening" (Grealy et al. 2005). However, Reed-Danahey (2001) argues that such behaviour also says something meaningful about the dislocation experienced in care settings.

Like putting on a coat, packing or carrying a suitcase makes a strong visual statement about the desire to leave a particular space and signifies being away from home. Careworkers described how when Florence first moved to the dementia unit, she "used to keep packing her case" because she "thought she was going home to her Mum," and would bring it into the lounge, waiting for the bus. As discussed, carrying a handbag similarly disrupts meanings of care homes as "homely" (Buse & Twigg 2014); and handbags were often part of rituals of waiting to go home. For instance, Lillian once sat by the door for a whole day clutching her handbags and asking: "when am I going home?" and "is this all I'm taking, these two bags?" On other occasions, women would rummage through their bags, fruitlessly looking for money for the "bus fare home." These dress practices suggest experiences of the care home as a liminal space of "waiting, waiting"; imbued with a similar "limbo quality" to that of a hotel lobby or waiting room (Tallack 2002: 144). The care home was interpreted by residents as a temporary space "to be passed through" (Auge 1995: 104) and was sometimes mistaken for other transient "non-places" such as a bus stop, hospital or even a hairdressing salon.

Therefore, dress can provide a means of "appropriation and redefinition" of the spatial meanings of the care home (Rocamora 2013: 162). This not only occurred through material dress practice, but also through "dress stories" (Weber & Mitchell 2004) which invoked narrative connections with other places – remembered, representational and imagined. Memories of place were intertwined with narratives of dressing up and going out; of "special" occasions and outfits. This is illustrated by Rita's vivid description of her "gold lamé jacket":

> I used to have a lamé jacket 'n all [...] that used to sort of light up when I was in a room, they'd all stare because it sort of shone. You how it does, lamé? [...] I liked it and I like that lamé ... it glittered, it stood out. Do get me? Sort of shone, like. It did! It's true.

Rita's account of her jacket is highly spatialised – embedded with images of being in a public space where she was the centre of attention, and her jacket "shone" causing people to "stare." She talked about this jacket to residents and staff in the care home and encouraged careworkers to refer to it in daily interactions around dress. By telling these stories,

Rita invokes "snapshots of energy, youth, and self-importance," transcending her current embodied dependency in the care home (Hockey 1989: 205). In this account, her lamé jacket takes on the role of a "quasi-object" akin to Dorothy's ruby slippers in the Hollywood Film *The Wizard of Oz* – a fetishised object imbued with "magical" properties, which exudes a "shine" or radiance (Schiermer 2011). Other women told similar stories of youthful nights out, of swishing petticoats, silver dance shoes and towering stilettos, which were intertwined with memories of place – dancehalls, restaurants, parties and cruise ships. There was a particular focus on clothing and shoes that were "special," glamorous and *impractical*, impossible within the confines of their current bodily and spatial limitations.

Dressing up narratives were most frequently told by women, reflecting a particularly female pleasure and camaraderie in "dressing up and going out" (Skeggs 1997). In contrast, men's dress stories tended to focus on work clothing, evoking images of building sites, offices and market places. However, some (particularly middle class) men did tell stories about dressing up – getting a suit made "for special occasions" or wearing "patent leather shoes" for dancing, which were connected to displays of class and status: "if a man was doing his best he wore patent leather shoes." For working class women, dressing up involved a careful negotiation of attractiveness and respectability, which can be reconciled through "glamour" (Skeggs 1997). Rita recalled how "you had to have pale rouge on ... because you were common if it showed red," while a gold handbag showed you were "someone." Her dress stories carry glamour and status forward into the context of care, and care home workers described her as someone who had "enjoyed the high life" and "been quite glamorous."

Clothing narratives not only invoked residents' past temporal and spatial trajectories, but also imagined futures beyond the care home (Hockey et al. 2012), in which they were not always going to "be here." One resident, Lillian, would regularly talk about going to the dance hall that evening, and what she might wear, asking the researcher "are you going?" and "have you got a new dress?" Florence talked about her Mum waiting for her at home, and how she had made all the garments she was wearing, and would "be cross" if she wasn't properly dressed. Another

woman, Marie, stated that she was "just here until I get better" and expected to return to her old life and her "real home" again, where her fur coats would be waiting for her:

> They were lovely coats [...] a real beaver lamb coat. A great big one that she left with me [...] I've got it at home somewhere. It should still be there.

These narratives illustrate the potential of dress for enabling "earlier identities to be revisited or released" and "future age-based identities to be accelerated or deferred" (Hockey et al. 2012). Dress not only disrupts linear temporal trajectories, but also enables a renegotiation of spatial boundaries and meanings. As argued by Jamie (2012: 71): "you are placed in landscape, you are placed in time. But within that, there's a bit of room for manoeuvre" (cited in Hockey et al. 2012). Thus, while age relations may be "constrained by space" (Laws 1997: 98), dress can provide that "bit of room for manoeuvre" – a means of escaping to other times and spaces, and revisiting the metaphysical place of "home."

Conclusion

At a time when the meanings of "the care home" are being debated and renegotiated in media, policy and academic literature, this article suggests that analysing material practice – specifically dress – can help illuminate the meanings of these spaces. In contrast to the rhetoric that care homes represent a "home from home," the dress practice of residents with dementia suggests a semi-private space, more akin to the hotel lobby. Private dress associated with being at home is difficult to reconcile with the lack of body privacy and space privacy experienced in care homes (Wiersma & Dupuis 2010), suggesting that perhaps they can never truly be home. However, at the same time our research highlights the potential of dress for transforming meanings and experiences of dementia care, providing a means of carving out personal space and transporting residents to other places and spaces – real, remembered and imagined.

Our research therefore adds to sociological and anthropological literature exploring how older people experience everyday life in care. Rather than viewing the actions of people with dementia as merely

symptomatic of their condition, we suggest that their behaviour conveys meaning and intention at embodied level (Kontos 2004) and indicates experiences of dislocation and loss of "home" (Reed-Danahey 2001). Previous research in this field has highlighted how care homes residents – including those with dementia – may renegotiate material and symbolic meanings of these spaces through embodied practice, including the use of material objects (McColgan 2005). Our research highlights an additional element of the constitution and negotiation of everyday life in the care home – that of dress.

The article also contributes to analysis of the relationship between space and dress, and extends this to the context of the fourth age, and dementia care. As argued by Hockey and colleagues (2013), dress is embedded in experiences of life-course transition, as well as transitions between spaces and places. However, there is little specific analysis of the relationship among dress, space and old age, particularly in terms of older people who are mentally or physically frail. Therefore, our research brings together analysis of dress and space, with the "spatiality of age relations" (Laws 1997). In addition, the article highlights the significance of considering dress in relation to "representational and imagined" spaces (Rocamora 2013), and how memories and narratives of dress may "transport the embodied subject to another place and space" (Potvin 2009: 1).

Lastly, the article demonstrates how insights from the wider Cultural Turn can contribute to the analysis of deep old age. Much of the work in the new field of cultural gerontology (Twigg & Martin 2015) focuses on the lives and experiences of younger old people, those in the Third Age, often centred on themes like consumption, representation, bodily appearance and leisure. This article demonstrates how such cultural approaches can fruitfully be extended to the context of the fourth age and to older people experiencing mental or physical frailty; and in doing so it expresses a commitment to the wider inclusions of such groups.

Acknowledgements

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REVIEWED by MARVIN FORMOSA*

The second half of the 20th century witnessed unprecedented demographic changes. Declining fertility rates and mortality levels, and major improvements of life expectancies at birth, had far-reaching effects on global population trends to the extent that the present epoch has been referred to as the "age of ageing" (Magnus 2008). As a result, it is not surprising that in recent years ageing policy has emerged at the forefront of social policies in many countries all over the globe. Indeed, various government statements highlight and refer to the *problem* of the ageing workforce, the *problem* of economic sustainability in long-term care, the *problem* of the lack of social participation on behalf of older persons, the *problem* in ensuring sustainable pensions for all, amongst others.

In forums, policy makers are quick to emphasise how global, regional and national strategies are hinged on an altruistic belief that no stone should be left unturned so that older persons are enabled to experience active, successful and productive lifestyles. Nevertheless, critical gerontology documents clearly show that demographic trends are secondary influences

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to the nature of the debate. As Walker and Phillipson (1986: 1) underlined so many years ago, "the major determinant [for social policy on ageing] is ideology." This collection of chapters is precisely a move in such an intellectual tradition, seeking to illustrate the ideological and institutional factors that underlie policy decisions relating to ageing in different European countries.

The Making of Ageing Policy demonstrates, as illustrated in Sara Arber's blurb on the book back cover, "the pivotal role of ideas and international organizations in shaping the policy and practice landscape" of welfare reforms for older persons in Europe. The book drives the point that seemingly neutral terms, such as active ageing, are ultimately grounded in an economistic rationale whose overriding *raison d'être* is to making people extend their working lives. Whilst there is nothing inherently wrong in such a policy direction, the fact that policy makers mask this ideological grounding in functionalist discourse of well-being should be a key point of deliberation in "critical" social policy analysis.

This collection of chapters emerged from an international workshop on "Ideas and practices of ageing policies: European and national perspectives" in Bergen, in March 2012, with most of the chapters the volume originating as presentations during such an event. It is welcome to note that contrary to most collections of edited books originating from workshop or seminar events, *The Making of Ageing Policy* includes a strong introductory chapter that puts forward the empirical and ideological context as a backdrop to the ensuing chapters. "Introducing ageing policy: Challenges, ideas and responses in Europe" provides a thorough assessment of the extent that a variety of paradigms unfold across various policy areas and national situations by outlining the demographic changes and challenges, whilst also operationalizing ageing policy.

The consequent ten chapters view critical and humanistic dimensions of ageing through various lens: the rhetoric, theory and practice of active ageing (Alan Walker and Liam Foster); ageing policy ideas in the field of health and long-term care (Nanna Kildal and Even Nilsson); policymaker's views on the inclusion of older people's interest organizations (Martha Doyle and Virpi Timonen); government policy recommendations on pension (Tord Skogedal Lindén); ageing policy in Germany (Christof Schiller), impact of the transition of market economy on ageing policy

(Anna Ruzik-Sierdzińska, Jolanta Perek-Bialas and Konrad Turek); policy paradigms on active ageing in Britain and Norway (Rune Ervik and Ingrid Helgøy); aging and long-term care in Poland and Italy (Zuzanna Drożdżak and colleagues); and strategies to meet long-term care needs in Norway, the United Kingdom and Germany (Rune Ervik, Ingrid Helgøy and Tord Skogedal Lindén). All these chapters make a major contribution to providing insights into the value basis and justifications of ageing policies, the potential for conflict and how policy ideas are embedded in the advocacy for reform of ageing policy. Authors deliver detailed normative analysis of polices on active, productive and successful ageing, whilst also contributing to the changing landscape of ageing politics and policies throughout Europe.

The final chapter includes a fitting closure to the book by returning to some of the key topics raised in the introduction and preceding chapters. This chapter revisits the challenges of population ageing, pinpointing the role of politics and policies in determining the scope of these contests. It also addresses the political dimension and the ways in which policy makers overcome resistance and create consensus, as well as reflecting on the ambiguity of the notions of active and productive ageing policies in European policies. At the same time, the concluding chapter presents some findings from comparative studies in three main areas of the welfare state – namely, pension, labour market and long-term care. It ends by posing a number of questions that merit further analysis in future treatises on the subject, such as "Did the European Year for Active Ageing have a real influence, or was it just cheap talk?" and "How will the financial crisis contribute to making of ageing policy?" There is no doubt that one expects many ageing policy reforms to be open to the study of the interaction, ideas and institutions in the foreseeable future.

This compendium of articles will certainly provide insightful ideas to students, academics and researchers alike who deal with demographic challenges across a wide spectrum of policy sectors. It will also appeal to practitioners in social and health care professions with an interest in ageing studies. There is no doubt that this publication has much to offer to theorising and empirical understanding of what it means to grow old in contemporary societies.

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Suzanne R. Kunkel, J. Scott Brown and Frank J. Whittington. (2014). *Global Aging: Comparative Perspectives on Aging and the Life Course.* New York: Springer, 311 pp. ISBN: 978 0 8261 0546 2 (paperback)

REVIEWED by CHRIS GILLEARD*

Increasing attention is being paid to the rising numbers of older people in countries across the globe such that, we are told by the authors, more than 1.2 million people join the ranks of the older population per month. That's certainly a lot of birthdays. But what other meanings are we to attach to these kinds of statistics? The authors state that it is their intention to provide a text for those teaching courses in global aging and their students and that it is also their wish to focus on the growth and value of research going on outside North America and Europe. In short, they offer a kind of gerontological travelogue, drawing attention to the fact that aging is happening everywhere.

If travel broadens the mind, then a book such as this also has as its subtext the desire to broaden our understanding of aging by examining how aging and old age are viewed from non-European, non-North American perspectives. But like the traditional travelogue, the danger is that a little knowledge does no good; the few snippets of information from countries chosen seemingly at random for their cultural or geographic distance from European/North American academic centers fails to enlighten even as at

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times it entertains. At the same time, various cross-national methodologies are outlined (such as the models of long term care (LTC)), but none of these are developed beyond the chapters in which they appear. Perhaps this is an inevitable consequence of involving so many writers (18) in what is a relatively small book. Even so, this makes it a work to be dipped into rather than to be read systematically or be used as the framework for a more systematic course program.

At the same time, there are several interesting chapters and essays which are enlightening – including Scott Lynch's essay on income and mortality differentials and Applebaum, Robbins and Bardo's chapter outlining cross country models of national long-term care systems. There is also a useful attempt in Chapter 2 to categorize approaches toward studying global aging. The problem with the book is that while several such interesting and potentially enlightening perspectives on global aging are outlined, these are not followed through in structuring the book itself. Thus, it does not demonstrate to the reader how the study of global ageing might expand gerontology's or aging studies' models of aging and old age, beyond noting how different and yet how similar our human responses to aging are.

At the end of the book, the authors identify some of the key messages they would like their readers to take away with them. What follows are their summary points: (1) The world continues to be divided into developed and developing nations; (2) the gap between the haves and the have-nots is shrinking; (3) human health is improving and longevity is increasing; (4) national populations are aging; (5) public opinion toward older people is changing; (6) the family provides the core of life for most older people; (7) work and productivity are universal values; (8) retirement even in developing countries is becoming more common; (9) older adults are becoming more involved in community affairs; (10) most national governments are beginning to enact policies to support their senior population; (11) older people are actively driving much of the change; (12) a global aging science is emerging.

While one may not disagree with any of these points, none of them seem to have emerged as the necessary conclusions of what has gone before. In short, the book is full of such interesting starts with no systemizing route that follows them up. The authors end by calling for "global leaders." Where exactly global aging is leading remains unanswered. More path clearing is needed.

Anita Wohlmann (2014). *Aged Young Adults. Age Readings of Contemporary American Novels and Films*. Bielefeld: Transcript Verlag, 261 pp. ISBN 978 3 8376 2483 0 (paperback)

Reviewed by Maricel Oró Piqueras*

In *Aged Young Adults*, Anita Wohlmann aims to explore an area within age studies that has received little attention so far: age awareness in characters that are in their twenties and thirties. Age critics tend to focus on old age, that is, from sixty years old onwards. By age-awareness, Wohlmann refers not only to the negative connotations that Western culture has attributed to old age and the aging process in general but also to those roles and behaviour, appearance and objectives, which are considered appropriate for a specific age. In that sense, Wohlmann's study represents a step forward in the study of age and aging from a cultural point of view. Departing from Janice Sokoloff's *The Margin That Remains: A Study of Aging in Literature*, Wohlmann extends Sokoloff's thesis by focusing on recent American novels and films that have appeared in the first decades of the new millennium. By looking at Joel Zwick's *My Big Fat Greek Wedding*, Sam Mendes's *Away We Go*, Miranda July's *The Future* and *It Chooses You*, Jonathan Franzen's *The Corrections*, Don DeLillo's *Cosmopolis*, Tom Perrotta's *Little Children* and Benjamin Kunkel's *Indecision*, Wohlmann discerns the narrative conventions as well as the cultural discourses through which the young characters of each of these works express a conflictual relationship to their

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chronological age, and analyses to what extent capitalism and consumer culture dictate the achievements each life stage presupposes.

The book is divided into five chapters in which seminal theories in age studies and life course studies are revised in conversation with the newest publications in the field that serve as a basis for a thorough analysis of the uses and abuses of age references and their implications in each of the fictional works analysed. The first chapter, "Age and Aging in Theory and Practice," revises the concept of *Bildungsroman* as one of those "invisible narrative practices" that Margaret M. Gullette describes as naturalising age expectations and conventions and juxtaposes it to the "coming-of-age narratives" (2014: 46). In her analysis of coming-of-age narratives, Wohlmann refers to those invisible expressions and connotations on temporality and timing in which age awareness and age appropriateness are implicit. Another important concept that Wohlmann revises in the first chapter is the concept of age as a "movable marker" (2014: 50) that calls attention to expressions such as "age performance," "age accomplishment" and "age coding," which prove age to be a constructed category that contemporary society tries to relate to "coherent and meaningful" (2014: 62) narratives of the self. This pinning down of concepts related to conceptions of age and ageing is a refreshing way of reviewing the literature on the topic that has been published in the last 20 years and setting the ground for the analysis of the young old characters.

The second chapter analyses Zwick's *My Big Fat Greek Wedding* and Mendes's *Away We Go* with a special focus on the aged young adults portrayed in these films. In Zwick's film, 30-year-old Toula is haunted by the figure of her grandmother as an old, unattractive, and demented woman, and she keeps on postponing entering into a normative adult life. In Mendes's *Away We Go*, Burt and Verona, both in their early thirties, are presented as "delayed adults" who try to find their path to maturation while they reflect on their conflictual relationship with time after they find out they are going to have a baby. The third chapter presents a revision of the shifting meanings of adulthood in American society which surfaced in the 1970s with the oil crises. Within that background, the delayed adulthood of the young protagonists in Perrotta's *Little Childen* and the premature ageing of the young protagonist in Franzen's *The Corrections*

exemplify the blurring of life stages and challenge the cultural implications of youth, adulthood and old age. Despite looking and being chronologically young, the characters in these fictional texts feel old and inadequate. In that sense, *Aged Young Adults* proves the extent to which Western society has attached negative connotations to old age, and how well these are ingrained in our cultural imaginary and have a powerful impact on conceiving ourselves and our life course.

In the fourth chapter, interesting relationships are established between mental health and age, on the one hand, and liberal capitalism and consumer culture, on the other. In a time in which individuals are held responsible for constructing definitions of the self, their lifestyles, lives and career decisions, terms such as success and failure occupy centre stage. In this sense, what is age appropriate is very much related to the success a character is supposed to have achieved at a certain age. In the case of Kunkel's *Indecision* and DeLillo's *Cosmopolis*, the young characters position themselves in relation to the ideal of successful entrepreneurship. Whereas Dwight Wilmerding in Kunkel's novel is the perfect example of a failed entrepreneur who feels like an outsider unable to conform to the cultural expectations of his age and social status, the hero in DeLillo's *Cospomolis* constitutes the prototypical successful entrepreneur until he realises he cannot fight mortality. Decline, time acceleration and obsolescence are the words that not only define the accelerated ageing processes of these characters but also characterise our contemporary world.

The fifth chapter explores more positive imaginaries to a world defined by decline as the only alternative beyond youth. According to Wohlmann, July's *The Future* makes its characters and, by extension, the audience negotiate "accelerated and frozen time" (2014: 229) as well as their future selves in order to face alternative imaginaries to the decline narrative. By crossing the boundaries of reality and illusion, genres and format conventions, as well as through the use of playfulness and magic, July allows the aged young adult characters question and re-evaluate time, the future and ageing as synonymous with decline and loss. In her conclusion, Wohlmann acknowledges the loaded implications of age references at a metaphoric level, which are usually overlooked or unnoticed both in fictional works and in day-to-day interactions. In this respect, the analysis of age presented

in this book involves narratives about time, death and decline that are not exclusive to characters in their old age but which are prevalent throughout the life course. Moreover, looking at fictional texts constitutes a fruitful way of reflecting upon existent imaginaries and trying to come up with alternative ones.

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Eva Jeppsson Grassman and Anna Whitaker (eds.) (2013). *Ageing with Disability. A Lifecourse Perspective.* Bristol: Policy Press, 142 pp. ISBN 978 1 44730 522 4 (hardback)

REVIEWED by VALERIE D'ASTOUS[*]

Ageing and long-term disability do not generally overlap in current theory, policy or practice leaving the issues of and people with these experiences poorly recognised, understood and supported. *Ageing with Disability: A Lifecourse Perspective*, edited by Jeppsson Grassman and Whitaker, is a timely and valuable contribution to the ageing and disability discourse. It provides a vital, critical context to increase understanding and awareness of the unique experiences of individuals ageing with a disability acquired in early life. This perspective is of substantial importance for many students, academics, professionals, advocates and policy makers. The editors and contributing authors to this text have expertise and research experience in the fields of disability, ageing and social policy. The aim of the book is to discuss from a lifecourse perspective what it means to live and age with a long-term disability. The text is punctuated by subjective accounts that highlight the implications, challenges and changes over time both for the individual and within social and political environments. A comprehensive scope of ageing with long-term physical and mental disabilities, and a diversity of caregiving roles are presented. These are framed within the lifecourse perspective and so contest current concepts of successful ageing, confront limitations in policy and practice, and inform gaps in knowledge.

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The editors bracket contributor chapters with an introduction to create the platform and a summary and conclusion to reiterate key points and emphasise the need for continued research. Chapter two by Jeppsson Grassman outlines a life trajectory with chronic illness and disability where bodily changes, cumulative impairments and complications shape lives and life experiences of ageing. It accentuates a life of constant adaptations to new challenges and disablements across the lifecourse. Chapters three and four by Holme and Taghizadeh Larsson respectively highlight how early life stages with a long-term disability affect later life, as do changes in the social context, environmental accommodations and policy over time. They challenge and explore the potential of successful ageing with a disability or impairment. With effective environmental, financial and supportive conditions individuals ageing with a long-term physical disability are able to maintain and achieve an active, engaged, self-realising lifestyle. In contrast, chapter five, by Bulow and Svensson, describes a lifecourse of decreased engagement and socially isolated lives prescribed by long-term mental disabilities as not compatible with successful ageing. Chapters six and seven (Whitaker and Torge) frame the experiences of ageing and caregiving for loved ones with long-term disabilities from the perspectives of a parent and a partner. The lasting responsibilities, balance and imbalance, and acquired expertise over the years are permeated by worry, effort and love.

The organization, not just on the chapter level but also in the threading of the lifecourse perspective of ageing with disability throughout the text, is noteworthy and underscores distinct aspects. For example, in a long life characterised by mental and physical disability, chronological age and advancing years hold varied meaning, and are perceived and experienced differently. Moreover, time is often marked by the length of the experience of disability or chronic illness, or from timeframes between complications or treatments. As age norms are replaced with illness norms, a heightened awareness of the possibility of a shortened life referenced by that of peers appears to be commonly experienced. Policy and social changes acknowledge advancements and detailed outstanding disabling barriers.

This book presents a missing perspective in the discourse of ageing and disability. Drawing on a wealth of longitudinal and cross-sectional qualitative research with a strong sense of narrative, the chapters in this

book clearly articulate the intersections and interrelatedness of ageing with a long-term disability or chronic illness. However, greater detail to the overall structure of the book may have created a more fluid and well-defined representation of key themes and arguments. The chapters often seem disjointed with no linking statements or transitions. A reordering of the chapters to first introduce disability, identity and ageing to set the stage for the other aspects of ageing with a long-term disability may have been preferable. While most authors identify who is being quoted, some do not. Consistency in the presentation of vital demographics of informants, including age, gender and disability, following quotes would add meaning to the reference. Nevertheless, these minor suggestions in no way diminish the book's value in encompassing the discourse of ageing with a long-term disability.

The influence of this book should extend beyond the gaps in knowledge that it fills to stimulate reflection and advocacy about these issues. Undoubtedly, this text will serve as a leverage point from which further research and policy platforms may be developed. The ability to achieve and maintain independence and autonomy in spite of fundamental daily dependence and interdependence on support and services requires further detail and dialogue. The awareness that successful ageing with a long-term disability or illness involves optimising adaptations, enhancing capacities and compensating for losses or limitations across the lifecourse compels greater awareness. This is an important book that deserves a readership from political sociology, to gerontology and disability studies.

Lars Bovenberg, Casper van Ewijk and Ed Westerhout (eds.) (2012). *The Future of Multi-Pillar Pensions*. Cambridge, UK: Cambridge University Press, 434 pp. ISBN 978 1 1070 2226 3 (hardback)

REVIEWED *by* DAVID HOLLANDERS*

In 1994, The World Bank report *Averting the Old Age Crisis* which proposed three pension pillars initiated a lively public- and academic debate regarding ageing and pensions. *The Future of Multi-Pillar Systems* – bringing together 11 chapters of 15 authors – aims to assess what has come of that debate and to reconsider "the multi-pillar pension scheme against the background of demographic and other trends and a severe financial and debt crisis."

Hinz, a World Bank-affiliated author, pictures the current World Bank position, which is essentially unaltered. Pension systems have three functions (corresponding with the three pillars): redistribution, including poverty alleviation; insurance; and consumption smoothing. Hinz proposes that individual savings or privately managed accounts are more efficient. This may deepen capital markets.

Other authors state that individual accounts face difficulties. Bodie and Prast point out that most participants lack financial knowledge, postpone decision making, and are influenced by framing. Just as citizens do not have to operate by themselves when sick, they should be able to leave

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investment decisions to experts. According to Bodie and Prast, however, there should be some broad and easily understandable choices related to investments' risk profiles. Another author, Barr, does not focus on the demand side (i.e. participants) of the pension market but instead on pension plan providers. Individual plans are prone to agency risks, including fraud and misalignment of incentives of fund managers and plan participants. This does not mean that defined-benefit plans, guaranteed by a sponsoring employer, are the solution. Barr states that "a cynical view is that in corporate plans the firm creams the surplus in good times and reneges on pension promises in bad times," leading to a false sense of security.

An alternative for employer-led collective plans and individual pension plans is an increased government role. Contributing co-editors Bovenberg and van Ewijk point out that in an efficient pension system, risks are shared by all citizens. If the system is optimal, people with a low income (if risk-aversion is income-dependent) as well as the elderly (habit-formation) should be exposed to relatively small risks. Collective, nationwide risk-sharing suggests a role for the government. The government is also crucial in at least another respect. Several authors, for example Bohn, point out that macro-risks can only be shared between – but not within – generations. This however implies that participation of an ex-ante efficient pension scheme needs to be mandatory. Otherwise, young participants might want to leave a risk-sharing pension scheme after a negative financial shock, as ex-ante efficiency leads to ex-post redistribution. Only governments can impose mandatory participation. However, the government may also abuse its powers. There is thus a trade-off between intergenerational risk sharing (which is efficient) and government involvement (which may be inefficient). Authors Beetsma and Bucciol present simulations regarding another role that governments may play. The government can complete financial markets, by issuing inflation- and/or longevity-linked bonds that are not available on financial markets. The authors suggest that such bonds may improve efficiency.

Most chapters in the book focus on the second pillar (i.e. work-related supplementary pensions). This is generally a good choice as the first pillar (i.e. publicly provided basic pensions) has already been discussed at length, in research as well as in the wider public debate. The chapter about

the first pillar indeed paints the well-known picture of aging and the negative implications that may have on public finance. However, one less well-known fact is also worked out. There is considerable variety in the extent that European countries age. In Denmark, for example, it is expected that by the year 2060, there will be 60 people aged 65 years and older for every 100 people aged between 15 and 64 years. In Ireland, this number is 37, only slightly higher than the current number in Denmark.

Taken together, the book thus offers a variety of approaches and considerations. The World Bank position as well as several alternative views and perspectives are presented. As such, the book achieves its goal to reconsider the pension debate. Given the different evaluations of individual pension plans – which is the corner stone of the World Bank proposal as well as the route many countries are taking – it would have been interesting if different authors could have directly reacted to one another. In the absence of a discussion between authors, the reader in the end has to make up his or her own mind about the current state of pension affairs and preferable policies. The contribution of this book, however, lies in providing the reader with the perspectives and approaches to do so in an informed manner.

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The International Journal of Ageing and Later Life (IJAL) serves an audience interested in social and cultural aspects of ageing and later life development. The title of the journal reflects an attempt to broaden the field of ageing studies. In addition to studies on later life, IJAL also welcomes contributions focusing on adult ageing as well as relations among generations.

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