

**Title:** Dementia: Challenges for Social Work Education in Europe

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## **Abstract**

Dementia has been identified as a global challenge across the spectrum of health and social care (WHO, 2012). This paper will explore the implications of this for social work education and the challenges it poses. There is a lack of a focus on social work with older people and people with dementia in social work education. Based on calls for an infusion of content on ageing and dementia in social work curricula, this paper proposes that we should adopt a person-centred philosophy alongside gerontological social work competencies to achieve this. The specific aim of this paper, therefore, is to explore how we can use these ideas as teaching tools to engage social work students in the discourse on dementia and to develop appropriate skills to work with people with dementia, their families and carers.

Key words: Ageing, dementia, gerontological competencies, person-centred, social work education

## **Dementia: Challenges for Social Work Education in Europe**

Dementia has been identified as a global challenge across the spectrum of health and social care (WHO, 2012) as well as a policy priority area in Europe (Bamford, 2010; Tanner, 2013). This paper will explore the implications of this situation and starts from the premise that this issue also presents significant challenges for social work education (SWE) globally and in local contexts. It has been suggested that these challenges will require social workers to keep abreast of these developments to improve and develop practice for people with dementia, their families and carers (The College of Social Work, 2015). It has been argued that to respond effectively to the challenges dementia can bring, social workers need honed skills and competence in practice (Hokenstad & Roberts, 2011; Parker & Penhale (1998). Kane & Houston-Vega (2004: 293) suggested that social work educators are in influential positions to 'sensitize future practitioners to stigmatized and vulnerable groups'. This paper therefore proposes that, as a starting point, this competence and skill can be developed during social work training and education.

The challenges for SWE in relation to dementia is five-fold. Firstly, there are predictions for a rapid increase in the incidence and prevalence of dementia over the next few decades (Prince et al, 2014). Secondly, the rapid increase will also be accompanied by significant demographic changes influenced by migration and forced movement of people across national borders in Europe and elsewhere. Thirdly, we lack a strong evidence base for social work practice for people with dementia (pwd) due to the medicalised approach to dementia care. Fourthly, there are fewer numbers of social workers working in the field of gerontology and direct practice with older people than in other spheres of social work practice. Finally,

there is a distinct lack of a focus on older people in general and more specifically pwd in social work curricula. For example, on an anecdotal level, the author was presenting a paper on dementia and reminiscence and arts practice at the European Schools of Social Work Biennial Conference in Milan (2015) and asked the 20+ social work educators in the room how many provided input on dementia in their programmes. Sad to say that only a few indicated that they include dementia content in their curricula.

The present paper will explore these challenges and will argue that there is scope for SWE to respond to these challenges given the value base of social work and its commitment to social justice. Drawing on the work of Kit wood (1997) and the gerontological social work competencies framework (CSE Gero-Ed Center, 2016). It will offer suggestions for themes, topics and core content that can be incorporated into social work curricula to raise the profile of dementia. Kitwood's model has been reviewed in this journal previously (Tanner, 2013; Rainieri & Cabriani, 2015), but their focus was on exploring links between ideas of personhood and relational social work and identity and selfhood respectively. Although Kitwood's ideas are well known in the general field of older people and dementia, it does not seem so present in social work literature.

The specific aim of this paper, therefore, is to explore how we can adopt insights and guidance from these frameworks and use it as teaching tools to engage social work students in the discourse on dementia and to develop appropriate skills to work with people with dementia, their families and carers. These frameworks are suggested given the World Health Organisation's (2012) call that person centred practice should be among the core competencies for all staff working with pwd. Moreover, Sanderson & Lewis (2012) argued that person-centred practice can change the lives

of pwd and help them to achieve the outcomes they want. A word of caution, the focus on dementia in this paper does not suggest that the complexities of ageing are reduced to the simple status of dementia (Lymbery, 2014: 370).

### **The context**

As indicated above, dementia has been identified as a global challenge (WHO, 2012) and that the numbers will double each twenty years over the coming decades. In Europe there are 9m+ people diagnosed with dementia (Prince et al, 2014). However, it has to be acknowledged that these figures are based on those who have been given a diagnosis of dementia and it has been estimated that in any given population, there is at least 44% of people who have undiagnosed dementia (Prince et al UK, 2014).

The following is known about pwd:

- Two thirds of pwd are women,
- One in six pwd are aged 80 and over,
- 80% of people in care homes for older people have a form of dementia, and
- A significant number of deaths are attributable to dementia (Prince et al UK, 2014).

### *Challenge 1: Increase in numbers*

Statistics show that globally there are over 35 million pwd and that this number is likely to grow. It has to be noted that these numbers are based on those who have been formally diagnosed with dementia. It can take up to two years for someone to be diagnosed with dementia, which means it can go undetected for a long time (Bamford & Greengross, 2011; Edwards et al, 2013; Milne, 2010). Moreover, it has

been argued that General Practitioners are not adequately trained or equipped to diagnose or treat dementia (Connolly et al, 2011). The higher numbers of pwd also has serious social and psychological implications for families and carers (Prince, et al, 2014). The evidence shows that a significant number of families and carers provide informal care and support for relatives or friends of pwd (Hokenstad & Roberts, 2011; Prince et al, 2014).

This challenge means that social workers, regardless of their field of practice, are likely to encounter someone who may have a diagnosis of dementia or who may provide care and support to someone who has been affected by dementia (Hokenstad & Roberts, 2011). The question this raises is: how effectively does SWE prepare students to be equipped to respond to this challenge?

### *Challenge 2: Demographic changes*

Recent migration patterns shows significant number of people coming to Europe for a 'better life' – the recent increase in swathes of people from Syria and other countries provides a case in point. It has been argued that within these communities there will be diverse perceptions of dementia (Kane & Houston-Vega, 2004) such as differing values, beliefs, behaviours, attitudes and coping strategies. For example, there may be beliefs that symptoms of dementia are what is termed 'normative aspects of ageing' (Kane & Houston-Vega 2004). Spiritual beliefs that affect service utilisation may also predominate. Families from migrant and refugee communities may also believe that care giving is their sole responsibility and may have particular views on who should be involved in providing care (Torres & Lawrence, 2012). The challenge for SWE is that we need to adopt what Torres & Lawrence (2012: 1) term '...practices that are not just old age sensitive, but also

international migration aware'. These demographic changes also require SWE to respond to the disadvantages linked to migration as well as to how dementia is construed and perceived within these communities.

### *Challenge 3: Lack of evidence base in working with dementia*

Berkman (2011) posited that there is a clear link between a strong evidence base and effective practice. However, in a study to examine the nature and extent of the evidence in relation to social work practice with older people it was found to be limiting and lacking (Richards, et al, 2014). These authors found a distinct lack of research that focuses on social work interventions for older people. It is interesting to note that this lack of evidence on dementia care and social work has been identified in a review undertaken over fifteen years ago by Parker (2001 a). Similar patterns in relation to evidence on dementia care and the role of social work have been identified in the USA (Kaplan & Berkman, 2011).

It can be argued that this lack of evidence on older people and those with dementia is due to the medicalised approaches to studying dementia. To date the focus and interest have been on developing the most effective tools to diagnose dementia, finding the most effective treatments and ultimately seeking a cure for dementia (Kaplan & Anderson, 2013; Kitwood, 1997; Parker 2001 b). This overlooks the fact that dementia in addition to its devastating physical impact, also has significant social and psychological impact on individuals, their families and carers (Kitwood, 1997). Brooker (2007) suggested that bio-medical approaches to dementia care can have positive effects in reducing the effects of negative physical symptoms, but if used in isolation, cannot address the broader social and psychological impacts of dementia on individuals their families and carers.

#### *Challenge 4: Lack of interest in social work with older people*

Older people and those with dementia comprise the largest group of service users who utilise Local Authority services (Lymbery, 2014). Yet, social work with older people has been the area of slowest growth in the UK and elsewhere (Kane & Houston-Vega 2004; Kaplan & Berkman, 2011; Lymbery, 2014; Sanders & Swails, 2011). Ray et al (2015) reviewed the situation in the United Kingdom (UK) and suggested that social welfare policies undermined gerontological social work as a specialist area of social work practice. Lymbery and Postle (2010) posited that this undervaluing of the role of gerontological social work and its low status in relation to social work with children and families has been fuelled by neo-liberal policies across Europe. It has been suggested that the reasons for this lack of interest in practice with older people are amongst others ageism, anxieties about ageing, lack of skills in working with older people and dementia (Kane & Houston-Vega 2004; Lymbery, 2014). Kaplan & Berkman (2011) noted that social workers lack competence to work with pwd despite the fact that social workers are in unique positions to provide appropriate interventions and support in relation to dementia care. Moreover, their broad knowledge base can enable them to respond to the complexities associated with ageing in general and dementia care specifically (Ray, et al, 2015).

#### *Challenge 5: Lack of focus on dementia in SWE*

Given that most Social Work curricula will contain some content on psychology, human development or human behaviour in the social environment, it is surprising that there is a dearth of content on older people generally and pwd specifically (Parker, 2001 a; Richards et al, 2014). This lack of focus on dementia in SWE is not



peculiar to the UK, but can also be found in the USA (Kaplan & Anderson, 2013) as well as across Europe (Parker, 2001). For example, Richards et al (2014) conducted a survey of social work programmes in the UK and found widespread neglect on issues of ageing in teaching content and concluded that we should 'infuse' social work curricula with content on older people. This echoes calls for a focus on processes of ageing, including dementia, that have been made as far back as 1991 in the UK (TOPPS, 1999) that still seem relevant today.

### **Social Work Education and Dementia Care**

The previous sections have clearly identified that SWE has failed to address the challenges of dementia, so this section will explore the implications of the challenges reviewed in the previous section and provide pointers for addressing or overcoming these challenges. It has been argued that to respond to the challenges of dementia it is imperative that SWE curricula should embrace a commitment to active ageing (Lymbery, 2014; Zrinščak & Lawrence, 2012). Active ageing is aimed at enabling individuals to realise their full potential for physical, social and mental well-being and providing adequate support and protection when they need help.

Drawing on Kitwood's (1997) ideas of personhood and person-centred care this section will explore how this can inform social work curricula and teaching. However, it is not suggested that this is the only model that can inform dementia care and teaching about it. This model is proposed based on suggestions that we need alternative or complimentary models to counter the dominance of medical models in dementia care (Kaplan & Anderson, 2013). It has been suggested that the physical, social and psychological dimensions of dementia are interdependent and that we therefore need to seek ways to integrate medical and social approaches to dementia

care (Brooker, 2007; Parker 2001 b). Kitwood's model also fits neatly with the Council on Social Work Education (CSWE) competency framework for gerontological social work that will be outlined below.

Kitwood (1997) challenged the traditional paradigm for dementia and suggested a model based on personhood. His ideas have been reviewed and critiqued in this journal recently (Rainieri & Capriati, 2015) and will not be revisited here. Kitwood (1997: 8) defined personhood as:

'... a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both according of personhood, and the failure to do so, have consequences that are empirically testable'.

It is through personhood that pwd can retain a sense of self, connections with the past and the future (Tanner, 2013). Kitwood (1997) proposed a model of dementia that comprise of 5 factors, i.e., neurological impairment, personality, biography, physical health and malignant social psychology (See Rainieri & Cabiati, 2015 for a fuller explanation of these concepts). These factors all interact together to 'create' dementia (Rainieri & Cabiati, 2015: 5) and is foundational to person-centred care.

Applying this model to social work practice can enable students to explore the whole person and help them to develop an understanding of the pwd in their broader social and cultural context. This model can be used as a tool for assessment, intervention and evaluation in practice to explore the 5 factors that constitute dementia as proposed by Kitwood (1997). This offers a way of exploring the entire context of the pwd and not in a mechanistic way as can be found in some assessment tools. It can also be used as a tool for engagement, which is particularly relevant given the anxieties that students may have in working with older people and pwd as identified

earlier (Kane & Houston-Vega 2004; Lymbery, 2014). Students can be directed to assist the pwd to develop a sense of personal worth, increase and support their ability to control their situation as far as possible, strengthen their ability to engage with others and have a sense of hope for the future. This, for example, can be achieved through life story work. A person-centred approach can also assist students to challenge ageist constructions of pwd (Crampton, 2011) and help them to adopt empowering and advocacy roles to support and promote greater independence and voice for pwd (Hokenstad Jr & Roberts, 2011).

Another framework that can inform person-centred approaches to dementia care is the CSWE's set of competency domains for gerontological social work (CSWE Gerontological Center, 2016). This framework encompasses the following domains: ethical and professional behaviour; diversity and difference in practice; human rights and social justice; practice-informed research and research-informed practice; policy practice; engage with individuals, families, groups, organisations and communities; assess individuals, families, groups, organisations and communities, intervene with individuals, families, groups organisations and communities; and evaluate practice with individuals, families, groups, organisations and communities. These competencies can equip students with the necessary skills, knowledge and values to respond fully to the needs of pwd, their families and carers (Greenfield, et al, 2013).

These frameworks can be usefully adopted to inform how social educators infuse their curricula and teaching with positive approaches to ageing and dementia and work towards inculcating gerontological social work competencies in social work students.

A focus on the 5 challenges referred to above will require students to work in multi-disciplinary contexts, so this should be another area of knowledge and skill development for social work students. This should also enable them to approach the physical, social and psychological impact of dementia in an integrated manner. It is argued that infusing social work curricula with dementia content, drawing on gerontological competencies referred to above can help social work education to reclaim much lost ground in relation to gerontological social work (Ray, et al 2015)

### **Overcoming the challenges**

Social work programmes should adopt/incorporate gerontological competencies referred to above into the programme learning outcomes alongside promoting person centredness as a theoretical approach that is appropriate for practice. A starting point for introducing students to these frameworks can be courses on psychology and Human Behaviour in the Social Environment. A focus on dementia in social work education can also be enhanced by developing practice learning opportunities for social work students and directing students to dementia as a possible topic for dissertation projects. Milne & Adams (2014), for example demonstrated that developing placement in care homes for pwd can enable them to develop appropriate critical reflection skills for working with older people.

Inter-professional education is another way of addressing the challenges identified above. D'Amour & Oandsan (2005) suggested that interprofessional education can lead to collaborative and person-centred practice. The WHO report (2012) also suggested that competence in working with pwd can be developed through inter-professional education and training. It can help to transcend the expertise of different professional groups towards a shift to developing and providing care that is focused

on the needs of the pwd and their families and carers. Social Work Educators should therefore seek and create opportunities for interprofessional learning.

Evidence based practice has been promoted as the best way to address human need. Social work educators should be exploiting opportunities to gain research funding to develop the evidence base in relation to dementia practice. For example, the UK Government's strategy for dementia (DH, 2009) was supported by significant sums of money for research, yet it is not known how many social work educators actually responded to the calls for proposals. The evidence base can also be strengthened by developing socially oriented interventions for working with pwd. This has been done with great success in the field of community mental health nursing (reference here). Research should also focus on the effectiveness of person centred practice for pwd.

Another way of overcoming the challenge of a lack of an evidence base is to devise intervention studies to examine how person-centred gerontological social work competencies can be embedded in practice (Nehen & Hermann, 2015; Olsson et al, 2012). For example, the evaluation of a programme in the US that aimed at infusing social work curricula with gerontological competencies and providing placements in age related settings found that students scored higher on knowledge and skills outcomes than students who were not exposed to these (Birkmaier, et al, 2012).

## **Summary**

This paper examined the challenges of dementia for social work education and explored how gerontological social work competencies and Kitwood's (1997) model

of personhood and person-centred care can be used in teaching curricula to overcome these challenges drawing on these frameworks. It has been suggested that a focus on personhood and person-centred care can assist social work educators and students to move beyond the narrow focus on diagnosis to the broader social and cultural context of the person with dementia. It has to be acknowledged that there are other ways of responding to dementia such as for example, the creative arts, music, etc. However, Kitwood's philosophy and ideas have been presented as a vehicle for social work education to engage with dementia as these ideas fit with the value base of social work and gerontological social work competencies.

The ideas proposed in this paper may not be novel, but given that social work and social work educators have not taken up the call for including dementia content in their curricula, it is vital that this call be revisited. Moreover, the steady projected rise in dementia demands that social work and social work education can no longer ignore the challenges that this bring. Ray et al (2015) suggest that social work should reclaim its role in relation to older people, including those with dementia, their families and carers. Social work embraces a commitment to social justice and it is therefore SWE's moral, ethical and social duty to face up to the challenges of dementia.

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