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Supporting black and minority ethnic carers

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Key Messages

- 1** Being a carer is very common. Irrespective of their ethnic or cultural background, carers play a vital role in supporting others with disability or illness, frequently extending how long those they care for can remain at home.
- 2** Carers save the economy an enormous amount of money but often at significant cost to themselves both to their well-being and in financial terms. As a result, carers themselves often need support.
- 3** The experiences of black and minority ethnic carers are frequently different and may be more challenging than those of white carers.
- 4** Black and minority ethnic carers are not only less likely to access services but may also find services less satisfactory than white carers.
- 5** The effect of personalisation and the Care Act (2014) on black and minority ethnic carers remains unclear.
- 6** Evidence for the effectiveness of supportive interventions for carers in general is disappointing and evidence of their impact specifically on black and minority ethnic carers is hard to find.

Introduction

Society is ageing and people are living longer with illness and disability. Such changes are clearly positive but they also mean that more people need support from families and friends if they are to stay at home. Most people in the UK want to remain in their own homes for as long as possible and most would also prefer to die there (Gomes et al., 2011; Department of Health, 2013). Families and friends, often referred to as carers, play a significant role in supporting people living at home. For example, about two thirds of people in the United Kingdom (UK) with dementia live at home (Prince et al., 2014) and their primary support comes from families and friends.

These carers can be defined as:

'... anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.' (Carers Trust, 2018)

A key point here is that these carers are unpaid and are distinct from paid care workers.

The vital role of carers in supporting others with disability or illness

Being an unpaid carer is commonplace – three in five of us will be carers at some point in our lives and it is estimated that there are currently approximately 6.5 million carers in the UK (Office of National Statistics, 2015). With ageing populations and improved medical care, the number of carers is expected to rise – it is anticipated that by 2030, there will be approximately 10 million carers in the UK. Carers and their caring situations are very diverse and there is probably no such person as a typical carer. However, overall female carers outnumber male carers although as they age, the number of male carers increases disproportionately compared to females. By the time they reach 85 years, there are slightly more male than female carers (Office of National Statistics, 2015).

The 2011 Census showed that there were just under 600,000 black and minority ethnic carers in England and Wales and as with carers in general, this group is steadily increasing in number. The majority of black and minority ethnic carers are working age and, as is typical for this age group, many simultaneously manage unpaid care and paid employment (Yeandle et al., 2007; Carers UK, 2011a).

Most carers from all demographic groups provide practical help such as preparing food or shopping and generally keeping an eye out for the person they care for. Other support includes help with finances and benefits, medication and personal care such as washing and dressing. The number of hours spent being a carer vary hugely but approximately four million carers in the UK care for between one and 19 hours per week and 1.4 million provide over 50 hours care per week. Many carers juggle caring roles, paid employment and child care. (Carers UK, 2015).

Carers need support as their role affects their own well-being and finances

Carers are vital to society – they play a crucial role in allowing older people and those with disabilities to remain in their own homes often delaying the need to move to residential care (Gomes et al., 2011). Financially carers are extremely important to the economy - it has been estimated that they save the UK economy £132 billion annually (University of Sheffield, University of Leeds and CIRCLE, 2015) – similar to the cost of the National Health Service (NHS) (HM Treasury, 2015). However, there is also research showing that caring frequently has financial consequences for carers. For example, a third report a £20,000 drop in their household income as result of reductions in paid working hours and the additional costs of caring (Carers UK, 2014). Although often rewarding and satisfying, being a carer can be challenging with adverse effects on carers' well-being. Numerous studies show that carers frequently describe negative changes in their mental and physical health with increased tiredness and social isolation (Pinquart and Sörensen, 2006). Some studies also suggest that declines in carer health and well-being are linked with earlier institutionalisation of the person they care for (e.g. Elliott and Pezent, 2008).

Despite this, a commonly reported concern is that carers may not ask for support either from statutory services or families and friends – whether for financial or other support. This may be because they may not see themselves as carers – for example, regarding themselves as parents or partners as opposed to 'carers' (Netto, 1998; Robinson and Williams, 2002, Ribeiro et al., 2007). Indeed, many take on the caring role without question - saying they do it out of love or duty and because it is time to pay back for the support they received from their parents.

Experiences of black and minority ethnic carers are different and more challenging

Set against what we know about carers in general, evidence is growing that the experiences of black and minority ethnic carers are frequently different and may be more challenging than those of their white counterparts. For example, black and minority ethnic carers are more likely to be struggling financially and are more likely than majority white carers to care for 20 or more hours a week (56% compared to 47%) (NHS Information Centre, 2010).

These greater hours of caring may increase black and minority ethnic carers' risk of poor health, difficulties in keeping paid employment and social exclusion. For example, higher levels of isolation have also been reported for Pakistani and Bangladeshi carers (Carers UK, 2011a) and greater anxiety and depression have also been identified for British Indian carers (Manning et al., 2014).

Furthermore, research suggests that many black and minority ethnic carers are even less likely to self-identify as carers than white carers (Ahmed and Rees-Jones 2008). This may in part be explained by the fact that in some languages such as Bengali, Gujarati, Urdu and Punjabi, there are no words that translate as 'carer' perhaps suggesting the role may not be recognised by all ethnic groups and that caring may not be being regarded as distinct from other familial relationships (Williams and Johnson, 2010). This may have implications in terms of whether these carers ask for and access support for their role.

Black and minority ethnic carers access services less frequently and find them less satisfactory

Despite their additional challenges, evidence suggests that compared to their white equivalents, black and minority ethnic carers are even less likely to access and engage with formal services (Dunlop et al. 2002), even though they report greater need for support (Giunta et al., 2004; Scharlach et al., 2006). There remain concerns that there are misconceptions amongst service providers about the availability of support from extended families (Afyia Trust, 2008) but other possible barriers to accessing and engaging with services may include cultural expectations, stereotypes and language barriers (Greenwood et al., 2015). Explanations for the delayed and low uptake of services also include unwillingness to admit to caring for someone with stigmatised conditions such as mental illness, dementia or HIV. Also, many carers may simply not want to acknowledge needing outside help. This may be related to a belief that caring for relatives is the family's responsibility and cultural beliefs about duty. Added to this, information about services may not be provided in culturally appropriate ways (Williams and Johnson, 2010).

There is also some research suggesting that black and minority ethnic carers are more likely to find services insensitive to their needs. Black and minority ethnic carers are more likely to say they were unlikely to use services, not only because they were unaware of them but also because they found them too expensive and too inflexible (Yeandle et al., 2007). Furthermore, some surveys have found that black and minority groups rate services as less satisfactory than white carers (Thomas et al., 2009; Health and Social Care Information Centre, 2013) but clear explanations for this have yet to be identified (Greenwood et al., 2017). Other research by Greenwood and colleagues interviewing black and minority ethnic carers of stroke survivors described not only the importance of recognising people's cultural and religious needs in service provision but also the huge amount of effort required to access services. Accessing services was reported to be difficult by most carers but was made more difficult by the lack of information and frequently having English as a second language. Some carers said they would prefer the support to be provided by care workers from their cultural backgrounds as this enhanced understanding of their individual needs but, in contrast, others emphasised concerns about maintaining confidentiality in often small communities (Greenwood et al., 2015).

In addition, evidence from Carers UK also shows that black and minority ethnic carers are not only less likely to be in receipt of practical and financial support but are also more likely to wait longer to access it. Explanations for this delay are similar to those for failing to access services altogether - lack of information provided in culturally appropriate ways, language and literacy barriers and poor knowledge of services and entitlements (Carers UK, 2015).

Although, language differences are undoubtedly a barrier, simply translating information into multiple languages is only an initial step. It remains vitally important that people are told about services - more needs to be done to develop outreach services so that minority ethnic communities know what services are available. Carers UK (2011a) recommend that translated leaflets alone should not be expected to increase uptake but organisations should work with community groups using their staff's language skills to help people without fluent English learn about available services.

Providing culturally sensitive services can also be challenging for social care staff. This is not only because of insufficient cultural knowledge but also because staff often

struggle to involve minority groups in developing and providing services (Manthorpe et al., 2012). The involvement of these users would be expected to help develop more sensitive, accessible services.

The impact of personalisation and the Care Act on black and minority ethnic carers

Personalisation is a broad term but refers to trying to offer services that fit with individual user needs. It may be especially helpful to carers giving them greater control in how they manage their caring role (Carr, 2011). We know carers from black and minority ethnic groups often have differing needs and experiences to other carers making personalisation potentially very important when supporting them. Ways of achieving personalisation vary but include e.g. personal budgets and direct payments. However, the evidence for the benefits for black and minority ethnic carers is limited because available research often fails to distinguish between users by ethnic groups (Moriarty, 2014). As a result, although the evidence generally suggests that personalisation can give people more control and choice, it remains unclear whether black and minority ethnic carers benefit any more or less than other groups. For example, a survey by Carers UK (2011b) reported that carers from black and minority ethnic groups said that services arranged using personal budgets were better than if they were organised by their local council. However, very few carers from these minority ethnic groups participated in the research making it difficult to know if these findings are representative of most carers from these diverse groups.

The Care Act (2014) replaced most previous law regarding carers and people being cared for. The overall focus was very much on preventing illness and disability and enhancing well-being but importantly for carers, it outlined how local authorities should carry out carer's assessments, how eligibility for support should be determined and how the support should be paid for (DH, 2016). However, to date, there appears to be no available evidence to determine whether it has had a positive impact, or indeed whether the Act has benefited any demographic groups in particular.

The impact of supportive interventions on black and minority ethnic carers

Overall syntheses of the available research conclude that, in general, interventions for carers such as respite or counselling irrespective of ethnic groups seldom have a clear, demonstrable impact on them, although they are often very well received. For example, Thomas et al. (2017) in a review of systematic reviews concluded that there was some evidence that some carers in specific groups benefited from available interventions but no 'one size fits all'. However, when trying to assess the impact on carers from black and minority groups, there is very little good evidence with many studies not reporting the ethnicity of the carer participants. This review was a very comprehensive meta-review but the authors identified few studies that looked at ethnic differences and they concluded there was a clear gap in the evidence relating to carers from minority groups. An exception was a review by Phillipson et al. (2014) who looked at ethnicity and the use of carer respite. This study showed, for example, that preferences for in-home versus out-of-home respite vary by ethnic group suggesting that diverse groups' preferences should be routinely taken into account (Phillipson et al., 2014).

However, active involvement of carers from black and minority ethnic groups in service design and delivery is showing promise in improving services. A positive example of carer support incorporating service users and other stakeholders in Australia comes from Goeman et al. (2016). Focusing on dementia, these authors developed an inclusive model of culturally sensitive support, incorporating a specialist dementia nurse, to facilitate access to health and social care for people with dementia and their carers from culturally and linguistically diverse communities. They concluded that the inclusion of these service users and other expert stakeholders helped the success of the project as demonstrated by the increased uptake of community support services including activity groups and respite care. However, more evidence is needed in order to be confident that these findings are generalisable to all service development.

Conclusions

The demographic profile of the UK is changing and so are family structures (Centre for Policy on Ageing, 2014). It is anticipated that our older population will become increasingly diverse (Lievesley, 2010) potentially increasing the demands on carers from black and minority groups. The reasons for the delayed and lower uptake of services by minority ethnic carers remain unclear and work is required to address this differential access. Support services for carers need to ensure active involvement of carers from all ethnic groups in service design and delivery (Vickers et al., 2012). Such involvement can be expected to improve the chances that services are accessible and meet carers' needs. The increasing role played by the voluntary sector in supporting carers should also mean that services can be tailored to the local demographic profile of the carers making them better able to meet their specific requirements.

It is also worth highlighting that many of the explanations put forward to explain why minority ethnic carers fail frequently to access services or find them unsatisfactory are also relevant to carers in general, irrespective of their ethnicity (Joseph Rowntree Foundation, 2010; Greenwood et al., 2015). However, for minority ethnic carers the situation is often made harder as they are more likely to suffer ill-health (Modood et al., 1997), poverty and inequality (Ahmad and Atkin, 1996). Language barriers and concerns about cultural and religious suitability add to their challenges.

Finally, discussions about carers from black and minority ethnic groups may obscure their diversity, not only in relation to ethnic and cultural diversity but also in terms of their other demographic characteristics such as age or gender and their individual caring situations. It is paramount that we acknowledge the diversity within these large, general categories and also keep in mind the relatively hidden and under-researched white minority carers and refugees, whose experiences are rarely explored and reported.

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- Minority Ethnic Carers of People Project) has several useful resources on its website: www.mecopp.org.uk/resources-bme_articles_reports_links.php?section_id=230
- National Family Care Network describes some local resources: www.familycarers.org.uk/resources/by-tag/black-minority-ethnic-carers

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