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Special Issue on

Populations within a Population

Vulnerable Older Adults

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And
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FOR OUR READERS

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Editorial

Sandi Hirst RN, PhD, GNC(C)
and
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We appreciate the opportunity to explore the unique needs of "populations within a population" - vulnerable older adults - from the perspective of the nursing care that they might require. It has often been expressed that older adults are a diverse group and some of this diversity is captured within the title of "populations within a population". More important than a title, however, is the reality that many older adults within these populations may be described as vulnerable.

The experiences and circumstances that create vulnerability among older adults can ultimately lead to a very poor quality of life or even death. Vulnerable older adults are defined as those whose reserve capacity falls below the threshold needed to cope successfully with the challenges that they face. The difference may arise either from lack of reserve resources or from particularly serious challenges, such as mental health concerns or developmental disabilities.

Compensatory supports may intervene to modify the effects of challenges and to rebuild reserve. The series of articles in this edition of the *Indian Journal of Gerontology* explores the diversity of vulnerability in older adults and strategies to help replenish their diminished reserve within selected "populations within a population."

The domains of challenges and required nursing care are discussed, with emphasis on demographic and other influences on the availability of family, social, and governmental support. The

promotion through the life course of healthy lifestyles and the acquisition of coping skills, strong family and social ties, and active interests will develop reserves and ensure that they are strong in later life. Some of the physical and psychological challenges that adults may face as they age cannot be modified, but others can. Interventions to develop compensatory supports include access to stable housing, good acute care and rehabilitation when needed, substitute professional social and psychological help in times of crisis, long-term help and income support. Policy initiatives to reduce vulnerability can ensure that adults reach later life with 'reserve', thus reducing the challenges they face in later life.

There is much work that remains to be done to meet the nursing needs of these older adults.

We hope that you enjoy this issue.

Sandi and Annette

Early Onset Dementia: A Narrative Review of the Literature

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ABSTRACT

Over the past forty years, significant research has been conducted on the epidemiology of late onset dementia. Less is known however, about the prevalence, incidence and burden of illness of early onset dementia (occurring prior to 65 years of age). The purpose of this narrative review is to examine existing literature regarding the experiences and implications of living with early onset dementia for patients, caregivers, and family members. The following questions were addressed: (1) What is the impact of early onset dementia on patients, families and carers? and (2) What are the needs of patients with early onset dementia and their family and carers? Key findings from this review are presented.

Key Words : Onset dementia, Caregivers, Family members, Needs of patients.

Dementia is characterized by the development of deficits in multiple domains of cognition which may be due to a specific etiology such as Alzheimer's Disease (AD), Vascular Dementia (VaD), or front temporal dementia; from the effects of a general medical condition; or from the persisting effects of a toxic or intoxicating substance (Harvey, *et al.*, 1998a). Diagnosis is based on the application of validated clinical criteria such as the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-IV – TR) (American

Psychiatric Association, 2000), the World Health Organization 10th International Classification of Diseases (ICD–10) (World Health Organization, 1993), or the National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association (NINCDS/ADRDA) research diagnostic criteria for AD (McKhann *et al.*, 1984).

Late Onset Dementia

The epidemiology of dementia in the elderly (over 65 years of age), termed late onset dementia (LOD) has been well-studied for over 40 years, with prevalence numbers of AD or VaD clearly showing an age-related increase. Three studies conducted in the late 1980's and early 1990's confirmed that the prevalence of dementia after the age of 65 years doubles with every 5 year increase in age (Kokmen, *et al.*, 1987; Jorm, *et al.*, 1987; Rocca *et al.*, 1991). In the World Alzheimer's Report 51.2 million people in south Asia were over the age of 60 years and 4.5 million people were diagnosed with dementia (Alzheimer's Disease International, 2009). Given that dementia prevalence increases with age, the number of people with dementia in south Asia is expected to increase to 9.31 million people by 2030 (a 108% increase) and to 18.12 million people by 2050 (a 304% increase). These LOD figures have driven service planning and research priorities for the elderly with dementia, with the burden of illness in terms of care provision and cost well-established.

Early Onset Dementia

Less well known are the prevalence, incidence, and burden of illness of early onset dementia (EOD), described as dementia occurring in the under 65 years of age group. The most common dementia diagnosis among young adults is Alzheimer's disease, followed by VaD (Sampson, *et al.*, 2004). Diverse behavioural, cognitive, neurological and psychiatric symptoms characterize EOD; these include memory loss (particularly short-term memory loss), depression and anxiety, delusions and hallucination, and difficulties with word-finding and concentration (Harvey *et al.*, 1998b).

The prevalence of early-onset AD in the UK has been found to be 35 out of every 1,00,000 individuals age 45 to 64 (Harvey, *et al.*, 2003). Additionally, this prevalence was reported to approximately double

with each 5 year increase in age after the age of 35 (Ibid.). This extrapolates to approximately 18,319 (15,296 – 21,758) people under the age of 65 with dementia in the UK. According to the publication *Rising Tide – The Impact of Dementia on Canadian Society*, it is estimated that there are over 70,000 people under the age of 65 in Canada with a dementia; 50,000 of these people are estimated to be under the age of 60 (Smetanin *et al.*, 2010). In an epidemiological study conducted in an urban centre in India over a 3 year period (1998 – 2001), the projected crude prevalence rate of dementia was 0.43 per cent for persons over 40 years of age (Vas *et al.*, 2001). This is a somewhat lower prevalence than in developed countries but is consistent with other India-based studies of dementia.

The Review

Aim of the Review

The purpose of this narrative literature review was to examine existing literature and the current state of knowledge regarding the experiences and implications of living with EOD for patients, caregivers, and family members. The following questions were addressed:

1. What is the impact of early onset dementia on patients, families and carers?

2. What are the needs of patients with EOD and their family and carers?

Design

The review is situated within our theoretical assumption that the impact of early onset dementia influences patient and family outcomes. We used a narrative overview design (Baumeister & Leary, 1997; Green, *et al.*, 2001; Oxman, *et al.*, 2002) to guide this comprehensive synthesis of the literature related to the experience of living with EOD. Preliminary criteria for inclusion in this review were papers: (a) in which the phenomena of early onset dementia was described, (b) showed relevance to the concept of living with dementia and/or included a focus on the experiences or implications living with EOD for carers and families, (c) pertained to adult populations (e.g. = 18 years to = 65 years of age) and (d) were written in English and published between January 1998 and November 2012.

Studies were excluded if they dealt specifically with causes, diagnostic or other medical aspects of EOD; evaluation of support strategies and/or service provision; or were primarily focused on prevalence and incidence of dementia. As well, studies were excluded if participants were > 65 years of age, were not written in English or were from the gray literature.

Search Strategy

First, we searched the on-line databases Allied and Complementary Medicine (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, and PsychInfo (Figure 1). Dissertations or conference proceedings were not included in the initial search. Key terms for this phase of the search included early onset dementia OR young onset dementia OR young people with dementia OR Alzheimer's* dementia combined with the terms "ethnicity', "care*", "outcomes", "quality of life", "family", "experience" and "impact".

Figure 1
Search Strategy for Preliminary Search

The following bibliographic databases were searched for the years 1998 – November 2012: ASP, CINAHL, Medline, and PsychInfo.

MeSH ® Terms
expl caregivers
exp family
exp quality of life

AND
Early Onset Dementia

AND
Dementia
Alzheimer's Disease
Frontal Lobe Dementia
Vascular Dementia

We reviewed papers published in English language journals that examined the experiences of patients with early onset dementia, including Alzheimer's disease, vascular dementia, and frontal lobe dementia; and those with a focus on caregivers and family outcomes.

This initial search strategy yielded 30 titles and abstracts. The first author assessed the titles and available abstracts electronically using these preliminary inclusion criteria. The non-applicable papers resulting from the broad search terms related primarily to year of publication (i.e. prior to 1998; n= 5), and studies focused on prevalence and epidemiological issues related to dementia (n=10).

Search Outcomes

Combining the search terms revealed a limited set of journal papers with a specific focus on quantitative and qualitative studies describing needs and impact of early onset dementia on patients, carers and families. Reference lists from original papers were scanned for additional relevant papers. The majority of papers included in this review were drawn from research conducted in North America and Europe. Using the preliminary inclusion criteria15 articles were retained. The results of this process are illustrated in Figure 2. All papers were successfully retrieved.

Figure 2
Screening Process
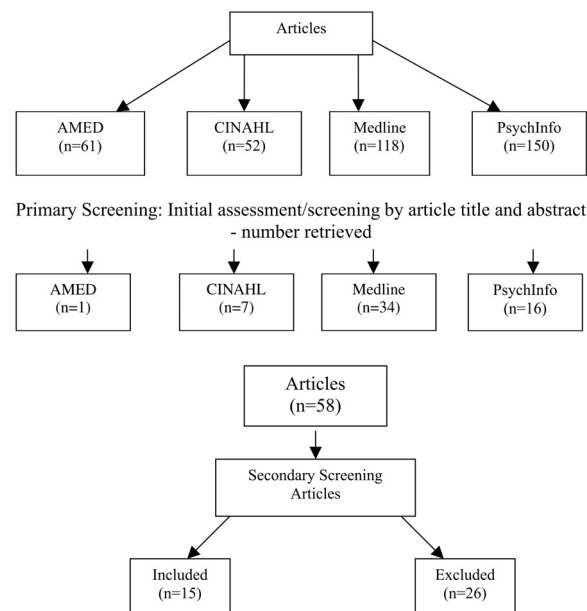
Quality Appraisal

Inclusion in the final sample was guided by three criteria: (1) the report of original quantitative or qualitative research, discussion paper, or literature review; (2) a focus on patients with early onset dementia including Alzheimer's disease, vascular dementia, and frontal lobe dementia, and (3) a conceptualization of the impact of EOD that included a focus on quality of life, family and/or caregiver outcomes. Specifically, quality of life of the patient, family and/or caregiver, and family/carer outcomes including burden or strain must have been addressed. The final screening was also done by the first author, with consensus of the co-author on the final selection. Fifteen articles remained in the final data set. These papers and pertinent characteristics are described in Table 1

Synthesis

The papers remaining in this systematic review of the literature reflect an increasing interest among researchers and clinicians about the experiences of patients and family living with early onset dementia. Not surprisingly however, there were no clinical trials found for this review; there were 6 systematic reviews (narrative), 1 retrospective review, 4 descriptive studies (cross-sectional survey and comparison studies), 3 qualitative reports, and 1 health report found. The results were therefore summarized in narrative format. Sample sizes of studies included in this review were generally small (i.e. < 40) and sampling methods were primarily convenience. Power analyses were not reported for the quantitative studies, thus it is difficult to determine the precision or generalizability of findings. The measures used in the quantitative studies to examine the outcomes of interest for either the person with EOD or the caregivers were also inconsistent. We therefore elected to critique each quantitative and qualitative article in the final selection for validity (Green *et al.*, 2001) and if rendered valid, synthesize the authors' interpretations of study findings (Oxman *et al.*, 2002). The mechanism used for coming to agreement regarding study validity and findings was consensus between authors.

Table 1

Characteristics of Included Studies

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Beattie A, Daker-White G, Gilliard J, & Means R.	'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. (2004).	Health & Social Care in the Community, 12(4), 359–368.	14 interviews with younger people with dementia in the southwest of England	Qualitative study	Comparative textual analysis of themes: ● General experience of having dementia ● Dementia diagnosis ● Importance of age ● Risk and danger issues	● Majority of participants articulate and insightful about their experiences and needs. ● Challenge is to engage with and consult individuals with dementia directly about their experiences and what they want from dementia services ■ Time to diagnosis ■ Feeling invisible ■ Age ■ Risk and danger perceived differently

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/14	Harris PB, Keady J.	Selfhood in younger onset dementia: Transitions and Testimonies	Aging and Mental Health (2009)	23 younger people with dementia 15 carers	Qualitative – Grounded Theory	• Exploration of the meaning and constructio n of selfhood and identity; • psychosocia l impact of younger onset dementia	• Loss of identity as a 'worker' • Identity of abandoned individual – social isolation • Sexual identity • Family identity • Self-identity – engaged in living
2012/11/15	Harris, PB	The Perspective of Younger People with Dementia: Still an Overlooked Population	Social Work in Mental Health (2003), 2(4):	23 younger people with dementia	Qualitative – interviews	Subjective experiences of younger people with dementia	• Trouble obtaining a diagnosis • Marginalization • Changing relationships within entire family structure • Work/force/retirement issues • Off time dependency • Lack of meaningful occupation • Issues of self-esteem • Awareness of changes in self

1. *EOD-Patient*

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/13	Roach P, Keady J, Bee P, & Hope K.	Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. (2008).	Reviews in Clinical Gerontology, 18(2), 165–172.	Younger people with dementia	Narrative literature review	Subjective experiences of younger people with dementia	• Primary research involving those with young-onset dementia and their families is lacking. • Services and research need to consider the needs and experiences of the person with EOD's networks (family, friends and colleagues) when working with younger age groups • Include the younger person with EOD in the research • Themes for improvement include early diagnosis, information provision and support for families. • Consider age, employability, current family composition and presentation of dementia symptoms in assessing the experiences of those with EOD.

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Tolhurst E, Bhattacharyy a S, & Kingston P.	Young Onset Dementia: The impact of emergent age-based factors upon personhood. (2012).	Dementia 0(0) 1–14. 2012.	Young onset dementia	Literature review	The concepts of 'personhood' and young onset dementia-appro aches to outline and bring together.	• Competing views of dementia as medical/biological condition and the impact of psychosocial factors (biomedical perspective vs. experiential perspective). • Discussed awareness as related to disease being a threat to sense of self, and patients attempt to control responses and others views of themselves. • Discusses use of person-centred care approach, and social constructionist theory. • Lack of literature which examines personhood and young onset dementia, as opposed to self and identity. • Examined effect of social definitions of dementia, and association with aging. These contribute to a separated view within health care services and management. • Lack of age appropriate services and associated dissatisfaction with care.

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
							• Discussed unique age-related impact in finances and families. • Unique caregiving considerations for those patients who are younger and physically functioning. • Calls for integration of these concepts into future and further research to adequately support the early onset population.

2. EOD– Carer and Family

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Freyne A, Kidd N, Coen R, & Lawlor BA.	Burden in carers of dementia patients: higher levels in carers of younger sufferers. (1999).	International Journal of Geriatric Psychiatry, 14(9), 784–788.	22 EOD patients, and sample of community dwelling LOD patients.	Comparative study	Comparison of clinical characteristics of LOD and EOD patients as well as caregiver burden.	• Increased burden found in carers of EOD group. • Those caregivers of EOD patients had been caring for up to 2 years longer than those with LOD patients. • EOD patient caregivers perceived less social support available and increased sense of isolation. • Did not extensively look at the effect on children; however majority agreed that they suffered psychological or emotional problems which lead to conflicts with parents and in school.

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
March 24, 2011.	Harvey R, Rossor M, Skelton-Robi nson M & Garralda E.	Young Onset Dementia: Epidemiology, clinical symptoms, family burden, support, and outcome. (1998).	NHS RFG045. http://dementi a.ion.ucl.ac.uk		Report		
2012/11/07	Luscombe G, Brodaty H, & Freeth S.	Younger people with dementia: Diagnostic issues, effects on carers and use of services. (1998).	International Journal of Geratric Psychiatry, 13, 323–330.	102 EOD carers.	33 item questionnaire/ survey	EOD patient caregivers experience– including diagnosis, services, financial considerations and overall satisfaction.	• Discussed difficulties in obtaining diagnosis, health information and prognosis. • 75% of carers were female, and typically were spouses, relatives or had some relationship with the patient. • Average number of professional consultations for AD was 2.8, and included GP's (89%), neurologists (64%), & psychogeriatricians (9%). • Average time to diagnosis for AD was 3.6 years. • Emotional or psychological problems were stated by 57 per cent of caregivers (predominantly by females), and family conflict as a result of caregiving role was identified in 41 per cent.

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Svanberg E, Spector A, & Stott, J.	The Impact of young onset dementia on the family: A literature review. (2011).	International Psychogeriatrics (2011), 23:3, 356–271.	Patients with early onset dementia	Narrative literature review – 26 studies	• Impact on individual • Impact on family – carer and children	• Young onset dementia has wide ranging impacts on individuals and their family due to symptoms, lifestyle and role changes. • Studies of younger people with dementia highlight their subjective experiences but emphasize the lack of research conducted. • Future research should address frequency of diagnostic difficulties and stigma in dementia • Amount of research on carers of younger patients with dementia indicative of the greater negative outcomes related to caring experience.
2012/11/10	Van Kliet D, de Bugt ME, Bakker C, Koopman RT, & Verhay FR	Impact of early onset dementia on caregivers: a review (2010).	Geriatric Psychiatry, 25, 1091–1100	17 articles	Narrative literature review	Impact of EOD on informal caregivers and children of EOD patients	• Difference in impact between EOD and LOD caregivers unclear • EOD caregivers do experience high levels of psychological suffering and specific problems related to phase of life.

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/10	Werner P, Stein-Shvach man I, & Korczyn AD.	Early onset dementia: clinical and social aspects	International Psychogeriatric s (2009), 21:4, 631–636.		Narrative literature review	• Clinical aspects of EOD: prevalence, causes, symptoms, diagnosis, and manage-ment • Social aspects of EOD: Cost of care, challenges, services available	• Research needed that explores: ■ Effective diagnosis and management ■ Allocation of funds ■ Development of services suitable to the unique needs of young people with dementia

3. EOD and Needs and Services.

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Barber, R.	A Survey Of Services For Younger People With Dementia. (1997).	International Journal of Geriatric Psychiatry, 12(9), 951–954.	254 hospital and community trusts.	Postal survey	Assessment of services available for EOD people in England, and potential of specialization.	• The most vulnerable carer was seen to be those who are younger females with competing caregiving demands (male patients, children and parents). • Of those carers working, only 42 per cent employment continued the same, and 5 per cent had reduced hours to part-time. This also was seen to be the cause of most financial problems for the majority of carers. • 3.4 years was the average time seen till diagnosis. • 101/254 agreed with the necessity of specialization, with some of those preparing to do so. However, more viewed specialization as unnecessary (314/254). • 52 of the trusts conducted an assessment of practice and the majority concluded there was a need development of a dedicated service. • Found that availability of community services, attitude, and competency of staff among the largest problems.

1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/13	Beattie AM, Dake-White G, Gilliard J, & Means R.	Younger people in dementia care: A review of service needs, service provision and models of good practice.	Aging and Mental Health, 6:3, 205–212	74 papers	Literature review	Review of the literature on younger people with dementia, in dementia care	● Need for flexible, age-appropriate, and dedicated services was the central theme ● A person-centered approach recommended with a tailor-made model of care ● Recommendations for inter-agency collaboration, early assessment and an awareness of individual needs were based largely on the practical experience of professionals and paid carers, not through scientific evidence.
2012/11/07	Harvey R, Roques P, Fox N, & Rossor M.	CANDID – Counselling and Diagnosis in Dementia: a national telemedicine service supporting the care of younger patients with dementia. (1998).	International Journal Of Geriatric Psychiatry, 13(6), 381–388.	Calls received at a telephone helpline over a 2 year period (n=1121).	Restrospective review	Details of calls received to a London UK telephone helpline ● caller and patient they were caring for; ● reason for call, ● advice given	● service rapidly accepted and used by families of patients and general public: 547 registered calls related to 241 individual patient issues ● healthcare professionals made less use of service; ● calls pertained to ■ general information ■ clinical advice ■ advice on social issues

EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/13	Williams T, Dearden M, & Cameron IA.	From Pillar to Post – a study of younger people with dementia	Psychiatric Bulletin (2001). 25, 384–387	132 patients with EOD	Health needs assessment – postal survey	• Gateways to specialist investigation and care • Access to information & services • Coordinated services and daycare	• Needs of younger people with dementia very different from older people • Prevalence rate and experiences of carers and patients justifies the existence and further development of EOD services • Single gate-way to coordinated service provision and ensure continuity of care • Provide duffers and carers with information, advice, and expertise.

Overview of selected papers

Results

Patients

Individuals with EOD face significant psychological and emotional challenges, including a loss of independence as their ability to perform everyday activities diminishes (Woods, 1999; Williams, *et al.*, 2001; Harris, 2004; Werner, *et al.*, 2009); these challenges are compounded by changing relationships with partners and other family members. Werner *et al.* (2009) describe three psychological and emotional implications of EOD for patients. There is a loss of independence resulting from difficulties accomplishing normal everyday tasks; this loss of independence leads to changes in the relationships within the family. For example, the parent with EOD becomes the 'cared for' and children often assume part of the caregiving role – a role reversal that contributes to feelings of diminished self-worth for the parent. Third, EOD often results in loss of employment for the patient with subsequent impacts on the family, the patient's self-esteem and sense of self-worth (Ibid.). Loss of employment benefits can also add to the strain felt by the patient and family and can lead to deterioration in marital quality as relationships change (Williams *et al.*, 2001; Beattie, *et al.*, 2004). These findings are supported by other researchers examining the impact of EOD on patients and families (Beattie, *et al.*, 2002; Svanberg, *et al.*, 2011). As younger patients are often more physically fit than those with LOD, the inability to engage in valued activities leads to a loss of independence and social isolation which in turn contributes to low self-esteem and depression for patients with EOD. Beattie *et al.* (2002) reported that as the ability to perform everyday tasks becomes impaired, further deterioration in self-esteem and mood is likely. Included in this are difficulties in maintaining an intimate relationship with a partner due to cognitive impairment, which further increases feelings of diminished self-esteem and self-worth.

Beattie *et al.* (2002) and nearly 10 years later, Svanberg *et al.* (2011), reported that the individual experience of the patient with EOD is still lacking in research and the need to speak with younger people about living with EOD is imperative. In a report by Alzheimer's Australia (2007), this sector of the dementia population was

characterized as a minority group with issues specific to this group – a need for a holistic approach to care and services, and recognition of the emotional impact of the diagnosis of EOD. This approach is supported by Tolhurst, *et al.,* (2012) in arguing that psychosocial (i.e. psychological, situational and social) as well as biological and medical factors impact on the nature of EOD and influence how the younger person will experience the condition.

Roach, *et al.,* (2008) also reiterated the need to further examine the phenomenon of EOD and in a review of the literature identified 3 key themes as resonating across the studies. These themes echo the findings of earlier researchers, with recognition of changes and associated stigma, isolation, guilt, helplessness and role and relationship changes surfacing as significant factors for those living with EOD. Harris and Keady (2009) also examined the psychosocial impact of EOD for patients, reinforcing the loss of identity and sense of isolation experienced by those living as a younger person with dementia.

Carers & Family

Informal carers of younger adults with EOD are typically a family member and often a spousal partner (Harvey *et al*., 1998; Luscombe, *et al.*, 1998; Svanberg *et al*., 2011). The task of providing care can be associated with physical and emotional burdens, with levels of burden often rated higher for carers providing support for patients with EOD as compared to those providing care for those with LOD (Beattie *et al*., 2004). Freyne, *et al.,* (1999) also conducted a comparative study examining the levels of carer burden between community-dwelling people with EOD and LOD and their carers. They discovered that while carer burden is significant for both groups, the perception of burden for those caring for the EOD group was significantly higher than the LOD group. In a more recent review of the literature, Van Vliet, *et al.,* (2010) explored the impact of EOD on caregivers and reported that while EOD caregivers reported high levels of burden, stress, and depression, the results were inconclusive when compared with LOD caregivers. These researchers reported caregivers of EOD patients experience psychosocial problems which seem to be age or stage of life related. These include relational issues,

family conflict, employment problems, financial difficulties, and problems obtaining a diagnosis. These difficulties are compounded by the lack of formal and informal support available to carers and family when assuming a caregiving role that may extend over a long period of time (Arai, *et al.*, 2007).

Anxiety and depression have been found to be common consequences of assuming the caregiver role for patients with EOD. Harvey *et al*. (1998) reported that anxiety was described by over 60 per cent of caregivers (higher in female carers) and for spouses as caregivers, depression was very prevalent; one cause might be related to feeling inadequately prepared for the caregiving role. (For caregivers, EOD often leads to financial insecurity, high stigmatization, and negative impacts on marital quality (Svanberg *et al*., 2011). These reactions may be compounded by the lack of appropriate community services that 1) fit the needs of younger patients with EOD and 2) fit the needs of a carer who must work to support the family.

Luscombe *et al*. (1998) conducted a cross-sectional survey of 102 carers of people with EOD to assess psychological, physical, occupational and financial impacts of illness on carers and children. 81 per cent of carers reported frustration and other psychological effects, more so in female than male carers ($p < 0.001$). The younger the carer, the more psychological and physical effects were experienced. 92 per cent of carers felt their children had experienced problems related to the dementia. These issues remain unresolved in reviews conducted on the impact of EOD on caregivers and family nearly 10 years later (Arai *et al*., 2007; Van Vliet D *et al*., 2010).

Needs of Early Onset Dementia Patients, Carers and Family

Patients

Williams *et al*. (2001) reported that many patients (and carers) in Leeds, UK felt the diagnostic phase of their disease was stressful, as they were referred from their general practitioner to various specialists over the course of reaching a definitive diagnosis. Many patients were referred to at least two different consultants, including neurologists and psychiatrists. This process of seeking a diagnosis is not uncommon in other parts of the world (Vas *et al*., 2001; Alzheimer's Australia,

2007); and patients continue to feel the path is too complex, uncoordinated and too lengthy (Roach *et al.*, 2008; Svanberg *et al.*, 2011). Luscombe *et al.* (1998) also reported that patients and carers encounter problems with the diagnostic process, often related to lack of knowledge on the part of the service provider.

Roach *et al.* (2008) reported that patients with EOD and their carers desired information about the meaning and nature of the diagnosis and contact with services. While health care/service providers may feel that patients and carers are not ready to receive the definitive EOD diagnosis, patients and carers feel that not having this information limits their ability to obtain timely follow-up for major areas of concern (Ibid.). Few were actually referred to an early onset dementia team and many felt they had not received enough information, practical help, support or counseling (Williams *et al.*, 2001).

Apparent in many of the articles reviewed was the need for age-appropriate services that take into account the social and psychological differences between younger people with dementia and older people (Arai *et al.*, 2007; Luscombe *et al.*, 2008; Freyne *et al.*, 2009; Van Vliet *et al.*, 2010; Svanberg, *et al.*, 2011). Beattie *et al.* (2004) reported that patients with EOD felt mixing with other younger people with memory difficulties were a positive experience, whereas care and services in older person's settings were viewed negatively. Age-appropriate settings and services gave patients with EOD a place to meet new people, socialize and engage in meaningful activities such as sporting events. Unfortunately for many patients with EOD, this type of service is not available in their community setting. Assessment of services within community settings has been recommended by several researchers, with a specific focus on applicability and support of younger patients with dementia (Harvey, *et al.*, 1998; Barber, 2007).

Carers & Family

Caregivers and family members living with a person with EOD are often relatively young, with full and active lives outside of the home setting. Becoming a caregiver in the context of EOD thus entails a long duration of caregiving with little formal or informal support available.

Key issues identified in this literature review related to carers and families included:

1. The ability to have a break from caring – which necessitates access to appropriate respite care when needed. Respite care might include such things as day centres, hospital or nursing home care, or in-home services (Luscombe *et al*., 2008), with options for hourly, daily or overnight or out-of-hours services/care available.

2. Access to age-appropriate day care services. Many carers are employed outside the home and leaving the patient with EOD at home alone is often the only option open to them in order to provide financial security for the family. As the disease progresses, safety of the person with EOD in the home becomes an issue and leaving the patient home alone is no longer an option. For many, this results in the carer taking time away from work, calling on extended family and friends for support, or asking children to provide supervision. Thus it is apparent that day care services need to be flexible to fit the needs of the family carer as well as the patient. Carer's advocate that this service should include flexible opening hours to accommodate the carer's working day, and the provision of transport (Ibid.).

3. Finding appropriate homes for permanent care – many carers in this review identified difficulties when searching for an alternate care facility when it becomes apparent the person with EOD can no longer be cared for at home. The carers felt they were not provided with information needed to streamline their search for a facility that offered age-appropriate care (Freyne *et al*., 1999; Murray, *et al.*, 1999; Van Vliet *et al*., 2010).

Discussion

It is important to remember that most family and friends involved in providing informal care take pride in their role, and perceive many positives. In Canada, 80 per cent of a nationally representative sample of carers of people with dementia were able to identify positive aspects when asked to do so (Harris & Keady, 2009). These included companionship (23%), fulfillment (13%), enjoyment (13%), providing quality of life (6%) and meaningfulness (6%).

Nevertheless, carers of people with dementia also experience high levels of strain, psychological morbidity and, possibly, impaired physical health.

The negative consequences of caregiving have been widely studied. In LOD, high levels of burden (Vas *et al*., 2001), stress, distress (Werner *et al*., 2009), and depression (Williams *et al*., 20012) have been identified in caregivers. While less research has been conducted with caregivers of individuals with EOD, this population has also been found to have high burden, stress (Baumeister & Leary, 1997; Williams, *et al*., 2001; Werner *et al*., 2009), and distress (Beattie *et al*., 2002; Beattie *et al*., 2004). Some of this may well relate to the unexpectedness of the diagnosis in a young person and the difficulty experienced in the process of reaching a diagnosis. In a qualitative study of caregivers of individuals with EOD, the most central theme in discussions was the burden of caring experienced (Svanberg *et al*., 2011). Younger caregiver age is significantly related to negative psychological and physical impacts (Smetanin *et al*., 2010) possibly related to the length of time one provides care to a person with dementia. This is likely to be longer in the EOD group given the younger age of both patient and carer, thus the burden of care may be perceived as being greater.

One element of living with EOD that did not appear in the literature in this review and may impact the burden of living with EOD relates to grief. Luscombe *et al*. (1998) did report that 73 per cent of the population included in a cross-sectional study of 102 carers of younger people with dementia, reported experiencing grief. However, there was no further discussion about the implications of grief in the context of EOD. It is likely that grieving the loss of self, partner, parent, or family member contributes to the psychological difficulties experienced by all people living with EOD.

Younger people with dementia are more likely to be employed outside the home at the time of diagnosis, have dependent children or family, have significant financial burdens, and may be more physically fit or active than those over age 65 with dementia. Caregivers of individuals with EOD are also likely to be working at the time of dementia diagnosis, and one study found that 59 per cent of these carers had to reduce their hours or stop working due to their

caregiving role (Luscombe *et al*., 1998). Thus, to develop services for younger people with dementia and their caregivers, it is important to define the needs of service users according to age, activity and social relations. However, in most cities and countries, services for patients with dementia are based on the identified needs of the over 65 years of age group and their caregivers. It is important to actually talk to patients with EOD for perspective about these needs – they are still able to communicate their needs and wants and often feel they are being overlooked in the process.

The Alzheimer's Association (2011) in the United States (US) has emphasized that the occurrence of EOD is frequently unexpected, and therefore may result in different concerns. Due to more drastic changes in roles and activities of the individual with EOD, the impact of the diagnosis and the challenges faced by the patient and caregiver may be greater (Tolhurst *et al*., 2012). Researchers from the UK, US, and Canada have found that EOD patients and caregivers experience difficulties in finding and accessing services appropriate to their needs (Murray *et al*., 1999; Alzheimer's Australia, 2007; Smetanin *et al*., 2010). In a survey of dementia services in England, only 12 out of 254 providers had specialized services for EOD (Arai *et al*., 2007). Individuals with EOD and their caregivers have commonly expressed a desire to connect with others experiencing EOD and do not feel they "fit" into existing services targeted for older individuals (Luscombe *et al*., 1998; Freyne *et al*., 1999).

Conclusion

While researchers have been exploring the needs and experiences of EOD from the perspective of patients, carers and families, changes in service provision for this population have been slow to follow. As identified by Werner *et al*. (2009), research is needed that will provide evidence to support patients and carers with services structured to meet the needs of those with EOD. This means conducting prospective studies to appreciate changes over time that will affect service needs, and clinical trials to assess strategies for meeting the needs of this special population.

Acknowledgements

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Depressive Symptoms Among Iranian Elderly Inpatients: Prevalence and Correlates

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ABSTRACT

Depressive symptoms are often not detected properly in the medically ill elderly. A great inconsistency exists in prevalence rates and associated factors in literature. The aim of the present study was to explore the prevalence of depressive symptoms and possible correlated factors among the elderly within hospitals. In a cross section study, 235 elderly inpatients were screened. Thirty eight individuals in the sample were excluded, leaving 197 participants for analysis. The Hospital Anxiety and Depression Scale (HADS), Cumulative Illness Rating Scale (CIRS) and Abbreviated Mental Test Score (AMTS) were used to assess depressives symptoms, burden of medical conditions and cognitive competency respectively. A self rating questionnaire was also used to detect socio-demographics and clinical variables. Participants included elderly between the ages of 60 to 90 years, with mean age of 68.2 years old. Of the 197 participants, 83 (42.1%) of the sample were female and 114 (57.9%) were male. The mean score on the depressive subscale of HADS was 9.1(±4.8). Sixty six point five per cent of the sample were identified as having significant depression. Using the cut-off score for HADS, 33.5 per cent of the sample scored in no significant range, 26.4 per cent in mild to moderate range and 40.1 per cent scored in the severe range of the depressive

subscale. Depressive symptoms were associated with a high medical condition burden (p=0.001) This study is in line with previous studies showing the high prevalence of depression in elderly inpatients. Results suggest a proper screening for depression among elderly who have been hospitalized because of physical health problems.

Key Words: Depressive Symptoms, Inpatients, Elderly, Physical health problems

Depression is often not detected properly in elderly population. A great inconsistency exists in the prevalence rates of depression in earlier studies. Prevalence of depressive symptoms varied from 13.5 per cent to 36.8 per cent in community dwelling older adults (Blazer & Williams, 1980; Beekman, *et al.*, 1999; Torija *et al.*, 2007). Research examining depressive symptoms in elderly inpatients reported an increase over community dwelling older adults, with a prevalence of depressive symptoms ranging from 23 per cent to 54 per cent (Koeing, *et al.*, 1988). Loss of social support, female gender, physical disorder, cognitive failure, low income and history of depressive illness are considered to be implicated in depression among older people.(Koeing *et al.,* 1988; Blazer, *et al.*, 1991; Sartorius, 1993; Beekman *et al.*, 1995; Beekman *et al*., 1999; Heun & Hein, 2005).

Controversy still remains to the precise prevalence and correlates of depressive symptoms among clinical samples of older people. Meanwhile there is a general agreement that depression is common in elderly hospital population (Lindesay, 1990; Bryant, *et al.,* 2008). The prevalence of anxiety disorders have been reported with a rate of 18 per cent in older people with pulmonary disorder (Yohannes, *et al.*, 2000).

While studies have been less focused on anxiety than depression, there is some evidence that both anxiety and depression in combination with physical illnesses are correlated to poor functioning (Lenze, 2001).

Physical illnesses are common in older people. Older adults have a high rate of use of health services and hospital admission. Higher use of health services brings about high cost to the community and patients as well. Mental health and physical health affect each other in

older adults. Mental illnessesleads to poor outcomes for physical disorders such as stroke, cardiovascular disorders etc. (Astrom, 1996; Sullivan, *et al.*, 1997). It is suggested that medical services are places that should be considered for proper detection and management of psychiatric problems in this population. Without precise knowledge about the prevalence and correlation of depression and anxiety in the medically ill elderly, appropriated services cannot be planned.

Lack of data will hinder proper service and treatment planning. The aim of the current study was to explore the prevalence rates of depression and possible correlated factors among elderly inpatients hospitalized in university hospitals affiliated to Shiraz University of Medical Sciences in Iran. This is an important area of study because of the paucity of data about depression in elderly inpatients in Iran. The study hypothesis was that there would be a significant rate of depressive symptoms among elderly inpatients. We also hypothesized that there would be a correlation between depressive symptoms and the burden of medical conditions, poor social support and duration of hospital stay.

Method

This was a cross sectional study conducted in the reference university hospitals. Patients 60 years of age or older admitted to various wards were selected based on a regular weekly time table. Subjects were excluded if they had significant cognitive deficit, hearing problems, severe pain and were using mechanical ventilation.

Assessment Measures

Sociodemographic Characteristics

Information regarding age, educational level, marital status, income resource, occupational status, family pattern, past and family history of psychiatric problems and history of substance use was obtained from the patient or a close family. For the self report measures, a Farsi version of the tools were used.

Abbreviated Mental Test Score (AMTS)

The Mental Test Score (MTS) instrument was developed to screen cognitive failure such as dementia and delirium. The AMTS is

short version of MTS with 10 items assessing orientation, concentration, short and recent memory.

The Geriatric version of Cumulative illness rating scale (CIRS-G) was used to check the burden of medical illnesses .(16)

Hospital Anxiety and Depression (HADS)

HADS is a brief self-report measure developed to detect depression and anxiety in physically unwell patients. It includes two separate 7 item subscales for depression and anxiety. The score of each subscale ranges from 0–21.

Data was analyzed using SPSS 15. Descriptive analyses was done to detect the mean, the prevalence, and the standard deviation of variables. To detect the association between depressive symptoms and categorical and numeral variables, the Chi-square test and Pearson correlation were performed, respectively.

Results

The sociodemographic characteristics of the sample are provided in Table 1. The majority of the participants were married (79.7%). The mean age was 68.2 year, and ranged from 60 to 90 years.

Table1
Sociodemographic Characteristics of Study Sample

Variable	n	%
Age range		
60– 69		59.9
70–79		28.4
= 80		11.7
Sex		
Male	113	57.4
female	84	42.6
Marital status		
Married	157	79.7
Widowed	27	13.7

Cont'd...

Single	6	3
divorced	7	3.6
Living area		
Rural area	49	24.9
Town	56	28.4
capital	92	46.7
Medical ward	83	
Surgery	114	42.1
medicine		57.9
Education		
Illiterate	89	45.2
= 9 grade	92	46.7
= 9 grade	16	8.1
Employment Status		
Currently employed	51	25.9
House wife	75	38.1
Retired	32	16.2
unemployed	39	19.8
Income Resource		
Superannuation	35	17.8
Family support	54	27.4
Organizations	20	10.2
Assets	11	5.6
Salary from current	66	33.5
other	11	5.6

Eighty three (42.1%) patients were hospitalized in surgical wards and 114 (57.9%) were hospitalized in internal medicine wards. The mean number days for hospital stay was 6.4 days and ranged from 1 to 60 days. Six (3%) reported personal psychiatric problems and 19 (9.5%) reported a history of psychiatric problems in their relatives. Almost 67 (34%) used various kind of substances including tobacco and opium.

The mean score on the depressive scale was 9.1(SD±4.8). Using the cut-off score, 66 (33.5%) of the sample were identified as not having

clinically significant depression. Twenty sic individuals (13.2%) were identified as having mild depression, 26 (13.2%) moderate depression and 79 older adults having (40.1%) severe depression.

In further corelational analyses, the presence of depressive symptoms was positively correlated to the cumulative burden of physical disorders (p=0.001). However, there was no significant association between sex (p=0.907), marital status (p=0.922), duration of hospital stay (p=0.469), living area (p= 0.403) and depressive symptoms amongst the sample. Additionally, there was no significant association between the family history of depression and depressive symptoms (p=0.5965). The ratio of depressive symptoms did not change between the age ranges.

Discussion

This study explored depressive disorder among elderly inpatients in public university hospitals and revealed a prevalence rate of 66 per cent, as well as a significant association for depressive symptoms and cumulative burden of physical illnesses.

The prevalence rate found in this study is similar to some previous studies (Sherina, *et al.*, 2006; Mendes-Chiloff, *et al.*, 2008), but in contrast to some population based studies, showed lower rates (Blazer & Williams, 1980; Torija, *et al.*, 2007; Brayant, *et al.*, 2008). The higher prevalence rate in this study might be due to the medical conditions of the older adults. This rationale is line with findings that reveal an association between depressive symptoms and more physical illnesses. Moreover, a greater number of medical conditions demand greater hospitalization time (Sartorius, 1993). While pre morbid depressive episodes were not investigated, only 3 per cent of patients reported a history of psychiatry problems in themselves. While several studies found more depressive symptoms in elderly women (Blazer *et al.*, 1991; Beekman *et al.*, 1995), no significant difference was found between male and female participants in our study.

It is possible that depressive symptoms detected in our sample presented psychological reactions to medical conditions and their subsequent disabilities. Findings from this study, however, confirm controversial results in the literature about the correlation of depression to age. In our current study, there was not a meaningful

difference in depressive scores among the age ranges (Koeing *et al.*, 1988; Snowdon, 2002; Heun & Hein, 2005). In ourstudy, depressive symptoms were not different between subjects with various psychosocial variables such as occupational status, marital status, living area, income and educational level.

In line with the literature review, higher depressive symptoms are associated with higher morbidity and mortality (Baldwin, *et al.*, 2003). On the other hand, individuals with depression might use more health services. Given the mutual impact of depression and physical health, it is rational that depression be diagnosed and treated appropriately in elderly inpatients. Non psychiatric health professionals must consider the importance of detecting and treating depression in this population.

A limitation of this study is that the cross sectional design does not discern direct causality and etiological factors. Additionally, structured interviews for diagnosing depression were not used. The AMTS also does not detect cognitive deficit due to frontal lobe damage which could be associated with depression.

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Growing Old with a Developmental Disability

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ABSTRACT

An extensive review of the literature specific to the health and nursing needs of adults who are ageing with a developmental disability was conducted. We asked the questions: (1) What is unique about individuals who are ageing with a developmental disability? (2) How is health experienced in this group of adults? and (3) What interventions could be used by gerontological nurses that might enhance health outcomes for this group? The literature reviewed indicated several key findings: (1) The onset of age-related changes for individuals with developmental disabilities is similar to that of the general population unless they have severe levels of cognitive impairment, Down syndrome, cerebral palsy, or multiple disabilities; (2) The potential synergistic effects of increasing age with concomitant membership in a vulnerable population group (e.g. ageing with a developmental disability) increases the risk of experiencing poor health; and (3) The health problems that sometimes accompany ageing present challenges for individuals with developmental disabilities.

Key Words: Ageing, Developmental disability, Health issues.

Individuals with moderate or severe disability are now routinely living into their late 50s and into their 60s (Bittles, *et al.* 2002; Maaskant, *et al.*, 2002). Yet, many nurses have little experience in how to provide services for aging individuals with developmental disabilities. Developmental disability is characterized by lifelong mental or

physical functional limitation that manifests early in life after birth (Crews, 2011). It describes a population of individuals with significant limitations in developmental functioning and adaptive conceptual, social, and practical behaviour skills that commence before the age of 18 years (Schalock, *et al.,* 2010). It is commonly associated with neurological disorders such as cerebral palsy (Patja, *et al.*, 2001b) and Down syndrome (Sherman, *et al.*, 2007).

Based upon this context, we asked the following questions:

- What is unique about individuals who are ageing with a developmental disability?
- Are there specific health challenges that this group of adults face?
- What interventions could be used by gerontological nurses that might enhance health outcomes for this group?

Method

A search of the following databases: Medline, CINAHL, ERIC, Psychlit, Sociological Abstracts, PubMed, and Dissertation Abstracts was conducted. The review criteria included the period between January 2000 and December 2011 and used the search terms: ageing, older adults, disability, developmental disability, intellectual disability, and health. We used a combination of words to eliminate articles specific to young children and adolescents. The query initially produced over 17,500 citations. This listing was reduced to 973 articles, with the addition of the following parameters: items with full text on line, limited to articles from peer review journals, and printed in English. The removal of the term ageing further reduced the list to 209 articles. A total of 167 articles were reviewed.

A data analysis grid was developed by the researchers to identify the key themes emerging from the literature that answered the 3 above mentioned research questions.

Findings

What is unique about individuals who are ageing with a developmental disability?

Due to pre-existing neurological, functional, and physical impairments, individuals with developmental disabilities may demonstrate

signs of ageing in their 40s and 50s that the general population tradi-tionally may not experience until 20 to 30 years later (Evenhuis, *et al.,* 2001; Thomas, *et al.*, 2010; Crews, 2011).

How is health experienced in this group of adults?

Physical Health

The major health risks in older adults with developmental disabil-ities are identified as being cardiovascular disease (Janicki *et al.*, 2002; Draheim, 2006; Coppus, *et al.,* 2008; Kozma, 2008; Tyrer & McGrother, 2009), respiratory disease (Patja *et al.*, 2001b), hyper-tension, gastrointestinal conditions, osteoporosis, oral health conditions (Owens, *et al.*, 2006; Turner, *et al.*, 2008), obesity, cancer (Duff, *et al.*, 2001; Patja, *et al.*, 2001a; Sullivan, *et al.*, 2004), and thyroid conditions (Yang, *et al.*, 2002; Prasher & Gomez, 2006).

There is evidence in the literature of a correlation between the presence of specific developmental conditions and these identified health risks. To provide a few examples, while older adults with devel-opmental disabilities have high levels of dental and gum disease, those with cerebral palsy are particularly at risk (Liptak, 2008). In the United Kingdom, death due to respiratory causes are more common in the population of individuals with cerebral palsy compared to the general population, especially for those younger than 40 years (Hemming, *et al.*, 2006). In a prospective longitudinal cohort study of 506 individuals with Down syndrome (Coppus, *et al.,* 2008) cardiac failure was the second leading cause of death in individuals with Down Syndrome without a dementia. In a study of Americans with Down syndrome, cardiac conditions were again attributed as the second most frequent rationale for death, with a standard mortality odds ratio of 29.1 for congenital heart defects and 0.42 for ischemic heart disease (Yang *et al*., 2002). In an Australian study of 1,332 individuals with Down syndrome, coronary artery disease was the cause of mortality in 10 per cent of those over 40 years of age (Bittles, *et al.*, 2007).

Also from a specific condition perspective, the incidence of cancer is high in those with Down syndrome (Patja, *et al.,* 2001a; Yang *et al.,* 2002). In one study, a cohort of 4872 Swedish and Danish individuals with Down syndrome were followed from 1965 to 1989. It

was found that there was an elevated incident of acute lymphatic and nonlymphotic leukemias, testicular cancer, liver cancer, and stomach cancer (Hill *et al.,* 2003).

Strydom *et al.,* (2009) conducted a review of the published literature from 1997 to 2008 with a focus on the epidemiology of dementia in developmental disability in general, as well as in specific conditions. They reported varied methodologies in diagnosis yielded a wide range of reported prevalence rates of dementia. They found that the rates of dementia in the population under study – due to other developmental disabilities besides Down syndrome – are comparable or higher than the general population. Alzheimer's disease onset in individuals with Down syndrome appears earlier and the prevalence increases from under 10 per cent in the 40s to more than 30 per cent in the 50s, with varying prevalence reported for those aged 60 and over.

Standardized mortality odds ratios in a population of individuals with Down syndrome showed that this population had a significantly greater likelihood of having a diagnosis of dementia on their death certificate (Yang *et al.,* 2002). In the aforementioned study of 4872 Swedish and Danish individuals with Down syndrome, there was also a high mortality from dementia and Alzheimer disease (Hill *et al.,* 2003). Coppus *et al.,* (2008) used a prospective longitudinal design to study dementia and mortality in 506 adults with Down syndrome aged 45 and over. They found that relative preservation of cognitive and functional ability was associated with better survival. In a cross sectional study, Alzheimer's dementia was three time more prevalent in those with developmental disabilities than the general population, with a significant prevalence of 8.6 per cent (Strydom, *et al.,* 2009). The implication of this finding is evident in a British study of 2995 individuals with developmental disabilities. During a 14-year study period, the standardized mortality ratios indicated that the degree of mortality due to dementia was twofold greater than the general population (Tyrer & McGrother, 2009). Other researchers have also identified the high prevalence of dementia symptoms in individuals with Down Syndrome (Janiciki & Dalton, 2000; Yang *et al*., 2002; Coppus, 2006).

Psychosocial and Psychiatric Issues

From a psychosocial perspective of health, individuals with developmental disabilities are living longer and thus experiencing death among their family and peers. However, their grieving is not well recognized (Stoddart, *et al.*, 2002; Dodd, *et al.*, 2005).

Psychiatric disorders are also more common among older adults with developmental disabilities due to additional vulnerability risk factors such as neurological changes, sensory impairment, pain, loss of confidence, bereavement and loss, deteriorating physical health and diminishing social networks and activities (Luty & Cooper, 2006). Hubert and Hollins (2000) reported that the higher rates of psychiatric disorders included dementia, anxiety, depression, and affective and delusional states. Holland (2000) suggested that the increase in psychiatric disorders in this group can be attributed to the aging process and associated social changes.

What interventions could be used by gerontological nurses that might enhance health outcomes for this group? There were four key interventions that were identified through the review of the literature.

The first key intervention involved the importance of *conducting a thorough assessment.* Assessment for health conditions is often confounded with co-morbidities, in addition to underlying cognitive and functional impairments related to a developmental disability. Since cognitive or communication impairments may contribute to delayed reporting of symptoms with this population, there is a greater need for inter-professional communication between disciplines to achieve quality health care (Sullivan, *et al.*, 2004).

Assessing dementia in this population of older adults should include medical histories, mental status, cognitive functioning, and physical findings (Torr, 2009). Coppus *et al.* (2006) noted a relationship between dementia and depression history and the use of anti-epileptic medications. This finding highlights the importance of careful assessment and monitoring to avoid misdiagnosis of dementia due to an underlying depression or epilepsy. The early symptoms of Alzheimer's disease are similar to those of pathologies, many of which can be treated; for example, delirium resulting from urinary tract

infections. A thorough diagnostic procedure will identify such conditions. This imperative is complicated by the inherent difficulties of diagnosing Alzheimer's disease in adults with developmental disabilities. Essentially diagnosis involves identifying a pattern of change in an individual's functional capacity over time and must use previous levels of functioning as the benchmark. Standard measures of functioning and diagnostic tests based on population norms are not appropriate for use with adults with developmental disabilities.

Health promotion and screening is another intervention which emerged from the reviewed literature. Many adults with developmental disability are not included in health promotion programs or screening programs for age-related pathologies such as prostate cancer or breast cancer (Lennox, *et al.*, 2001; Heller & Marks, 2002). It is not clear whether the reasons for this relate to their omission from databases and therefore they were not invited to participate or whether such invitations are not seen as relevant by them or by care providers supporting them. Davies and Duff (2010) suggested the former might be the case. The implication is that these adults experience aging from a position of vulnerability rather than strength.

The study of Cooper *et al.* (2006) provided evidence of the value of health screening compared to standard treatment in a sample of people with developmental disability. They reported a twofold increase in the identification of health needs as well as a significant increase in meeting these new health needs, health promotion, and health monitoring. Other health risks for aging individuals with developmental disabilities that should be monitored include hearing, vision, nutrition, activity, obesity, oral health, gastroesophageal reflux disease, constipation, osteoporosis, and tobacco use (Krahn, *et al.*, 2006; Haveman *et al.* 2010). Screening is important because symptoms of hypothyroidism may go unnoticed as they are characteristic of individuals with Down syndrome, such a reduced energy or motivation, dry skin, excess weight, and bradycardia (Smith, 2001). A decline in cognitive functioning, due to hypothyroidism, may be mistakenly attributed to Alzheimer's disease (Prasher & Gomez, 2006).

Kirby and Hegarty (2010) reported that nurses working in developmental disability settings did not promote breast awareness for women with developmental disabilities. At the same time, the literature shows that in a population of individuals with Down syndrome, nearly half lacked physician care within a year and 38 per cent had not seen a physician in three years (Henderson, *et al.*, 2007).

Employing communication skills was another identified intervention in the reviewed literature. Even when nurses are skilled in communicating with adults with developmental disabilities, additional time is required and reliance may have to be placed on second hand descriptions of symptoms and changes. Placing these in the context of an individual's medical history may be difficult. For those who live in supported accommodation, staff turnover or the process of deinstitutionalization may mean that an individual's history is lost or forgotten (Bigby, 2002).

The final intervention identified was the importance of *providing of support.* Supporting individuals who are aging with developmental disabilities to change aspects of their lifestyle and health behaviours is an important strategy. Participation in structured exercise programs, restructuring everyday life to extend the amount of physical activity and health education have the potential to build a healthier lifestyle. Heller, *et al.,* (2004) demonstrated the ability of older adults with developmental disabilities to participate and enjoy structured exercise programs, as well as to exercise choice and gain new knowledge and skills.

Discussion of Findings

There is a need to understand biological aging and functioning throughout the life span of adults who are aging with developmental disabilities. The pre-existing health conditions of some adults with developmental disabilities may increase their risk of or the impact of age-related diseases. For example, many people with Down syndrome experience sensory loss in childhood. The impact of age-related sensory change will be much higher than if no previous loss has been experienced. Long-term use of medication to control seizures may

increase the risk of osteoporosis. Chronic health conditions may be compounded by age-related changes.

Reduced Understanding of Aging Process, Communication Problems and Challenges in Adapting to Changes

Individuals with developmental disabilities often have little understanding of the aging process. For instance, they may have little understanding of knowledge related to sexual changes that occur with age. McCarthy (2002) demonstrated that women with a developmental disability have little knowledge about menopause and its symptoms. This finding reinforces the need to promote learning about age-related issues for individuals, and the importance of supportive staff and/or family members who in turn have access to education, support, or specialist materials.

Ageing individuals with developmental disabilities may have had poor experiences of health treatment in the past. Lack of under-standing of procedures can result in confusion and a lack of cooperation on the part of these aging adults. Additionally, they may have difficulty communicating what is happening to their bodies, including bodily sensations and the kinds of discomfort experience. Further, the physical inaccessibility of equipment in examination rooms for adults with physical disabilities adds to the difficulties in diagnosing.

The ability of aging individuals with developmental disabilities to adjust to aging may be hampered when health – related changes are interrelated with pre-existing health conditions or physical and sensory impairment. The compounding of multiple health issues may be greater because of the reduced adaptive capacity of adults with developmental disabilities. For example, difficulties in adapting to or learning to use aids such as hearing aids, glasses, or walkers may be exacerbated in adults with developmental disabilities. Staff attitudes and support to learn or persevere with such aids are critical in this respect. If staff underestimate an individual's potential for social engagement, they unlikely to encourage the wearing of glasses or a hearing aid.

Death and Dying

One of the few studies examining death in those with developmental disabilities was completed by Brown and Gill (2002). They found that while specialist developmental disability services were willing to accommodate death and support people to die at home, individuals with developmental disabilities were unprepared for the issues that arose. These issues include how care should be delivered and who should make health care decisions on behalf of those with developmental disabilities, particularly when alternative legal decision-making processes are necessary and on what basis are these decisions made by others. For instance, some of these issues include the withdrawal of active treatment, transition from curative to palliative care, and where to die.

We suggest that the unique circumstances of each individual should determine the nature of decisions about health treatment and appropriate decision-making processes. These should be informed by best practices surrounding a 'good' death. Reliance on the informal may be difficult for an older adult whose parents have died and for whom an informal substitute decision maker may not be apparent. To ensure decisions that do not disadvantage the adult by delaying appropriate actions, decision-making processes and preferences articulated by the person with the disability or others close to him or her should be documented and acknowledged by those involved with care. Decisions that depart from clinical pathways or other significant end-of-life decisions, such as cessation of active treatment, should be made in a formal case conference involving those who are close to the adult who is aging with a developmental disability.

Obstacles experienced by adults with developmental disabilities in dealing with their grief arise from the misconceptions of others and from their communication difficulties. If these older adults are to negotiate the changes that occur in later life, the first step is to acknowledge them as emotional beings, with similar feelings and needs as their non-disabled counterparts, including the importance of expressing and resolving difficult emotions. This means that individuals who work with those aging with a developmental

disability need to adopt strategies across the lifecycle to increase protective factors and bolster coping skills.

Individuals with developmental disabilities should have the same access to palliative care as other members of the community, although its provision must take account their social context and possible communication difficulties. The focus of palliative care is the patient and family, but for adults with developmental disabilities living in supported accommodation, this should be broadened to include formal care givers. However, support staff may have little knowledge of death and dying and thus require education so that they may better support an aging adult with a developmental disability who is grieving.

Promoting Health

Good health is the outcome of multiple interacting factors between the individual with a developmental disability and the environment. Access to quality healthcare is a necessary, but not sufficient condition, for maintaining health into later life. Multiple strategies that address prevention, surveillance, treatment, and adaption are necessary. Preventative strategies should start early in life and be supported by prompt identification and recognition of problems, assessment, and appropriate treatment throughout the life course. Keys to ensuring good mental health are good communication, orientation by professionals and family that is sensitive to changes in behaviour, an approach to ensuring appropriate investigation occurs, and treatment and support are provided. This necessitates combining knowledge and understanding from multiple sectors, developmental disability, mental health, dual diagnosis, and geriatric mental health.

Elements of good practice in working with this population group are similar to those implemented across the life course. Attention to communication strategies and simple adaptations to the environment can optimize social involvement and their ability to engage in daily activities. Similarly, these elements can compensate for age-related changes, particularly those of a sensory nature.

Researchers have validated that engagement and minimization of life stressors have a preventative value and can lead to prolonged life and stable health status. Life factors that provide for sound nutrition,

access to valued activities, and safe and pleasant housing, can all have a health promotion effect and can minimize psychopathology and reactive behaviours. A quality old age for adults who are aging with developmental disabilities will be based on the same factors that provide for quality old age among other persons (Thorpe, *et al.*, 2001).

Dialogue with adults who are aging with a developmental disability should include how to best empower them to participate in their own health care. Such action is consistent with basic principles and practices of normalization and human rights recognition. In addition, interventions need to target health inequalities and focus on health promotion to reduce the mortality rate of this population group.

Adults who are aging with a developmental disability need to be educated, as they tend to lack knowledge of the age related issues they face. Providing them with accessible information at a level they can understand will enhance their ability to communicate with health care professionals. It is important to establish a task force of health care professionals and policy makers to create curricula to improve knowledge and clinical practice skills. Health care professionals lack knowledge and skills specific to the health care needs of adults who are aging with developmental disabilities. Since many health problems go undetected by the population of individuals with developmental disabilities, gerontological nurses need to be aware of the increased risk for specific health conditions for this population, be watchful for these conditions, and ensure periodic monitoring for potential complications.

Limitations

There are a number of limitations that can hamper the generalizability of these findings. First, definitions of populations within the "developmental disabilities" category varied across studies, making comparisons difficult. For example, what is considered "old" within the developmental disability literature and research varies from 45, 50, to 65 years of age. Secondly, chart review studies only examined reported cases of health challenges; however, the actual number of health challenges is probably greater. Third, data collected by the

researcher or agency may differ in terms of severity and complexity, from cases that are not reported. Finally, the results of several studies may not be generalizable to other specific subpopulations of adults who are aging with developmental disabilities due to cultural differences and the practices of the country where data collection took place.

Conclusion

Adults with developmental disabilities experience the aging process from different and disadvantageous starting points than the general population. Factors such as genetic make-up, lifestyle, health conditions and medical treatments, disadvantaged socio-economic status, as well as the poor healthcare experienced in the earlier parts of their lives singly or in combination have a detrimental impact on the aging process and quality of life.

Life expectancy for adults aging with developmental disabilities is lengthening towards that of adults without such disabilities. However, researchers indicate that this aging is often not a healthy one. Adults aging with development disabilities encompass an even greater heterogeneity than is found in the general aging population. Every individual needs to be evaluated individually in the context of his or her unique history.

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Housing Options for North American Older Adults with HIV/AIDS

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ABSTRACT

A new "population within a population" – older adults with HIV/AIDS – is emerging within Canada, the United States of America (USA), and other developed countries. This grouping of the older age population will provide new challenges for health and social sectors. Within this paper, we discuss who comprises this sub-population of older adults, the challenges faced by these individuals in securing safe and suitable housing and implications for nurses, research and policy makers.

Key Words: Older adults, HIV/AIDS Health, Housing

Within the western world, there is a growing population within the older adult population – those with HIV/AIDS. These older adults not only encounter a myriad of health challenges, but may also experience great difficulty finding appropriate housing. The usual housing options for older adults, including independent dwellings such as homes or apartments, retirement facilities or nursing homes, may be less accessible to older adults living with HIV/AIDS. The inability to find safe, suitable housing can lead to inappropriate housing choices, which can have significant deleterious impacts upon the health of older adults with HIV/AIDS. Within this paper we

address who comprises this "population within a population", how this group has emerged and their health care challenges. We discuss why housing is so important for everyone with HIV/AIDS and highlight an approach proposed within the literature for conceptualizing housing and HIV/AIDS. We then present the findings of a review of the research on housing options for older adults with HIV/AIDS and propose implications for nurses, researchers and policy makers. Within our implications, we delineate why housing for those with HIV/AIDS is even more crucial and complex for older adults, than the adult population in general.

Who Comprises this Population and Incidence of Older Adults with HIV/AIDS?

Within North America, individuals 50 years of age and older with an HIV/AIDS diagnosis comprise the "older adult" population. This group includes those who are newly diagnosed, as well as those who have lived with HIV/AIDS for decades. There are several reasons why the boundary of "older" is set at 50 years of age, instead of the North American standard of 65 years of age. First, health agencies such as the Public Health Agency of Canada and the United States Center for Disease Control have used this age grouping (Furlotte, 2012). Secondly, HIV and long-term use of HIV medications are believed to expedite the aging process. For instance, older adults with HIV are at a greater risk than their HIV negative counterparts for cardiovascular disease, liver disease, cancer, bone loss and depression (Robinson, *et al.* 2008; Reust, 2011). Reciprocally, these illnesses may accelerate the progression of HIV (Health Resources and Service Administration, 2009).

In Canada and the USA, approximately 10 per cent of individuals infected with HIV are considered to be older adults (Emlet, 2006b; Public Health Agency of Canada, 2010; Furlotte *et al.*, 2012). However, it is projected that the percentage of those 50 years of age and older living with HIV will increase dramatically over the coming years. For instance, one projection suggests that by 2015, 50 per cent of individuals living with HIV in the USA will be 50 years of age or older (Effros *et al.*, 2008). Because of the efficacy of ART (anti-retro viral therapy) in the last 15 years, HIV has increasingly become a chronic illness and individuals are living into older age with this disease (Emlet,

2006a: Leaver, *et al.*, 2007). Also, the numbers of older adults whose HIV status has progressed to AIDS is increasing; for example, the percentage of older adults who were previously HIV positive but now have progressed to AIDS has increased from 16 per cent in 1999 to 22 per cent in 2008 (Public Health Agency of Canada, 2010). As discussed, this accelerated progression is in part related to other illnesses in old age that may expedite HIV progress; it is also due to the fact that diagnosis in this older age category often occurs later in the disease process than young adults, resulting in some older adults receiving and HIV and AIDS diagnosis simultaneously (HRSA, AIDS Bureau, 2009).

Why is Housing so Important for Individuals with HIV/AIDS?

Housing is crucial for anyone one with HIV/AIDS. The presence or absence of housing impacts health related behaviours, life style choices and health outcomes of adults with HIV/AIDS. Although the following research addresses the importance of housing for adults in general with HIV/AIDS, we suggest that housing may be even more complex for older adults, as housing needs may change with increasing health conditions related to aging.

Stable, safe housing promotes better health choices in those with HIV/AIDS; it provides the context within which individuals can follow complex drug regimens, ensure adequate rest, sleep and nutrition and maintain regular monitoring and treatment from health care professionals (Leaver *et al.,* 2007). Additionally, secure housing significantly reduces the risk of individuals with HIV/AIDS in engaging in risky behaviours, such as drug or IV drug usage and unprotected sex (Aidala *et al.,* 2005).

Conversely, essential health promoting behaviors such as individuals consistently taking medications and receiving regular monitoring and treatment from health care professionals are less likely to be followed when housing arrangements are precarious (Leaver *et al.,* 2007; Wolitski *et al.,* 2010). And without the structure of a safe home, individuals with HIV/AIDS are more likely to engage in risky behaviours. In one study, Aidala *et al.* (2005) found that individuals with HIV/AIDS who have unstable housing arrangements were 3–6 times more likely to use hard drugs, and use or share needles. Similarly, lack of appropriate housing may lead to risky sexual

behaviours. In baseline interviews in the study conducted by Aidala *et al.* (2005), 19 per cent of homeless individuals and 15 per cent of those who had unstable housing admitted to having exchanged sex for money, drugs or a roof over their heads within the past 6 months.

As stable housing appears to considerably influence positive health and lifestyle behaviours and notably reduce risky behaviours in individuals with HIV/AIDS, some researchers consider housing to be a structural prevention measure in the spread of HIV/AIDS (Aidala *et al.*, 2005; Aidala & Sumartojo, 2007; Shubert & Bernstine, 2007). Simply stated, a decrease in unsafe activities by those who have HIV/AIDS will reduce exposure to those who are HIV negative, thereby decreasing the spread of illness to HIV negative individuals. While these researchers have examined the effect of housing upon adults with HIV/AIDS and not specifically older adults, they present a strong argument on the importance of housing to promote both individual and public health.

An Approach for Conceptualizing the Issue of Housing and HIV/AIDS

Within the above cited arguments about the importance of housing for individuals with HIV/AIDS, the researchers (e.g. Aidala *et al.,* 2005; Shubert & Bernstine, 2007) recommend a shift in how HIV/AIDS treatment and prevention are considered. Within North America, disease is generally perceived as a health care sector problem, with duty to treat falling upon health care professionals and responsibility for self care placed upon ill individuals. Rather than consider treatment and prevention as the sole purview of individuals (both health care professionals and patients), HIV/AIDS can be conceptualized as both a health care and a social sector problem.

This broader understanding of HIV/AIDS as a social problem recognizes that housing is a social determinant of health. It also acknowledges that housing provides the environment through which individuals can take care of their health and avoid risky behaviours (public prevention).

Housing as a Social Determinant of Health

Housing is a social determinant of health. Social determinants of health are conditions in which individuals are born that impact their health, including poverty, which then affect housing options (WHO, 2012). Poverty and housing are known to impact the ability of individuals to promote their own health.

In the previously mentioned studies examining the impact of housing upon adults with HIV/AIDS, it is clear that stable housing promotes health facilitative behaviours in those with HIV/AIDS and reduces behaviours that may spread HIV/AIDS. Housing, therefore, provides the context within which individuals can remain healthier longer: when housing is stable and safe, individuals are better able to focus attention on keeping well and a stable, secure home means that adults do not have to exchange sex (as mentioned in the study by Aidala *et al.*, 2005) for lodging. Understanding housing as a social determinant of health shifts some of the responsibility of health maintenance from older adults with HIV/AIDS onto the broader context within which these individuals live. Hence, housing and HIV/AIDS among older adults becomes not just a health issue, but also an issue for the social sector.

The notion of housing providing the frame of reference within which individuals can maintain their health is not new. For instance, safe housing has been determined to be a substantial factor in significantly mentally ill individuals maintaining stability. Historically, housing models for the severely mentally ill focused upon improvement in mental health status through medication and treatment program compliance, prior to receiving housing. The underlying assumption was that the severely mentally ill were not capable of maintaining housing without significant improvement in mental health status (Tsemberis, *et al.*, 2004). This resulted in some individuals with mental illness choosing to remain on the street, rather than to comply with the rules of the treatment/housing program. However, the Housing First project (within the USA) operates on a very different underlying assumption. Within this approach, the severely mentally ill can receive housing without strict adherence to a treatment program. Housing is conceptualized as a basic human right

(Tsemberis, *et al.*, 2003), rather than a privilege to be earned through compliance.

How effective is such an approach, whereby individuals receive housing irrespective of compliance? Tsemberis and colleagues (2004) conducted a longitudinal experimental study to examine the impact of the Housing First program upon individuals with mental illness and substance abuse. Half of the two hundred and twenty five individuals were randomly assigned to receive housing based upon psychiatric treatment and sobriety (control group) and the remainder received immediate housing without the conditions to receive treatment. They found that over the 2 year study, those in the Housing First group accessed housing sooner and remained securely housed. The Housing First participants also reported feeling more in control of their lives. No differences were found between the control and experimental groups in the use of substances or in symptoms of mental illness. The researchers concluded that individuals with mental illness were able to maintain continuous housing without jeopardizing their mental health symptoms or substance use.

We proffer that appropriate housing for older adults with HIV/AIDS is a basic human right. Just as those in the Housing First project receive housing as a foundation to manage their mental health, we suggest that for older adults with HIV/AIDS, secure housing may provide the context within which they can better manage their health, feel in control of their lives and connect with appropriate treatment.

Housing as a Preventative Measure for the Public

Stable housing may be viewed as a public health strategy to contain the spread of AIDS in North America. As shown by the research already cited, stable housing enables individuals with HIV/AIDS to take better care of themselves and avoid risky behaviours, while unstable housing becomes a risk factor for individuals engaging in unsafe activities. Reducing risky behaviours in those infected by HIV reduces the risk of the spread of HIV/AIDS to the general public. Hence, housing for those with HIV/AIDS not only benefits those inflicted, but also the public at large.

How cost effective is the provision of housing to older adults with HIV/AIDS? Research has shown that stable housing reduces the

number of emergency room visits and inpatient hospitalizations for individuals with HIV/AIDS (Wolitski *et al*., 2010). The results of the study of Wolitksi *et al.* (2010) has prompted the North American Housing & HIV/AIDS Research Summit Series (2011) to declare that these savings to the health care sector offset the costs of housing intervention.

Literature Search

Recognizing that the above cited information pertains to adults in general, and not older adults with HIV/AIDS, we sought to appraise the existing research examining housing options for older adults with HIV/AIDS. As such, we accessed multiple data bases, including: CINAHL, MedLine (Ovid and Ebsco), Social Work Abstracts and SocIndex. We utilized the following search terms: "older adults", "housing", and "HIV/AIDS" from 1990–2012. Research that specifically examined accommodation options for older adults with HIV/AIDS fit within our inclusion criteria. Exclusion criteria for our search included studies that were reported in languages other than English.

Most of the research we located utilizing the above mentioned search terms focused upon AIDS risk awareness and prevention in older adults (e.g. Agate, *et al.*, 2003; Falvo & Norman, 2004; Ward *et al.*, 2004; Ward, *et al.*, 2011), rather than on housing options for this population. We secured two studies focused upon challenging aspects of aging with HIV/AIDS in which aspects of living arrangements (e.g. social isolation, experiences of stigma) were briefly mentioned (e.g. Emlet, 2006a; Emlet, 2006b). In these two studies, the majority of older adults living with HIV/AIDS lived alone. Our search yielded only one study that specifically examined the access challenges faced by older adults with HIV in finding suitable housing (Furlotte *et al*., 2012).

Furlotte *et al.,* (2012) examined the experiences of older adults with HIV/AIDS looking for housing in Ottawa, Ontario, Canada. They interviewed 11 individuals between the ages of 52–67 years to explore various aspects of living with HIV, including accessing suitable housing. Of these 11 individuals, 3 reported living in rental units, 4 either owned or were mortgaging a home, 2 lived with family members and 2 were homeless. In addition to the 2 individuals

homeless at the time of this study, 2 other participants noted that they had previously been homeless and a further 2 believed that they were in danger of becoming homeless. Most of the study participants lived alone (8) and all but one individual were retired. Obtaining sufficient food was a concern for the study participants, with 7 admitting to using food banks and 8 individuals reporting periodic use of community meals.

Most of the study participants admitted to significant worries about accessing appropriate housing, either now or in the future. Projecting towards the future, some participants worried about whether or not they would find acceptance within retirement homes or nursing homes. Issues such as co-residents' fear of HIV and stigma related to sexual orientation were discussed. Further, the older adults who used marijuana for pain control were concerned about whether or not these alternative practices would be accepted within retirement or nursing homes.

Securing subsidized or low income housing was also a concern for several of the study participants. With its limited availability, accessing subsidized housing was difficult. Not only was limited availability an issue, but stipulated income cut-offs also disqualified one individual in the study by Furlotte *et al.,* (2012). This older adult's income was determined to be too high for him to access this housing option. And yet, as noted by the researchers in this study, outreach workers may not take into consideration the amount of monies spent by some older adults with HIV/AIDS for complementary therapies to deal with their illness. In these situations, the gross income figures do not accurately represent the actual funds with which some older adults with HIV/AIDS have to survive.

Besides the stress and worry of being homeless, living in homeless shelters may be particularly precarious for the health of older adults with HIV/AIDS. Individuals within Furlotte *et al.'s* study (2012) reported that being exposed to germs and illnesses within homeless shelters was damaging to their health. Further, one participant who struggled with IV drug use noted that while in a shelter, he was unable to abstain from injection drugs, due to the ready availability of such substances.

Implications

We suggest that there are a number of implications for nurses, researchers and public policy makers arising from this research review. We also recognize that because this population of older adults with HIV/AIDS may vary in severity of symptoms (both those related and not related to HIV), diverse housing options that span later life requirements will need to be available. The progressive levels of care needed within housing (e.g. subsidized housing and then moving to a retirement home or a nursing home) adds to the complexity of this issue in older adults.

Nursing Implications

The population of older adults with HIV/AIDS within the overall older adult population is relatively new. As such, nurses may not be knowledgeable about the health and social issues facing these older adults. First, nurses need to recognize that this population not only encompasses those who were infected many years ago, but that new cases of HIV/AIDS are being diagnosed every year within the older adult population (HRSA, AIDS Bureau, 2009). Health care professionals may espouse beliefs that older adults do not engage in behaviours that put them at risk for HIV/AIDS. However, HIV is spread by the same transmission routes in older adults as in their younger counterparts (Furlotte *et al.,* 2012). Additional factors may increase the risk of HIV/AIDS in the older population. For instance, physiological changes in men and women that occur with aging may increase the risk of older adults to HIV infection (Eldred & West, 2005). As well, out of loneliness related to widowhood or divorce, older adults may seek companionship and sex from new partners and not be aware of the riskiness of unprotected sex with older adults.

Secondly, not only should nurses be aware of the risk of HIV/AIDS in older adults, they need to familiarize themselves with the health and social challenges faced by this population. Thus, nurses working in a variety of settings, such as homeless shelters, community outreach teams, retirement homes/lodges and nursing homes, should be aware of issues of poverty, homelessness, isolation and fear of stigma. Understanding these issues and knowing how to respond –including referrals to applicable resources – will enable nurses to assist this population of older adults.

Staff in retirement facilities and nursing homes may require education regarding HIV/AIDS and medications specific to this illness. They may also benefit from education regarding older adults whose gender identity is non-traditional, such as gay, lesbian and transgendered older adults (Schneider, 2008). Further, staff may need to learn to relate to these older adults in a way that is respectful, non-judgmental and preserves their dignity, irrespective of personal beliefs (Lane & Hirst, 2012). As identified in the study by Furlotte *et al.* (2012), as well as in other studies examining concerns about aging in younger gay, lesbian and transgendered younger adults, fear that gender identity will affect future care is very real (Hughes, 2009).

Implications for Research

As we located only one study specifically examining housing access issues faced by older adults with HIV/AIDS, more research needs to be conducted addressing the access issues faced by this population. What are barriers to accessing subsidized housing and what can be done to address these obstacles? In addition to exploring the concerns of older adults with HIV/AIDS entering nursing homes, what strategies can be put into place to assist this group of individuals to adjust to the new environment?

Further, as older adults with HIV/AIDS may need, at some point in their lives, to transition to nursing home care, research should be conducted on what triggers nursing home placement in this cohort? Also, if stable housing is provided, can this housing delay institutionalization? And, if stable housing does indeed delay nursing home placement, what are the cost benefits of this?

Implications for Policy Makers

The North American Housing & HIV/AIDS Summit Series has convened since 2005 to present research on HIV/AIDS and housing to those with HIV/AIDS, researchers and policy makers (The North American Housing & HIV/AIDS Summit Series, 2011). While there is some awareness of the importance of housing for vulnerable adults (e.g. those with severe mental illness or HIV/AIDS) in the USA, we suggest that Canada has lagged somewhat behind our North American counterpart. Policies need to be put in place that stipulate housing as a

right for older adults with HIV/AIDS, understanding that housing is not only the context within which older adults with HIV/AIDS may care for their health, but also a preventative action for the public at large. Housing, however, needs to stretch beyond basic subsidized housing. Older adults with HIV/AIDS need to have access to retirement homes and nursing homes when more supervision and care is needed.

Whether there should be nursing homes or nursing home units designated for those with HIV/AIDS or for those from sexual minorities is another question to be raised. In New York city, a nursing home has opened that is specifically tailored for older adults from sexual minorities (Schneider, 2008). Should there be nursing home units specifically geared toward working with older adults with HIV/AIDS?

Conclusion

While older adults with HIV/AIDS is a relatively new "population within a population" within North American countries and other developed nations, this population will continue to grow in the coming years. In order to provide effective care to these individuals over a period of years, suitable housing options spanning across levels of care need to be available. Not only will this provide the context within which older adults with HIV/AIDS can take care of their health, it may lower costs to the health care system and be a public preventative measure. More research should be conducted to examine the housing and care needs of this population, as well as barriers to finding suitable lodging.

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Personhood in Nursing Homes: Results of an Ethnographic Study

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ABSTRACT

What is personhood and how is it operationalized? Within this paper, we examine the construct of personhood, particularly as it pertains to older adults residing in nursing homes. We present a review of the research examining personhood of older adults living in nursing homes, and then present an ethnographic study conducted by the first author. Finally, the results of this study, as well as implications for nurses and researchers are presented.

Key Words: Nursing Homes, Personhood, Older and adults Nurses

If you deny a man the food of the soul, such things as dignity, justice, truth, and he never again will he be fully human (St. Thomas, as cited in Pegis, 1945).

What is personhood? Defining personhood is challenging and definitions vary depending upon the paradigm of the academic or professional discipline. Nursing, as a profession, recognizes the importance of acknowledging and honouring the personhood of individuals who are ill and often very vulnerable, such as older adults residing within nursing homes. How do older adults within nursing homes – as institutions which remove some decision-making power of residents – experience personhood and how does staff facilitate and hinder that expression? Within this paper, we examine what the construct of personhood is and what it entails. We present how nurses have taken

up and applied the construct of personhood in older adults residing in nursing homes. Then, we present the findings of a study conducted by the first author (SH). Finally, we offer implications for nurses working with this "population within a population" – older adults living in nursing homes.

What does the Construct of Personhood Entail?

The construct of personhood is somewhat abstract and difficult to define. In its simplest definition, personhood refers to "the state or condition of being a person" (The Free OnLine Dictionary, 2012). However, this definition does not reflect the somewhat intangible aspects of this construct; that is, it does not address the aspects of personhood that move beyond the physicality of the body, such as self-identity, decision-making and self-expression. The following two disciplines – the law and philosophy – illustrate this variance in understanding of personhood.

By necessity the law has to grapple with the issue of personhood and how persons live together in community. From a legal definition, person is defined as *a human being*. (The Free OnLine Dictionary, 2012). The emphasis regarding personhood is upon the regulation of behaviour within society– an outer system of control (laws) with punishment for unacceptable actions, behaviour, rather than an inner locus of motivation, such as empathy and conscience. Martin Luther King spoke eloquently of the necessity of law as well as its limitations when he said, "It may be true that the law cannot make a man love me …. But …it keeps him from lynching me, and I think that's pretty important also" (1962).

In the Canadian province in which this nursing study was conducted, an important piece of legislation seeks to protect those in care of publically funded institutions, such as long term care settings; this is the Protection for Persons in Care Act (PPCA). This law is intended to shield seniors in publically funded nursing homes from abuse and neglect.

While the law seeks to provide protection for individuals "from without", philosophy tends to focus on the inner, ethereal aspects of the human being. Words such as *soul, spirit* and *essence* are used to reflect the parts of a person that are not physical. The intangible

individual, then, includes conscience, memories, emotions, beliefs, talents, passions; these impact how one experiences the world and relates to it.

Sometimes the intangible elements of the human being are described in religious terms. The belief that there is an immortal part of an individual that lives eternally, able to commune with the divine, is called soul or spirit (Wikipedia, 2012). The ethereal elements of personhood, in relationship to others (and sometimes the divine) are understood to give an individual worth and dignity; the development of the soul through self-discovery, meaningful decision-making and self-expression being integral; and the validation of that personhood is believed to be necessary for the essence of a person to thrive, or even to live. "Without the human community, one single human being cannot survive" (The Dalai Lama).

Personhood in older adults residing within nursing homes: A review of the literature/research

Within the literature examining personhood in older residents in nursing homes, the construct of personhood is linked with the notion of identity and individuality of older residents (Donovan & Dupuis, 2000; Cook, 2010). Personhood is connected with individual values (Heliker, 1999), to the ability of older adults to make decisions and do what is meaningful for them, even within the context of a nursing home (Cook, 2008). It also involves spirituality, history and strengths (Coker, 1998). Gress and Bahr (1984) offered a distinction between personhood and person. "Person describes the essence of human nature incorporated in the body, mind, and spirit of the individual. Personhood describes the continued development of one's total being in the physical, psychological, sociological, and spiritual dimensions toward self-actualization" (p. 20).

A theme within the literature regarding personhood in nursing homes involves the impact of institutional life upon the personhood of older residents. The structured, medicalized routines of nursing homes strip away the autonomy, decision-making and identity of older residents, and hence is viewed as depersonalizing. In order to address and combat depersonalization, suggestions are proffered to enhance the experiences of older adults (e.g. Coker, 1998; Cook, 2010; Thornton, 2011).

There is relatively little nursing research that specifically examines the construct of personhood of older adults within nursing homes. Most often, personhood is nested within other foci; for instance, Hutchison and Bahr (1991) explored the types and meanings of caring behaviours among older nursing home residents. They determined that caring behaviours demonstrated by older residents towards each other was a means to retain their self-identity and sense of personhood. Normann, *et al.,* (1998) investigated the narratives of 20 staff members working in nursing homes in Sweden. These nursing staff gave accounts of 92 episodes of lucidity among older adults with severe dementia. The researchers determined that when severely demented residents experienced episodes of lucidity, these occurrences were linked to staff that exhibited caring and regarded the older adults as valuable human beings. Normann *et al.* (1998) suggested that further research needs to be conducted, as the assumption that severe dementia destroys personhood may be fallacious.

Additionally, there is research that analyzes the person-centred approach or model of care for older adults with dementia (McKeown *et al.*, 2010; Rosvik *et al.*, 2011). The person-centred model of care is based upon the work of Kitwood (1997). Person-centred care involves a thorough knowledge of the older adult, involvement of family, communication (such as topics of conversation) that is tailored to the individual, provision of meaningful activities, a supportive environment and community involvement (Thornton, 2011). Within this approach, the person is to be focus or centre of care.

In summary, there is little nursing research examining personhood of older adults within the context of nursing homes. Further, there is scant research conducted to understand personhood from an ethnographic perspective. We suggest that an ethnographic approach, which utilizes observation and interviews to examine the culture of nursing homes and behaviours of staff and older residents that impact personhood, is a gap in the current research.

Method

An ethnographic study was initiated to explore elder abuse within nursing homes. (The findings presented in this paper on personhood are a small aspect of this larger study). Ethnography is a

means to access the behaviours, beliefs, and practices of a culture, and permits the observer to view phenomena in the context in which they occur. This approach is based upon symbolic interactionism, derived from the work of Blumer (1969). The symbolic interactionist advocates that the human being has a self, human action is constructed by that self and human action occurs within a social setting.

Participants and Sampling

Four groups in five Canadian urban nursing homes participated: registered nurses (RN), para-professional (PP) staff, older adults (OA), and significant others (SO). Participants were recruited through explanatory letters left on the units, information sessions, and older adult council meetings. A convenience sampling procedure was used as those individuals who contacted the researcher were screened using inclusion criteria (ability to speak English, described themselves as the older adult's significant other). Significant others, when they contacted the researchers, were asked for permission to approach their older member residing in the facility. Approval for the study was obtained through the university ethics board and the facilities.

A description of participants is presented in Table 1.

Table 1
Participants' Profile

Registered Nurses	
N = 10	
job title	
educator/manager	3 (30%)
staff nurse	7 (70%)
highest education level	
diploma	7 (70%)
diploma/gerontology certificate	1 (10%)
undergraduate degree	(10%)
	1 (10%)
master's degree	
	1 (10%)
length of time working in long-term care	
institutions	7 to 24 years

Cont'd...

average	13.62 years

Significant Others

N = 5
age
range	44 to 72 years
average	64 years

relationship to older adult
child	2 (40%)
family member (other than	
spouse or child) 1	(20%)
friend	1 (20%)
spouse	1 (20%)

Older adults
N = 11
age
range	78 – 89 years
average	80.4 years

length of time in long-term care institution
range	2.3 – 9.1 years
average 6.3 years	

Mental Status Questionnaire
range of errors	1 – 5
average errors	3

previous place of residence
own home	7
lodge	3
other	1

Para-professional Staff
N = 11
first language
English	7 (63.63%)
not English	4 (36.36%)
length of time working in long-term care institutions	1 to 17 years
average	8.8 years

The four groups were chosen since variance in views often exists between different stakeholder groups (Parr & Green, 2002; Joosten & Potts, 2003; Barrio *et al*., 2007).

Data Collection and Analysis

Initially, eight weeks were spent in two of the facilities doing participant observation for shifts of 4 to 8 hours over a 24 hour day. The researcher (SH) gained an understanding of the environment of nursing homes. Field notes documented the styles of interaction among those who live and work within these settings, daily routines, the types and use of touch, recognition of personal space, and other interventions specific to meeting the needs of older adults.

The researcher conducted two to three individual interviews with each participant and contributed to two population specific focus groups. Interviews were held at a time and location selected by the participant, with the exception of the older adults. These interviews were held in the privacy of their rooms within the nursing home. Focus groups were held at each of the facilities. The researcher developed a list of questions to provide consistency in data collection for the interviews and focus groups. Field notes continued to be maintained throughout the study documenting participants' behaviours and the researcher's thoughts.

Data collection and analysis occurred concurrently, enabling the researcher to shape the study as it proceeded. Analysis involved replaying each audiotape of an interview or focus group and re-reading each transcript and field notes to identify themes emerging from the data and the relationships between them. Through continuous reflection upon the data, initial coding categories emerged into themes, which were verified with participants. This enhanced the credibility and trustworthiness of the data.

Findings

Within this study, two themes specific to personhood emerged from the data. By what they said, all groups of participants related how personhood is acknowledged, or not acknowledged by others within the nursing home environment.

Acknowledgement of Personhood

The first theme was the acknowledgment of personhood, which means that participants voiced its presence, or lack thereof, within the nursing home environment. Participants recognized the importance of personhood to the well-being of older adults. In order to visualize the spectrum of responses by participants from various groups (e.g. RNs, OAs, etc.), a diagrammatic axis is presented below to demonstrate the range of responses (see Figure 1).

Figure 1
Acknowledgment Axis

⇔

| Low | Hig |
| Acknowledgement | Acknowledgement |
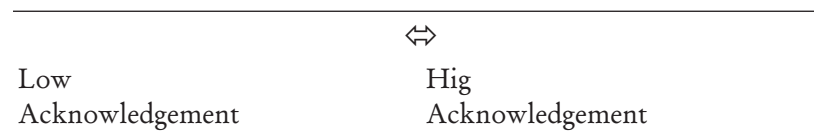
At the "high" end of the axis, there is recognition of the worth and uniqueness of an older adult. One participant voiced *we need to honour all our older adults but it should not be an add-on to care but rather just something we do* (RN). Others expressed that *my mum is special to me, and so are all the other mums here* (SO); and *we just need to let them do it at their own pace instead of doing it for them, it makes them feel good* (PP). Part of acknowledgement is voicing how one wants to be treated: *like a brother or sister would treat you* (OA); and *basic Christian values, like the Bible said, the way you yourself would want to be treated* (OA).

At the axis's "low" end, personhood is not acknowledged. Participants stated *we get routine fixation and ignore the older adult* (RN); *if they knew my mother, they would never call her by her first name, she never liked anyone doing this* (SO); and *I don't like it when they (staff) use my first name without asking* (OA). A simple, yet significant aspect of validating the personhood of each resident is demonstrated through using his or her name. By using the older resident's name, the RN or PP acknowledges the identity of the person. When a name is not used, identity is disregarded. When staff did not perceive older adults as

individuals, disease objectification resulted, leading to comments such as *we have a lot of dementias on this unit* (RN).

Field notes provided the opportunity to analyze staff-older adult interactions observed by the researcher; 98 per cent of the interactions were instrumental. Of these instrumental activities, toileting, assisting with meals and personal hygiene activities dominated. These types of interactions are objective and rote, in that the intent was to facilitate the completion of daily living tasks for the older adult. However, older adults, including those who reside in nursing homes, live their lives through subjective and meaningful experiences. As one participant voiced, *I used to teach the exercise program here, then they got in a therapist and she said I couldn't do it. I used to lead the classes here and they (other older adults) liked it* (OA). The comment by this older adult reveals a sense of loss, meaning and identity in being removed from a task that gave her purpose and pleasure.

Strategically organized routines that facilitate the smooth operation of the nursing home, such as scheduled meals, scheduled bath times, scheduled activities, preparation for bed and lights out, may demean the personhood of older residents. Such strictly regulated activities transform an older adult from a person to an object, with little ability to participate in decision-making activities. The staff members' focus is upon the completion of activities; hospital-like structure and routines become the normative culture. As a registered nurse said, *we have to do it for them, that's why they're here.* However, the clash of staff objectivity and older adults' desire for subjectivity devalues personhood.

Participants held different positions about how personhood should or should not be acknowledged, as evidenced on this axial diagram. Some expressed a high level of insight into the importance of acknowledging personhood, even if their insight did not translate into actions. For instance, one para-professional stated *we make the choices for them and that's not always appropriate or fair.* Others expressed less awareness about the worth of acknowledging the personhood of older adults, and hence occupied lower positions on the axis. For instance, one staff member stated *if they act like babies, then they should be treated*

as babies (PP). Acknowledgement of personhood was not static, however. Some participants expressed movement along this axis: *you can't always remember that they (older adults) are people, when there is so much going on around here* (RN), and *we have to give them back their dignity* (RN). Movement suggests that acknowledgement is fluid and subject to change. In part, acknowledgement of personhood is fluid because it is situation dependent, that is, it relates to some specific domain, situation, or context. That being said, the further an individual moves to either end of the continuum and the longer one remains there, achieving a staid position, the more difficult it may become to move away from that bearing or approach.

Personhood Behaviours

"Personhood behaviours" was the second theme. Behaviour is a product of one's background and an expression of an individual's self. Behaviour may be evaluated by others as common, unusual, acceptable, or unacceptable. The acceptability of behaviour is evaluated using social norms and regulated by means of social control. Participants in this study described a variety of physical and verbal behaviours that they perceived as acknowledging or not acknowledging personhood: *I know most of the staff by name and they call me by my first name, it's easier for them. I would prefer my last name* (OA). Other examples included: *it would be nice if they (staff) told you what they were doing, all of a sudden the water was cold, it just shot down my back* (OA), and *her (staff member) kids came to see me on my birthday, because they knew I had no one* (OA). Within this theme, two types of behaviours emerged.

Valuing Behaviours

Valuing behaviours are those that give significance to older adults' personhood. One registered nurse said y*ou have to take the time to listen to them, to listen to their stories* and another participant stated *sometimes just closing a door if that's what the older adult wants says it all, because it means you listened to them* (PP). The staff member who valued personhood was attentive and used humour to foster a feeling of specialness in the older adult. *I always have a joke for her, my kids buy*

me joke books just for her (older adult), she'll often have one for me, but hers are a bit raunchier than mine (RN).

Some members of the facility were committed to acknowledging the personhood of older adults: *you can't just do physical care* (RN), and *you have to look at the person* (PP). The driving force seemed to be an understanding of the importance of showing respect to the older adult and a recognition that the personhood of an individual extends beyond the physicality of the body.

Devaluing Behaviors

Some behaviours indicate older adults' personhood was devalued. Examples included: *you would think that I was a piece of furniture if you saw them (staff) move me* (OA), and *they told her (older adult) off – in front of me ... just like you would tell a child* (SO). These comments reveal a sense of humiliation and embarrassment.

Field notes revealed that when devalued, the actual posture of older adults changed as they responded: shoulders fell and faces saddened. The responses of these older adults reveal that while personhood extends beyond their physical bodies, devaluation of their personhood was responded to in a physical manner.

Discussion of Findings

This study aimed at deepening nursing's understanding of personhood and how it is experienced by older adults within nursing homes. It is through the acknowledgement of personhood that individuals feel connected to others and their surroundings. The findings of this study reveal that individuals can value and devalue others' sense of personhood and the importance of relationships to foster it. We suggest that the importance of acknowledging the personhood of older adults within nursing homes is heightened by virtue of the life circumstances of many residents: physical illness, cognitive impairment, multiple life losses and living within a highly structured environment.

Relationship Building

Individuals' sense of personhood is influenced by the behaviours of others. The kinds of behaviours that value personhood are varied

and conducted by a variety of individuals who are in relationship with older adults. In this study, older adults themselves were often actively involved in promoting the personhood of others, such as one older man assisting another to put on a shirt protector. When nursing staff spend time with older adults, this may be perceived as valuing personhood. For instance, Horn, *et al.,* (2005) reported that the amount of time registered nurses spent in functions related to older adult care had a positive influence on quality of care. Further, when nursing staff are relationally engaged with older residents, personhood is promoted. For example, in their investigation of family members' perceptions of care provided to older adults, Looman, *et al.,* (1997) found that the ability to acknowledge an older adult as a person was perceived as an attribute of an engaged nurse. This finding of the significance of engagement has been supported in later studies (Robichaud, *et al.*, 2006; Choi, *et al.,* 2008). The implication is that the older adult's sense of personhood exists throughout the course of life changes. This also lends credence to the previously cited statement by Gress and Bahr (1984) that personhood involves the continuous development of one's self. We suggest that "continuous" has both time and quality elements: the need to possess a sense of personhood remains throughout one's lifetime, as well as there needs to be quality and meaning in one's life in relation to how personhood is expressed and valued by others.

Language used in constructing relationships influences personhood. Nursing staff members' use of supportive phrases and affirmative tone of voice, as well as their concentrated focus on the older adult rather than the disease, acknowledged personhood. The results of this study supports work by Pringle (2003): to intentionally engage older adults is to enhance their quality of life and promote personhood.

The Work Place

The workplace environment may influence how staff value and devalue each other, and subsequently, value and devalue older adults. The facility, through its behaviours and traditions, shapes its members' common sense, prejudices, values, and knowledge. As such, staff members of various professional groups learn how to relate to

each other. To move towards the higher end of the acknowledgement continuum, a cultural member needs to be able to be open to interact with many professionals in the environment and learn from them. This is not possible when movement along the continuum (of acknowledging personhood) is restricted because of factors within the nursing home, such as strictly adhered to norms of how one professional (for example, para-professional) relates to another from a different classification (example, RN). When staff members are continuously exposed to these norms, they absorb these ways of being which become part of their personal knowledge and that of the nursing home, and they become habitual.

Unfortunately, when some staff members are not treated with value, their sense of personhood suffers. In her ethnographic study examining power relations between nurses and aides who worked in a nursing home in the United States of America, Jervis (2002) found that aides reported that RNs treated them poorly and devalued their contribution and knowledge of residents. This led to continuous conflict and power struggles between staff members, who in theory, were employed to enhance the lives and care of older adults. Discord is demonstrated in the distance that separates some groups from others, for example para-professional from professional staff. As one para-professional said, *if you're on a good team, it's great, but if it's a bad team, then you each do your own thing* (PP). Being forced to "do your own thing" may lead to greater psychological stress in para-professionals, than in their RN counterparts (Harrisson, *et al.*, 2002), and may disadvantage older adults who need help from more than one staff person at a time (for instance, with lifting or walking).

Another aspect of the workplace environment that may impact personhood involves economics. If a nursing home is primarily focused upon making money, the care of older adults may suffer. In these situations, the focus is upon the smooth facilitation of structure and routines in order to reduce the number of working staff with older adults. This may result in older adults being treated as objects, or as one older adult stated within this study, *a piece of furniture,* in order for hard working staff to even complete the amount of work required. Sadly, this assembly line type of nursing home care devalues older

adults, as well as staff. As noted in the study by Jervis (2002), nursing aides who spent time to socialize with older adults (and hence value their personhood), were penalized for having "sloughed off" (p. 18).

While many staff in nursing homes value working with older adults, regrettably, some staff in nursing homes may be impacted by societal attitudes towards aging (Gilbert & Ricketts, 2008; Horton, *et al.*, 2008; Allan & Johnson, 2009). These staff may view working with older adults – particularly those within a nursing home setting – as a "dead end job" (Jervis, 2002). Their inability to move beyond this position may hamper how they view and relate to older adults.

Implications for Nursing Practice

This ethnographic study demonstrated that the personhood of older adults can be promoted or devalued by staff and others within nursing homes. Because culture shapes the behaviour and since all its members play a role in providing quality care to older adults, it makes sense to examine the factors that mediate the links between culture and outcomes.

Influencing Staff

Staff members make decisions about the care to be provided to older adults and how to behave with them. To recognize such experiences as influencing personhood, they need to use a person-centred approach. Kitwood (1997) suggested that those in a caring relationship need to demonstrate recognition and respect, foster trust, and address the five primary needs of the older adult. These needs (comfort, attachment, occupation, inclusion, and identity) overlap, coming "together in the central need for (practical) love" (p. 81), and are foundational to personhood for older adults within nursing homes. To illustrate this point, Kitwood described *occupation* as: "...to be involved in the process of life in a way that is personally significant, and which draws on a person's abilities and powers" (p. 83). Hence, staff members in nursing homes require knowledge about an older adult's past social context so that they may strategically use aspects of the past to forge relationships and promote meaning in present.

One possible strategy to foster person-centred care, including enhancing the knowledge of staff about an older adult's past history, is

to utilize a "life story work" approach (Heliker, 1999; Bakken, *et al.*, 2009; McKeown *et al.*, 2010). The life story work approach involves working with the older adult and family members to find out about the life of the older adult, documenting aspects of his or her journey and utilizing the information with the older adult in care. This can be done by using a life story book, a photo book of significant life events or by creating a memory box. Creating such legacies provides the opportunity for older adults to talk about their lives, particularly what is meaningful for them, and then staff members can utilize relevant information from these stories to support their care (Bakken *et al.*, 2009). This information can even be used in formal care plans (Coker, 1998).

Another important strategy to address the acknowledgement of personhood in nursing homes involves the *teachable moment*. The teachable moment is the potential learning interaction which might occur between staff members at the bedside or an educator and a family member on the unit. It may be triggered by an action noticed by the staff member or by a comment heard by the educator. It provides the opportunity to examine behaviours, verbal or nonverbal, that influence personhood, either positively or negatively. The value of the teaching moment lies in its ability to directly relate immediate behaviours to the care of the older adult.

Changing the Administrative Perspective

Valuing personhood must be included in a nursing home's policies. Opportunities might be provided for staff, significant others, and older adults to contribute to policy development. One possibility is a mentoring program. Staff members who promote personhood could be partnered with colleagues who are learning these skills.

Also, administrators need to challenge the current emphasis on routines and structure in many nursing homes, and allow for decision-making on the part of older adults around routines such as bath times and bedtimes (Crandall, *et al.*, 2007). Further, staff time spent with older adults in socializing and laughing needs to be reconceptualised as valuing personhood, rather than as "sloughing off" (Jervis, 2002). Focusing more on relationships than routines will

enhance meaningful engagement between staff and older adults, thus enhancing the sense of personhood experienced by residents.

Encouraging Research

Findings from this study support the need for research into personhood within the context of nursing homes. How does personhood change with the onset of physical and cognitive decline, primary reasons for older adults' admission into facilities? Why does one value or devalue older adults? How do organizational variables potentially influence personhood? Researchers might use mixed methodologies and longitudinal perspectives to answer some of these questions.

Conclusion

Recognition of the need for quality care for older adults within nursing homes has gained prominence over recent decades. One of the consequences of this recognition is awareness that those who live, work, and visit nursing homes initiate behaviours that influence the personhood of older adults, either positively or negatively. Acknowledgment of personhood recognizes the integral worth of another human being and demonstrates this in one's behaviours. It must be at the forefront of nursing actions.

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The Attitudes of Older People and Nurses Towards Chronic Pain: A Critical Literature Review

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ABSTRACT

The paper aims to present a comprehensive literature review to critically appraise research focusing on the attitudes of nurses and older people towards chronic pain. It is well known that the global population is ageing. Given that chronic pain is a common problem in later life. Pain assessment and management should be a priority for nurses working with older people. However, pain management is impeded by widespread misconceptions about chronic pain amongst both older people and nurses. All the studies meeting the inclusion criteria were obtained from electronic searches and hand searches of journals, books and research reports, with further references obtained from the bibliographies of retrieved articles. Among the large number of studies retrieved, only twenty relevant papers were selected and finally, a total of sixteen papers were included in the review. The findings of this review revealed that misconceptions regarding chronic pain and ageing influenced the attitudes of older people and nurses towards chronic pain assessment and management. Also, that there are some barriers which contribute to negative attitudes of older people and nurses towards chronic pain. This review emphasizes a broad need for a multi-dimensional approach in assessing and understanding older people and nurses' attitudes towards chronic pain. In addition, need for further research is also highlighted to understand its broad complexity. The findings will assist educators in

further research planning, pain education development for: 1) nurses to support and strengthen their abilities so they can recognise, understand and predict older peoples' health behaviours, and 2) older people to facilitate their pain assessment and management process.

Key Words: Chronic pain, Persistent pain, Attitude, Older people, Health care practitioner, Critical literature review.

Implications for Clinical Practice

Pain is the most common reason for accessing the health care system for the majority of the population, irrespective of age and gender (Lansbury, 2000; Kumar & Allcock, 2008). However, older people are more susceptible to chronic pain than any other sector of the population (Hicks, 2000) and they often experience disabling pain (Gartrell, 2005). Yet older people in chronic pain often receive limited attention (Davis *et al.*, 2002) and face significant barriers that can hinder proper pain management (American Pain Society, 2010).

The high prevalence of pain in older people and its consequences for this age group makes this a public issue (Fox *et al.*, 1999) and as such, has begun to receive serious empirical consideration in health care policy and health related research (Gagliese & Melzack, 1997). Nevertheless, few studies have focused on the attitudes of older people and nurses towards chronic pain (Gartrell, 2005). Therefore, a critical review of the literature is proposed to investigate possible reasons for barriers to proper pain management which explores the attitudes of nurses and older people themselves.

Background

Globally, the population is going through a major shift in the age distribution of older individuals (WHO, 2010). The ageing process may be associated with physical and mental deterioration (Ibid); nevertheless, pain is not an inevitable part of ageing. Pain is an unpleasant sensation and involves an emotional response to that sensation (IASP, 1994) which is associated with actual or potential tissue damage or described in terms of such damage (Ibid). Pain is chronic if it persists beyond normal tissue healing time; that is, longer than three months (McElhaney, 2001) and adversely affects the function or well-being of the patient, and is attributable to any non-malignant aetiology (ASA,

1997). Nearly 5 million people worldwide aged 65 and over are in some degree of pain or discomfort, severe enough to interfere with their normal functioning, most commonly from arthritis and neuralgias (Kumar & Allcock, 2008; Gagliese & Melzack, 1997). However, often attention is given only to the cause rather than other related aspects of pain in older people (Kumar & Allcock, 2008).

Whether working in a hospital, nursing home or community setting, nurses should work closely with the older person in treating his or her pain. As the expression and description of one's pain experience is individual in nature, the ability and skill of health care providers to effectively identify, assess, treat, manage and relieve pain among the older population is an important challenge (Gartrell, 2005). However, pain treatment among older people has been a neglected part of health care both in research and clinical practice (Ibid). The situation is beginning to improve in developed countries more recently with chronic pain in older people being addressed in various guidelines and frameworks such as the guidelines by the British pain society (BPS), British Geriatric Society (BGS), the Department of Health (DOH, UK), and the American Geriatric Society (AGS), however there are still some gaps to be addressed (Ebener, 1999; BPS & BGS, 2007). Understanding chronic pain from the perspective of both nurses and older people has important clinical implications and, of course this aspect should be given more emphasis (Gullacken & Lidbeck, 2004; Sofaer *et al.*, 2005).

Aim and Objectives of the Study

The aim and objectives for this review are as follows:

Aim: The aims of the review are to carry out a critical appraisal of the literature which focuses on attitudes of nurses and older people towards chronic pain.

Objectives

To explore:

- Attitudes of nurses and older people towards chronic pain.
- Barriers contributing to negative attitudes of nurses and older people regarding chronic pain management.

Methods

Criteria for Selection of Studies

Inclusion Criteria

Inclusion criteria were determined on the basis of following four categories:

1. Type of Study

    Surveys and qualitative studies published in English language between 2000–2010 were included.

2. Type of Participant

    Nurses and older people (both male and female) aged 65 or above.

3. Type of outcome measures

    (Both main outcomes and sub-outcomes were included)
    – Attitude of nurses
    – Attitude of older people
    – Attitudinal barriers

Exclusion Criteria

1. Study papers focussing on dementia pain, cancer pain and cognitively impaired older people.

2. Studies unavailable in full text

Literature Search Strategy

Keywords Identified for this Review were

*   Older people, geriatric,
*   Chronic pain, persistent pain
*   Attitude, experience,
*   Health education, knowledge
*   Care home, community, hospital, geriatric centre

Literature Search

We conducted a literature search of the following databases: SCOPUS, CINAHL, SCIENCEDIRECT, MEDLINE/OVID,

SWETSWISE, INTERNURSE, WILEY INTERSCIENCE, GOOGLE SCHOLAR AND EMBASE, as well hand searches (including footnote chasing) were also carried out to find relevant articles. An electronic search was carried out using subject heading and free text searching. Sensitivity of the search was increased by the use of wild cards, truncation, and Boolean operators. A total of 20,004 articles were retrieved through electronic search but only 33 articles met the inclusion criteria. Also, 2 articles were selected through a hand search. A record of the searches undertaken each time was maintained in a diary manually which included details such as: database searched, date of search performed, search term used/keywords, number of references retrieved, titles, abstract and search results (Beverly *et al*., 2006).

Figure 1
Selections of Studies and their Reasons for Exclusion (N = No. of Studies)
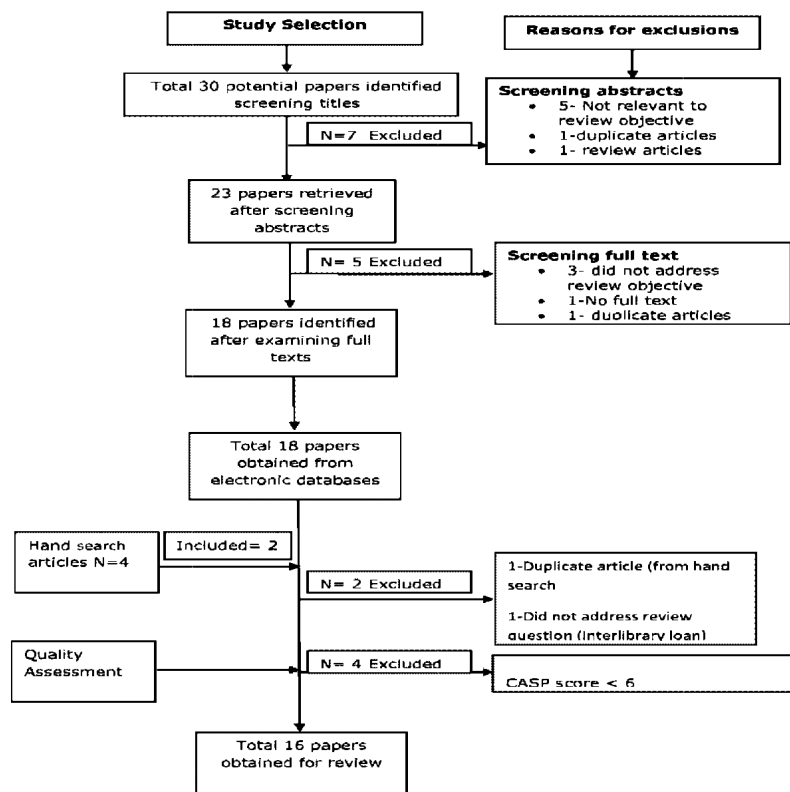
Study Selection

Study selection (Figure 1) for this review was carried out with an initial screening of titles and abstracts against the inclusion criteria, followed by a screening of full papers that were obtained after initial screening (Beverly *et al.*, 2006; CRD, 2009). Two independent researchers reviewed the articles and disagreements were resolved through discussion, however, there were no major discrepancies. Also, the reasons for exclusion of studies were recorded to aid transparency.

Quality Assessment

Quality assessment of the articles was carried out to select the important studies for the review since every article obtained from the search did not possess the desired quality and standard (Booth, 2006a; CRD, 2009) on which to base sound conclusions. The qualitative and quantitative studies included in this review required different quality assessment tools as no single quality assessment approach is appropriate for every type of study (Booth, 2006b).

A qualitative appraisal tool developed by the Critical Appraisal Skills Programme (CASP), initiated by the NHS Public Health Resource Unit (PHRU) (Booth, 2006a), was used to appraise the qualitative studies retrieved in order to determine their credibility by assessing each study's aim, methodology, and justification for the sampling strategy (Booth, 2006a, p. 113). CASP (Appendix 1) is the most commonly used appraisal tool which consists of a series of ten questions against which the studies are appraised. As there was no CASP tool for a survey approach, the survey appraisal tool (Appendix 2) designed by Booth (2006a) was used for assessing the quality of survey studies. This survey appraisal tool consists of a series of eight questions, against which the studies were measured for their quality in terms of validity, reliability and applicability.

Although there are no specific criteria for excluding papers on the basis of quality assessment scores, it was assumed that studies scoring =50 per cent of the total score were of low quality and thus were excluded. Out of the total score, a score of one was given for each of the questions that fulfilled the measure and a zero for those that did not fulfil the criteria or where a measure was not reported. Finally,

studies which scored less than 6 (for qualitative studies) and less than 4 (for surveys) were excluded.

Scores were then divided into high, medium and low quality papers. The score allocated for survey studies were converted out of 10 rather than 8 in order to divide them into categories of high, medium and low. Out of 10, studies that scored 8 and above were categorised as high quality papers, studies with 6–7 score were marked as medium quality papers and papers with score of less than 6 were marked as low quality papers and those low quality papers were excluded. Two members of the research team independently scored papers and then compared scores, discussed any discrepancy and agreed a final score. Overall, there was a good level of agreement between reviewers with no major discrepancies.

Data Extraction

Studies meeting the inclusion criteria and quality standard underwent data extraction by one reviewer and were checked by another reviewer. Data extraction focused on: the author, setting, participants, outcome, and findings from each selected study.

Analysis and Data Synthesis

A methodological matrix was used for analysis of extracted data which included information on the author, year, and level of knowledge, methods and findings of each study and the data was synthesized by emerging themes with summaries and summary tables.

Results

Description of the Reviewed Studies

Study Design

Out of eleven quantitative studies, six reported the type of method they used – a survey (Mrozek & Werner, 2001; Sloman *et al.*, 2001; Weiner & Rudy, 2002; Allcock *et al.*, 2002; Weiner *et al.,* 2005; Yu & Petrini, 2007), while the remaining five did not. Furthermore, a study by Tsai *et al.* (2004) used stratified random sampling method but others used a purposive sampling method for selecting the population

sample. Regarding the data collection method, Blomqvist & Hallberg (2001) used face-to-face interviews using a structured questionnaire, preceded by open-ended questions, whereas other studies used only a structured face-to-face questionnaire and a study by Allcock *et al.* (2002) used a structured postal questionnaire as a method of data collection.

In regards to qualitative studies, Lansbury (2000) and Davis *et al.* (2002) specified that they used a grounded theory, while the other three studies (Blomqvist & Hallberg, 2001; Blomqvist & Edberg, 2002; Blomqvist, 2003) did not specify the type of qualitative approaches used, but appear to have used a broadly phenomenological approach. Only Davis *et al.* (2002) specified the properties of the themes and clearly mentioned the data collection methods (refer Table 1). Blomqvist & Hallberg (2001) and Blomqvist (2003) used probability sampling methods and the other three qualitative studies (Lansbury, 2000; Davis *et al.,* 2002; Blomqvist & Edberg, 2002) used a purposive sampling method.

Only six of the quantitative studies (Katsma & Souza, 2000; Allcock *et al.*, 2002; Blomqvist & Edberg 2002; Blomqvist, 2003; Tsai *et al.*, 2004; Yu & Petrini, 2007) mentioned ethical issues and discussed informed consent and approval.

Population and Setting

In this review, the included studies explored attitudes of older people (sample size ranged between 57–150) and nurses (sample size ranged between 27–621) towards chronic pain management. Six studies were conducted in the USA (Katsma & Souza, 2000; Mrozek & Werner, 2001; Horgas & Dunn, 2001; Davis *et al.*, 2002; Weiner & Rudy, 2002; Weiner *et al.*, 2005), four in Sweden (Blomqvist & Hallberg, 2001; Blomqvist & Edberg, 2002; Blomqvist & Hallberg, 2002; Blomqvist, 2003) and two in Australia (Lansbury, 2000; Sloman *et al.*, 2001). Only one study was from each of the following countries: Taiwan (Tsai *et al.*, 2004), UK (Allcock *et al.*, 2002), China (Yu & Petrini, 2007), and Finland (Murola *et al.*, 2007).

Studies by Lansbury (2000), Davis *et al.*(2002), Allcock *et al.* (2002) and Tsai *et al.* (2004) were carried out in nursing homes, whereas the study by Blomqvist & Edberg (2002) involved older

people who lived in their own homes. Hospitals were the sites of three of the studies: Yu & Petrini (2007); Katsma & Souza (2000); Mrozek & Werner (2001). One study (Blomqvist, 2003) was conducted in two settings i.e. nursing homes and special accommodation. The other five studies (Sloman *et al*. 2001, Blomqvist & Hallberg 2001, Horgas & Dunn, 2001; Weiner & Rudy, 2002; Blomqvist & , 2002.) considered a wide variety of settings (nursing homes, the community, hospital and long-term care facilities). Finally, studies conducted by Weiner *et al*. (2005) and Murola *et al*. (2007) were located in universities.

Overview of Reviewed Studies

Table 1
Qualitative Research Studies

Author/ Year	Study Design	Population and Setting	Sampling Technique and Method of Data Collection	Outcomes
Blomqvist, K. 2003	Not reported explicitly, but appears to be phenomenol ogical	–52 nursing assistants, registered nurses and P/OT –Nursing home and special accommodatio n	Stratified random sampling Interviews were audio taped	*Nurses:* Believed that most often older people tend to hide their pain; considered painas a part of ageing, saw pain as temporary and inevitable. *Barriers:* Lack of appropriate education among health care practitionrs.
Blomqvist, and Hallberg, 2001	Not reported explicitly, but appears to be phenomenol ogical	–66 older people (75 years and above) and 56 contact nurses –Nursing home and geriatric rehavilitation centre of Sweden.	Simple random sampling Interviews Open ended and semi-structured questionnaire	*Nurses:* Showed lack of interest towards older people's pain complaints *Barriers:* Poor communication, lack of empathy towards older people's pain complaints, feeling powerlessness. *Older people felt that nurses lack empathy in managing their pain.*

Cont'd...

Blomqvist, K. and Edberg, A.K. 2002	Not reported explicitly, but appears to be phenomenological	–90 older people (75 years and above) –Municipality of Southern Sweden.	Purposive sampling technique Personal interviews were audio taped Open and structured questions.	*Older people* Unwilling to put a strain on others: feared losing Independence felt lack of empathy by health professionals: believed that others will not understand their pain: believed that health care practitioners ignored their pain complaints. *Barriers:* Lack of empathy
Davis, G.C; Hiemenz, M.L. and White, T.L. 2002	Grounded theory	–57 older people (65 years and above) –Own home or congregate retirement setting	Non-probability sampling technique In-depth interviews and focus groups were audio taped and transcribed verbatim	*Older people:* Saw pain as part of ageing: believed that pain shoud be tolerated. *Older people believed that health practitioners* See pain as a part of ageing and have lack of knowledge. Barriers: No attention given to *older peoples pain complaints,* older people not involved in pain management process, education required for health care practitioners.
Lansbury, 2000	Grounded theory	–72 older people (65 years old and above) –6 suburbs of Sydney, Australia	Theoretical purposive sampling technique In-depth interviews and focus groups were audio taped and transcribed verbatim	*Older people* Feared dependence/losing independence did not like to bother other: felt health professionals have no empathy and lack sensitivity; feared they would not get complete relief; expected pain as a part of ageing; felt other do not understand their pain; where not involved in their pain management process. *Nurses:* Held ageist attitudes, *Barriers:* Lack of time, lack of empathy and sensitivity, lack of education.

Table 2
Quantitative Research Studies

Quthor/ Year	Study Design	Population and Setting	Sampling Technique and Method of Data Collection	Outcomes
Allcocl, N; McGarry. J. and Elkan, R. 2002	Descriptive Survey	–68 nurse home managers –Two health authority nursing home registers within a geographically defined area in UK.	Purposive sampling Pre-piloted postal survey questionnaire	*Nurses:* Tended to underestimate residents' pain. *Barriers:* Lack of good communication with older people; lack of formal pain related educationamong health care practitioners; low priority accorded to older people
Blomqvist, K. and Hallberg, I.R. 2002	Descriptive questionnaire	–94 older people (aged 75 years and above) and 52 nurses, physiotherapists and occupational therapists. –Ordinary care homes and special accommodation of Sweden municipality.	Purposive sampling technique Face-to-face structured questionnaires. Preceded by an open ended intervies.	*Older people:* Accepted pain as a part of ageing process. *Nurses:* Regarded pain as a part of ageing
Horgas, A. and Dunn, K. 2001	Descriptive Questionnaire	–45 nursing home residents (65 years and above) and 16 nursing assistants –One private, for-profit nursing home located in a large metropolitan area in the Midwest Florida.	Purposive sampling Interviews Questionnaire	*Barriers:* Lack of appropriate education among health care practitioners regarding chronic pain.

Cont'd...

Katsma, D.L. and Souzq, C.H. 2000	Descriptive questionnaire	−89 long term care nurses −Hospitals from 6 rural counties in California.	Convenience sampling Questionnaire	*Barriers:* Lack of experience regarding care of older people; lack of empathy towards older people; lack of education among health care practitioners.
Mrozek, J.E. and Werner, J.S. 2001	Descriptive questionnaire	−27 nurses −Long-term care facilities located in the Midwest U.S.A.	Purposive sampling Questionnaire	*Nurses:* Ignored older people's pain complaints. *Barriers:* Lack of experience in caring older people; need for continued education among health care practitioners.
Murola, L.N; Nieminen, J.T.; Kalso, E, and Poyhia, R. 2007	Descriptive questionnaire	−430 students from the −University of Helsinki in Finland	Purposive sampling Questionnaire	*Nurses:* Anxiety in treating pain. Barriers: Need more education for nurses regarding chronic pain; lack of empathy towards older people; lack of experience in the care of older people.
Sloman, R; Ahern, M; Wright, A; MappSc and Brown, L. 2001	Descriptive survey	−300 registered nurses −Community, nursing home and hospitals of randomly selected clinical areas of Sydney metropolitan areas.	Purposive sampling Survey questionnaire	*Barriers:* Knowledge deficit among health care practitioners regarding chronic pain; lack of experience in caring for older people
Tsai, Y.F; Tsai, H.H. Lai, Y.H. and Chu, T.L. 2004	Descriptive questionnaire	−150 nursing home residents (aged 65 years or above not having severe cognitive deficit as determined by mini-mental state examination). One of the selected eight nursing homes in Taiwan.	Stratified random sampling Self-report and semi-structured questionnaire.	*Older People:* Felt ignored. Barriers: Lack of Knowledge among health care practitioners regarding chronic pain.

Cont'd...

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Weiner *et al.,* 2005	Descriptive survey	–104 geriatric fellows and fellowship directors. –Ninety-six accredited allopathic and osteopathic geriatric medicine fellowship programme, Department of Medicine, Division of geriatric medicine, U.S.	Purposive sampling method Survey Question-naire	*Nurses:* Believed that older people accept pain as a normal part of ageing and fear being addicted to analgesic; ignored older people's pain complaints. *Barriers:* Lack of proper education among nurses.
Weiner, and Rudy, 2002	Descriptive survey	–150 nurses and certified nursing assistant and 75 nursing home residents (75 years and above) –Six community-bas ed nad one veterans affairs long-term care facility of USA	Purposive sampling method Survey questionnaire –Separate questionnaire for residents, nurses and certified nursing assistants.	*Older people:* Accepted pain as a normal part of ageing; believed that pain treatment is unnecessary in the face of adequate function; believed that persistent pain has little potential for change; feared addiction and functional dependence; desensitized; tended to stifle pain complaints; feared that they will go unheard; believed that nurses will not believe that they hurt if not physically visible. *Nurses:* Ignored older people's pain complaints; believed that pain is a expected part of ageing, believed in pathology that persistent pain is unlikely to respond to treatment *Barriers:* No priority given to older people's pain complaints; lack of time.

Cont'd...

Yu. H.D. and Petrini, M.A. 2007	Descriptive survey	–621 nurses working –3 hospitals located in an urban area of the Wuhan region of Hubei province in China.	Purposive sampling technique Survey questionnaire	*Barriers:* Knowledge deficit among health care practitioners regarding chronic pain; cultural barriers.

Description of Themes

Themes were identified after assessing and synthesising the findings from all the included articles. Themes that addressed the review question only were selected and others were excluded. Finally, the selected themes were categorised under two different headings which are illustrated in the figures below.

The following graphs illustrate the number of themes to emerge from the 16 studies in the review.

Figure 2
Attitudes of Older People and Nurses
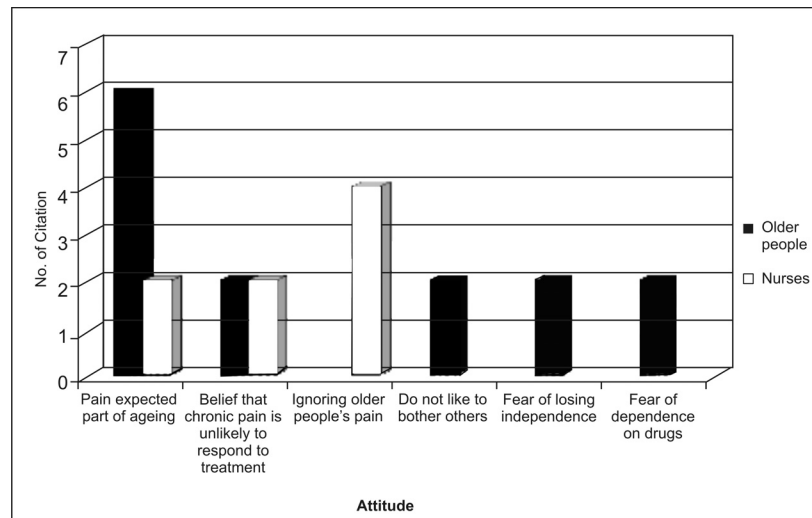
Figure 3
Barriers Contributing to Negative Attitudes
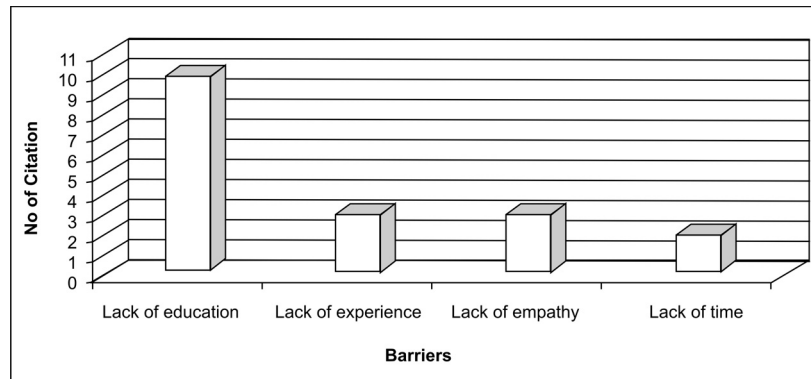
Attitudes of Older People and Nurses

Pain Expected as Part of Ageing

Within our review, both older people and nurses' belief that pain is an expected part of ageing was found to be a major challenge in providing proper pain management (Lansbury, 2000; Allcock *et al*., 2002; Blomqvist & Hallbery, 2002: Davis *et al*., 2002; Weiner & Rudy, 2002; Blomqvist, 2003). This attitude of older people towards ageing was a dominant theme to emerge from the studies reviewed, whereas nurses' beliefs towards ageing was least indicated in the studies. Almost all of these studies emphasized that due to the existence of such attitudes from both older people and nurses, pain tends to be ignored and thus appropriate assessment and treatment is neglected.

Belief that Chronic Pain is Unlikely to Respond to Treatment

In our findings of the reviewed studies, we found that attitudes of older people and nurses towards chronic pain was seen to be negatively influenced by the belief that chronic pain will never be cured (Lansbury, 2000; Allcock *et al*., 2002; Weiner & Rudy, 2002). Due to this belief regarding chronic pain, older people were reluctant to express their pain. Nurses also tended to ignore older people's pain complaints; this links to the next theme "ignoring older people's pain complaints" explained below.

Ignoring Older People's Pain Complaints

Studies by Blomqvist and Edberg (2002), Morzek and Werner (2001), Weiner and Rudy (2002) and Weiner *et al.* (2005) revealed that nurses tend to ignore older people's pain. Reviewed studies revealed that ignoring pain was found to be linked with the themes 'pain expected as part of ageing' and 'belief that pain is unlikely to respond to treatment'.

Do not Like to Bother Others

Older people expressed unwillingness to 'bother' nurses about their pain and thus did not petition help from nurses, thinking that questions about their condition and treatment would remain unanswered (Lansbury, 2000; Blomqvist & Edberg, 2002; Weiner & Rudy, 2002). This theme links to the theme 'fear of losing independence' which is explained below.

Fear of Losing Independence

Fear of losing independence emerged from the theme 'do not like to bother others' within the research literature and we believe, these two themes are interlinked. Studies revealed that older people do not want to lose their independence by undergoing procedures for their pain treatment and thus they may not express their pain (Lansbury, 2000; Blomqvist & Edberg, 2002). Moreover, older people wish to be independent rather than being passive recipients of pain treatment (Lansbury, 2000).

Fear of Dependence on Medication

The majority of the older people tended to suppress their pain due to the fear of addiction to medication (Allcock *et al.*, 2002; Weiner & Rudy, 2002). However, studies did not further explain the reasons behind this attitude of older people.

Barriers Contributing to Negative Attitudes

Lack of Education

This is one of the dominant themes to emerge from the studies reviewed. Lack of education and poor communication are closely related to negative attitudes of both older people and nurses

(Lansbury, 2000; Horgas & Dunn, 2001; Allcock *et al*., 2002; Davis *et al.*, 2002; Murola *et al*., 2006). Nurses held misconceptions regarding chronic pain in older people because of lack of proper pain education and thus tended to ignore older peoples' pain complaints (Lansbury, 2000; Katsma & Souza, 2000; Sloman *et al*., 2001; Mrozek & Werner, 2001; Weiner *et al*., 2005). Misconceptions on the part of the nurses ultimately leads to poor communication between nurses and older people which may influence older people to choose not to share their pain condition with nurses (Lansbury, 2000). All of these studies emphasized the importance of pain education and good communication among nurses and older people for proper pain assessment and management to take place. Furthermore, these studies stress the involvement of older people in their own pain management process.

Lack of Experience

The personal and professional experiences of nurses directly influence their attitudes towards chronic pain management in older people (Blomqvist & Hallberg, 2002; Weiner & Rudy, 2002). The more nurses are experienced and educated, the more positive their attitude towards pain management in older people (Mrozek & Werner, 2001; Blomqvist & Hallberg, 2002). However, two studies indicated that the personal and professional pain experiences did not aid in positive attitude towards chronic pain management among older people (Katsma & Souza, 2000; Weiner & Rudy, 2002).

Lack of Empathy

An assumption that nurses lack empathy contributes towards older people remaining silent about their pain condition (Lansbury, 2000; Blomqvist & Hallberg, 2001; Murola *et al*., 2007). There appeared to be consistency within these reviewed studies regarding the influence of lack of empathy towards older people in pain, from the older person's perspective. Murola *et al* (2007) stress that empathy facilitates the nurse/patient interaction. Older people felt more comfortable to express their pain to those nurses who showed a supportive nature and indicated understanding of how it feels to be in pain (Lansbury, 2000; Blomqvist & Hallberg, 2001; Murola *et al*., 2007). However, the authors did not explain the possible reasons behind lack of empathy among nurses (Murola *et al*., 2007).

Lack of Time

Reviewed studies revealed a lack of time as a hindering factor in pain management (Lansbury, 2000; Weiner & Rudy, 2002). These studies emphasized that, to facilitate the pain management process, nurses need to devote adequate time to trying to understand and explore older people's perspectives and views regarding their pain treatment.

Discussion

Methodological Issues

Study Design

Most of the studies in this review were quantitative, while only six of them were qualitative (refer table – overview of selected studies). Even though most of the included studies used non probability sampling, which eliminates the possibility of producing a representative sample and may introduce bias, the methodological quality scores were good (refer quality assessment). However, some of the studies neither reported the reasons for choosing non probability sampling over probability sampling method nor indicated the type of specific research method used (Table 1 & 2). This lack of information obviously limits the transparency of the study and lacks the clarity for the reader to determine the relevance of the study. For future research, design providing more comprehensive information on the method and sampling technique is an important consideration.

One of the major strengths in any research study is the consideration of ethical issues. Lack of information regarding ethics in ten of the studies weakens their strength and causes doubt about their ethical soundness, scientific quality and legal propriety (Johnson & Long, 2006). However, we suggest that a lack of detailed reporting of ethical issues may be due to restrictions in word limits for publication of journal articles.

Population

None of the quantitative studies included in this review addressed power calculations (Booth, 2006b), while only one qualitative study (Lansbury, 2000) mentioned data saturation to determine sample size.

Three of the studies (Mrozek & Werner, 2001; Horgas & Dunn, 2001; Allcock *et al.,* 2002) reported findings from a small sample size (refer table) as only a few participants showed willingness and ability to participate in the studies and responded to survey questionnaires. However, the sample sizes of the reviewed qualitative studies were quite large (refer to table) which may have hindered the in-depth exploration of the phenomenon under investigation.

Setting

The setting of a study is also a key methodological consideration to judge whether a study has external validity for generalisability and transferability (Polit & Hungler, 2001; Polit & Beck, 2010). As evident from the above, most of the studies were carried out in western countries, while very few were carried out in eastern countries (refer table – overview of selected studies). Reasons may differ from one country to another but, this may have been due to the low priority given to older people in some societies or lack of resources may have acted as a hindrance in conducting research. Using more than one setting in the study (e.g. Sloman *et al.*, 2001) can make study findings more likely to be applicable to other similar settings (Beverly *et al*., 2006; Polit & Beck, 2010), rather than using only one setting. However, selection of setting depends on the aims and methodological framework underpinning the design (Polit & Beck, 2010).

Discussion

Findings from this critical literature review illustrate the complexities of assessing and managing pain due to the attitudinal barriers found amongst older people and nurses. The result from most of the reviewed studies (see themes) highlighted that many older people and nurses believe pain to be a normal part of ageing and unlikely to respond to treatment. Further, the studies revealed that older people tended to fear becoming addicted to analgesia and also feared losing their independence. Perhaps due to these attitudes, older people are often resigned to their pain and therefore are reluctant to express their pain which, ultimately, can lead to delays in seeking treatment (Gibson *et al*., 1994). Moreover, some older people did not express their pain to the nurses as they felt the nurses had no time to listen to their pain concerns (Francke & Theeuwen, 1994). This

situation could be improved by taking simple steps to improve communication, such as asking older people about the presence of pain and encouraging older people to talk about their pain.

However, sometimes older people may consider their health good when they see other older individuals as being worse off than themselves and thus may not express their pain. (Wadensten, 2008). Another possibility is that nurses may encourage older people to express their pain but, because of prolonged pessimism regarding their pain, older people may be unwilling to do so. Developmental theories suggest that as people age, body, illness or pain may be perceived as less important to their existence and this may account for why they feel their health is good despite being in pain (Wadensten, 2008; Thorsen, 1998).

The reviewed studies also suggested that many nurses hold similar negative and misinformed attitudes about ageing and pain; thus they tend to ignore older people's pain concerns which resulted in dissatisfaction for older people. Madjar (1999) points out those nurses should not doubt the reality of older people's pain but must acknowledge its existence and should provide opportunity to voice their concerns without feeling inhibited, irrespective of their physical and psychological function. Differential attitudes regarding chronic pain management among older people with a range of physical function may be worthy of additional future study.

Davis *et al*. (2002) stress that nurses can assist in dispelling older people's own inaccurate age-related expectations, but first they need to correct their own misconceptions through proper pain education. This was emphasized in most of the reviewed studies stating that lack of adequate and accurate pain knowledge might be one of the reasons for poor communication and for excluding older people from their own pain management. Nevertheless, some nurses may be educated but may lack experience and be unable to understand older people's perspectives about chronic pain and vice versa (Katsma & Souza, 2000; Weiner & Rudy, 2002).

Findings of this review revealed that nurses with more years of experience tend to have a more positive attitude towards chronic pain than less experienced nurses. This seems to support the popular view that there is no "teacher – like" experience. However, at some point in

life, virtually everyone experiences some type of pain and nurses who have experienced this pain might show an empathetic attitude towards older people with chronic pain. Moreover, older people tend to express their pain to those nurses who seem to be supportive, caring and understood their pain situation (Yates *et al.*, 1995).

Although most of the studies revealed that positive attitudes of the nurses towards chronic pain was directly proportional to the years of experience, it is interesting to note the findings of two studies (Katsma & Souza, 2000; Weiner & Rudy, 2002), where personal and professional experience of nurses did not influence their attitudes towards older people in chronic pain. McCaffery and Ferrell (1997) suggest that some nurses working with older patients for long periods are used to dealing with their pain complaints and therefore may become insensitive to older people's pain complaints. However, additional research is needed to determine whether the years of experience affect nurses' attitudes towards older people in chronic pain.

As the older population is projected to increase dramatically in the coming years (WHO, 2010; IASP, 2010), issues related to attitudes are not only deserving of increased investigation, but imperative to address for optimal pain management. Therefore, at a broader, societal level, there is a need to continually strive to combat the stereotypical views of ageing which shape the beliefs of both nurses and older people (Allcock *et al.*, 2002).

Implications for Clinical Practice

As the way in which older people view themselves and their pain differs, nurses need to assess and manage older people's pain experiences individually so that they feel the environment is conducive to express their pain. Furthermore, they need to acknowledge older people's experiences, give opportunities for the older person to ask questions, listen to and accept their concerns about chronic pain. In everyday practice, there is a need for reflective discussions among nurses about their feelings towards older people in chronic pain. Moreover, nurses should be educated in chronic pain management so that they understand its broad complexity and approach in assessing older people's pain.

Limitations of the Review

For this review, only studies published in English and those available in full text through hand searches and electronic searches of journals and books were included. As a result, this could have left out potentially relevant and useful studies. Most of the studies reviewed explored attitudes towards chronic pain from the older person's perspective. This might have further led to exclusion of nurses' perspectives and experiences.

Conclusion

It is important that the misconceptions of older people and nurses regarding chronic pain be clarified. This will, however, take time and combined effort on the part of many people. Since the care of older people and treatment should be based on the needs and wishes of the individual older person, understanding from this perspective is fundamental. Including chronic pain assessment and management issues in curriculum for nurses, frequent skills enhancing trainings, various educational sessions for older people involving nurses would provide conducive environments for assessing and managing chronic pain. Moreover, conducting research focusing on how nurses can assist older adults with chronic pain will be important. Although establishing new ways of looking at chronic pain and practicing differently will not be achieved immediately, it is paramount to deliver quality care to older people within the constantly changing health care environment.

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Appendix-I

Critical Appraisal Skills Programme
Making Sense of Evidence

10 Questions to help you make sense of Qualitative Research

This assessment tool has been developed for those unfamiliar with qualitative research and their theoretical perspectives. This tool presents a number of

questions that deal very broadly with some of the principles or assumptions

that characterise qualitative research. It is *not a definitive guide* and extensive

further reading is recommended.

General Comments

- The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

- The subsequent questions ask you to read the main question in bold first and then use the sub-questions underneath to give more detailed feedback.

- Record your answers to each question in the spaces provided.

- The 10 questions have been developed by the national CASP collaboration for qualitative methodologies

concerning reproduction or use in other circumstances should be addressed to CASP.

Screening Questions

1 Was there a clear statement of the aims of the research?	Yes ☐	No ☐
HINTS: What was the research trying to find out? *Why is it important?* *What is its relevance?*		
2 Is a qualitative methodology appropriate?	Yes	No
HINT: Does the research seek to interpret or illuminate the actions and/or subjective experiences of research participants?	☐	☐

Detailed Questions

Appropriate Research Design	
3 Was the research design appropriate to address the aims of the research?	*Write comments here*
(a) Has the researcher justified the research design? (eg have they discussed how they decided which methods to use)	
Sampling	
4 Was the recruitment strategy appropriate to the aims of the research?	*Write comments here*

Has the researcher explained how the participants were selected? (a) Have they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study? (b) Are there any discussions around recruitment? (eg why some people chose not to take part)	
Data Collection	
5 Were the data collected in a way that addressed the research issue?	*Write comments here*
(a) Was the setting for data collection justified? (b) Is it clear how data were collected? *eg: focus group, semi-structured interview etc* (c) Has the researcher justified the methods chosen? (d) Has the researcher made the methods explicit (eg for interview method, is there an indication of how interviews were conducted, or if they used a topic guide?) (e) If methods were modified during the study, has the researcher explained how and why? (f) Is the form of data clear (eg tape recordings, video material, notes etc) (g) Has the researcher discussed saturation of data?	

Reflexivity (research partnership relations/recognition of researcher bias)	
6 Has the relationship between researcher and participants been adequately considered?	*Write comments here*

Is it clear:
 	
  (a)   If the researcher critically examined their own role, potential bias and influence during:
 	
  –   formulation of research questions
 	
  –   data collection including: sample recruitment, choice of location
 	
  (b) How the researcher responded to events during the study and whether they considered the implications of any changes in the research design?	

Ethical Issues	
7 Have ethical issues been taken into consideration?	*Write Comments Here*

(a)   Are there sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained?
 	
  (b)   Has the researcher discussed issues raised by the study (eg issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study?)
 	
  (c) Has approval been sought from the ethics committee?	

Data Analysis	
8 Was the data analysis sufficiently rigorous?	*Write comments here*
(a) Is there an in-depth description of the analysis process? (b) If thematic analysis is used, is it clear how the categories/themes were derived from the data? (c) Does the researcher explain how the data presented was selected from the original sample to demonstrate the analysis process? (d) Is there sufficient data presented to support the findings. (e) To what extent is contradictory data taken into account? (f) Did the researcher critically examine their own role, potential bias and influence during analysis and selection of data for presentation?	
Findings	
9 Is there a clear statement of findings?	*Write comments here*
(a) Are they explicit? (b) Is there adequate discussion of the evidence both for and against the researchers' arguments? (c) Has the researcher discussed the credibility of their findings? (d) Are the findings discussed in relation to the original research questions	

Value of the Research	
10 How valuable is the research?	*Write comments here*
(a) Does the researcher discuss the contribution the study makes to existing knowledge or understanding?	
Eg – do they consider the findings, in relation to current practice or policy, or relevant research based literature? – do they identify new areas where research is necessary? Have the researchers discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used	

Appendix-II

Questions for Critical Appraisal of a Survey

A. Are the results valid?

1. *Objectives and hypotheses*
-   Are the objectives of the study clearly stated?

2. *Design*
-   Is the study design suitable for the objectives?
-   Who/What was studied?
-   Was this the right sample to answer the objectives?
-   Did the subject represent the full spectrum of the population of interest?
-   Is the study large enough to achieve its objectives? Have sample size estimates been performed?
-   Were all subjects accounted for?
-   Were all appropriate outcomes considered?
-   Has ethical approval been obtained if appropriate?
-   What measures were made to contact non-responders?
-   What was the response rate?

3. *Measurement and observation*
-   Is it clear what was measured, how it was measured and what the outcomes were?
-   Are the measurements valid?
-   Are the measurements reliable?
-   Are the measurements reproducible?

B. What are the results?

4. *Presentation of results*
-   Are the basic data adequately described?
-   Are the results presented clearly, objectively and in sufficient detail to enable readers to make their own judgement?

- Are the results internally consistent, i.e. do the numbers add up properly?

5. *Analysis*

- Are the data suitable for analysis? Are the methods appropriate to the data? Are any statistics correctly performed and interpreted?

C. Will the results help locally?

6. *Discussion*

- Are the results discussed in relation to existing knowledge on the subject and study objectives?
- Is the discussion biased?
- Can the results be generalised?

7. *Interpretation*

- Are the authors' conclusion justified by the data? Does this paper help me answer my problem?

8. *Implementation*

- Can any necessary change be implemented in practice? What are the enablers/barriers to implementation?

Source: Booth, 2006

Effect of Concurrent Task on Gait Parameters and Gait Stability in Elderly Adults

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ABSTRACT

The purpose of this study was to investigate the effect of concurrent cognitive task on velocity, cadence, lateral stepping over and stops while walking in elderly. The study design was of experimental, repeated measures type. A sample of 70 older adults, 60 to 80 years old took part in the study. Subjects were divided into two groups according to their gender. Group 1 consisted elderly females and group 2, elderly males. The gait variables calculated were velocity, cadence, lateral line stepping over and stops during performance of single task, as well as dual task. The results of the study showed that there was a significant difference between the male and female subjects in walking velocity without any concurrent cognitive task and with arithmetic task, and simultaneously a significant difference in lateral line stepping and stops between the groups in all the three conditions. The data obtained from this study shows a trend of age related decline in gait parameters and that dual task has more effect on the gait parameters of elderly females as compared to males.

Key Words: Dual task, Gait, Falls, Elderly

Postural control is the ability to maintain the body's centre of gravity over the base of support during quiet standing and movement (Hageman *et al.*, 1995). Postural control plays a very vital role in human gait. Age related impairments have been proposed at every stage of the postural control system (Maylor & Wing, 1996). In one population study, 15 per cent of the subjects over 60 years had some abnormality of gait (Desforges, 1990). Previous studies have shown that with advancing age, performing an attention demanding task while walking interferes with gait performance (Bloem *et al.*, 2001, 2003). For example, Lundin-Olsson et al. (1997) noted that institutionalized elderly persons who were unable to maintain a routine conversation while walking had a high risk of falls. That is, concurrent execution of two different tasks might lead to falls in the case of a generally restricted capacity of brain.

This gave rise to a series of investigations, which showed that high level processing is important in balance control. Shumway-Cook *et al.* (2000) showed that with aging, attentional demands for postural control increases as sensory information decreases. Walking requires more attention among older adults compared to young adults (Woollacott & Shumway-Cook, 2002). Hsieh-Ching *et al.* (1997) demonstrated that when walking, the risk of contacting an obstacle increases when attention is divided. They found that attention demand is greater in older adults than in young adults for successful implementation of proactive balance control mechanisms. Also, obstacle clearance is not an easy task for older adults because a large amount of attention has to be allocated not only to the normal gait pattern but also to its modification.

Dual task related gait changes are usually interpreted as interference caused by competing demands for limited attentional resources, highlighting the idea that walking is not only an automated process but also an attention demanding task. In health young adults, there were noted changes in gait patterns while simultaneously performing a dual task (counting backward). Dual task caused a small decrease in stride velocity and a slight increase in the stride to stride variability of stride time (Beauchet *et al.,* 2005). Identifying and comparing cognitive correlates of functional performance is particularly important in order to design interventions to promote independence and prevent functional disability (Wood *et al.*, 2005).

Cho *et al.* (2004) demonstrated gender differences in gait. They found that females walked slower than males due to shorter stride length. Kerrigan *et al*. (1998) found an effect of gender on specific joint biomechanics during gait. Females had significantly greater hip flexion and less knee extension before initial contact, greater knee flexion moment in pre-swing and greater peak mechanical joint power absorption at the knee in pre-swing. Oberg *et al.* (1993) showed significant sex differences in all gait parameters. Gait velocity and step length were lower and step frequency was higher for women than for men. These studies will help us in developing an understanding of changes in gait patterns due to a simultaneously performed cognitive task in men and women. From this we can target special groups who need training for impairments.

Methods

A sample of 70 older adults, 60 to 80 years of age, took part in the study. Subjects were divided into two groups according to their gender. Group 1 consisted of 35 elderly females, and Group 2, with 35 elderly males. The subjects who volunteered for the study were residents of Vasant kunj, New Delhi and Faridabad, Haryana India. The following inclusion criteria was: age above 60 years, no history of falling, no neurological disorders, no major orthopaedic diagnosis involving the lower back, pelvis or lower extremities, does not use walking aids, and MMSE score above 24. Subjects with acute medical illness that might interfere with participation in the study were excluded.

The study design was an experimental, repeated measures type. Demographic data was collected from the subjects who met the inclusion criteria of the study. Then the subjects were assessed using the Mini mental state examination (Folstein). The study was explained to the subjects in detail. They were asked to sign a consent form and were assigned into gender related groups. Participants were asked to perform in randomized order the following tasks. First, the subjects were asked to walk on the paper walkway a distance of 10 metres at their usual speed. Then, the second time, they were asked to count backward with a difference of three starting from fifty while walking. The third time, they were asked to enumerate animal names while walking. The whole procedure occurred during a single session assessment that lasted for approximately 30 minutes for each subject.

Each subject was given one trial walking before the final assessment to become familiarized with the walking condition. Each subject completed one trial for all of the testing conditions. This walking trial was realized on a paper walkway (10x 0.5 metres) in a well lit environment, at a self selected speed and wearing socks. Oil paint method was used to obtain foot prints. Oil was put on the socks of the subjects to get the footprints. The subjects were asked to move and told not to step outside the margins of the paper. Following this, the subjects were assessed on four gait parameters that included time, steps, lateral line stepping over and stops. Walking time in seconds was noted with the help of a stopwatch in all the three walking conditions. The number of steps was noted by counting the number of footprints on the paper walkway. Number of lateral line stepping over was noted by counting the number of footprints occurring outside the lateral border of the paper walkway. Stops were noted by counting the number of times the subjects stopped while walking on the paper walkway. The time taken and number of steps were used to calculate the walking velocity and cadence (number of steps per min). Both the acceleration and deceleration phases of gait were excluded for data analysis; that is initial and final distance of 1.5 meters was excluded in all the three walking conditions.

Data Analysis

Statistical analysis was performed using the SPSS 17 software. An independent sample t-test was used to find the changes in walking velocity and cadence between groups and the Mann Whitney test was used to find changes in lateral line stepping and stops between groups in different walking conditions. ANOVA was used to find changes in walking velocity and cadence and Bonferroni's test was used to analyze the pair wise comparison of the changes in the walking velocity and cadence in different conditions within groups. Friedman's test was utilized to find changes in lateral line stepping and stops and Wilcoxn's sign ranked test was used to analyze the pair wise comparison of the changes in lateral line stepping and stops within groups. The significance level of $p = 0.05$ was fixed.

Results

The mean age of subjects in group 1 was 66.1 yrs and for group 2, it was 66.2 yrs. Other characteristic of the subjects are mentioned in Table 1. The results of the study showed that there was a significant difference between the male and female subjects in walking velocity without any concurrent cognitive task and with the arithmetic task. There were no changes while enumerating animal names, and there was no significant difference in cadence (Table 2), lateral line stepping and stops between the groups (Table 3) in all the three conditions. There was a significant difference between walking velocity and cadence in both groups during a within group analysis (Table 4). Pairwise comparisons showed a significant difference in walking velocity in both groups and in cadence between pairs without cognitive task and walking with arithmetic task and in pair without cognitive task and walking while enumerating animal names. No significant differences in pair between arithmetic task and enumerating animal names (Table 5) were found. There was significant difference between lateral line stepping and stops in group 1 and in stops in group 2 in a within group analysis (Table 6). Pairwise comparison showed a significant difference in lateral line stepping for group 1 and group 2 and stop in group 1 between pairs without cognitive task and walking with arithmetic task and in pair without cognitive task and walking while enumerating animal names. No significant differences were found in pair between arithmetic task and enumerating animal names while walking in lateral line stepping for group 1 and group 2 and stop in group 1 (Table 7).

Table 1
Demographic Characteristics of the Subjects

Patient Characteristics	Group 1 – Females n=35 Mean ± S.D.	Group 2-Males n=35 Mean ± S.D.
Age(Yrs)	66.1± 4.4	66.2± 4.1
Height(cm)	159.9 ± 2.4	163.5 ± 3.5
Weight(kg)	59.6 ± 3.5	67.6 ± 3.1
MMSE	28.3 ± 1.3	28.6 ± 1.2

Table 2

Comparison of Walking Velocity and Cadence between Groups in Different Conditions Using Independent Sample T Tset

Variable	Walking Condition	Group 1 Females, n=35 Mean ± S.D.	Group 2 Males, n=35 Mean ± S.D.	t	p
Velocity (m/s)	Without cognitive task	0.68 + 0.19	0.87 + 0.18	−4.189	.001
	Arithmetic task	0.37 + 0.11	0.46 + 0.15	−2.956	.004
	Enumerating animal names	0.35 +0.12	0.43 + 0.14	−2.462	.016
Cadence (steps/min)	Without cognitive task	83.91 + 17.98	88.09 + 16.55	−1.012	.315
	Arithmetic task	53.08 +13.17	56.51+ 14.50	−1.035	.304
	Enumerating animal names	51.67 + 13.92	53.34 + 14.73	-.487	.628

Table 3

Comparison of Lateral Line Steeping and Stops between Groups in Different Conditions Using Mann Whitney

Variable	Walking Condition	Group 1 Females, n=35 Mean ± S.D.	Group 2 Males, n=35 Mean ± S.D.	z	p
Lateral Line Stepping	Without cognitive task	0.00 + 0.00	0.00 + 0.00	.000	1.00
	Arithmetic task	0.37 + 0. 68	0.14 + 0.42	−1.579	.114
	Enumerating animal names	0.17 + 0.45	0.08 + 0.28	-.777	.437
Stops	Without cognitive task	0.00 + 0.00	0.00 + 0.00	.000	1.00
	Arithmetic task	2.68 + 1.49	2.25 + 1.71	−1.359	.174
	Enumerating animal names	2.94 + 2.01	2.60 + 1.16	-.747	.455

Table 4

Comparison of Walking Velocity and Cadence within Groups in Different Conditions Using ANOVA

Group	Variable	Walking Without Cognitive Task	Walking Arithmetic Task	Walking Enumerating Animal Names	F	p
Females Females, n=35 Mean ± S.D.	Veolcity	0.68 + 0.19	0.37 + 0.11	0.35 +0.12	66.32	0.001
	Cadence	83.91 + 17.98	53.08 +13.17	51.67 + 13.92	72.15	0.001
Males Males, n=35 Mean ± S.D.	Veolcity	0.87 + 0.18	0.46 + 0.15	0.43 + 0.14	98.76	0.001
	Cadence	88.09 + 16.55	56.51+ 14.50	53.34 + 14.73	77.17	0.001

Table 5
Pair wise Comparison of Walking Velocity and Cadence
within Groups in Different Conditions Using
Bonferroni's Test

Group	Variable	Walking Conditions	Mean Difference	SE	p
Females Females, n = 35	Velocity (m/s)	Without cognitive task vs Arithmetic task	.307	0.031	0.001
		Arithmetic task vs Enumerating animal names	.016	0.016	0.929
		Without cognitive task vs Enumerating animal names	.323	0.028	0.001
Group 2 Males, n = 35	Velocity (m/s)	Without cognitive task vs Arithmetic task	.403	0.030	0.001
		Arithmetic task vs Enumerating animal names	.032	0.014	0.067
		Without cognitive task vs Enumerating animal names	.435*	0.031	0.001
Females Females, n = 35	Cadence (steps/min)	Without cognitive task vs Arithmetic task	30.828*	3.042	0.001
		Arithmetic task vs Enumerating animal names	32.23	2.671	0.001
		Without cognitive task vs Enumerating animal names	32.236*	2.670	0.001
Group 2 Males, $n = 35 $ Mean ± S.D.	Cadence (steps/min)	Without cognitive task vs Arithmetic task	31.583 *	3.055	0.001
		Arithmetic task vs Enumerating animal names	3.166	1.400	0.091
		Without cognitive task vs Enumerating animal names	34.750 *	2.780	0.001

Table 6

Comparison of Lateral Line Steeping and Stops within Groups in Different Conditions Friedman Test

Group	Variable Mean ± S.D.	Walking Without Cognitive Task	Walking Arithmetic Task	Walking Enumerating Animal Names	χ^2	p
Females Females, n=35	Lateral Line Stepping	0.00 + 0.00	0.37 + 0. 68	0.17 + 0.45	11.529	0.03
	Stops	0.00 + 0.00	2.68 + 1.49	2.94 + 2.01	43.952	0.01
Males Males, n=35	Lateral Line Stepping	0.00 + 0.00	0.14 + 0.42	0.08 + 0.28	4.33	0.115
	Stops	0.00 + 0.00	2.25 + 1.71	2.60 + 1.16	52.56	0.001

Table 7

Pair wise Comparison of Lateral Line Steeping and Stops within Groups within Groups in Different Conditions Wilcoxn Sign Ranked

Group	Variable Mean ± S.D.	Walking Without Cognitive Task	Walking Arithmetic Task	Walking Enumerating Animal Names	z	p
Group 1 Females, n=35	Lateral Line Stepping	0.00 + 0.00	0.37 + 0. 68	—	–2.739	0.006
		—	0.37 + 0. 68	0.17 + 0.45	–1.461	0.144
		0.00 + 0.00	—	0.17 + 0.45	–2.121	0.034
Group 1 Females, n=35	Stops	0.00 + 0.00	2.68 + 1.49	—	–4.892	0.001
		—	2.68 + 1.49	2.94 + 2.01	-.679	0.497
		0.00 + 0.00	—	2.94 + 2.01	–5.184	0.001
Group 2 Males, n=35	Stops	0.00 + 0.00	2.25 + 1.71	—	–4.926	0.001
		—	2.25 + 1.71	2.60 + 1.16	–1.528	0.126
		0.00 + 0.00	—	2.60 + 1.16	–5.180	0.001

Discussion

The results of the data analysis showed significant differences between females and males for velocity during simple walking. Oberg *et al.* (1993) also demonstrated that gait velocity and step length were

lower and step frequency was higher for women than for men. The mean value for time taken and number of steps while counting backward during walking showed significant difference between females and males. The mean value analyzed for lateral line stepping over while counting backward during walking was higher for females as compared to males, but the difference is not statistically significant. The mean value for velocity during the performance of verbal fluency task showed significant difference. This could be explained by presence of sex differences in gait parameters (Kerrigan *et al.,* 1998; Cho *et al.,* 2004).

The mean value of velocity, while simply walking for the first time, performing a task of counting backward while walking for the second time and performing a task of verbal fluency while walking for the third time showed significant difference in both males and females. Changes in gait patterns due to a simultaneously performed cognitive task have been reported previously among older adults (Lundin-Olsson *et al.*, 1997; Bloem *et al.*, 2001, 2003).

The mean value of cadence, lateral line stepping over and stops did not show any significant difference between two dual tasks: counting backward while walking, and performing verbal fluency task while walking. However, the findings among our sample of community dwelling older adults showed that two different cognitive tasks can have a different impact on lateral stability. The lateral line stepping over while performing a mental arithmetic task had a mean value greater than while performing a verbal fluency task while walking in both the groups, though the difference is not statistically significant. We therefore suggest that the choice of the walking associated task in dual task gait assessment among older adults must be made carefully. The clinical relevance of dual task related gait interferences is important for geriatric fall prevention because a safe locomotion depends on efficient gait control. There is increasing evidence that a strong relationship exists between dual task related gait changes and the risk of falling among frail older adults (Beauchet *et al.,* 2005).

Dual task related gait changes result from an interference between gait and the attention splitting task (Woollacott & Shumway-Cook, 2002; Verhaeghen & Cerella, 2002). The current understanding of dual

task interference is based on the cerebral capacity to share attentional resources between gait and the attention splitting task (Verhaeghen & Cerella 2002). The allocation of attention is mainly controlled by executive functions. Executive functions generally refer to higher cognitive processes, but can also be involved in the organization of lower automated cognitive processes to modulate behavior patterns if required. It has been suggested recently that equal gait changes are observed in dual task walking independent of the walking associated task (Bloem *et al.,* 2003). However by choosing two cognitive tasks that engage in two different paths of cognitive processing, we found significantly different gait changes in our study sample. Whereas walking velocity decreased with both the verbal fluency and the arithmetic task, the frequency of lateral line stepping over was higher while counting backward as compared to enumerating animal names, though the difference was not statistically significant. Both tasks used in our study are declarative cognitive tasks. Verbal fluency relies on the semantic memory that has no direct relation to executive functions. Counting backward, however, depends on the working memory which is a system for temporary storage and processing of information that is directly related to executive functions (Hittmar-Delazer *et al.*, 1994). Because gait control requires more attentional resources with parallel activation of executive functions in older individuals, it appears that combining an arithmetic task with walking created a competitive demand for executive functions in our older study participants. Assuming that two concurrently performed tasks cause greater interference if they compete for the same paths of cognitive processing, a competitive interaction with executive functions could explain the decrease in lateral stability found for walking in combination with counting backward (Beauchet *et al*., 2005).

In a study conducted by Beauchet, *et al.,* (2005), frail elderly adults showed lateral line stepping over and stops during simple walking. In our study, the lateral line stepping over and stops were found to be absent during simple walking. While interpreting the findings of this study, the characteristics of the subjects should be kept in mind. The subjects in our study were elderly people who were self reliant in the daily activities and were more mobile in the community.

Thus, they represent a range of older adults who are fairly active and have a fairly good health.

Most studies have focused on dual task related gait changes in the anteroposterior direction. However, gait changes in mediolateral direction have a particular importance for gait stability. The lateral gait direction deviations observed in our sample of community dwelling older adults reflect dynamic instability. Thus the specific effect of counting backward on lateral gait stability could be helpful for the development of a predictive test for falls.

Cognitive motor interference may be of considerable clinical importance for several additional reasons. A typical therapy regime itself involves concurrent performance of cognitive and motor tasks. Poor dual task performance may therefore complicate therapy. Patients may benefit either from therapies which minimize the requirement of dual task performance or from therapies specifically selected to improve levels of dual task performance. The level of dual task interference and the precise conditions and task conditions under which it occurs may vary between patients. Therefore assessment and monitoring of a person's dual task performance could contribute to informed goal setting and treatment planning.

Finally, many everyday activities involve concurrent cognitive and motor components, a motor task performed under dual task conditions may provide a better index of functional everyday ability than a motor task performed under the single task conditions of typical neurological assessment. Understanding the nature, prevalence and prognosis of dual task decrements could therefore form an important part of assessment and rehabilitation. In our study, the sample for the age and gender cohorts was too small to serve as definitive reference data for comparison with patient scores. Future studies are therefore recommended, which includes a larger sample and also subjects above 80 years to broaden the generalizability of the data. Studies are also needed to define the performance level of the community dwelling elders with assistive devices.

Conclusion

The data obtained from this study shows a trend of age related decline in gait parameters while simultaneously performing cognitive

task during walking in comparison with single task. Thus, the hypothesis that the concurrent performance of cognitive tasks will affect spatial and temporal gait parameters in community dwelling elderly in comparison with single task holds true and dual task has more effect on the gait parameters of elderly females as compared to males.

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A Critical Literature Review on Non-Pharmacological Approaches Used by Older People in Chronic Pain Management

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ABSTRACT

The paper aims to conduct a critical appraisal of the literature focused on non-pharmacological approaches used by older people in chronic pain management. Chronic pain is a common health problem amongst older people, accounting for prevalence rate twice that of their younger counterparts. Despite this, there has been surprisingly little attention paid, on a global level, to the issue of pain management in older people and even less on non-pharmacological approaches to chronic pain management. A total of 69 studies published in English between 2000 to 2010 were obtained from various electronic databases, hand searched journals, research reports, and references obtained from the bibliographies of retrieved articles. After assessing the title, abstract and full text, quality assessment was performed by two independent assessors and ultimately nine papers were included. Of the total nine papers included, five were quantitative, three were qualitative and two were of a mixed method design. The findings revealed that older people tend to use cost effective, readily available and convenient non-pharmacological approaches for managing pain such as exercise, rest, heat/cold application, massage, distraction, relaxation, support groups and bracing/splinting/bandaging – for managing pain. This review highlights the preferences of older

people to use more than one non-pharmacological approach to manage chronic pain. However, it also warrants the need for additional systematic literature reviews and empirical studies to determine the effectiveness of non-pharmacological approaches. The evidence obtained on the efficacy of active involvement of older people and the combined use of non-pharmacological approaches in chronic pain management offers a new insight in the decision-making process. Also, it provides directions for further research planning and knowledge/skill update among health care professionals.

Key Words: Chronic pain management, Non-pharmacological approaches, Self management strategies, Complementary therapies, Older people, Critical literature review

Chronic pain is a common health problem in older adults (Middaugh & Pawlick, 2002) leading to impairment in physiological and psychological health status (Benca *et al*., 2004), thereby reducing quality of life (British Pain Society, 2008). Despite the high prevalence of pain in older adults, pain management in this population has been a neglected aspect (Pickering, 2005; Schofield, 2005). There is evidence suggesting under representation of older people in research, while only a few studies have given importance to the aspect of non-pharmacological approaches to chronic pain management (Middaugh & Pawlik, 2002). Therefore, we conducted a review of the research around *non-pharmacological approaches used by older people for chronic pain management* to identify areas where further work may be carried out in the future.

Background

The population of older people over 65 is increasing globally and is estimated to represent two thirds of the pain population by the year 2020 (Gibson, 2002) and double by 2050 rising from 17.5 per cent to 36.3 per cent (US Census Bureau, 2009). Although, the epidemiology of pain in the older adult has not been widely studied (Schofield, 2005), about one in seven of older people is reported to have chronic pain (Pain Association Scotland, 2002). According to the International Association for the study of Pain (IASP) (2004), chronic pain is prevalent equally in both the developing and developed countries

affecting about 20 per cent of the adult population, especially older people and women.

According to Pickering (2005), the prevalence of chronic pain is twice the rate in older people than their younger counterparts. However, there has been surprisingly little attention on a global level to the issue of chronic pain management in older people (Schofield, 2005). Similarly, little information on the experience and control of pain in older people is addressed in the literature (Sofaer *et al.*, 2005). Further, studies related to pain are found to be fewer in developing countries than higher income countries (Harstall & Ospina, 2003).

The IASP (2001) defines pain as: '*an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage*' (IASP, 2001, p.1). Chronic pain is defined as the 'continuous, long term pain of unknown physical cause which extends beyond the normal tissue healing time of more than 3 months' (IASP, 2001, p.1). Pain in older people remains often untreated, unrecognized, overlooked or mistakenly ascribed to dementia, depression and normal part of ageing (Bonifazi, 2000). Untreated pain can have numerous negative impacts on the health of older people such as impaired quality of life (Ibid.), including depression, suicidal risk, anxiety, poor sleep, impaired appetite, impaired cognition and limitations in the performance of activities of daily living (American Geriatric Society (AGS), 2002; Kumar & Allcock, 2008).

Chronic pain, being more complex than acute pain, requires a range of more varied strategies (Schofield, 2005). The increased risk of multiple co-morbidities and poly pharmacy in older people resulting in various adverse drug reactions demands the need for non pharmacological approaches alone or in combination with pharmacological measures for pain management (Cynthia & Stephen, 2003). *Non-pharmacological* has been used interchangeably with the terms *alternative, complementary, unconventional and non invasive* and stands for those therapies 'that does not involve drugs' (McCaffery & Pasero, 1999).

Research Question

What are the non-pharmacological approaches used by older people for chronic pain management?

AIM

To critically review evidence regarding non-pharmacological approaches used by older people for chronic pain management.

Objectives

- To explore different types of physical therapies used by older people in chronic pain management
- To explore various psychological therapies used by older people in chronic pain management

METHODS

Inclusion Criteria

Inclusion criteria were set on the basis of the following categories:

1. *Types of Participants*

Individuals 65 years of age or older.

2. *Types of Outcomes*

Physical and psychological therapies used by older people in chronic pain management.

3. *Type of Studies*

Studies addressing the topic and published in the English language between 2000 to 2010.

Exclusion Criteria

We excluded studies focussed on chronic cancer pain, or those not available in full text, as well as low quality papers (papers with CASP score less than 6).

Search Strategy

Our search was conducted from 2000 to 2010 in various electronic databases such as OVID, CINAHL, SCIENCE DIRECT, SCOPUS, SWETSWISE, Age Line and in GOOGLE SCHOLAR. We also performed a hand search of journals and reports. A total of 69 studies were identified combining key terms such as chronic pain, persistent pain, non pharmacological approaches, self management strategies, older people, older adult and geriatric using truncation ($ or

*), wildcard (? Or #), or Boolean operators (OR, AND). Of a total of 69 papers, nine papers were included after screening titles, abstracts and conducting quality assessment (Figure 1). A few papers were found to be duplicate so these were eliminated to avoid publication biasness. A manual record of the search carried out was maintained in a diary with details such as date, databases searched, keywords, number of references and titles of selected articles.

Figure 1

Selection of Studies and Reasons for Exclusion of Studies
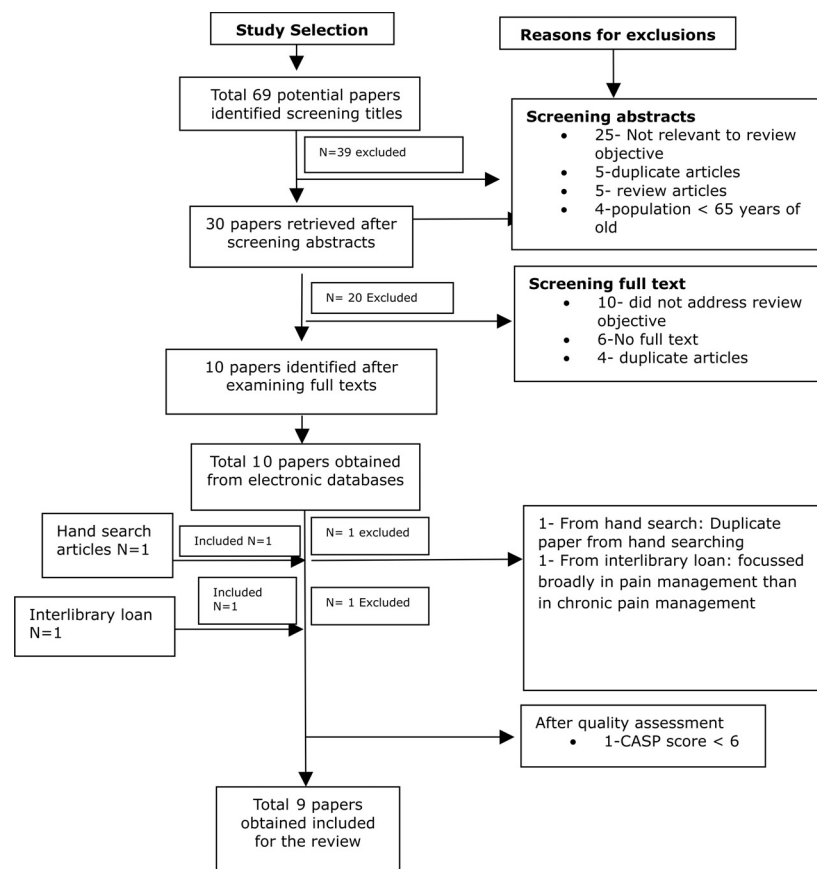
Note: N= Number of papers

Quality Assessment

In order to assess the quality of the quantitative and mixed survey designs, a survey appraisal tool with 8 questions developed by Booth (2006) was used. A CASP score was used to assess quality for qualitative studies. Assessment was done independently by each of the authors and found scores of high concordance of not more than ± 2 points difference. Two studies were found to be of high quality (Score = 8) while seven studies of medium quality (Score 6–7). Studies with a score of less than 6 were excluded.

Data Extraction

Data from each paper was extracted manually by two independent reviewers that included details such as the name of the author, year of publication, the setting, participants, sample size, research design, interventions, and outcomes or the main findings.

Analysis and Data Synthesis

The summary of the information obtained from the studies were presented thematically in a methodological matrix on the basis of the author, year, paper, number, level of knowledge, boundaries, methods used and the findings (Davies, 2004).

Results

Characteristics of the Reviewed Studies

Studies were conducted from countries all over the world with three from Sweden (Blomqvist & Hallberg, 2002; Blomqvist & Edberg, 2002; Jakobsson *et al*., 2004), one from Australia (Lansbury, 2000), one from China (Tse *et al*., 2005) and one from Taiwan (Tsai *et al*., 2004). Three studies (Barry *et al*., 2004; Dunn & Horgas, 2004; Barry *et al*., 2005) were from USA. Four studies were conducted in the community (Lansbury, 2000; Barry *et al*., 2004; Dunn & Horgas, 2004; Barry *et al*., 2005), two in nursing homes (Tsai *et al*., 2004; Tse *et al*., 2005), one in a primary care centre (Barry *et al*., 2004) and three included both nursing home and community (Blomqvist & Hallberg, 2002; Blomqvist & Edberg, 2002; Jakobsson *et al*., 2004). Sample sizes of the included studies ranged between 44 and 294.

Study Design

Of the total nine studies, four were descriptive cross sectional (Blomqvist & Hallberg, 2002; Jakobson *et al.,* 2004; Tsai *et al.*, 2004; Dunn & Horgas 2004), three were qualitative (Lansbury, 2000; Blomqvist, Edberg & 2002; Tse *et al.,* 2005) and two were mixed method studies (Barry *et al.*, 2004; Barry *et al.*, 2005).

Methodological Quality

Among the nine studies, only two described the sampling technique used: either stratified random sampling (Tsai *et al.*, 2004) or convenience sampling (Dunn & Horgas, 2004). Regarding the data collection method, all of the studies used either structured or in-depth interviews except the studies by Barry & colleagues (2004) that used a telephone survey.

Data coding, categorization, tape transcribing and other software packages (e.g. SPSS) were used for analysis in all of the qualitative studies, while the study by Blomqvist & Edberg (2002) used content analysis as well. In addition to the statistical analysis (e.g. ANOVAs, chi square test) used in all quantitative and mixed methods, studies by Jakobsson *et al.* (2004) also used cluster analysis while Barry *et al.* (2005) and Tsai *et al.* (2004) also used content analysis. Only two studies (Blomqvist & Edberg, 2002; Barry *et al.* 2005) have clearly addressed the ethical consent. In overall, seven studies were of medium quality (CASP score 6–7 out of 10) while two were of good quality (CASP score = 8).

Overview of Selected Papers

Table 1
Quantitative Research Studies

Author/ Year	Level of Know-ledge	Focus/ Boundaries	Methods and Sampling/ Critique	Themes
Dunn & Horgas, 2004 Florida, USA	Explanat-ory	To explore the use of religious and nonreligius coping in older people who were experiencing chronic pain. **Population** 200 older people ≥ 65 years old	Descriptive cross sectional study Convenience sampling	*Physical Therapies:* Heat, cold, massage, exercise

Cont'd...

		Male population (n, %) = 46 (23%) Female Population (n, %) = 154 (77%) **Medical Diagnosis** Diagnosis of Older people - not mentioned **Locations of Pain** Percentage of older people reporting pain in these sites in (n = number and % = percentage) Lower extremities - (65%), Hip (46%), Upper extremities (41%), Head (18%), Back (17%), Abdomen and chest - (10%) Settings Community: 2 senior apartment complexes, one health-O-Rama, and one Volunteer centre in the Detroit metropolitan area	Self administered questionnaire	Psychological Therapies: Distraction, relaxation, Imagery, hypnosis, music *Other:* Ignoring, reinterpretation, self statements
Jakobsson et al., 2004 Sweden	Explanat-ory	To describe and compare the use and perceived effectiveness of pain management methods among elderly people with chronic pain who require help with activities of daily living under different living condition. **Population** 294 older people aged ≥ 75 years old Male-90(31%) Female-204(69%) Medical Diagnosis 37% reported they had not received any diagnosis or don't know the reason for pain Osteoarthritis (34%), Rheumatic diseases such as Sjogren's syndrome, Systematic Lupus Erythematosus (SLE), fibromyalogia, unspecified rehumatic disease (14%), Rheumatic arthritis (6%), Osteoporosis (2%) and musculosketetal pain (1%) **Locations of pain** Legs (33%), back/neck (22%), Hip/pelvis (15%), Shoulder/arms/hand (14%), Joints (6%), Other not specified (6%), Whole body (4%) **Settings** Community of Southern Sweden	Descriptive quantitative Purposive sampling Postal questionnaire followed by structured personal interview	*Physical Therapies:* Resting, exercise, TENS, acupuncture, Brancing/stretch bandage, hot bath/whowe, heat, cold *Psychological Therapies:* Distraction, relaxation, support group, *Other:* Talking to people who understand

Cont'd...

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Blomqvist & Hallberg, 2002 Sweden	Explana-tory	To describe and compare a group of older persons in persistent pain with a group of professional care providers concerning the methods they had used/administered during the previous week and how helpful they perceived these methods to be in relieving pain **Population** 94 older people of≥ 75 years old Male - 26(28%) Female - 68(72%) **Medical diagnosis** Diagnosis not mentioned **Locations of Pain** Leg (36%), back (25%), arm/s (14%), multiple location/whole body (12%) heat/thorax (6%), other (5%) **Settings** Community + Nursing home: Inner City, suburban and rural parts of Sweden municipality	Descriptive suty Purposive sampling, Personal interview using fixed response alternatives with dichotomous and rank order items preceded by an open ended interview	*Physical Therapies:* Rest, exercise, massage, brancing/spli nt or bandaging, hot bath shower, TENS, *Psychological Therapies:* Distraction, relaxation, reducing stress, support group Others: talking to someone who understands
Tsai *et al.,* 2004 Taiwan	Explana-tory	To explore pain prevalence experiences, and self-care management strategies among elderly residents of nursing homes in Taiwan. **Population** 150 older people of ≥ 65 years old in 8 nursing homes of Taiwan, Total Male - 62(41%) Total Female - 88(59%) **Medical diagnosis** Hypertension (39.8%), Strode (29.%), diabetes (27.6%), fracture (26.5%), respiratory disease (14.3%), heart diseases (13.3%), digestive system diseases (9.2%), renal disease (7.1%), cataract (6.1%), urinary system disease (5.1%), cancer (4.1%), liver disease (2%) **Location of Pain** Knees (27.6%), Lower back (24.5%) and hips (18.4%) **Settings** Nursing Homes	Descriptive study Stratified random sampling Self report and semi structured questionnaire	*Physical Therapies:* lie down to rest, massage, use brace, keep joints warm *Psychological Therapies:* Distraction (watch TV to shift attention) Others: take Chinese medications, ignore, eat vegetables

Table 2
Qualitative Research Studies

Author Year	Level of Knowledge	Focus/ Boundaries	Methods and Sampling Critique	Themes
Lansbury, 2000 Australia	Exploratory	To explore the preferred strategies of elderly people and the barriers they encountered in trying to manage their pain. **Population** 72 older people (65 years old and above) Male - 14(19%) Female-58(81%) **Medical diagnosis** Musculoskeletal conditions such as arthritis, back and neck pain (69%), cardiovascular conditions such as angina and stroke (13%), unknown cause (18%) **Locations of Pain** Not mentioned **Settings** Community: 6 suburbs of Sydney, Australia	Grounded theory Theoretical purposive sampling technique In-depth interviews were audio taped and transcribed verbatim, Focus group	*Physical Therapies:* Massage and topical agents, heat application, Ice, acupuncture and acupressure, physiotherapy, exercise Psychological Therapies: Listening to music, praying Other: Home remedies, visiting neighbour, using humour, going on social outings to clubs

Cont'd...

Tse *et al.*, 2005 Hongkong, China	Exploratory	To explore pain relief interventions used by older people with people with chronic pain in Hong Kong along with the frequency and perceived effectiveness of non-prescription measures. **Population** 44 older people (60 years and over) Male-37(84%) Female-7(16%) **Medical diagnosis** Musculoskeletal problems (67.5%), hypertension (37.5%), heart disease (37.5%), diabetes mellitus (35%), cataract (35%), history of stroke (30%) **Locations of pain** Whole body (18.2%), legs (15.9%) back (15.9%), ankles and joints (11.8%) and knee pain (11.4%) **Settings** Nursing home: Hongkong, China	Descriptive qualitative studies Purposive sampling of Interviews (based on 10 point numerical scale) were audio taped and transcribed verbatim	Older people used Combination of physical and psychological therapies such as: Massage, bed rest, analgesic ointment. listening to music, ice pad, rest, analgesic ointment, watching TV, bed rest.
Blomqvist & 2002 Sweden	Exploratory	To explore sense of self, sense of pain, daily living with pain, sense of other and ways of handling pain in older people with persistent pain. **Population** 90 older people (75 years and above) Male - 24(27%) Female - 66(73%) **Medical diagnosis** Not mentioned **Locations of pain** Leg (84%), back (67%), arm/s (47%), chest (26%), stomach (24%), head (17%), other (8%) **Settings** Community: municipality of Southern Sweden	Descriptive qualitative study Purposive sampling technique Personal interviews were audio taped Open and structured questions.	*Physical Therapies:* Exercise, physiotherapy, rest, splint/brace or bandage, hot bath/shower, massage Psychological therapies; distraction Other: performing household shores or eating particular foods to prevent pain, communication concerning pain

Table 3
Mixed Type of Research Studies

Author / Year	Level of Knowledge	Focus/ Bondaries	Methods and Sampling/ Critique	Thems
Barry et al., 2005 USA	Exploratory + Explanatory	To identify strategies perceived as effective in reducing pain and to ascertain factors associated with their use. **Population** 272 older people of age ≥ 73 years old Male - 206(84%) Female - 39(16%) **Medical diagnosis** Musculoskeletal problem (71%), neuropathic problem (12%), trauma related (12%), other (13%) **Locations of pain** Lower back (38%), knee (29%) and leg (25%) **Settings** Community: New Haven, New York	Mixed design (Used both qualitative and quantitative approaches. Qualitative data recorded, transcribed, coded and categorized with content analysis Quantitative data were statistically analysed Purposive sampling Interview with open ended questions	*Physical Therapies:* Activity restriction (Rest), use of hot &/or cold modalities, exercise Psychological Therapies: cognitive method Other: complementary medicine, dietary modification, slow down pace of walking, alters body position
Barry et al., 2004 USA	Exploratory Explanatory	To identify the strategies used by older persons to cope with chronic non cancer pain, determine the perceived effectiveness of the strategies, and ascertain factors associated with their use. **Population** 245 older people ≥ 65 years old Male - 83(31%) Female - 189(69%) **Medical diagnosis** Not mentioned Location of pain Lower back (33%), knees (25%), legs (18%), hips (15%) and shoulders (13%) **Settings** Primary Care practice located at a Veterans Affairs medical Centre in New England.	Mixed design (Responses recorded, transcribed, coded and categorized while statistical tests applied for quantitative data) Purposive sampling Telephone survey with open ended questionnaire	*Physical Therapies:* Exercise, rest, hot/cold modalities, massage, TENS *Psychological Therapies:* Distraction, listening music, prayers Other: going out with family, nutritional management, emotional support, alter sleeping position

Themes

The following graphs illustrate the number of themes emerging from the nine studies in the review.

Figure 2
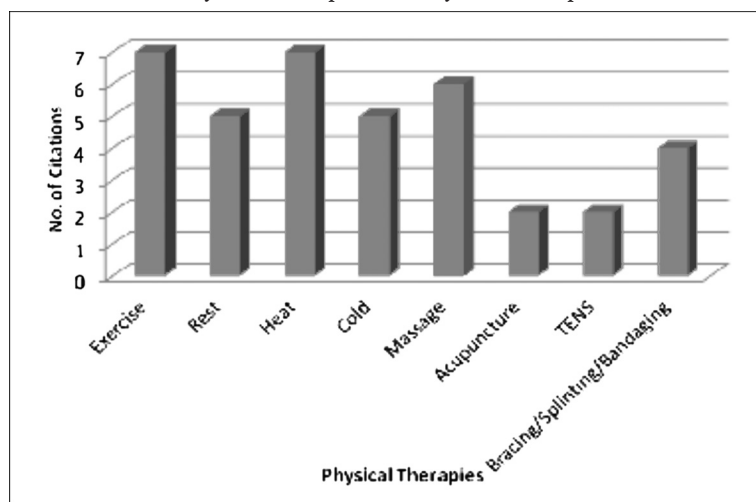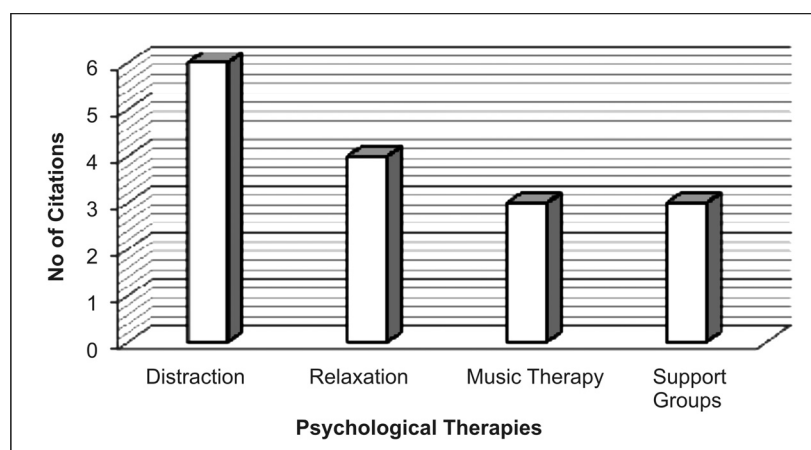*Physical Therapies Used by Older People*

Figure 3
Psychological Therapies Used by Older People

Outcomes

Physical Therapies

Non-pharmacological approaches are broadly classified into two sections: physical therapies and psychological therapies (Lansbury, 2000). Exercise, rest, massage, heat and cold application, TENS (Transcutaneous Electrical Nerve Stimulation), PENS (Percutaneous Electrical Nerve Stimulation), acupuncture, reflexology, and therapeutic touch are some of the widely known physical therapies (Lansbury, 2000; Blomqvist & Hallberg, 2002). These therapies are known to be particularly helpful for soothing musculoskeletal pain among older people (Dunham, 2005). In an attempt to explain and explore the physical therapies used by older people for chronic pain management, the following themes were extracted from the nine studies included.

Exercise

Exercise is one of the physical therapies that has been widely known to promote the function, mobility, fitness and some degree of reduction in pain in older people with chronic pain (Martin, 2007). This theme was identified in seven studies as described below.

Studies by Blomqvist & Edberg (2002), Barry *et al.* (2004) and Barry *et al.* (2005) revealed that exercise was the most preferred strategies used by 66 per cent, 35 per cent and 23 per cent of older people respectively. Alternately, though, while in two studies (Lansbury, 2000; Blomqvist & Hallberg, 2002) 50 per cent of the older people used exercise, they did not perceive it as a helpful approach. The main reasons older adults did not perceive exercise as helpful included fear of falling and the presence of disorders such as cardiac conditions.

Similarly, Dunn & Horgas (2004), Blomqvist & Edberg (2002) identified that older people performed some sort of mobility which ranged from going out for walk, performing solitary exercise, physiotherapy, everyday housework, as well as changing positions. While comparing the frequency of use of exercise, Jakobsson *et al.* (2004) found higher use of exercise in older people living in home (n=41, 18%) than those in special accommodations (n=9, 14%). The authors did not mention why this difference exists, however, it could be

because older people might be more comfortable to exercise at home than in special accommodations (such as nursing homes or group homes), where there are specific routines and schedules.

Rest

Dunham (2005) describes rest as a form of lying in bed, sitting in comfortable chairs, bed or orthopaedic chairs which helps with general comfort. This theme was identified in five studies.

Blomqvist & Hallberg, 2002; Barry *et al*., 2005 and Jakobsson *et al*., 2004 identified rest as the most commonly preferred strategy used by 42.55 per cent , 38 per cent and 20 per cent of the older people respectively. It is interesting to note that 67 per cent of older people preferred rest for managing chronic pain despite stiffness being reported as the major side effect (Blomqvist & Edberg, 2002). Just under 7 per cent of older individuals used rest in combination with other non-pharmacological approaches such as massage, ice pads, watching television, and listening to music (Tse *et al*., 2004). Older people living at home used rest more frequently (38%) than those living in special accommodations (32%) (Jakobsson *et al*., 2004). The reason for this was not illustrated in the study, however, it could be possible that older people living at home might have less choice of therapies to utilize than those living in special accommodations where health professionals are available.

Heat Therapy

Heat therapy has become a common treatment modality among older people for pain relief (Dunham, 2005). Heat treatment is known to ease inflammation, increase blood flow to the affected part, and increase joint movement, thereby relieving stiffness (Dunham, 2005). For this review seven studies revealed the use of heat therapy.

Heat applications were perceived as helpful and used frequently by 15 per cent, 28 per cent, 28 per cent and 38 per cent of older people respectively in the studies by Barry *et al.* (2004); Barry *et al.* (2005); Blomqvist & Hallberg, 2002 and Blomqvist & Edberg (2002). Older people used heat applications in the form of bathing or showering, electric blankets, lambswool boots, hot water bottle, heated pool, tub or shower, heating pads for relieving musculoskeletal and stomach

pain. Though the percentage used and the statistical significance were not mentioned, Lansbury (2000) and Tsai *et al.* (2004) mentioned that older people emphasized keeping joints warm as one of the effective heat applications. In a study by Jakobsson *et al.* (2004) older people living in home used heat therapy (such as hot water bottles) more frequently (12%) than those living in special accommodations (6%). This could be because older people living in home can get easier access to hot water bottles than other therapies commonly used in special accommodations.

Cold Therapy

The use of cold, usually in the form of cold packs, is one of the preferable, cheap and efficient strategies to relieve pain. Cold reduces inflammation when applied directly to the painful area (McCaffery & Pasero, 1999). Cold therapy was the least preferred behavioural strategies used by older people when compared with other pain relieving strategies (Barry *et al*., 2004; Dunn & Horgas., 2004; Jackobsson *et al*., 2004; Tse *et al*., 2005).

Massage Therapy

Massage has been used for centuries by different cultures to treat a range of disorders (Schofield, 2005). Despite lack of empirical evidence for this approach, it has been assumed that massage can cause mechanical stimulation of soft tissues. Stimulation of soft tissues can then result in changes in arterial, venous and lymphatic flow to produce reflex activity of the central, peripheral and autonomic nerves, thereby reducing pain (Dunn & Horgas, 2004). The theme of massage therapy emerged from six of the studies reviewed and is described below.

Massage was perceived as a useful pain relieving strategy in the studies by Blomqvist & Hallberg (2002), Blomqvist & Edberg (2002) and Dunn & Horgas (2004). Similarly, older people performed massage using a variety of topical agents such a pain relieving cream, tiger balm, vaporizing ointment and horse linament (Lansbury, 2000; Tse *et al.,* 2005). Surprisingly, Jakobsson *et al.* (2004) discovered that older people living alone at home used massage more (15%) than those

living with their family (5%). However, the authors did not explain the reason for the difference.

Acupuncture

Acupuncture involves piercing the skin with very fine needles at specific anatomic sites called acupuncture points. Acupuncture releases muscle tension, closes pain gates or stimulates the release of endogenous opioids that helps in relieving musculoskeletal pain (Hurley & Bearne, 2008). In this review, acupuncture was identified as a pain relieving strategy in only two studies.

Lansbury (2000) reported that older people gained considerable pain relief from acupuncture, in contrast to the findings in the study by Jackobbson *et al.* (2004) which identified acupuncture as less commonly used strategy by older people. The reason why acupuncture is a less commonly used strategy may be because the maintenance of long term benefits requires multiple courses of acupuncture to be delivered by acupuncturist, which may be really expensive (Hurley & Bearne, 2008).

Transcutaneous Electrical Nerve Stimulation (TENS)

TENS is commonly used to treat chronic pain. It involves the application of electrical energy in various waveforms, amplitudes, and frequencies to peripheral nerves through electrodes for the purpose of blocking pain messages to the brain (Dunham, 2005; Johnson & Martinson, 2007). TENS has been recommended as a safe, easily applied, non-invasive modality in the management of chronic low back pain, osteoporosis and osteoarthritis. Surprisingly, TENS was addressed by only two of the studies.

Jakobsson *et al.* (2004) and Blomqvist & Hallberg (2002) revealed that TENS was one of the less preferred strategies used by only 1 per cent and 1.06 per cent of older people respectively. This low preference of TENS despite of its concrete evidence of effectiveness (Fox & Sharp, 2007) may be because of difficulty in operating the device or unawareness of its use among older people.

Bracing/Splinting/Bandaging

Four studies reported the use of bracing/splinting and bandaging. Older people were found to use this type of treatment modality in the form of support stockings, corsets, splints, neck collars and orthopaedic shoes. Bracing/splinting/bandaging was one of the commonly preferred approaches used by 31 per cent and 18.08 per cent of older people in the studies by Blomqvist & Edberg (2002) and Blomqvist & Hallberg (2002) respectively. Jakobsson *et al.* (2004) however, revealed that older people living in home preferred it more (9%) than those living in special accommodations (6%). The preference of this approach over other approaches such as TENS, PENS or acupuncture, despite the lack of evidence on the efficacy of these approaches, may be because of their easy access and because they can be used easily without professional help. On the contrary, Tsai *et al.* (2004) reported that bracing or bandaging was least performed strategy, used by only two older people out of 109.

Psychological Therapies

Psychological therapies are considered to be most useful for musculoskeletal and malignant pain, particularly when the cognitive functioning of the individual is unimpaired (Lansbury, 2000). This includes a number of approaches such as relaxation, distraction, stress control, bio-feedback, participation in support groups, imagery, talking about pain and prayer. In an attempt to explore the psychological therapies used by older people, the following themes were extracted from the studies.

Distraction

Distraction involves focussing attention away from pain and concentrating on something else such as conversation with a friend, listening to music, watching television or going for a social outing (Martin, 2008). This theme was identified in five of the studies.

Study by Jakobsson *et al.* (2004) revealed that only 15 per cent of the participants used this strategy, unlike the studies by Blomqvist & Hallberg (2002) and Blomqvist & Edberg (2002) where more than 50 per cent of the participants were found to use distraction. Tse *et al.* (2005) purported that only 2.3 per cent of older adults used this

technique. According to these studies, older people used distraction in various forms ranging from social outings to clubs, visiting neighbours, listening to music, watching television, reading, doing needlework, cooking, meditation, prayer, travelling and meeting friends. The discrepancies in the use of distraction across studies may be because all but one study (Tse *et al.,* 2005), were conducted in the community where medications may not be readily available. Therefore, older adults might have used distraction more often to relieve pain. As the study by Tse *et al.* (2005) was conducted in a nursing home, medication would be a first option to relieve pain, while distraction might have been a secondary choice.

Relaxation

Research has revealed that relaxation in the form of deep breathing can reduce pain, anxiety and stress and can also lead to better sleep (Martin *et al.*, 2008). This modality was identified in three of the studies. It appears that relaxation is used less frequently among older individuals than some of the other non-pharmacological treatments. For instance, Blomqvist & Hallberg (2002) reported that 13.82 per cent of older adults used relaxation, followed by seven per cent in the study by Jakobsson *et al.* (2004) and 2.3 per cent in the study by Tse *et al.* (2005).

Music Therapy

Three of the studies reviewed mentioned music therapy. Music is thought to block the pain stimulus, and evoke intense emotions which can stimulate the release of endorphins (analgesic), reduce muscle tension and act as distraction (Schofield, 2005).

Despite the evidence supporting the therapeutic benefit of music, two of the studies (Dunn & Horgas, 2004; Tse *et al*., 2005) reported it to be used less commonly by older people. Tse *et al.* (2005) revealed that only 2.3 per cent of respondents used music in combination with other approaches such as analgesic ointment, bed rest and ice pad. Despite the fact that a few studies mentioned its low preference, an explorative larger study by Lansbury (2000) cited that it was one of the preferred strategies utilized by older adults. Further qualitative studies are therefore needed to identify the therapeutic benefits of music therapy.

Support Groups

Living with persistent pain is a challenge for older individuals and becomes more difficult when coupled with social isolation. Martin (2008) emphasized that support groups such as exercise or walking groups, discussion clubs or continuing education can be helpful for older people in minimising social isolation and loneliness. Three of the reviewed studies described support groups as one of the psychological therapies.

Support groups do not seem to be used often as a psychological strategy to relieve pain. For instance, Blomqvist & Hallberg (2002) only briefly mentioned that older people used support groups as one of the pain relieving methods and did not cite how many older adults use this strategy. Another study by Barry *et al.* (2004) revealed that only 4 per cent of older people seek support group while Jakobsson *et al.* (2004) reported that only 0.5 per cent of the participants preferred support groups. Perhaps older people were found to use support groups less because they were unaware about this strategy. Also, older adults might feel less comfortable talking about their pain in a large group, preferring to keep their problems to themselves.

Other Serendipitous Findings

Home Remedies and Dietary Modifications.

Other strategies perceived as helpful and frequently used by older people were home remedies ranging from dietary modifications such as garlic, vitamins and grapefruit to whisky (Lansbury, 2000; Blomqvist & Edberg, 2002; Tsai *et al.*, 2004; Barry *et al.*, 2004; Barry et al., 2005). Though the frequency with which older people reported to use these approaches is low, the variation in modalities used by older people provides a direction for further research.

Discussion

Methodological Issues

Although Randomized Control Trials (RCTs) are considered the 'gold standard' for evidence of effectiveness (Bowling, 2003) none of the studies used this approach. The generalisability of the studies is achieved by conducting research in various settings, through random

sampling and large sample size in that the samples can represent the population and findings can be applied in other similar settings (Bowling, 2003). However, only four of the studies were conducted in various settings (such as nursing homes, the community, primary care centres). Also, random sampling was utilized in only one quantitative study (Tsai *et al.*, 2004). Further, none of the quantitative studies used or reported on the usage of power calculation (Bowling, 2003). Although there are no rigid rules for sample size calculation for qualitative studies, sample size of 27–90 in four qualitative studies were well justified (Polit & Beck, 2010), as larger sample sizes in qualitative studies can lead to the quicker data saturation (the attainment of the point in data collection where sense of closure is attained because new data starts to yield redundant or information of less depth and richness) (Procter & Allan, 2006; Polit & Beck, 2010; Holloway & Wheeler, 2010). Unfortunately, only one study (Lansbury, 2000) mentioned that interviews were conducted until data saturation was obtained.

As the majority of the studies used interviews (such as personal, face to face, in-depth) as the method of data collection, rich information has emerged regarding non pharmacological approaches of participants.

Discussion

Exercise and rest were two of the preferred approaches in pain management found in the reviewed studies. However, too much rest cause more disability in the form of muscle stiffness and atrophy (Gill *et al.*, 2003), while strenuous exercise can cause more harm than good resulting in falls and exhaustion (Padawer & Levine, 1992). Therefore, older adults should be advised to maintain a balance between rest and exercise.

Although cold therapy has been proven to provide greater, faster and long term pain relief than hot therapy in chronic pain management (McCaffery & Pasero, 1999), it was among the least preferred strategies evidenced in this review. Interestingly, despite sparse and conflicting evidence on heat therapy (Brosseau *et al.,* 2004), it was relatively preferred more by older people for various musculoskeletal conditions, which could be because heat is considered to be more comforting than cold.

Further qualitative and quantitative studies are therefore needed to fulfill gap between evidence and practice. The reason for low preference of acupuncture, PENS and TENS despite their well documented evidence in relieving pain and improving function could be because of the cost, additional training and multiple courses to be delivered by specialist (Briggs, 2002; Hurley & Bearne, 2008). The frequent use of bracing/splinting/bandaging reported by older people in the majority of the studies might be because of its easy access, easier application and low cost.

Participants used distraction more than other psychological approaches, such as meditation, relaxation, and support groups. These findings are similar to those of Yates *et al.* (1995). The low preference of other psychological approaches (besides distraction) might be because of unawareness or an unwillingness to try these strategies by the older people (Barry *et al.*, 2005). Furthermore, the easy accessibility to distraction and the entertainment value of distraction therapy might make this form of psychological therapy more attractive to older individuals. Age may also have played an important role in the selection of psychological therapies. For instance, relaxation involves focussed activities such as slow, deep breathing, tension and relaxation of different muscle groups, which may be relatively difficult to perform in advancing age (McCaffery & Pasero, 1999).

Interestingly, participants living at home used approaches such as exercise, rest, heat, distraction and support groups more than those in special accommodation (such as nursing homes). This could be because of the easy accessibility and availability of these modalities, in the home and the greater use of prescribed medicine within special accommodations.

Overall, findings revealed that older people preferred easily accessible, easy to handle, convenient, inexpensive approaches and used a combination of non-pharmacological modalities. Additional research is needed to determine how and why older people choose and use a variety of methods for pain relief.

Implications for Clinical Practice

Health care professionals should respect the preferences of older people and inform older individuals about combining approaches that

are safe, cheap, easily accessible, and convenient, such as rest, heat, cold therapy, massage, meditation, relaxation, distraction, and support groups. These approaches do not necessarily replace pharmacological approaches; however, they can complement them in effective pain management among older people. Further non pharmacological approaches should be encouraged when there are concerns related to medication side effects and poly pharmacy.

Review Limitations

Within our review, potentially relevant studies might have been missed as only full text English published articles were included. Also, most of the studies were of a descriptive exploratory type, and therefore merely explored what were preferred strategies, and not why these strategies were employed. As such, this review offers only a limited discussion on these issues. This shows the gap between what really exists in the evidence and what is currently been practiced in the community.

Conclusion

In light of the above presented findings, there is generally no agreed or preferred non-pharmacological method for managing chronic pain. However, the evidence strongly recommends the use of multimodal therapy to control pain and enhance mobility and quality of life among older people. Empowering older people in their own pain management and understanding their reluctance to use those pain management strategies could be the corner stone for effective pain management for older people.

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A Comparison of Two Rehabilitation Therapies in the Elderly Stroke Population

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ABSTRACT

The rehabilitation of elderly patients living chronic stroke and residing in long term care settings is an important clinical issue. The purpose of this discussion paper is to compare Neurodevelopmental Treatment (NDT) and the Motor Relearning Programme (MRP) as rehabilitation methods post stroke and to highlight the importance of specialized stroke rehabilitation for the elderly living in long term care facilities. Both the NDT and MRP rehabilitation methods can be used with acute and chronic stroke patients. However, current research evidence does not clearly identify which method is best when working with chronic stroke patients. As such, controversy exists about the efficacy of NDT and MRP. Both clinicians and researchers cannot agree which method is superior and best suited for the stroke population regardless of severity. It is important that more research is conducted in order to determine the most appropriate rehabilitation method for the elderly chronic stroke patient and to identify whether or not stroke rehabilitation is adequately offered for the elderly residing in long term care. Improving rehabilitation outcomes for the elderly living in long term care should be a priority for those working with this population.

Key Words: Chronic Stroke rehabilitation, NDT, MRP, Elderly

Stroke is responsible for 6.2 million deaths worldwide (WHO, 2011), and is the primary cause of adult long-term disability in Canada (Heart and Stroke Foundation of Canada, 2012). The chronic effects and disability for stroke survivors vary upon discharge to home or long term care facility. In addition to chronic deficits, 84 per cent of stroke survivors with hemiplegia may develop other related injuries such as shoulder subluxation and shoulder pain (Teasell, *et al.*, 2004). In order to manage and treat hemiplegia post stroke, therapists and nurses use rehabilitation therapies such as Neurodevelopmental Treatment (NDT) and the Motor Relearning Programme (MRP).

NDT otherwise known as the Bobath (1970/1990) method and the MRP method developed by Carr and Shepherd (1987), are therapies that intend to improve outcome in stroke patients with impaired upper and lower extremity function. The aim of NDT is for the physiotherapist and nurse to reduce spasticity and promote normal postural tone by inhibiting abnormal movement (Bobath, 1990). Compared to NDT, MRP aims to promote relearning normal movement through training the stroke patient to perform specific tasks in a modified environment (Carr & Shepherd, 1987). The purpose of this discussion is to highlight and compare NDT and MRP as a rehabilitation method post stroke and to highlight the importance of specialized stroke rehabilitation for the elderly living in long term care facilities.

NDT and MRP Compared

Neurodevelopmental Treatment (NDT)

In 1943 Berta Bobath, a physiotherapist and her husband Karel Bobath created the Bobath concept otherwise known as NDT to manage and treat children with Cerebral Palsy (Lennon, 1996). NDT is based on neurophysiological theory that stroke patient movement problems are viewed as being related to abnormal patterns of coordination of posture, postural tone, and reciprocal innervations (Bobath, 1990). Physiotherapists and nurses use NDT in England at the Bobath Centre as well as throughout Europe as a primary therapy for stroke rehabilitation (Bobath, 1990, Paci, 2003). Physiotherapists and occupational therapists in North America know of and use NDT, but NDT

therapists more commonly use NDT in countries such as Japan, England, Norway, Germany, and the Netherlands.

The purpose of NDT is to reduce spasticity post stroke by promoting neutral posture, normal positioning, and normal movement (Bobath, 1990). Physiotherapists concentrate therapy on both the affected and unaffected side of the stroke patient. The focus of the physiotherapist is to promote normal movement and reduce spasticity through active and purposeful symmetrical movements bilaterally. Such symmetrical and harmonious movement of both sides of the hemiplegic patient facilitates normal body alignment and function. The goal is to suppress and alter abnormal movements of the affected side of the hemiplegic stroke patient in order to encourage normal patterns of movement.

According to Bobath (1990), the stages of recovery in adult hemiplegia are the initial flaccid stage, the stage of spasticity, and the stage of relative recovery. In the initial flaccid stage, the post stroke patient experiences a state of flaccidity and the physiotherapist initially focuses therapy on normal posture in mainly a supine position (Bobath, 1990). The treatments that support normal posture are practicing neutral pelvic placement, concentrating weight on the affected side, and weight transfer while sitting and standing (Bobath, 1990). Such treatments promote and aid the physiotherapist to work with the stroke patient on bilateral movement and function of the arms and trunk. According to Lennon (1996), physiotherapists stress the importance of correct normal movement of the patient at three 'key points' such as the trunk, shoulder girdle, and pelvis. The therapist helps the patient to obtain normal posture and movement by guiding the patient through the treatment. As tone and movements normalize, the patient begins to control distal movements and the physiotherapist control is progressively removed (Ibid.). However, in this stage of flaccidity, periods of spasticity can occur and therefore the treatment focus by physiotherapists is on preventing or decreasing periods of high tone (Bobath, 1990).

In the stage of spasticity, stroke patients present with different degrees of spasticity located in multiple muscle groups. Throughout the first 18 to 20 months of stroke onset, spasticity increases as the patient's activity level and effort increases (Bobath, 1990). NDT

techniques such as passive range of motion exercises for the shoulder girdle, neck, spine, and legs are used to prevent spasticity. In addition, treatment focuses on the ability of the patient to recover balance against gravity while sitting and standing (Lennon, 1996). After a period of time when the physiotherapist directs movements, the patient then can progress to using selective movements such as practicing pelvic tilt, knee flexion and extension, and preparing to walk by stepping forward with the unaffected leg with the physiotherapist (Ibid.). In this stage, the patient can stand with some or all of his or her weight on the affected leg to decrease spasticity. Bobath physiotherapists employ a series of exercises such as plantar and dorsiflexion of the ankle and toes, as well as flexion/extension of the leg, knee, pelvis (Bobath, 1990). The purpose of these exercises is to encourage the patient to practice normal patterns of movement and avoid further spasticity. Bobath (1990) insists that it is essential that the patient begin to walk independently only when normal patterns of movement occur without signs of spasticity. Once the patient can use normal patterns the physiotherapist then proceeds to teach the patient to sit and stand.

In the recovery stage, a stroke patient who has done well in treatment can walk independently unaided by a cane and have considerable use of the hemiplegic arm and hand (Bobath, 1990). In this stage, the risk of spasticity can still occur when the patient walks quickly, uses effort, and becomes excited thereby causing deterioration of coordination. To improve or fine tune gait the physiotherapist will work on the patient's ability to balance while standing in place and while moving. The patient achieves independence by practicing selective movements of the pelvis, knees, and dorisiflexion/plantarflexion of the ankle and toes (Ibid.). An example exercise is for the patient to practice balancing on the unaffected leg while moving a small trolley or skateboard with the affected leg and foot. Another example exercise is to have the patient step forward and backward with assistance from the physiotherapist using small steps to practice heel to toe walking. Each exercise and treatment in the recovery stage performed is to ensure the patient learns to correct abnormal movement and posture with minimal assistance from the therapist or other aide such as a tripod cane.

It is important to note that Bobath (1990) discusses the concept of hemiplegic treatment in stages but acknowledges that the three stages overlap. For example, some spasticity may be present in the flaccid stage and that independent movement in the spastic stage may exist depending on the patient's phase of recovery. In addition, Bobath (1990) suggests that the earlier treatment is initiated the better rehabilitation outcome for stroke patient. A positive impact of NDT is that practice will aid the patient to continue the use of normal posture outside of the therapy session in a challenging and structured environment such as conducting therapy in the patient's room to improve the patient's ability to perform everyday activities (Davis, 1996).

Motor Relearning Programme (MRP)

Carr and Shepherd (1987) developed the MRP method to provide a physiotherapy program for stroke patients that is task oriented and context specific. Based on a distributed model of biomechanical theory, Carr and Shepherd (1987) state the main concern is the length of muscles and the ways in which the stroke patient can relearn motor control. Therefore, physiotherapists place emphasis for treatment on practicing specific motor tasks, training of controlled muscle action, and control over the components of movement for the tasks. Carr, Shepherd, and Ada (1995) suggest the negative features that should be addressed are areas of weakness and loss of dexterity. To do so, specific movement components for a task are broken down for the stroke patient to relearn the movements he or she had prior to the stroke. The objective of rehabilitation in the MRP method is to train or retrain the stroke patient to improve motor control when performing tasks or essential actions.

In order to address ways to promote relearning of motor control the stroke patient should be an active participant. In MRP, it is critical that the stroke patient takes an active role because a negative experience in rehabilitation will affect the patient's recovery (Carr & Shepherd, 1987). Therefore, the MRP intervention strategy involves goal setting with the patient in order to obtain active participation. Physiotherapists organize and negotiate daily routines with the patient to ensure continual movements to prevent adaptive shortening of soft tissues (Ibid.). To encourage active participation of the stroke patient

the stroke patient practices different tasks both inside and outside of therapy sessions.

After the patient and the physiotherapist negotiate goals and routines, the patient begins to practice specific tasks with the physiotherapist. The tasks or motor skills practiced are everyday activities that the stroke patient has identified as being important and had meaning prior to the stroke. Possible everyday activities are moving from a seated to a standing position, walking, or reaching for an object such as a cup or a hairbrush (Carr *et al*., 1994). While the stroke patient practices and relearns the tasks and goals, the physiotherapist provides verbal feedback in the form of cues. Overtime the physiotherapist steps back to encourage the stroke patient to problem solve through tasks. However, the physiotherapist remains active throughout the rehabilitative process to ensure proper alignment of both the affected and unaffected sides of the stroke patient. The physiotherapist cues the patient regarding proper alignment when practicing and the patient actively incorporates alignment principles when attempting tasks (Carr & Shepherd, 1987).

In addition to goal setting, practice, and feedback, the MRP method incorporates the use of structured and challenging environments. The environment is not adaptive where the stroke patient uses tripod canes or other devices to adapt to hemiplegia. The environment is structured so that the stroke patient learns to eventually be independent in environments where everyday tasks are conducted (Carr & Shepherd, 1987). The stroke patient practices moving from a seated position to a standing position not just in the therapy department but practices in their room. For example, the stroke patient can practice sitting on and standing up from a toilet equipped with a raised seat. After practicing with proper body alignment of the affected and unaffected sides, the equipment is lowered on the toilet and eventually removed. The intent is for the structured environment to be reduced so that the patient becomes more independent and not predominantly reliant on adaptive equipment (Ibid.).

Another important element of the MRP method is to initiate active rehabilitation as soon as possible from the onset of stroke (Carr *et al*, 1994). An early discussion regarding the stroke patient's goals not only invites active participation but also promotes and facilitates an

atmosphere of relearning and continual practice. Carr and Shepherd (1987) stress that in the MRP method stroke patients conduct and practice different tasks throughout the day. The objective is to practice different tasks in real life or everyday situations in order to increase independence of stroke patients before they return to a home-like environment.

Similarities and Differences between NDT and MRP Methods

There are two main differences between the NDT and MRP methods. First, different theories of recovery post stroke underpin each method. NDT is based on a neurophysiology hierarchical model of neural recovery. Bobath (1990) suggests, "the abnormal types of postural tone and the stereotyped total motor patterns we see in our patients are the result of disinhibition, i.e. of a release of lower patterns of activity from higher inhibitory control". This disinhibition creates a release of tonic reflexes such as spasticity and related abnormal movement. Thus, treatment in the NDT method focuses on minimizing spasticity, abnormal movement, and abnormal postural tone. Conversely, Carr and Shepherd (1987) disregard this hierarchical model and embrace a biomechanics or theory of distributed control. The stereotyped post stroke movements may have a neural and musculoskeletal component and as such prolonged periods of inactivity and improper therapy techniques may increase the risk for abnormal muscle control and soft tissue contractures (Lettinga, *et al.*, 1999). The MRP method focuses on motor learning theory and assumes that the active practice of a task is remedial. The stroke patient has potential to relearn motor skills that he or she was once able to perform prior to the stroke.

Second, the NDT and MRP approach to physiotherapist involvement in the treatment of stroke patients is different. In the NDT method, the physiotherapist facilitates functional movement by manually placing the stroke patient's joint into a neutral posture (Bobath, 1990). This is done to prevent or reduce spasticity and abnormal movements while in therapy and while in a structured environment. The stroke patient performs certain exercises with the physiotherapist who manually corrects abnormal movements and postures. The physiotherapist facilitates continual normal movements

each time the patient exercises in preparation to move an arm, leg, or walk. In addition, the Bobath physiotherapist insists that the patient should not exert too much effort during therapy sessions as this leads to increased spasticity. On the other hand, the MRP method creates an atmosphere of learning where the patient receives feedback from the therapist in the form of cues such as promoting active effort when practicing activities. Initially, the physiotherapist observes the stroke patient performing a task and determines if the patient is conducting normal or compensatory movements. The physiotherapist instructs the stroke patient to practice any missing steps of the activity and then the whole activity. If spasticity occurs the physiotherapist provides verbal feedback and assists the stroke patient to problem solve activities in different environments until the task is retained (Carr & Shepherd, 1987).

In addition to the theoretical and treatment differences, NDT and MRP share three similar practice assumptions. First, both the NDT and MRP method reject an adaptive environment that uses adaptive equipment in stroke rehabilitation (Lettinga *et al.*, 1999). NDT and MRP methods support a structured and challenging environment that encourages the patient to use his or her hemiplegic side in daily exercises, activities, or tasks (Carr & Shepherd, 1987; Bobath, 1990). Second, the NDT and MRP methods encourage and promote symmetrical body movements. Both of these methods share a common goal, which is "the best possible recovery by training the integration of the hemiplegic side in functional tasks in order to improve the quality of independence" (Lettinga *et al.*, 1999). In fact, the success of the stroke patient depends greatly on the integration of normal movement and body alignment when performing exercises for movement or daily tasks.

Third, the NDT and MRP methods assume similar beliefs regarding when and where stroke rehabilitation occurs. NDT therapy is conducted in three stages and should be initiated as early as possible in the stroke patient's recovery. If therapy starts in the initial flaccid stage of recovery, the slow progression of spasticity can be reduced and prevented (Bobath, 1990). In the MRP method, Carr and Shepherd (1987) clearly argue for early rehabilitation to initiate the relearning process. Stroke patients prevent the learned non-use of the affected

side and reduce soft tissue contractures by starting early to relearn normal movements while performing daily tasks. In addition, both methods support the belief that consistent therapy inside and outside of therapy sessions improves stroke rehabilitation outcomes. In fact, Carr and Shepherd (1987) state that "time spent in individual therapy sessions without further practice throughout the rest of the day should be considered as time wasted" (p. 14). Both Carr and Shepherd (1987) and Bobath (1990) believe that rehabilitation throughout the day and night should become a way of life for the stroke patient and the rehabilitation team. Furthermore, all members of the team including nurses and families can ensure consistent rehabilitation for stroke patients. Bobath (1990) suggests that nurses have a critical role to play in the rehabilitation of patients who rely on a wheelchair or are bed bound requiring further nursing care. Carr and Shepherd (1980) also advocate consistent understanding and reinforcement of patient goals by the therapist, nurse and family throughout the day and night.

Review of Research Evidence

According to Shah (1998), controversy exists regarding which stroke rehabilitation therapy produces improved stroke recovery. A Canadian research group suggests that the Bobath approach provides a foundation from which the stroke patient's ability during therapy may be evaluated (Corriveau *et al*., 1988, Guarna *et al.,* 1988; Corriveau, *et al.*, 1992). However, authors reviewing research that compared NDT to other treatment strategies such as MRP, the Brunnstrom technique, or traditional adaptive physiotherapy, agree that the methods provide similar outcome post stroke and one method is not clinically superior to another (Hiraoka, 2001; Paci, 2003; Luke, *et al.*, 2004). In a review conducted by Lettinga *et al*. (1999), the authors concluded that MRP is complementary rather than superior to NDT. In addition, Paci (2003) concluded that evidence does not exist indicating that NDT is superior to other methods, but cautioned that NDT methodological merit should not be discarded.

In addition to reviews exploring different therapy methods for stroke rehabilitation, research also specifically compared NDT or Bobath (1990) method and the MRP method developed by Carr and Shepherd (1987). Similar to the review authors' conclusions,

comparisons conducted by two groups of researchers of NDT and MRP revealed controversial conclusions. First, in a double blind randomized controlled trial (RCT) conducted by Langhammer and Stranghelle (2000), 61 acute first-ever stroke patients were randomized into two groups based on gender and site of hemiplegia. Thirty-three patients received MRP therapy and twenty-eight patients received Bobath/NDT therapy post acute stroke. Outcome measures used in this study assessed motor function (Motor Assessment Scale-MAS, Sodring Motor Assessment Scale-SMES), activities of daily living (Barthel ADL Index), and life quality using the Nottingham Health Profile (NHP). Other outcomes included were length of stay in hospital, use of assistive devices, and patient accommodation after returning to home. The findings of this study revealed that both the NDT and MRP groups improved in MAS and SMES but the MRP group significantly improved in relation to overall motor function (p=0.05). In addition, the authors found that the average length of stay was lower in the MRP group compared to the NDT group (21 days compared to 34 days, p=0.008). The authors of this randomized controlled study concluded that different physiotherapy approaches, in this case MRP, affect the results of early rehabilitation of stroke patients (Langhammer & Stranghelle, 2000).

Nevertheless, Bobath supporters have challenged the Langhammer and Stranghelle (2000) study for two important reasons. First, it is suggested that Langhammer and Stranghelle (2000) have misrepresented NDT in terms of the theoretical framework and ability to use the therapy because they did not acknowledge that the Bobath concept has evolved since the 1990 Bobath publication (Barrett, *et al.*, 2001; Paturnin, 2001; Brock, *et al.*, 2002). In a focus group study conducted by Lennon and Ashburn (2000), the authors concluded that the Bobath concept evolved since the last publication in 1990. The authors organized expert physiotherapists into two focus groups by area of interest (neurology and elder care) and gave critical questions for group discussion. Both groups agreed that the basic principles of the treatment had somewhat changed, but differed regarding use of the therapy. The neurology group, comprised of Bobath purists, concentrated their key assumptions on control of tone and on preparation. Conversely, the elder care group focused on 'task

specific practice' and goal setting. It is this study by Lennon and Ashburn (2000) that challengers refer to in order to argue the worth of the Langhammer and Stranghelle (2000) study. Second, Gustavsen, *et al.,* (2002) assert that data comparing the NDT and MRP did not support MRP as a favorable therapy over NDT. Gustavsen *et al.* (2002) assert that the results indicate that the NDT group caught up to the MRP group in treatment outcome. However, depending on the interpretation of the study results both Langhammer and Stranghelle (2000) and Gustavsen *et al.* (2002) study conclusions are possible.

In a follow up RCT conducted by Langhammer and Stranghelle (2003) patients were contacted one and four years post stroke to investigate whether the NDT (n = 28) or MRP (n = 33) group had long term effects on mortality, motor function, activities of daily living, postural control, life quality, and use of community services. Using the same outcome measures from the earlier Langhammer and Stranghelle (2000) RCT (MAS, SMES, Barthel ADL Index, and NHP), Langhammer and Stranghelle (2003) measured motor function, activities of daily living, and life quality. Findings from this study indicate that mortality rates were similar in the NDT group and the MRP group by one and four years. As well, motor function was also similar in both groups and the use of assistive devices increased by 50 per cent in year 1 and 60 per cent by year 4. The authors found no differences in perceived life quality between groups but they note that life quality perceived from year one to year four improved (NHP for NDT, year 1 = 14, year 4 = 13; NHP for MRP, year 1 = 14, year 4 = 13). The researchers found an increased dependence on family members and revealed a gap between treatment and follow-up post stroke. Nevertheless, conclusions could not be made indicating that either the NDT or MRP methods were superior.

The second group of researchers to compare the Bobath/NDT and MRP methods is van *et al.,* (2005). Using a single blind RCT, van Vliet *et al*. (2005) compared the Bobath or NDT approach with a movement science approach based on Carr and Shepherd (1987). The purpose of this study was to evaluate the effect of NDT and a MRP approach on movement abilities and functional independence. van Vliet *et al*. (2005) randomized 120 stroke patients admitted to a stroke rehabilitation unit to either the NDT or the MRP groups. The

primary outcome measures used at baseline and at 1, 3, and 6 months are the Rivermead Motor Assessment and the Motor Assessment Scale (MAS). Secondary measures in the study included assessed walking speed, arm function, muscle tone, sensation, and functional independence. The Rivermead Assessment Scale and the MAS significance scores ranged from p = 0.23-0.97 and p = 0.29-0.87 respectively. The researchers concluded that there were no differences between groups in terms of movement abilities and functional independence, indicating that neither the NDT nor MRP is clinically superior.

Utility of Rehabilitation Therapies in Elderly Stroke Survivors

Current research including studies related to NDT and MRP is limited regarding ways in which elderly stroke patients are consistently offered rehabilitation. In fact, of the studies presented in this article none addressed how NDT or MRP could enhance the quality of life of the elderly stroke patient. Most included specific rehabilitation to those elderly patients with mild to moderate stroke deficits that could access a rehabilitation facility or sub acute stroke rehabilitation program (Carr & Sheppard, 1987; Bobath, 1990; Lennon, 2003; Langhammer & Stranghelle, 2003). Chronic stroke patients who typically reside in a long term care facilities due to significant disability require rehabilitation, but the question is: where does the elderly chronic stroke population receive rehabilitation?

Upon review of the literature, three research studies addressed the rehabilitation of elderly people living with chronic stroke. Ng and Hui-Chan (2005) used a cross sectional design to investigate whether a novel rehabilitation test entitled 'Timed Up and Go' or TUG was reliable to assess the mobility of patients with chronic stroke. The participants in the study included 10 healthy elderly patients and 11 patients ranging from 50–67 with chronic stroke. The researchers determined that the TUG test was reliable to differentiate between healthy elderly and those with chronic stroke (ICC > 0.95). Despite this finding, two issues are important to note. First, the study had a small sample size and was not a pilot study, therefore the findings may not be as generalizable as the researchers suggest. Second, the chronic stroke patients were seen in a rehabilitation centre as inpatients and does not address using the TUG test in a long term care facility where most chronic stroke patients live.

A similar study conducted by Kong and Yang (2006) sampled 100 elderly chronic stroke patients living at home who used outpatient rehabilitation services. Using a cross sectional design they sought to determine health-related quality of life (outcome measures: Short form health Survey (SF–36), Modified Barthel Index (MBI), and Becks Depression Inventory (BDI)) post stroke related to rehabilitation outcomes. The researchers found that a significant proportion of chronic stroke patients seeking rehabilitative care face both depression and physical disability as indicated by lower SF–36 scores (p, 0.001) in those who were depressed. It is unclear by these results whether patients who lived in a long term care setting would have similar health-related quality of life outcomes.

Finally, Denti, *et al.,* (2008) sought to identify outcome determinants for elderly stroke patients undergoing inpatient rehabilitation. The researchers established that both frequency of home discharge (79% of participants were discharged home) and functional ability as indicated using the Functional Independence Scale (FIM), were important outcome measures indicative of beneficial rehabilitation. The findings for this study are generalizable but not for chronic elderly patients who live in long term settings who require continued stroke rehabilitation. It is clear that further research is required to determine whether or not elderly patients living with chronic stroke deficits could benefit from rehabilitation such as NDT or MRP offered in long term care settings.

Conclusion

Controversy exists within the clinical and research community related to superiority of the NDT or MRP methods for stroke rehabilitation. The mixed conclusions presented by researchers regarding the effect of different therapies on the rehabilitation of stroke patients indicate that more research is required to determine if different therapy approaches effect motor movement post stroke. As well, more research is needed to address whether it is important to tailor therapy for elderly with stroke and related chronic deficits in long term settings. It is important to determine if the elderly in long term care are receiving adequate rehabilitation in order to meet their needs. This needs to be addressed for this population before therapy departments

and organizations choose either NDT or MRP as the primary therapy for chronic stroke patients.

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Cultural Values and Family Caregiving for Persons with Dementia

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ABSTRACT

The increasing prevalence of dementia highlights the continued importance of family caregiving to society. Increasing ethnocultural diversity of the older population means that it is important to understand how culture influences dementia caregiving. This paper reviews evidence about the influence of cultural values such as familism and filial piety on the process of caregiving. Three hypotheses based on the Sociocultural Stress and Coping Model (Knight & Sayegh, 2010) and stress, coping, and adaptation theory (Lazarus & Folkman, 1984) are examined. It is hypothesized that cultural values influence caregiver well-being indirectly through their influence on: (1) burden appraisal; (2) social support; and (3) coping. A review of reviews, supplemented by recent research about cultural values and family caregiving revealed some support for the first and third hypothesis. Research about social support and cultural values was rare. Overall, research that measures cultural values is limited and further research is needed.

Key Words: Caregiving, Culture, Ethnicity, Dementia

As a result of the ageing population, the prevalence of dementia is increasing (Alzheimer Disease International, nd). This increase in dementia prevalence amplifies the importance to society of family caregivers for persons with dementia. Some research suggests that the meaning of family caregiving may be ethnoculturally based (Dilworth-Anderson *et al.*, 2002; Nápoles *et al.*, 2010). Given the increasing ethnocultural diversity among older adult populations in many countries (e.g., Vincent & Velkoff, 2010; Touhy *et al.*, 2012; Katbamna & Matthews, 2006), understanding how cultural values influence caregiving is necessary in order to provide effective supports and services for persons with dementia and their family caregivers.

This paper reviews theory and research literature about ethnocultural aspects of dementia caregiving, focusing on evidence about familism, filial piety, and reasons for caregiving. Background information is provided about dementia caregiving and about ethnicity and culture in caregiving research. A stress and coping theoretical model of family caregiving, incorporating cultural values, is described. According to this model, cultural values influence outcomes for caregivers indirectly through their influence on caregiving appraisal, social support, and coping. A review of reviews, supplemented by recent research about cultural values and caregiving, summarizes evidence for each of these three pathways. Implications for future research are discussed.

Dementia Caregiving

Globally, by the year 2050 there will be 115.4 million people living with dementia (The Alzheimer's Society of Canada, 2011). Family caregiving is essential, both at home in early and middle stages of the dementia (Schulz & Martire, 2004) and continuing in later stages, even if the person with dementia is admitted to a nursing home (The Alzheimer Society of Canada, 2011). Most care is provided by informal caregivers, usually their spouse or adult child. In Canada, the total number of hours of informal care for persons with dementia is predicted to rise from 231 million hours in 2008 to 756 million hours by 2038 (The Alzheimer Society of Canada, 2011). Caregiving tasks vary over the course of dementia but generally caregivers provide social support, provide structure, supervise medical treatments, assist

with activities of daily living, and, eventually provide for physical care needs and supervise and ensure quality of paid care (Smale & Dupuis, 2004; McCleary *et al.*, 2005). Caregiving is associated with negative health outcomes including distress, depression, anxiety, and physical health problems (Schulz & Martire, 2004).

In many countries, the older population is increasingly ethnoculturally diverse. Visible minorities account for 9 per cent and 13 per cent of those aged 65 and older in Canada (Toughy *et al.*, 2012) and the USA (Vincent & Velkoff, 2010), respectively. Immigrants account for one third of Canadians over the age of 65 (Ng, 2010). Ethnocultural diversity of the aging population is important to consider for planning effective services for persons with dementia and their caregivers because ethnocultural factors can affect the caregiving experience and access to services. Several studies have noted less use of formal services by ethnic minority caregivers. Explanations for this include care providers' false beliefs that ethnic minorities would not access services due to values for family care (Bowes & Dar, 2000), lack of awareness of service and barriers to accessing them (Koehn *et al.*, 2012), stigma, language barriers, and hesitancy to use services that are regarded as culturally inappropriate (Daker-White *et al.*, 2002).

Measuring and Defining Ethnicity and Culture

Within the literature about dementia caregiving, as within the broader health literature, there is variability in definitions and measures of ethnicity and culture. It is not always clear what is meant by the term ethnicity in the research literature, which can lead to confusion (Singh, 1997). Ethnicity, or ethnic identity, is "part of an individual's self-concept that derives from his or her knowledge of membership in a social group (or groups) together with the value and emotional significance attached to that membership" (Tajfel, 1981, cited by Phinney, 1992, p. 156). Phinney (1992) suggests that measuring ethnic identity is more complex than asking a person what their ethnic origin is; in addition to self-identification with the ethnic group, ethnic identity measures should attend to sense of belonging to the group and attitudes towards the group. Such complex measures of ethnic identity were not identified in family caregiving literature

reviews. However, qualitative research has examined ethnic identity in relation to caregiving motivations (e.g., Willis, 2012).

Culture refers to "the distinctive ideas, customs, social behaviour, products, or way of life of a particular nation, society, people, or period" (OED Online, 2012). Cultural values and beliefs are intergenerationally transmitted and are associated with health behaviour (Egede, 2006). Culture is more complex than ethnicity, with considerable cultural diversity within ethnic categories (Ibid.). When researchers study relationships between caregiving and cultural factors such as language or immigration experience, it is a challenge to sort out the effects of ethnic or cultural differences from the effects of barriers to accessing support and services, such as not speaking the majority language (Torres, 2001; Koehn, 2009).

Most of the caregiving research uses ethnic origin, race, or ethnic minority status as a proxy for the multidimensional constructs ethnicity and culture. Ethnic origin is a person's self-identification with a particular ethnic category. Examples of ethnic categories in dementia caregiving research include: Hispanic, African-American, Chinese, Asian, and European. Comparison between groups based on ethnic origin or race are common in dementia caregiving research. Both ethnic origin and race are problematic as indicators of culture and ethnicity. The simple categorization masks variability of both ethnicity and culture within ethnic origin and race categories. Furthermore, when associations between ethnic origin or race and aspects of caregiving are tested, much of the research is unable to disentangle the confounding effects of variables that are simultaneously associated with both ethnic origin/race and health outcomes (e.g., socioeconomic disadvantage, inaccessible health and social care services, effects of minority status).

Research about culture and caregiving is less common than research about ethnic origin and caregiving. The most commonly examined aspects of culture are cultural values of familism and filial responsibility or filial piety (Nápoles *et al.*, 2010). Culturally-based beliefs about the meaning of mental illness and dementia have also been studied, particularly in relation to receiving a diagnosis and help-seeking (Milne & Chryssanthopoulou, 2005).

Familism "refers to strong identification and solidarity of individuals with their family as well as strong normative feelings of allegiance, dedication, reciprocity, and attachment to their family members, both nuclear and extended" (Sayegh & Knight, 2010, Ibid.). Familism can be measured as global concept. However, Sayegh and Knight (2010) argue that it is multidimensional, with subcomponents that may have differential impacts on caregiving. The subcomponents of familism are: family obligation (obligation to provide caregiving for family members); support from the family (expectation of support from family members when needed); and family as referents (rules about how life should be lived derived from the family) (Ibid.). Familism is an important aspect of what some of the caregiving literature refers to traditional vs. less traditional beliefs about caregiving. More traditional beliefs about caregiving involve expectations that families will provide care (Aranda & Knight, 1997; Rozario & DeRienzis, 2008). In a review of cross-cultural comparisons of familism among dementia family caregivers, Knight and colleagues (2002) found that familism was associated with acculturation to the Western value of individualism. The lowest levels of familism were found in White American samples, followed by African American, Japanese American, Korean American, Latino American, and Korean samples.

Filial piety is a fundamental value in Confusian ethics that requires respect for parents and placing family needs over individual needs. It involves "concern for parental health, financially supporting parents, fulfilling the housing needs of parents, and respect for parental authority" (Lai, 2010, Ibid.). It is a key value in Asian culture. Similar values are part of other cultures and religions (Bergman *et al.*, 2012). In Western culture, filial piety includes reverence for parents; gratitude and repaying a debt of gratitude to parents for their care; and expressing love and friendship for parents through care (Dai & Dimond, 1998). A meta-analysis of ethnic differences in family caregiving found that filial piety is higher in ethnic minority caregivers (Pinquart & Sörensen, 2005). In the caregiving literature, filial piety has been measured using general measures of filial piety and, more recently using a measure developed specifically for caregivers, the Cultural Justification for Caregiving Scale (CJCS, Dilworth-Anderson

et al., 2005). Items in the CJCS combine elements of filial piety and familism.

Sociocultural Stress and Coping Model of Caregiving

The dominant theoretical model of family caregiving is the stress process model (Pearlin *et al.*, 1990) an adaptation to family caregiving of Lazarus and Folkman's (1984) theory of stress, coping, and adaptation. A recent conceptual model of culture and caregiving (Knight & Sayegh, 2010) adapts Lazarus and Folkman's (1984) theory. Figure 1–1 is a diagram of stress, coping, and adaptation theory, including modifications suggested by Knight and Sayegh (2010) and specification of cultural values within characteristics of the caregiver. Modifications to the model to include cultural values are represented through italics. Larger arrows in the diagram indicate relationships between cultural values and other elements of the model.

Figure 1
Stress, Coping, and Adaptation Theory of Family Caregiving
Including Cultural Values
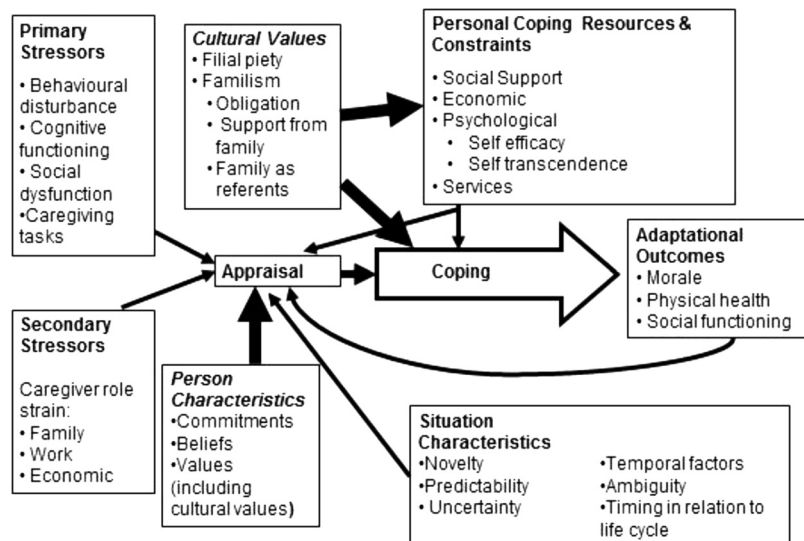
In this theoretical model, caregivers experience primary stressors due to the person with dementia's cognitive status, behaviours, and care needs. According to Pearlin *et al.* (1990), caregivers also experience secondary stressors due to impact on social roles (role strain). A potential stressor, such as the person with dementia's diminished ability to manage finances or behavioral changes, is a stressor if the caregiver appraises it as taxing or exceeding their resources or endangering their well-being (Lazarus & Folkman, 1984, Ibid.). Appraisal is influenced by characteristics of the caregiving situation (e.g., novelty, predictability, uncertainty, and duration); other events and timing in the caregiver's life cycle; the caregiver's resources (both intrapsychic and tangible) and constraints on using resources; and characteristics of the caregiver (e.g., age, gender, kin relationship, commitments, values, and beliefs) (Lazarus & Folkman, 1984). Caregiver characteristics include culturally based values and beliefs.

If the caregiver appraises the situation as stressful, the caregiver does something to try to cope with the situation. Coping is "constantly changing cognitive and behavioural efforts to manage specific external or internal demands (that are appraised as stressful)" (Lazarus & Folkman, 1984). Coping is categorized into two broad categories, emotion-focussed coping, when the caregiver seeks to lessen emotional distress; and problem-focused coping, when the caregiver tries to alter or manage the problem. A commonly used measure of coping in caregiving research has two factors, avoidant coping, which is a form of emotion-focused coping; and active coping, a form of problem-focused coping (Carver, 1997). Caregiver outcomes, including social functioning, morale, and physical health, are influenced by the effectiveness of the coping efforts. Caregiving research has primarily focused on aspects of morale (e.g., mental health, psychological distress, and caregiver burden) and, to a lesser extent, on physical health. Like appraisal, coping is influenced by the caregivers' resources and constraints on using resources. Coping is continually revised based on reappraisal of whether there is still a stressful situation (Lazarus & Folkman, 1984).

The Sociocultural Stress and Coping Model (Aranda & Knight, 1997; Knight & Sayegh, 2010) assumes that the stress and coping model is relevant across cultures. This is consistent with findings within various ethnic or cultural groups that the stress process model explains

relationships between dementia symptoms and behaviours as stressors, with higher levels of burden appraisal associated with worse health outcomes (Knight & Sayegh, 2010). The model focuses on how cultural values influence the stress coping process. It explains how cultural differences in outcomes or the process of stress and coping. In this model, cultural values such as familism and filial piety have a direct influence on coping and social support, which, in turn, have an influence on caregiver health.

Thus, according to stress, coping, and adaptation theory and the Sociocultural Stress and Coping Model, caregiver outcome is indirectly influenced by cultural values, through the influence of cultural values on: (1) appraisal of the caregiving situation; (2) social support; or (3) coping.

Review of the Literature

The following sections present the findings of a review of evidence about the influence of cultural values on caregiving. We conducted a review of reviews and a review of select relevant primary research. The review of reviews approach was used because there is a large amount of primary research about ethnic differences in dementia caregiving that has previously been reviewed for other purposes. Findings of these reviews are relevant to understanding the sociocultural stress and coping model. Most research compares ethnic or racial groups, with less research explicitly measuring cultural values. Thus, the review of reviews is supplemented by a review of highly relevant recent primary research that measured cultural values.

The search strategies were similar for identifying reviews and primary research. Medline, psychINFO, CINAHL, and Web of Science databases were searched using subject headings and key terms dementia, Alzheimer's disease, ethnicity, caregiving, culture, ethnic, cultural, and values. Reviews were also identified by scanning reference lists. To identify reviews, the publication type was limited to systematic reviews, literature reviews, or meta-analyses. The search identified 13 narrative literature reviews (Gonzales *et al.*, 1995; Connell & Gibson, 1997; Aranda & Knight, 1997; Braun & Browne, 1998; Dilworth-Anderson & Gibson, 1999; Janevic & Connell, 2001; Dilworth-Anderson *et al.*, 2002; Knight *et al.*, 2002; Milne & Chryssanthopoulou, 2005; Chan, 2010; Knight & Sayegh, 2010;

Botsford *et al.*, 2011; Sun *et al.*, 2012), 2 systematic reviews (Daker-White *et al.*, 2002; Nápoles *et al.*, 2010), and 1 meta-analysis (Pinquart & Sörensen, 2005).

Much of the research that measured cultural values was not included in the reviews because of publication after dates for inclusion in the reviews. For example, the Cultural Justifications for Caregiving Scale (CJCS, Dilworth-Anderson *et al.*, 2004) that measures cultural values and beliefs about caregiving is a recently published measure. Because of our focus on cultural variables, we also included recent publications of primary research that used the CJCS or other measures of familism or filial piety (Dilworth-Anderson *et al.,* 2004; Dilworth-Anderson *et al.*, 2005; Lai, 2010; Sayegh & Knight, 2010; Siegler *et al.*, 2010; del-Pino-Casado *et al.*, 2011; Romero-Moreno *et al.*, 2011; Khalaila & Litwin, 2011; Koerner & Shirai, 2012; Liu *et al.*, 2012). The objective of this review is to summarize evidence about three pathways through which cultural values theoretically influence caregiver wellbeing: (1) by influencing stress and burden appraisal; (2) through their association with social support; and (3) through their association with coping.

Cultural Values and Stress/Burden Appraisal

Findings from early research that compared caregivers based on their ethnic background or race suggests that there may be some differences in appraisal of caregiving as stressful. However, several reviews noted that evidence about differences in stress appraisal are equivocal because of problems with research design, measurement, and failure to account for important confounding effects (Gonzales *et al.*, 1995; Aranda & Knight, 1997; Connell & Gibson, 1997; Botsford *et al.*, 2001; Daker-White *et al.*, 2002; Dilworth-Anderson *et al.*, 2002).

Recent research measuring cultural values provides some evidence of an association between cultural values, stress appraisal, and caregiver well-being. In a review of research, Knight and Sayegh (2010) found that familism was not associated with caregiver burden appraisal. They hypothesized that these findings may result from measures and analyses that do not take into account the multidimensional nature of familism.

del-Pino-Casado *et al.* (2011) examined relationships between two facets of familism, reciprocity and obligation, and the extent to which

Spanish caregivers perceived of themselves as trapped by caregiving or felt that caregiving burden was excessive. Unlike most caregiving research that relies on convenience samples, this study used a large population-based sample. After controlling for duration of caregiving, intensity of care, and gender, obligation was not associated with burden appraisal. Reciprocity was negatively associated with burden appraisal. Caregivers who believed that the caregiving was gratifying reported lower levels of burden. These findings support the need to consider components of familism separately.

Liu *et al.* (2012) tested relationships between familism and other elements of the stress, appraisal, and coping model of family caregiving among dementia family caregivers in China. Higher levels of familism were associated with more caregiver satisfaction. Familism was not, however, associated with caregiver burden appraisal.

Three studies examined cultural values in samples of caregivers of older adults who may or may not have had dementia (Lai, 2010; Khalaila & Litwin, 2011; Koerner & Shirai, 2012). These studies are included in this review because they tested the stress and coping theoretical model of caregiving. Given the limited amount of research about cultural values in dementia caregiving populations, it is important to consider findings from closely related samples. None of the three studies reported the proportion of the sample providing care for persons with dementia.

Koerner and Shirai (2012) examined familism and caregiver outcomes in a sample of 67 Hispanic family caregivers. Familism and burden appraisal were assessed using validated measures. Familism was not significantly associated with burden appraisal.

Lai (2010) examined the relationship between filial piety and other elements of the stress-adaptation model of caregiving (caregiving tasks, burden appraisal, and caregiver burden outcome) in a random sample of Chinese-Canadian caregivers for older adults. Appraisal of burden was assessed based on perceived economic costs, satisfaction with caregiving, and perception that caregiving was worthwhile. In this study, caregiver burden was conceptualized as a caregiver outcome and was measured using a Chinese version of the Zarit Burden Interview (Chan, 2002, cited by Lai, 2010). Multivariate associations were tested using structural equations modeling. There was a direct

relationship between caregiving demands and caregiver burden appraisal. Filial piety was not directly associated with caregiver burden appraisal. It was indirectly associated with caregiver burden. Higher levels of filial piety were associated with positive appraisal (satisfaction with caregiving, perception that it is worthwhile, and economic costs of caregiving), which was, in turn, associated with lower levels of caregiver burden appraisal.

In the third study, Khalaila and Litwin (2011) investigated relationships between filial piety, perceived burden, and depression in a sample of adult children who were caregivers for older Arab-Israelis. Associations were tested using structural equations modelling. The model included amount of caregiving provided and care recipient needs. Lower levels of filial piety were associated with higher levels of burden assessment, which were, in turn, associated with higher levels of caregiver depression. Higher levels of filial piety were associated with larger family size, more needs of the care recipient, and higher number of hours spent caregiving.

In this section, research was reviewed for evidence about the hypothesized relationship between cultural values, caregiving stress appraisal, and indirectly, caregiver well-being. Findings of different associations between components of familism and burden appraisal (del-Pino-Casado *et al.*, 2011) support the importance of measuring components of familism. Two studies found that familism was not associated with burden appraisal (Koerner & Shirai, 2012; Liu *et al.*, 2012). These findings could possibly be explained by reciprocity and obligation components of familism having opposing effects on burden appraisal (Knight & Sayegh, 2009). Interestingly, both familism and filial piety were associated with the related concept, satisfaction with caregiving in two studies (Lai, 2010; Liu *et al.*, 2012), indicating a potential benefit of considering multiple ways of measuring burden appraisal. Higher levels of filial piety were associated with lower levels of burden appraisal in a Chinese Canadian sample (Lai, 2010) and an Arab-Israeli sample (Khalaila & Litwin, 2011). Khalaila and Litwin's (2011) findings that burden assessment mediated the relationship between filial piety and caregiver depression are consistent with the stress coping model of family caregiving.

Cultural Values and Social Support

This section reviews evidence of a hypothesized relationship between cultural values and social support that would ultimately affect caregiver well-being. Research has examined both formal support (from health and social care providers) and informal support for dementia caregivers. Research that compared caregivers based on their ethnic background or race found that ethnic minority caregivers tend to use less formal supports and may delay help-seeking early in the course of dementia (Dilworth-Anderson *et al.*, 2002; Milne & Chryssanthopoulou, 2005; Botsford, Clarke & Gibb, 2011; Sun *et al.*, 2012). A meta-analysis compared Asian, White non-Hispanic, Hispanic, and African American caregivers (Pinquart & Sörensen, 2005). Compared to White non-Hispanics, Asian caregivers used less formal services. There were no differences in service used for comparisons involving African American and Hispanic caregivers. Hypothesized cultural explanations for possible differences in formal support include tendency to use folk models instead of biomedical models to explain dementia symptoms, higher levels of stigma about mental illness, and greater tendency to attribute dementia to normal aging. However, the extent to which decisions related to initial help seeking are culturally explained is not clear (Koehn *et al.*, 2012). Delayed initial help seeking because symptoms are not recognized as dementia is common in non-minority samples (e.g., Bond *et al.,* 2005). Alternative explanations for delayed help-seeking or less use of formal services among minority caregivers include: priorities for other more pressing problems linked to inequalities (Daker-White *et al.*, 2002); language and cultural barriers in provision of formal supports and services (Dilworth-Anderson *et al.*, 2002; Sun *et al.*, 2012); and limited access to healthcare (Milne & Chryssanthopoulou, 2005).

There is limited research about specific cultural values and use of formal support services. Two studies of Korean and Korean American caregivers (Chun, 2004 and Kim, 2004, cited by Knight & Sayegh, 2010) found that higher levels of filial piety and East Asian values were associated with greater use of formal services. However, use of formal services was not associated with caregiver well-being and health outcomes.

With respect to informal social support, the reviews of research comparing caregivers based on ethnic background or race are mixed.

Narrative reviews of comparative research conclude that minority and non-minority caregivers use informal support similarly (Janevic & Connell, 2001; Dilworth-Anderson *et al.*, 2002). A meta-analysis found that compared to non-Hispanic White caregivers, minority caregivers (African-American, Hispanic, or Asian-American) had higher levels of informal support (Pinquart & Sörensen, 2005).

Chan (2010) suggests that family support may be a more important predictor of family burden in Chinese culture than in other cultures, possibly because of more dependence of the family for support and reluctance to share family problems with people outside the family. A review focused on Chinese American caregiving concluded that there is some evidence of insufficient family support for caregivers (Sun *et al.*, 2012).

Research about specific cultural values and informal support is rare. Knight and Sayegh (2009) report mixed findings from their review of cultural values and family support. Some research suggests that caregivers with high levels of the obligation component of familism are unlikely to perceive social support as available (Shurgot & Knight, 2005 cited by Knight & Sayegh, 2009).

This section reviewed evidence of a relationship between cultural values, social support, and, indirectly, caregiver well-being. There is very little research about familism or filial piety in relation to social support. Some evidence suggests that higher levels of filial piety are associated with more use of formal support and services (Knight & Sayegh, 2009). Cross-ethnic comparisons suggest that ethnic minority caregivers have more informal social support than non-Hispanic white caregivers do (Pinquart & Sörensen, 2005). However, there is insufficient evidence about possible relationships between informal support and cultural values.

Cultural Values and Coping

This section reviews evidence about the hypothesized relationship from cultural values to caregiver well-being, through the influence of cultural values on caregiver coping. Studies of differences between caregivers based on their ethnic background or race have identified differences in coping. There is inconsistency in findings of differences, possibly because of methodological limitations including small or non-representative samples, differences in methods of

measuring coping, and limited use of multivariate analyses to control for important confounding variables.

One of the most frequently studied aspects of coping is caregivers' reports of use of spirituality, religion, and faith (Nápoles *et al.*, 2010). Several reviews noted early research findings that compared to White caregivers, African American caregivers were more likely to use prayer, faith, and religion as part of coping (Gonzales *et al.*, 1995; Daker-White *et al.*, 2002; Nápoles *et al.*, 2010). A similar finding was noted for comparison of Latino and White caregivers, with Latinos more likely to use spirituality and prayer (Náploes *et al.*, 2010). However, there is some inconsistency in findings about religion and spirituality in relation to stress and coping (Dilworth-Anderson *et al.*, 2002). One study found that that self-perceived competence to cope with caregiving might have a stronger impact on outcome for African American caregivers than it does for White caregivers (Connell & Gibson, 1997).

Ethnic and racial group comparisons have also been made with respect to use of problem-focused or emotion-focused coping. African American caregivers may be more likely to use the emotion-focused coping strategy of positive reframing (Gonzales *et al.*, 1995). Compared to White caregivers, African American caregivers may be more likely to use emotion-focused coping strategies (Dilworth-Anderson *et al.*, 2002). Again, the findings are mixed. Some studies report more similarities than differences in comparisons of coping of African American and White caregivers (Connell & Gibson, 1997). Some studies report no differences in coping between ethnic groups (Janevic & Connell, 2001). A meta-analysis found that differences between ethnic minority and non-minority caregivers' coping were small (Pinquart & Sörensen, 1995). Minority caregivers used more emotion-focused coping strategies and there were no differences in use of problem-focused coping strategies. There were some inconsistencies when specific ethnic groups were compared, with differences between Asian Americans and African Americans.

Some research suggests that there may be differences in coping between Chinese or Asian American caregivers, African American caregivers, and non-minority caregivers (Janevic & Connell, 2001). However, Sun *et al.* (2012) concludes that there is insufficient evidence to make conclusions about culture and coping among Chinese

American caregivers. It has been argued that the dichotomy between emotion-focused and problem-focused coping, as conceptualized in stress and coping theory, may not be appropriate in Chinese or Asian cultures (Chan, 2010). This is consistent with Knight and Sayegh's conclusion "cultural values can shape the meaning of important constructs such as coping styles" (2010). Based on factor analysis of coping measures in different ethnic groups, they found that the meaning of coping and tendency to certain coping styles were different among Korean and Korean American caregivers than African American and White caregivers.

Ethnic group comparisons provide some evidence about the hypothesized mediating effect of coping on the relationship between cultural values and caregiver well-being. A comparison of Chinese and US caregivers (Shaw *et al.*, 1997 and Patterson *et al.*, 1998, cited by Janevic & Connell, 2001) suggests that there may be differences in how coping affects outcomes. That study found that coping strategies were associated with distress among American caregivers but not among Chinese caregivers. The emotion-focused coping strategy of avoidant coping was associated with higher levels of depression among American caregivers but not Chinese caregivers. Another study found that among African American caregivers but not White caregivers, emotion-focused coping was associated with higher levels of distress (Knight *et al.*, 2000, cited by Janevic and Connell, 2001). However, Pinquart and Sörensen (2005) found that there were too few studies of ethnicity, coping, and caregiver outcomes to conduct a meta-analysis of this more complex relationship.

There is some evidence about the association between cultural values, coping, and caregiver outcomes. In their review, Knight and Sayegh (2010) report conflicting findings about the possibility of cultural values influencing coping which in turn would influence caregiver outcome. A study of African American and White family caregivers found that higher levels of familism were associated with emotion-focused avoidant coping, which was, in turn, associated with poor caregiver health (Kim *et al.*, 2007, cited in Knight & Sayegh, 2010). Another study of Korean caregivers found that filial piety was associated with problem-focused active coping, which was, in turn,

associated with lower levels of depression (Chun, 2004, cited in Knight & Sayegh, 2010).

A study of Spanish dementia caregivers found that cultural reasons for caregiving were associated with an emotion-focused coping technique of reappraising the stressor by seeing the positive in negative situations (Romero-Moreno *et al.*, 2011). Cultural reasons for caregiving were measured using a revised version of the Cultural Justifications for Caregiving Scale (CJCS, Dilworth-Anderson *et al.*, 2005). "Because I have no alternative" was added to the scale as a reason for caregiving. The revised CJCS had two factors: intrinsic reasons, linked to the caregivers' values; and extrinsic reasons, linked to obligation and social pressure. Caregivers who had high levels of intrinsic personal values as reasons for caregiving and low levels of obligation and extrinsic reasons were more likely than other caregivers to use the emotion-focused reappraisal coping. Caregivers who had low levels of intrinsic personal values as reasons for caregiving and high levels of obligation and extrinsic reasons for caregiving had worse psychosocial outcomes. The research did not test pathways from cultural reasons for caregiving to coping to caregiver outcomes.

The finding that sense of obligation, a component of familism, is linked to worse health outcomes is consistent with findings from a longitudinal study of physical health of African American Caregivers (Dilworth-Anderson *et al.*, 2004). In that study, controlling for caregiver background, care recipient needs, and initial levels of psychosocial health, cultural justifications for caregiving were predictive of caregivers' psychosocial health 18 months later. This study used the original Cultural Justification for Caregiving Scale (Dilworth-Anderson *et al.*, 2005). Caregivers with very low or very high cultural justification for caregiving had worse psychosocial health at follow-up. Caregivers with moderate levels of cultural justification for caregiving had better psychosocial health. The authors' interpretation of this finding is that the caregivers with very low levels of cultural justification were providing care out of necessity, which could be related to worse psychosocial health, and that the caregivers with very high levels of cultural justification had a strong sense of obligation which might lead to engulfment in the caregiving role and also result in worse psychosocial health. Cultural justifications for caregiving were not associated with caregiver physical health.

Sayegh and Knight (2010) tested the effects of cultural justifications for caregiving and familism on coping and caregiver health in a probability sample of African American and White caregivers. A revised version of the Cultural Justifications for Caregiving Scale (CJCS, Dilworth-Anderson *et al.*, 2005) with the addition of two items, one about religious beliefs and the other about role modeling for one's children as reasons for caregiving. Structural equations modeling was used to test whether coping mediated relationships between cultural values and caregiver health. All analyses controlled for ethnic background, education, and age. Familial obligation was associated with emotion-focused avoidant coping, which was, in turn, associated with poor mental and physical health. Cultural justification was associated with problem-focused active coping. However, active coping was not associated with health outcomes. Cultural justification was associated with emotion-focused avoidant coping, which was, in turn associated with poor mental and physical health. Thus, these findings partially support the hypothesized pathway from cultural values, to coping, to caregiver outcomes.

In their study of familism and family caregiving among Chinese dementia caregivers, Liu *et al.* (2012) found that familism was not directly associated with coping. Coping was measured using a coping measure with two subscales, positive and negative coping. It is not clear how these subscales relate to coping as described in the stress and coping theoretical model. In tests of bivariate associations, higher levels of familism were associated with more positive coping. However, the results of structural equations modeling showed that the association between familism and coping was indirect. Familism was associated with caregiver satisfaction, which was, in turn, associated with positive coping. Positive coping was, in turn, associated with better caregiver psychological health.

This section summarized evidence about relationships between cultural values, coping, and caregiver well-being. Evidence from comparisons across ethnic groups suggests that there may be small differences, with ethnic minority caregivers using more emotion focused coping than non-minority caregivers do (Pinquart & Sörensen, 2005). Furthermore, specific coping methods may have differential effects on caregiver outcomes, depending on the ethnic

group (Janevic & Connell, 2001). The suggestion that the nature of coping in Asian caregivers is different than in White, Hispanic, or African American caregivers has not been investigated through research about specific cultural values.

Although the amount of research about cultural values and coping is limited, studies of coping were more likely than studies of social support or perceived burden to examine mediating effects. Several studies examined coping as a mediator of the relationship between caregiver values and well-being. The research suggests that higher levels of the obligation component of familism may be associated with emotion-focused avoidant coping and, in turn, with poor mental and physical health (Dilworth-Anderson *et al.,* 2004; Romero-Moreno *et al.*, 2011). Global measures of familism were associated with coping and poor caregiver health in two studies (Sayegh & Knight, 2010; Liu *et al.,* 2012). One study investigated filial piety, finding that high levels of filial piety were associated with problem-focused active coping and, in turn, with lower levels of depression (Chun, 2004, cited in Knight & Sayegh, 2010).

Methodological Limitations & Future Research

This review of reviews relied on existing reviews and recently published relevant research. For the most part, the reviews were narrative reviews that did not screen research for inclusion on the basis of methodological rigor. However, the reviews did point out the methodological challenges present in much of the caregiving research, including small convenience samples, differences in measures across studies, and, particularly in earlier research, failure to conduct multivariate analyses or control for important confounding variables. We did include a methodologically strong meta-analysis (Pinquart & Sörensen, 2005) and two systematic reviews (Daker-White *et al.,* 2002; Nápoles *et al.,* 2010).

Many of the reviews noted that comparisons across and within ethnic groups, with ethnic group used as a proxy for culture and ethnicity, were prone to findings that confused ethnicity or culture with health effects of oppression and barriers to accessing services and support. It is encouraging that recent research is measuring cultural values within and across ethnic groups. Three of these studies used

representative samples (e.g., del-Pino-Casado *et al.*, 2011; Khalaila & Litwin, 2011; Lai, 2010). Like much of the caregiving research, the remainder of the research about cultural values and caregiving relied on convenience samples that could be biased, which is less than ideal for illuminating effects of culture. A strength of several of the studies of cultural values and caregiving was their use of multivariate analytic techniques to test for causal pathways and control for confounding variables.

This review included three studies of caregivers of older adults who did not necessarily have dementia. Although it is likely that evidence about the stress and coping model of family caregiving from these studies is relevant to understanding dementia caregiving, further research with dementia caregivers is required.

Further research measuring specific cultural values is needed, both within ethnocultural groups and comparing across ethnocultural groups. As recommended by Knight and Sayegh (2010), future research should examine the cultural value of familism as a multi-dimensional construct. Research evidence about cultural values and elements of the stress and coping model of family caregiving is limited. We found very little research about social support, with more research about caregiver burden appraisal and coping. The possibility that coping may differ across cultures required further investigation.

Conclusion

There is a small but growing body of literature about the role of cultural values in caregiving. Like previous caregiving research, most of this research tests various aspects of a stress, coping, and adaptation theoretical model of family caregiving. By examining cultural values such as filial piety and familism within and across various ethnic groups, this research is beginning to bring a more nuanced under-standing of the role of cultural values in the process of caregiving.

This review focused on three possible pathways through which cultural values could influence caregiving well-being: (1) by influ-encing burden appraisal; (2) by influencing social support; and (3) by influencing coping. Overall, the evidence supports the adapted stress and coping theoretical model of family caregiving (see Figure 1). However, the evidence is limited. Although earlier research suggests

that social support for caregivers may vary across ethnic groups, there is insufficient evidence from research about cultural values to make event tentative conclusions about the second pathway (social support).

Global measures of familism were not associated with burden appraisal but were associated with coping and poor caregiver health. Future research should investigate burden appraisal and components of familism such as family obligation, support from the family, and family as referents, as suggested by Sayegh and Knight (2010). Research about family obligation suggests that high levels of family obligation may be associated with avoidant coping and poor caregiver well-being.

A few studies investigated filial piety. High levels of filial piety were associated with lower levels of burden appraisal (Lai, 2010; Khalaila & Litwin, 2011) and more use of problem-focused active coping (Chun, 2004, cited in Knight & Sayegh, 2010). Furthermore, both burden appraisal (Khalaila & Litwin, 2011) and coping (Chun, 2004, cited in Knight & Sayegh, 2010) mediated relationships between filial piety and caregiver well-being. These findings are consistent with the complex associations between cultural values and caregiver well-being in the stress, coping and adaptation theoretical model of family caregiving described in this paper.

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Reviving the Family Model of Care: Can it be a Panacea for the New Century?

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ABSTRACT

Issues of older people's care are in the spotlight of policy debate at the present time especially when the speed of social change is rapid and countries around the globe face financial hardship. Solutions are often explored around making families more responsible for the task of caring. However, questions are raised as to whether such policy shifts are based on the experiences of good practice or simply seen as a way to manage a crisis. In order to assess the feasibility of the family-based care model for the new century, a review has been undertaken regarding the past experiences and immediate challenges experienced in different cultural contexts and different parts of the world. This review is based on the published books, journal articles and reports pertinent to the theme and is followed by a discussion and conclusions. It was found out that there are diverse experiences and evidences suggesting positive and negative outcomes of family-based care. Changing social norms, issues of care-finance and inheritance, structural changes in families and migration have been identified as crucial factors which impact on the main subject. In conclusion it away be said that family support can still be a useful element in older people's care but it may be a risky approach to place excessive dependence on families for the care of older people. This review has identified some of the critical issues

that need to be addressed in the future policy work which is devising roles for families.

Key Words: Social Policy; Care; Older people; Family; Social Security

Along with the wave of modernisation and industrialisation, developed countries introduced different social security programmes for the wellbeing of vulnerable groups (including older people). Institutionalised care became an alternative to the home-based care of older people in many countries, something which largely relieved families from their traditional burdens in caring for their close elderly relatives. However, in recent times, there has been a desperate pursuit of maintaining the alternatives of both, i.e. the liberal social security approach as well as the institutionalised care of older people, as both of these have been seen to be problematic in different respects. On the other hand the demands inherent in older people's care have still remained largely within the family domain in many developing countries in Africa and Asia.

The mounting criticism against the quality of institutional care (mainly the issues of neglect and abuse of older people as well as the decline of their emotional health) (Spencer, 1994) and the notion of financial sustainability of liberal social security schemes have fuelled the debate and encouraged further the pursuit of alternative arrangements. In that endeavour, some countries have already introduced new policy measures that draw families back to the responsibility of care, for example in Sweden (Johansson, *et al.*, 2003) and in Japan (Ogawa and Retherford, 1993). In fact, the pursuits have gained momentum since 1982 when the World Assembly on Ageing strongly advocated the promotion of the family's primary role in older people's care. Similarly, several international organisations have also accepted 'family' as a strong institution able to cope with problems which are seen as having risen to unprecedented levels at the present time (UN, 2002; WHO, 2002).

There is a greater likelihood for many other developed countries to co-opt the policy of family-based care in the near future. However, questions have emerged as to whether these countries are adopting such polices to get rid of present, pressing problems or whether the shift is in fact evidence-based. Surprisingly, little discussion has taken

place about whether proposed policy shifts were based on lessons learned and whether they address the aspiration of inclusive societies for the future. Reviews of evidence to suggest whether such a reversal towards a family-based care-model will bear sustainable and desirable outcomes have also been scarce. In order to assist the potential policy shifts at global scale, a review of the present situation and past experiences and the assessment of the feasibility of revitalizing family models has become pertinent, which is the main purpose of this article.

Methods

Literature was searched using key search terms from electronic databases as well as google scholar. Electronic databases such as Academic Search Complete, ASSIA, Social Care Online, Sociological abstracts, Social services abstracts, CINAHL, PUBMed, MEDLine and Science Direct were used for this purpose and the review, apart from a few exceptions, included those articles which were published between 1990 and 2012. The searches were made using key terms such as: family, state, country, family-support, care, older people, elderly, care-finance, funds, quality of life, successful ageing, happiness, life satisfaction, adult children, friends, relatives, emotional, instrumental, culture, economic status and policy. The listed terms were searched either as keywords or in the titles of the documents. In the review/analysis phase, the identified literatures were pooled together and used to make a comprehensive picture of the issue under examination. Only those literatures which are critically important to illustrating negative or positive experiences of family based care are cited in the text. A further discussion explores whether family care can be a viable alternative for the new century. Politico-economic as well as socio-cultural differences between countries and continents were considered as pertinent. Along with highlighting positive and negative experiences of family-based care, the issues relevant for consideration in the proposed policy shift are also identified and discussed.

Family vs. Public Models of Care

There is a tendency in Western academia to present an idealised picture of family based care in non-Western countries (Merimann, 1984 cited in Stuart-Hamilton, 2000). Some native researchers from Southeast Asia are also found to exaggerate this ideal of family-based

care in those regions in light of the notion of Confucian heritage. In idealising the family for its role in caring older people, the disadvantages of the family as the primary care structure seem to have been overlooked. For example, in the case of a family in poverty or holding a low economic status, a family with some terminally ill members, children and/or disabled members or those with the experiences of migration may not be ideal for the care of older people. A presence or absence of particular members or kinsmen of the family would have significant impact on the quality outputs of care. Therefore, there is a risk and threat to the health, life and emotional wellbeing of older people in certain conditions, if policy takes an indifferent approach to all and puts too much pressure on the family for the care of older people.

On the other hand, it is not necessary to be overly critical of the public model of care for older people. Instead, it must also be evaluated in both its good and its bad aspects. In a case where the state is a liberal one and takes its share of the cost of the care, it may give huge relief to the poorer family to pay for the care of the older member of their family. There is research evidence that the supports and care provided by public sector complement to and fine tuned with the informal care from families (Johansson, *et al.*, 2003; Armi, *et al.*, 2008). Even when older people in their adult life have experienced difficulties and even misery, they can breathe a sigh of relief when the state pays for their care in their old age. This is an opportunity to free older people from the potential stress, tension and abusive relations with their younger family members, as has been reported in Asian countries. The state's involvement in care allows it to introduce strong regulatory measures that are required to enhance the standard of care. On the contrary, the state may not have a similar opportunity to regulate care standards when families are heavily involved in the financing of care.

Neo-conservatism: The Policy Context

In the present climate of worldwide financial crisis, resource-hungry Western states have seemingly sought an easy escape from their hitherto accepted responsibilities; widespread austerity measures have led to cutbacks in many services which had previously been in place. However, this policy action may be in danger of being

proved to be hasty and to risk further complexities and social anomalies down the line. Importantly, the policy intentions do not just consist of issues of organisation or arrangements of care (who cares, where and how), but the policy is more about the issue of financing care – although governments in the West have attempted to cover up this by employing notions of ideology, traditions and values. Conservative politics of idealising 'family values' is something which is used to cover up their fundamental political intention and this needs to be well understood when revisiting the appropriateness of family-based models of older people's care.

Family in Care: Past and Present Experiences

The care of the elderly by their spouse and/or adult children is a universal phenomenon (Kendig, *et al.*, 1992) seen across cultures and has been in practice since time immemorial. Both good and bad experiences of family-based care have been reported in different cultures and parts of the world. It is noteworthy that every outcome of family-based care depends on, or is at least influenced by, several background factors such as the influence of culture, the economic status of the society, family and individual and the wider environment in which they live. Family, especially spouses and adult children, are often counted as potential support providers in providing both emotional and physical support to older family members in need, in almost all cultures (Hao, 1997; Phillipson, *et al.*, 2001; Kabir, *et al.*, 2002). The range of literature has amply documented the importance of family networks for material, practical and emotional assistance in old age. Family care is recognised as a source of stable support in case when family members are paid for their care work and the service recipients, i.e. older people, are found to have rated family care above than the care received from friends or strangers (Matthias and Benjamin, 2008). Research studies have identified relational dynamics which outweigh perceptions of burden in family care and the way the family carers feel motivated to provide services to the older members of the family (Liu, 2000; Hsu and Shyu, 2003). Substantial discussions can be found highlighting the norms of filial piety and the ideal of family care and this aspect has been given central importance primarily in research from Asian countries (Hong and Liu, 2000; Hsu and Shyu, 2003; Teo, *et al.*, 2003).

Contrary to positive experiences of family care, there is also substantial literature presenting dismal pictures related to it. Despite the fact that a large number of older people, mainly in Asia and Africa, still live in multi-generational households (Bongaarts and Zimmer, 2002), this was often found to be a compulsion rather than choice on older people's parts (Hu and Chou, 2000). The literature has suggested that a tension may sometimes exist between siblings for the care of their parents (Brody, 1985; Lashewicz and Keating, 2009) and that the family can also regard older members' care as an unwanted burden (Liu, 2000). In case, when there is choice, older people in South Asian countries themselves opt to go for institutionalised care rather than preferring to live with their family. Older people in South Asian cultures were found to be increasingly dissatisfied with their lives in multigenerational households, whereas Asian societies were until recently celebrated for the better roles and respect given to older people (Goldstein, *et al.*, 1983). Similarly, a high suicide rate among such older co-residents – especially the women in Taiwan – indicates a general tension underlying multi-generational households (Hu, 1995). Reports of conflicts between generations (Teo, *et al.*, 2003) and older people's abuse (Soeda and Arak, 1999) at home have become almost commonplace in recent times. However, it is true that the glimpses presented here do not, of course, represent the entire incidences or experiences in numeric terms. At this stage a discussion is desirable as to which policy details or safeguard measures could be appropriate where countries have had to assign a greater role to the family in caring for their older members.

Discussion

Different Roles for Different Social Actors

The research evidences suggest different potentials and scope for different members of the family or the community to support older people. Some are found to be useful for emotional support only, while others are considered to be effective in instrumental help or in both (Askham, *et al.*, 2007). Based on the evidence, it has been more pertinent to suggest a hierarchy of social actors for their potential roles in care. Spouses, adult children, friends, relatives, and neighbours are all found to have played roles in different aspects of care, depending on

the culture and the individual condition/situation of service providers as well as on the recipients. By tradition, a deeper sense of filial piety and expectations of support from adult children is widespread in non-western cultures such as in Asia (Liu and Kendig, 2000; Hong and Liu, 2000; Hsu and Shyu, 2003; Teo, *et al.*, 2003) whereas the role of spouse is held in high regard in European-American cultures (Walsh and Mcgoldrick, 1998; Askham, *et al.*, 2007). It was also found to be the case in some instances, especially in western societies, that older people value friends highly, and no less than their family or their adult children; this perceived value may depends on the context and their individual situations. The overreliance on the role of adult children may impose conflict and stress onto their lives and affect their wellbeing. Comparatively little exploration has been done regarding immigrant families, inter-racial families, families involving step relations and those of same-sex relationships concerning their quality of relations and their arrangements for older people's care.

Based on the evidences discussed above, it can be argued that no policy will be efficient when it undermines the potential role of other social actors while assigning roles to others. Instead, a policy may be more likely to be robust and successful if it is designed so that all potential actors are drawn into a unified and co-ordinated roster of support providers.

Scope of Family Based Care in a Changing Societal Structure

Families worldwide have changed remarkably over the last half century. They have changed in age structure, generational composition and marital patterns and, thereby, their expectations have also changed regarding public and private support (Bengtson and Putney, 2005). Household sizes have become smaller in size and more and more older people are living alone in present times than in the past (Bongaarts and Zimmer, 2002). Consequently, smaller family sizes would ultimately mean a more limited availability of support for older people even when the older people live in a multi-generational household. Due to the increasing longevity of older people, 3–4 generations living at the same time although not necessarily in the same household) has become a more common experience (Bengtson and Putney, 2005) which may cause negative attitudes and stereotypes to

arise among younger people about the older generations. Thus, changing family structures as well as longevity essentially create a situation where there is an increasing demand for, and a decreasing supply of, care giving hands in the family (Armi, *et al.*, 2008). There is an abundance of evidences suggesting a decline of material support for older people in present times but the reasons for such decline are not yet fully understood (Aboderin, 2004). However, a decline has been witnessed in recent times in the material support available to older people in relation to the changes taking place in families and social structures at large. Questions are being raised about the functionality and effectiveness of family based care in Asian countries too (Ng, *et al.*, 2002); countries which have until recently been celebrated for the ideals. In that context, it may be a risky approach to slide back towards a policy approach in which the family is given a key role in the care of older people.

Migration and Social Isolation

In many developing countries, rural to urban and even international migration has been widespread, leading to an increasing social isolation for older people (Joseph and Phillips, 1999). Migration has been taking place in the more developed parts of the world too although there, it may have taken place at a lesser magnitude. And, noticeably, older people are the group who are often left behind at the place of origin when adult children migrate in the pursuit of education and work. Thus, once older people are separated from their children, it is less likely that their children will return to assume caring responsibilities. Any policy that puts its emphasis on, and envisages dependence on, the role of family for the care of older people may therefore not be an appropriate solution to the problems of the present time. When it comes to making the decision between migrating abroad for jobs, careers and education on the one hand and caring responsibility at home on the other, the adult children of the older people may likely to choose the first option. Even when they do the opposite, the outcome may not be pleasant either for older people or their adult children (Liu, 2000).

The reverse situation is also equally problematic where older people are also involved in family migration. Research has shown that

among those who had migrated, older people were found to be vulnerable, and to feel isolated and insecure (Kim, 1999; Choudhry, 2001). A study has ascertained that the older people's financial dependence on their children and lower levels of environmental competence caused by their lower levels of acculturation turned out to be a causal factor for their lower sense of control (Jang, *et al.*, 2006). Based on these evidences, it is not straightforward to tag on the effectiveness of family based care for both contexts i.e. where older people are either included or excluded from the family migration. Instead, a rigorous investigation may be essential and a corresponding arrangement may be desirable in order to identify the most effective arrangements.

Normative Decline and Generational Issues

Recent research studies have highlighted the changes in the younger generation in relation to their attitude to older people. The change and decline in roles and respect for the aged in the family has been marked across different parts of the world (Dak and Sharma, 1987; Sung, 2000; Teo, *et al.*, 2003) where intergenerational conflict has arisen leading to a decline in family support to older people (Joseph, 1987; Gangrade, 1999). There are evidences about how older people are being regarded as a burden on the family (Nayar, 1992). Studies from Asian countries have shown that the sense of filial piety in the younger generation towards the older generation is reportedly eroded (Bhat and Dhruvarajan, 2001; Ng, *et al.*, 2002) and the situation in urban areas shows a rejection of older people by the younger generation; this is spreading to rural areas (Desai, 1985). The new generation is much influenced by changing societal norms, primarily those of independence, individualism, consumerism and selfishness (Desai, 1985; Bhat and Dhruvarajan, 2001; Serow, 2001), where the age-old idealistic rhetoric has simply not been enough to motivate them to fulfil their filial duty to the older members of the family.

It seems equally true that the relationships between older people and their adult children are less likely to be smooth and harmonious when the demand for care exceeds the capacity to give it, or in a situation when one needs to choose between a career (work and/or education) and caring responsibilities. Evidences are available to

suggest how a flexible policy at work (employment and leave in particular) may be helpful for someone to continue a dual role in both caring and retaining a job, which may eventually lead towards a harmonious care environment (Pavalko and Henderson, 2006). Therefore, future policy makers should consider using this evidence when designing family-based care policies. Together with this, it can also be argued that the needs, aspirations and practicalities and the potential stress involved in the supply-side (i.e. as experienced by the adult children or other family members) should not be overlooked when prioritising older people's care. In the absence of such sensitivities being built in to policy, idealising a family-based care model appears to be a false prescription for solving the problems of older people's care.

Older People's Psychological Motivations

Evidence suggests that there are certain psycho-social elements which can increase the likelihood of happiness and satisfaction for older people (Borg, *et al.*, 2006) and these may be different to the elements which apply to younger generation. Research into older people's psychology or on their cognitive structure has illustrated that the older people tend to be much self-contained; they value their self-esteem and are oriented towards ego-defence (Pratt and Norris, 1994). Older people often demonstrate altruistic behaviour (Caro, *et al.*, 2010) and are reluctant to take help and support from others (Kenneth, Shah and Gooberman-Hill, 2004) unless such help is, in their view, extremely essential. In fact, they are reluctant to take anyone's help and support unless they believe that they can pay it back by some means. This is something which is crucial to understand, and which may have deeper meaning in the debate around family-based care. Their wellbeing is enhanced when they believe that their contribution has been recognised and that they are, or have been, of positive use to their family and society. Evidence suggests that the older people feel a great attraction towards independence and freedom (Crist, 2005) and that has cautioned everyone from idealising supported lives. Older people may be unhappy and dissatisfied with their existence if they develop dependence and are compelled to live dependent lives.

Financial Issues and Inheritance

Studies from both western and non-western countries have unanimously underscored the importance of the financial independence of older people in the promotion of their care and their overall wellbeing (Goldstein, *et al.*, 1983; Jang, Kim and Chiriboga, 2006). As noted earlier, there is widespread evidence of neglect and abuse of older people in their own homes and also of different kinds of conflicts between generations. There are indications that one of the potential sources of conflict between older people and their children can be matters of finance. Financial factors seem to have played a role in the arrangement of older people's care and in the relative potential for their comfort. Exchange theorists have repeatedly suggested that the relations between older people and other social actors, including their adult children, are influenced by their economic relations (i.e. flows of resources) in the past, present and also in the future (Dowd, 1975; Brackbill and Kitch, 1991; Shi, 1993). It is noticeable how suicide-related morbidity is higher among older women than in men in Taiwan (Hu, 1995) and that economic dependence is identified as being at the root of this phenomenon.

A lot of discussion has taken place regarding the nature and direction of flows of financial resources between older people and their adult children and families (Deindl and Brandt, 2010). However, a clear scenario has not yet emerged to enable the issue to be understood theoretically. Resource flows are found to have taken place from children to their parents in some parts of the world, for example in Eastern Europe, Southeast Asia and Southern India. A reverse trend is found in other locations, such as Western Europe, Northern India and Indonesia. Rather than being a spatially specific matter, it seems that the direction of the flows of resources is determined by numerous factors, such as the relative economic statuses of the older people and their children, normative factors, the quality of the relationships between adult children and their parents, the availability and quality of welfare services in the countries where they live, and so on (Ibid.).

The notion of inheritance is also a matter of critical importance in these debates. It appears to be a permanent matter of stress and conflict between children and their parents and also between siblings. The general expectation across cultures is that children care for their parents in their old age and are in return entitled to inheritance of the

wealth and possessions of their parents. However, in real life situations, individual often seem to overlook this logical relationship. Adult children in many instances may have presumed that their entitlement to their parent's property is independent to the care services they provide (or do not provide). Older people, in many cases, are therefore not cared for properly and are regarded as a burden on children and families. Interestingly, however, families were found to be a stable source of care provision if they are paid, and older people were much more satisfied with their care compared with having friends or strangers as paid carers instead of family members (Matthias and Benjamin, 2008). Based on these evidences as well as the potential of abuse and neglect of older people at home in cases when care providers' interests are not met, a new, innovative arrangement may be desirable.

Firstly, the issues of care and its financing must be clearly separated and the whole notion of family-based care should be limited to the idea of support and care not the financing. An effective arrangement could be made by which all care works are paid directly at the time they are received by older people. The state can pay the family members for their services at the time when they provide services. Regarding the financing side, the state should have access to older people's possessions and properties. Thus, rather than the older people's properties passing onto their children almost independently from the care they provide, the new arrangement seems to have potential to bring change. An increased access for the state towards the property and savings of older people may enhance the state's ability to finance older people's care.

Can Family Based Model be an Alternative?

This review has accrued a mixed picture of family-based care models as they are used and practiced in different ways across different countries and regions. Although family-based care undoubtedly has its merits, it cannot be blindly suggested as a brilliant solution for the care and wellbeing of older people. In fact, family support and care may be useful in certain conditions if they are used in harmony with the wider spectrum of societal resources. Indeed, a grave mistake could be made if the policy change attempts to abandon present arrangements which are already in place simply in order to promote family-based models.

As highlighted in the above discussion, there may be certain issues which appear to be preconditions for the family-based care model to be successful. Family care should be disentangled as being two elements, i.e. support and care on the one hand and the financing of care on the other. Accordingly, an arrangement where support and care provided by family members can be paid directly at the time when the service is received is desirable. The public or financial sectors can engage to develop a financial mechanism which gives states the ability to make payment of care-services against the capital of the older people's inheritable property. Family support and care is seemingly effective in emotional terms and new policy work should not overlook the need and aspirations of the supply side, i.e. the family/adult children. Simultaneous efforts to enhance older people's skills, competencies, and inclusion in society may help to overcome potential value conflicts, neglects and abuses against older people. Multi-generational households must not be taken as evidence of effective family care but instead policy should provide a choice to older people about the kinds of living arrangements they would choose to live in.

The new policy work should outline special measures to ensure suitable care for older people who are isolated, have no family or whose families have experienced migration. Apart from the roles and space which should obviously be available for family, opportunities for enriching friendships, participation in community and for voluntary work should be promoted as these may build bridges between families and the communities and create something which may have the potential to fill any gaps which exist. In all cases, the common issues discussed above must be addressed in country-specific policy work alongside addressing the local issues experienced in individual countries.

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