# Transcultural nursing strategies for carers of people with dementia

Melissa Bunting and Catharine Jenkins investigate the effect of caring among different cultural groups and recommend culturally congruent interventions to support carers

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## Abstract

Caring for a family member with dementia is stressful, and carers from all backgrounds often feel overwhelmed and under-supported. Professional and family carers' perceptions of the challenges and satisfactions of caring are influenced by culturally derived expectations. However, experiences of caring often differ from stereotypical norms.

Experiences of carer stress and beliefs about the nature and extent of support that can be expected from social networks and statutory services may differ between cultural groups in the UK, but sensitive advice, information, and emotional and practical support are universally required. Transcultural comparisons reveal similarities between carers' needs and enable identification of values-based culturally congruent recommendations that nurses can use to promote black and Asian minority ethnic carers' confidence and wellbeing.

This article, based on practice experience and a literature review, explores the effect of caring among different cultural groups and offers recommendations for culturally congruent interventions to support carers. It provides evidence-based guidance to enable nurses to meet their responsibilities for transcultural working, as laid out in the Care Act 2014. A scenario illustrates recommendations for practice.

**Keywords**
carer burden, carers, dementia, diversity, older people, transcultural care

PEOPLE LIVING with dementia experience a range of problems with memory, cognition, language, day-to-day orientation, planning and daily self-care (Downs and Bowers 2014). As dementias are progressive, over time those affected require increasing levels of support, which can become overwhelming for family carers (Department of Health (DH) 2010, Springate and Tremont 2014). Carers face physical, emotional and economic stressors, so require support and collaborative care from multidisciplinary health, social, financial and legal systems (DH 2010, Bekhet 2013, Royal College of Nursing (RCN) 2016). There are an estimated 670,000 families and friends from diverse social and cultural backgrounds who act as primary carers for individuals with dementia in the UK (Alzheimer's Society 2014a). These carers alleviate pressure on statutory services saving £11 billion a year (Alzheimer's Society 2014b).

This article, based on practice experience and a literature review, explores the effect of caring among different cultural groups and offers recommendations for culturally congruent carer support interventions. It provides evidence-based guidance to enable nurses to meet their responsibilities for transcultural working as set out in the Care Act 2014.

## Supporting carers

Carer support is vital, not only because of the savings they provide for the state, but, more importantly, for their own wellbeing and that of the individual living with dementia. Although caring has its rewards, including job satisfaction, reciprocation of care and increased closeness to a loved one (Brodaty and Donkin 2009), carers are at high risk of depression (Kmietowicz 2013). Many become 'hidden patients', because of the mental and physical

toll that providing care has on them (Brodaty and Donkin 2009). Therefore, carers' needs should be considered alongside those of people with dementia to reduce the stress on both parties (DH 2010, Kim *et al* 2012, Springate and Tremont 2014).

Dementia affects people from all backgrounds and carers are similarly diverse (Cross and Bloomer 2010). The All-Party Parliamentary Group on Dementia (APPG) (2013) found that people from black, Asian and minority ethnic (BAME) backgrounds were less likely to receive a diagnosis or formal support, while carers were not getting the support they needed (Grand *et al* 2011).

Support should be responsive to carers' needs and strengths, taking into consideration cultural norms and values (Joas and Wiegandt 2008). For example, it may be a traditional norm in the family for an older person to be cared for by a daughter-in-law (Jutlla 2015). However, it is important to ensure that this person is willing to take on the caring role, that they have accessible information in their first language or audio-recorded and clear signposting to further support (Dyson 2004).

Transcultural nursing involves focusing on the needs of individuals in their cultural context to provide culturally congruent, meaningful and beneficial care (RCN 2016). Simple, practical issues to consider may include arranging community visits to respect religious occasions and prayer times, being mindful of appropriate dress, and phrasing questions about alcohol and suicidal thoughts sensitively (Bolliger 2014).

Use of the acronym BAME risks promoting a blanket response that fails to acknowledge diverse individual needs (Butt 2006). Supporting this view, Rauf (2011) used the expression 'communities within communities' to distinguish the range of beliefs, language and cultural norms and practices found in particular groups. However, the acronym does focus attention on groups that share similar experiences of migration and racism and face particular challenges in getting the support they need (APPG 2013).

People from BAME groups are under-represented in dementia services, as are their carers (Moriarty *et al* 2011). Carers UK (2015) found 15% of BAME carers reported negative experiences of health and social care, with 10% reporting these experiences to be 'terrible'. In 2012, in England and Wales, there were 25,000 individuals living with dementia who were from a BAME background (APPG 2013), including 'invisible' white minorities such as Irish and Eastern European service users (Cemlyn *et al* 2009). It is estimated that this figure will double to 50,000 by 2026 and to more than 172,000 by 2051 (APPG 2013), meaning that the number of carers is also expected to rise (Carers Trust 2011, Prince 2015).

## Carer stress

The psychosocial effect of caring in different cultures is under-explored (Institute for Research and Innovation in Social Services (IRISS) 2010). People from BAME groups tend to present to services later or at crisis point (Mukadam *et al* 2011). Across most communities, dementia is often perceived as a natural part of old age, while some minority group understandings include 'craziness' or supernatural explanations such as possession (Botsford and Harrison Dening 2015), leading to shame, isolation and reluctance to ask for help (Jutlla 2015).

Lack of a term in some languages to describe the concept of dementia is sometimes used as an explanation for late access to services at the point of crisis (Botsford and Harrison Dening 2015). However in 2007, La Fontaine *et al* found that family doctors stereotyped BAME elders and did not make their access to services easy. In 2015, Jutlla's respondents perceived that services were stigmatising, inaccessible, unsuitable and potentially damaging, echoing their previous experiences of racism. Most carers from all communities reported services were often inadequate (Newbronner *et al* 2013), but specific learning opportunities may arise from transcultural comparisons (Shim *et al* 2013).

Levels of carer stress or 'burden' vary between individuals and within cultures (Sayegh and Knight 2011, Giger 2013). This may be due to relative perceptions of dementia-related problems, some of which may transgress cultural norms more significantly in specific cultural groups. Cox (1995) found that carer stress varied between black and white carers.

In the black carer group, participants were most affected by poor physical functioning and subsequent restriction of activity, while the white carer group was more concerned about disruptive behaviour. If a behavioural symptom – for example, apathy, swearing or repeating stories – matches with cultural norms or expectations of old age, then it is much less likely to be problematic. Similarly, if caring is part of normal life, a person would not necessarily see themselves as 'a carer', and the process of identification with the role and subsequent help-seeking would take some time (Mukadam *et al* 2011). Botsford *et al* (2012) and Parveen *et al* (2011) found that spousal carers were less stressed than daughter or daughter-in-law carers, perhaps demonstrating continuity in caring between partners, or acculturation in second-generation carers (King

and Christou 2008) who may, for example, prioritise further education and career development and so experience role conflict.

The extent of support from a person's social network also affects stress levels (Lamura *et al* 2008). Kim *et al* (2012) and Foster *et al* (2014) agree that the less support a carer receives from family and friends and the more hours a carer provides, the higher the level of burden experienced. 'Familism', that is, loyalty and attachment to family members, is important among South Asian cultures (Parveen *et al* 2011). However, the stereotype of 'looking after their own' is not always reflected in actual support from the extended family and so does not reduce the stress, distress or depressive symptoms experienced by individual carers (Parveen *et al* 2011). Taking on the caring role may result more from obligation than choice (Sayegh and Knight 2011).

White British participants in Parveen *et al*'s (2011) study had more support from friends, family and services. South Asian carers seemed to be motivated by cultural expectations, in comparison with white British carers whose motivation was more intrinsic (Parveen *et al* 2011). Feeling in control or having a sense of autonomy seems to be positively associated with effective coping with caring, while avoidant coping, or distancing self from the problems, is associated with perceived cultural obligation and increased stress (Sayegh and Knight 2011).

Evidence of the effect of caring on different groups is conflicting. Depression in the white British group was associated with using substances as a coping strategy (Parveen *et al* 2011). Use of substances such as alcohol may indicate poor coping mechanisms that aim to resolve, but exacerbate, low mood (Barlow 2010). Black *et al* (2013) found higher levels of unmet need and depression among non-white carers, while Skarupski *et al* (2009) found that white carers reported more depressive symptoms than black carers. Despite these apparent contradictions, learning from transcultural comparisons may reveal underlying themes that can be used to make recommendations for sustainable and culturally congruent carer support interventions.

## Cultural aspects of support

La Fontaine *et al* (2007) suggested that it is important to look at similarities as well as differences between cultures. In Sussman and Regehr's (2009) study, 70% of all carers did not have regular help from family and friends, and 52% of participants wished for more regular support. Emotional and practical support from family and friends, as well as statutory services, reduces carer stress (Samia *et al* 2012, Jutlla 2015) and has a positive effect on the wellbeing of people with dementia (Brodaty and Donkin 2009).

Interventions from statutory services include educational programmes, respite, day care, carer support groups and one-to-one support (Sussman and Regehr 2009, Newbronner *et al* 2013). The Alzheimer's Society (2014a) also recommends more financial support, accessible information, more support for carers in employment, comprehensive home-support services and more involvement in decision making. These recommendations respond to the needs that carers have in common, regardless of their cultural context. The literature exploring cultural similarities and differences in caring experiences offers further insight that could make culturally appropriate interventions easier. Despite apparent differences between groups, emerging themes indicate underlying values based needs are universal, although they may be expressed differently.

## Autonomy and control

The need for carers' autonomy and control was evident across the literature (Sayegh and Knight 2011, Parveen *et al* 2011, Jutlla 2015). It was shown in the importance of choosing to care and feeling confident about caring skills. Choosing to care does not mean choosing to care in isolation and without adequate support. The Care Act 2014 indicates that carers' rights are as important as those of the cared-for person. Part of the multidisciplinary team's assessment involves exploring a carer's ability and willingness to fulfil the role. An example of this is set out in the case study on page 24. The names of the people involved in this scenario have been changed to preserve their anonymity.

Brodaty and Donkin (2009) say that carers who take part in training develop confidence in their coping abilities, and tend to experience less burden and depressive symptoms, while Lopez *et al* (2012) found that self-efficacy combined with spiritual meaning is associated with lower levels of carer depression.

Understanding the nature of dementia and learning about skills can promote carer confidence. Samia *et al* (2012) found that an advanced carer training programme alleviated feelings of lack of support when caring and built confidence in coping with the demands of caring. Learning from earlier life experience can enhance caring skills and Jutlla (2015) found that experiences of migration resulted in resilience and self-efficacy, which were transferable to caring roles. Botsford *et al* (2012) suggested a similar dynamic in black carers who

## Case study

**Saira had been married to Ahmed for a couple of years when it became obvious that her mother-in-law, Aisha Bibi, had worsening memory problems.**

**Saira and Ahmed had good jobs and, as their two children attended after-school clubs, they were able to work full-time. Aisha was becoming less able to cope with her diabetes and at a family meeting, her sons agreed that between them they would take turns in looking after their mum.**

**Saira found she was expected to take on the majority of this role and supervise and support Aisha for three months a year. Recognising the need for support and advice, Saira contacted her GP who, after some prompting, arranged for Shanice, the practice nurse, to visit Saira and Aisha early one evening. Shanice was a good listener.**

**Saira opened up about the stresses she was under and could foresee in the future and became tearful.**

**Saira was concerned that her job was in jeopardy and that Ahmed was less supportive than she had anticipated. Shanice had developed a good network of contacts in the area and was able to refer Aisha, with her consent, to a local day care centre where staff spoke South Asian languages and where the food options met with Aisha's approval.**

**Shanice was able to spend time with Saira answering her questions and offering advice, while the children were chatting with grandma. Shanice gave Saira contact details for the Alzheimer's Society so that she could access further information online and they agreed that Saira would get back in contact with the practice when necessary.**

became more independent following separation from family networks after migration.

'Meaningfulness', or a sense of the significance of caring, seems to be associated with autonomy. The decision to care is motivated by an individual's values. Spousal carers, who may see caring in terms of 'keeping a promise', and those with strong religious beliefs find meaning in caring and this seems to promote emotional wellbeing. Finding meaning in caring appears to be an evolving process that has a positive effect on the carer and individual living with dementia (MacKinlay and Trevitt 2012, Shim *et al* 2013).

## Recommendations for practice

The Care Act 2014 legislates that carers are entitled to support that promotes their wellbeing and this is a government priority (DH 2014). Interventions to support carers should acknowledge the context of individuals in their family, cultural groups and wider society. However, austerity measures may threaten availability of statutory services (Alzheimer's Society 2014b). Nonetheless, accessible and acceptable community-based services are essential to support growing numbers of carers from BAME groups and to reduce the need for more expensive hospital or care home admission (Brodaty and Donkin 2009).

The effect of services can be enhanced for all groups by promoting congruence with cultural values. The following recommendations build on cultural understandings:

- Promote self-efficacy through carer education and reinforcing effective coping strategies. Transgression of norms by a person with dementia increases stress for a family carer.

### References


**All-Party Parliamentary Group on Dementia** (2013) *Dementia Does Not Discriminate: The Experiences of Black, Asian and Minority Ethnic Communities.* APPG, London.

**Alzheimer's Society** (2014a) *Carer Support.* tinyurl.com/z5jwwjg (Last accessed: February 24 2016.)

**Alzheimer's Society** (2014b) *Dementia UK.* Second edition. Alzheimer's Society, London.

**Barlow J** (Ed) (2010) *Substance Misuse: The Implications of Research, Policy and Practice.* Jessica Kingsley, London.

**Bekhet A** (2013) Effects of positive cognitions and resourcefulness on caregiver burden among caregivers of persons with dementia. *International Journal of Mental Health Nursing.* 22, 4, 340-346.

**Black B, Johnston D, Rabins P *et al*** (2013) Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *Journal of the American Geriatrics Society.* 61, 12, 2087-2095.

**Bolliger M** (2014) *What Patients Don't Say If Doctors Don't Ask.* Second edition. Influence Publishing, New York NY.

**Botsford J, Clarke C, Gibb C** (2012) Dementia and relationships: experiences of partners in minority ethnic communities. *Journal of Advanced Nursing.* 68, 10, 2207-2217.

**Botsford J, Harrison Dening K** (Eds) (2015) *Dementia, Culture and Ethnicity: Issues for All.* Jessica Kingsley, London.

**Brodaty H, Donkin M** (2009) Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience.* 11, 2, 217-228.

**Butt J** (2006) *Are We There Yet? Identifying the Characteristics of Social Care Organisations That Successfully Promote Diversity.* Social Care Institute for Excellence, London.

**Carers Trust** (2011) *Being an Older Carer Has a Devastating Impact on Your Health.* tinyurl.com/j7bzpsy (Last accessed: February 24 2016.)

**Carers UK** (2015) *Carers UK Welcomes New Rights for Carers, But Remains Concerned Over Funding.* tinyurl.com/jsesjkd (Last accessed: February 24 2016.)

**Cemlyn S, Greenfields M, Burnett S *et al*** (2009) *Inequalities Experienced by Gypsy and Traveller Communities: A Review.* Equality and Human Rights Commission, Manchester.

**Cox C** (1995) Comparing the experiences of black and white caregivers of dementia patients. *Social Work.* 40, 3, 343-349.

**Cross W, Bloomer M** (2010) Extending boundaries: clinical communication with culturally and linguistically diverse mental health clients and carers. *International Journal of Mental Health Nursing.* 19, 4, 268-277.

**Department of Health** (2010) *Recognised, Valued and Supported: Next Steps for the Carers Strategy.* DH, London.

**Department of Health** (2014) *Carers Strategy: Second National Action Plan 2014-2016.* tinyurl.com/jx6ynbh (Last accessed: February 24 2016.)

**Downs M, Bowers B** (Eds) (2014) *Excellence in Dementia Care: Research into Practice.* Second edition. Open University Press, Maidenhead.

**Dyson S** (2004) T*ranscultural Nursing Care of Adults.* tinyurl.com/h5akg36 (Last accessed: February 24 2016.)

**Foster C, Herring J, Doron I** (Eds) (2014) *The Law and Ethics of Dementia.* Hart Publishing, Oxford.

**Giger J** (2013) *Transcultural Nursing: Assessment and Intervention.* Sixth edition. Mosby Elsevier, St Louis MO.

**Grand J, Caspar S, Macdonald S** (2011) Clinical features and multidisciplinary approaches to dementia care. *Journal of Multidisciplinary Healthcare.* 4, 125-147.

**Institute for Research and Innovation in Social Services** (2010) *Improving Support for Black and Minority Ethnic (BME) Carers.* tinyurl.com/gs3ojul (Last accessed: February 24 2016.)

**Joas H, Wiegandt K** (Eds) (2008) *The Cultural Values of Europe.* Liverpool University Press, Liverpool.

To minimise perception of norm transgression and reduce the effect, nurses should teach family carers about the nature of dementia, talk through problematic issues and collaborate on identifying strategies to minimise problems. Nurses should be aware of stressors that have different effects on different groups and consider culturally congruent advice. For example, if a person with dementia is not able to fulfil a previous role, the nurse could suggest more achievable alternatives, such as dusting rather than vacuuming, or watering plants rather than weeding. If behaviour communicates distress, the nurse could explore ways with the carer to meet unmet needs.

- Promote the meaningfulness of caring in the carer's own belief system. Explore reframing negative experiences as overcoming adversity, building competence and living according to deeply held values, whether spiritual or humanistic.
- Promote carers' autonomy and choices, avoiding assumptions based on cultural norms, while being sensitive to family expectations and the need to engage the wider social network to support individual carers. As carers risk isolation in group-orientated as well as individualistic cultural groups, the importance of mutual support, sharing the caring role and making use of services should be emphasised from diagnosis.
- Promote carers' resilience by reflecting on previous challenges and how they were overcome, and acknowledge the survivor identity and structure processes to develop further resilience. Explore life histories and experiences of migration to support the identity of the person with dementia and their carer, and recognise the strengths which build resilience.
- Acknowledge the effect of racism and develop culturally competent, non-discriminatory services. Listen to carers, avoid exploitation, and advocate for protection and improvement of high-quality, culturally congruent services. Challenge racism, sexism and ageism. Raise awareness in self and others of the effect of oppression and discrimination and, in collaboration with carers, structure future services to promote wellbeing in a diverse society.

## Conclusion

The extent of carer stress varies within and between different ethnic and cultural groups (Springate and Tremont 2014), while cultural identity influences perceptions of 'burden' and coping styles (Sayegh and Knight 2011). This highlights the importance of adopting an individualised, culturally sensitive approach to supporting carers of people living with dementia (IRISS 2010).

Interventions delivered by culturally competent nurses and their multidisciplinary colleagues should promote congruence with cultural values, and ensure effective support and social inclusion for all service users.

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**Conflict of interest**
None declared

**Jutlla K** (2015) The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing and Society.* 35, 5, 1032-1054.

**Kim H, Chang M, Rose K *et al*** (2012) Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing.* 68, 4, 846-855.

**King R, Christou A** (2008) *Cultural Geographies of Counter-Diasporic Migration: The Second Generation Returns 'Home'.* tinyurl.com/z9wzn8y (Last accessed: February 24 2016.)

**Kmietowicz Z** (2013) Opportunistic screening for depression can improve carers' health, says college. *BMJ.* 346:f3099.

**La Fontaine J, Ahuja J, Bradbury N *et al*** (2007) Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing.* 60, 6, 605-614.

**Lamura G, Mnich E, Nolan M *et al*** (2008) Family carers' experiences using support services in Europe: empirical evidence from the EUROFAMCARE study. *The Gerontologist.* 48, 6, 752-771.

**Lopez J, Romero-Moreno R, Marquez-González M *et al*** (2012) Spirituality and self-efficacy in dementia family caregiving: trust in God and in yourself. *International Psychogeriatrics.* 24, 12, 1943-1952.

**MacKinlay E, Trevitt C** (2012) *Finding Meaning in the Experience of Dementia: The Place of Spiritual Reminiscence Work.* Jessica Kingsley, London.

**Moriarty J, Sharif N, Robinson J** (2011) *Black and Minority Ethnic People with Dementia and Their Access to Support and Services.* Social Care Institute for Excellence, London.

**Mukadam N, Cooper C, Livingston G** (2011) A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry.* 26, 1, 12-20.

**Newbronner L, Chamberlain R, Borthwick R *et al*** (2013) *A Road Less Rocky: Supporting Carers of People with Dementia.* Carers Trust, London.

**Parveen S, Morrison V, Robinson C** (2011) Ethnic variations in the caregiver role: a qualitative study. *Journal of Health Psychology.* 16, 6, 862-872.

**Prince M** (2015) *Dementia as a Global Issue.* tinyurl.com/j2mywej (Last accessed: February 24 2016.)

**Rauf A** (2011) *Caring for Dementia: Exploring Good Practice on Supporting South Asian Carers Through Access to Culturally Competent Service Provision.* Meri Yaadain Dementia Team, Bradford.

**Royal College of Nursing** (2016) *Dementia: Supporting Carers.* tinyurl.com/h3hjrsu (Last accessed: February 24 2016.)

**Samia L, Hepburn K, Nichols L** (2012) 'Flying by the seat of our pants': what dementia family caregivers want in an advanced caregiver training program. *Research in Nursing & Health.* 35, 6, 598-609.

**Sayegh P, Knight B** (2011) The effects of familism and cultural justification on the mental and physical health of family caregivers. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences.* 66B, 1, 3-14.

**Shim B, Barroso J, Gilliss C *et al*** (2013) Finding meaning in caring for a spouse with dementia. *Applied Nursing Research.* 26, 3, 121-126.

**Skarupski K, McCann J, Bienias J *et al*** (2009) Race differences in emotional adaptation of family caregivers. *Aging and Mental Health.* 13, 5, 715-724.

**Springate B, Tremont G** (2014) Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *American Journal of Geriatric Psychiatry.* 22, 3, 294-300.

**Sussman T, Regehr C** (2009) The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health & Social Work.* 34, 1, 29-39.