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Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature

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What is known about this topic

- Numbers of carers from minority ethnic groups and their support needs are increasing, but they often fail to access services.
- There is some evidence that compared with majority ethnic users, minority ethnic users tend to be less satisfied with social care services.

What this paper adds

- This paper confirms the dearth of research investigating satisfaction with social care and barriers to access among minority ethnic carers.
- Language and concerns about services' cultural and religious appropriateness are the main perceived barriers to accessing social care specific to minority ethnic carers.
- Other barriers identified by carers from minority ethnic groups are potentially relevant to all carers, irrespective of ethnicity, highlighting the importance of understanding and reducing barriers faced by all carers.

Abstract

As populations age, the numbers of carers overall and numbers of carers from minority ethnic groups in particular are rising. Evidence suggests that carers from all sections of the community and particularly carers from minority groups often fail to access care services. This may relate to barriers in accessing services and service dissatisfaction. The aim of this systematic review was to identify and summarise minority ethnic carers' perceptions of barriers to accessing community social care services and their satisfaction with these services if accessed. The following databases were searched from their start until July 2013: Social Care Online, Social Policy and Research, Scopus, PsychINFO, HMIC, ASSIA, MEDLINE, Embase, CINAHL Plus and AMED. Thirteen studies met the inclusion criteria. Most investigated either barriers to access or satisfaction levels, although three explored both. Only 4 studies investigated minority ethnic carers' satisfaction with social care, although 12 studies reported perceived barriers to accessing services. Few studies compared minority ethnic carers' perceptions with majority ethnic groups, making it difficult to identify issues specific to minority groups. Most barriers described were potentially relevant to all carers, irrespective of ethnic group. They included attitudinal barriers such as not wanting to involve outsiders or not seeing the need for services and practical barriers such as low awareness of services and service availability. Issues specific to minority ethnic groups included language barriers and concerns about services' cultural or religious appropriateness. Studies investigating satisfaction with services reported a mixture of satisfaction and dissatisfaction. Barriers common to all groups should not be underestimated and a better understanding of the relationship between perceived barriers to accessing services and dissatisfaction with services is needed before the experiences of all carers can be improved.

Keywords: barriers, caregiving, carers, ethnic minorities, satisfaction, social care

Background

Carers' low service uptake and barriers to accessing social care

There is increasing understanding of the essential role played by carers in supporting people with long-term conditions. Worldwide, the number of

carers (or caregivers as they are also referred to) is growing as people live longer (Harwood *et al.* 2004). In many developed countries, the number of carers from minority ethnic groups in particular is rising as the demographic profile of these populations ages with increasing proportions of older people (Lievesley 2010). These demographic changes are not only associated with an increase in carer numbers but also in carers' support needs.

Despite the demands of caring, there is international evidence that the uptake of formal support services by carers in general is low (Toseland *et al.* 2002, Brodaty *et al.* 2005, Stockwell-Smith *et al.* 2010). As use of support services can make significant differences, for example, in delaying moves to long-term care facilities (Gaugler *et al.* 2005) and improving carer quality of life (Winslow 1997), understanding reasons for this low uptake is important. Delays in support may also mean that carers only come to the attention of services on reaching crisis point (National Black Carers and Carers Workers Network 2008).

However, reasons for low uptake are poorly understood and are likely to be multi-factorial and complex. Much of the available research focuses on specific carer groups (often disease- or service-specific) and frequently does not distinguish between access to support from health and social care services. For example, Brodaty *et al.* (2005), focusing on carers of people with dementia, reviewed the available literature and concluded that there were four main reasons for low support service uptake. These were: services not perceived as needed (e.g. carers felt that they already had adequate support); reluctance to use services (e.g. caring was viewed as their role or duty); service characteristics (e.g. carers may want to use services but cannot because of factors such as cost or low availability); and lack of information about services. Similar findings have been reported for other carer groups. For example, in a review of barriers to support for carers looking after someone at the end of life, Funk *et al.* (2010) suggested that these included lack of information; no perceived need; previous negative experiences with services and perceptions of poor service quality; carer personality (e.g. coping style); sense of responsibility and duty; and culture and beliefs about family care.

Many of these reasons for not accessing services may be relevant to carers in general, irrespective of the health condition concerned, but the situation is likely to be compounded for carers from minority ethnic groups. Not only are minority ethnic groups more likely to suffer ill-health and poverty (Modood *et al.* 1997), but language differences, cultural appropriateness of services and cultural notions of duty are also likely to influence service uptake (Williams & Johnson 2010). Poverty and inequality (Ahmad & Atkin 1996), and racism (Katbamna *et al.* 2002) may add to their disadvantage.

Indeed, with a few exceptions (e.g. Scharlach *et al.* 2006), much of the available evidence suggests that minority ethnic carers are less likely to use formal services than their White counterparts (Dilworth-Anderson *et al.* 2002, Dunlop *et al.* 2002). This is despite the fact that minority ethnic carers are more likely to express greater need for services than White carers (Giunta *et al.* 2004, Scharlach *et al.* 2006). For example, in the United Kingdom (UK), carers from minority ethnic groups are known to provide more care than majority groups and are more likely to suffer from ill-health (Carers UK 2011). Yeandle *et al.* (2007) also reported that in the UK, minority ethnic carers were more likely to say that they were not aware of services, that services were insensitive to their needs and that their use of services was restricted by lack of information, cost and lack of flexibility. Looking internationally, Pinquart and Sörensen (2005) reviewed 116 articles and concluded that compared with White carers, minority ethnic carers were of lower socioeconomic status, were younger and were less likely to be spouses. They provided more care than White carers and had stronger filial obligation beliefs.

Cultural values and beliefs are likely to influence the context of care-giving with an impact on service uptake and on which family members adopt the caring role (Giunta *et al.* 2004). Research has highlighted the importance of notions of 'duty' often derived from religious beliefs in some Asian groups (Ahmed & Rees-Jones 2008). Furthermore, particularly in relation to conditions such as dementia, cultural norms vary in terms of the stigma and meanings associated with health conditions, which influence interaction with health and social care service systems (Janevic & Connell 2001). Some evidence also suggests that use of informal support may differ among ethnic groups, with minority ethnic groups using more informal than formal support (Giunta *et al.* 2004, Chow *et al.* 2010).

Service satisfaction

As well as carer demographic characteristics, their perceptions and expectations of services, whether from personal experience or derived from hearsay, influence service uptake (Giuntoli & Cattan 2012). Positive perceptions and expectations are likely to enhance uptake, while negative perceptions are likely to have the opposite effect. For example, if services

are regarded as poor quality or are not expected to be beneficial, carers may not even attempt to access them in the first place. Or, if access proves challenging, carers may give up more readily in their attempts to obtain services. This makes understanding the relationship between perceptions of services (including service evaluation in terms of satisfaction ratings) and access important.

User evaluations of health services, often in the form of satisfaction surveys, have proliferated in the UK, United States (US) and increasingly in mainland Europe (Bowling 2002) and there is a considerable body of literature concerning satisfaction with healthcare. Satisfaction surveys are now recognised as an important outcome measure not only in health but also in social care. For example, in England, the white paper Modernising Social Services required the use of satisfaction surveys to monitor important aspects of service quality (DH 1998). However, despite pressure to gain users' perspectives as a means to gauge service quality (Qureshi & Rowlands 2004), until recently, there was relatively little focus on user evaluation of social care (Bauld *et al.* 2000). In England, the development and national roll-out of the national User Experience Survey and the Carer Experience Survey provide a major resource for service funders and policy makers when considering outcomes and cost-effectiveness (DH 1998, Health and Social Care Information Centre 2013).

Satisfaction research

Given the limited research investigating satisfaction with social care, the following section about issues with the research on satisfaction relies heavily on the literature relating to satisfaction with healthcare. Although there are important differences between health and social care services (Bauld *et al.* 2000) in terms of, for example, location of service provision (hospital versus other community-based and care home services) and intervention aims (e.g. clinical treatment or care and support), most of the concerns are relevant to social care as they relate to the overall concept of satisfaction with services.

Relatively early in service evaluation research, several concerns were raised about the concept of service satisfaction (e.g. Williams 1994) and about its measurement. Issues include the concept's vagueness (Sitzia & Wood 1997); difficulties with defining it (Crow *et al.* 2002); the 'user as customer' model (Qureshi & Rowlands 2004); the consistently high user satisfaction ratings (Williams *et al.* 1998); and difficulties especially with global measures of satisfaction (Bauld *et al.* 2000). Researchers have also high-

lighted differences in expressed satisfaction depending on the methods used to investigate it. Qualitative investigations provide a more in-depth understanding, but often suggest lower satisfaction than quantitative research (e.g. Greenwood *et al.* 1999), and some authors have suggested the importance of using composite measurement methods (Powell *et al.* 2004). Impersonal methods, such as mailed questionnaires, tend to result in lower satisfaction and more criticism of services (Crow *et al.* 2002).

The relationships between health service satisfaction and user characteristics such as gender, ethnicity and age remain uncertain and research findings are often contradictory. Some authors report that older people, men and majority ethnic groups are more likely to be satisfied (Parkman *et al.* 1997, Campbell *et al.* 2001, Boydell *et al.* 2010, Bowling *et al.* 2013), but not all studies report this (e.g. Commander *et al.* 1999, Greenwood *et al.* 1999).

Despite these concerns, satisfaction with services remains an important outcome measure as long as these challenges are borne in mind when considering research findings.

Definitions and explanations

For the purposes of this review, the following definitions were used.

Social care refers to support offered by both statutory, commercial and voluntary sectors and includes personal care, day centres, short breaks, respite, support with activities and leisure, as well as carer services and support groups. It can include services primarily aimed at supporting carers or the person they care for. The focus of this review was services in the community; therefore, services provided in long-term care facilities and care homes were not included.

Carers, sometimes described as 'informal carers' to distinguish them from paid care workers, can be defined as:

Usually family members who provide unpaid assistance for their dependent relatives who live in the community. (Heaton 1999, p. 759)

English legislation defines a carer as:

A person (aged 16 or over) who provides or intends to provide a substantial amount of care on a regular basis for an adult or a disabled child. The person may or may not be a relative and may or may not be living with the person for whom they are caring. (DH 2005, p. 22)

However, particularly when considering carers from minority ethnic groups, it is important to take

account of perceptions of what being a carer means and what the role entails, as these may vary with cultural and religious expectations. There is evidence that some carers from majority White groups in the UK may not see themselves as carers (Netto 1998, Robinson & Williams 2002, Ribeiro *et al.* 2007), often preferring to describe themselves as spouses or family members, but this point may be even more relevant among carers from some minority ethnic groups (Ahmed & Rees-Jones 2008). Indeed, in some languages such as Bengali, Gujarati, Urdu and Punjabi, there is no word that translates into carer, suggesting that in these groups, the role may not be recognised (Williams & Johnson 2010).

Minority ethnic groups refer to:

A group within a community which has different national or cultural traditions from the main population. (Oxford English Dictionary)

In the studies included here, the majority populations were described as 'White'.

Although the terms minority and majority ethnic groups are used throughout this paper, it must not be assumed that adopting such categories implies that these groups are either homogeneous or static (Bhopal 2004, Salway & Ellison 2010, Willis *et al.* 2013) or that its members are solely defined by their ethnic group membership (Coker 2001).

Barriers to care and support services: some authors in the included studies specifically referred to barriers, but other reported reasons carers gave for not using services. The term barrier is used to apply to any studies investigating difficulties with service access and acceptability by carers from their perspectives.

Aims

This paper therefore aims to summarise and review the published literature to answer two main research questions:

1 What are the perceived barriers to receiving social care among minority ethnic carers?
2 How satisfied are minority ethnic carers with social care services?

Methods

Using the Centre for Reviews and Dissemination (CRD 2009) guidelines for undertaking literature reviews, a systematic literature review, as opposed to a narrative review, was selected because:

Systematic reviews aim to identify, evaluate and summarise the findings of all relevant individual studies, thereby mak-

ing the available evidence more accessible to decision makers ... Systematic reviews adhere to a strict scientific design based on explicit, pre-specified and reproducible methods. (CRD 2009, p. 5)

To capture the range of studies identified, a narrative synthesis of the findings was adopted. This was not only because of the methodological diversity of the studies identified but also because of the diversity of the settings and outcome measures (CRD 2009, p. 45).

Search strategy

The following electronic databases were searched from their first records until the second week in July 2013: Social Care Online, Social Policy and Research, Scopus, PsychINFO, HMIC, ASSIA, MEDLINE, Embase, CINAHL Plus, AMED (Allied and Complementary Medicine Database). These databases were searched using various combinations of the following MeSH terms (in italics) and keywords with truncation where relevant. Terms used in the search were selected by looking at known research on the topic.

(i) *Social work, Home care services, Social support, Voluntary workers*, social care service*, social care*, voluntary sector*, voluntary service*, voluntary care service*, community care*, social service; (ii) *Ethnic Groups, Minority Groups, Culture, African continental ancestry group, European continental ancestry group, Continental population groups, Asian continental ancestry group*, ethnic minorit*, ethnic communit*, ethnic population, black and minority ethnic, Asian, Indian, Pakistani, Black, black African, black Caribbean, African Caribbean, Afro Caribbean, British, race*, ethnic group*; (iii) *Caregivers, Family*, carer*, care giver*, caregiver*; and (iv) *Patient satisfaction, Consumer satisfaction*, service satisfaction, satisfaction, consumer satisfaction, client satisfaction, experience*.

After selection of relevant articles, their references were hand searched to determine if any other studies fitted the inclusion criteria. In addition, the King's Fund and experts in the topic were contacted to ask if they could identify any further research.

Inclusion criteria

The following types of studies were included (services could be either for the carer or for the person they care for): investigations of carer satisfaction with social care, which included minority ethnic carers; carers of adults and/or children with disability; investigations of carer access or barriers to social care in the community, which included minority ethnic

carers; qualitative and quantitative studies; published in peer-reviewed journals; in the English language.

Exclusion criteria

The following types of studies were excluded: investigations of barriers or satisfaction with only health services (e.g. mental health treatment services or clinical palliative care); investigations of the perceptions of child carers; investigations of services not provided in the community (e.g. care homes); studies where it was not possible to distinguish between satisfaction with or barriers to accessing health and social services; investigations of carers of children without disability; studies where it was impossible to distinguish between carer and non-carer participants; non-peer-reviewed; PhD theses; conference proceedings; review and comment articles.

Three authors independently reviewed the titles and abstracts of studies identified in the electronic search. The first author (N.G.) reviewed all the articles and two other authors (R.H. and R.S.) shared the double reviewing, ensuring that all articles were scrutinised by at least two authors.

Quality assessment

Quality assessment was performed by two authors (N.G. and R.H.) independently using the QualSyst scales devised by Kmet *et al.* (2004). These scales are designed for use with both qualitative (maximum score 20) and quantitative (maximum score 22) research. Initial differences in ratings were small (no more than one point) and consensus was easily achieved with discussion. Quality scores were not used to exclude studies, but were used to identify their strengths and weaknesses.

Study categorisation, data extraction and synthesis of included studies

Data were extracted from included articles using pre-defined categories (see Table S1) and were categorised into those focusing on barriers and those on satisfaction with social care, even if these were not the original study foci. Usually, barriers or satisfaction were terms used by the study authors but, for example, Hensel *et al.* (2005) referred to 'experiences' and 'attitudes' which, since they were evaluative, were categorised under satisfaction. Study methods were categorised as qualitative or quantitative. The original study sometimes used both methods (e.g. Fazil *et al.* 2002), but categorisation here relates only to elements of studies relevant to the review.

Synthesising the evidence from qualitative and quantitative in one review creates difficulties, for example, in evaluation and presentation of the findings, but can broaden the generalisability of the findings (Whittemore & Knafl 2005). The findings from the qualitative and quantitative studies were therefore compared to identify similarities and differences in the findings derived from the two approaches.

Findings

Thirteen studies fitting the inclusion criteria were identified.

The main reasons that studies were excluded after initial scrutiny of abstracts of all 1849 studies were:

1 not investigating service satisfaction;
2 not investigating barriers to accessing social care;
3 focusing on healthcare only;
4 it was impossible to determine whether the participants were describing health or social care.

These were similar to the reasons for the later exclusion of 51 of the 64 full-text studies, which were scrutinised in more detail and then excluded leaving 13 studies (Figure 1). Some studies initially appeared to match the criteria, but were excluded either because they were only about healthcare (e.g. Kokanovic *et al.* 2006), it was impossible to disaggregate perceptions of health and social care (e.g. Hatton *et al.* 1998) or because it was not possible to be sure whose responses (e.g. carer or cared-for person) were
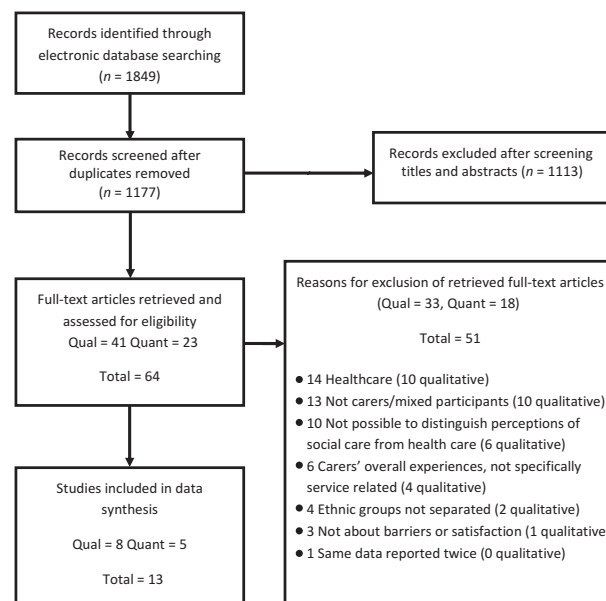

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher *et al.* 2009) showing the process of including and excluding articles.

reported, for example, Giuntoli and Cattan (2012) and McGrath *et al.* (2006). Approximately two-thirds of these studies were qualitative. Similar reasons applied to the exclusion of both qualitative and quantitative studies.

Focus and methods

The majority of the included studies (nine) focused on barriers to accessing social care and one (Townsend & Kosloski 2002) on satisfaction with social care. Three studies investigated both subjects (Hensel *et al.* 2005, Hepworth 2005, Hubert 2006).

The earliest of the included studies was published in 1998 (Netto 1998) and the latest in 2011 (Casado *et al.* 2011). Close to half came from North America (US: five; Canada: two) and the remainder came from the UK. Five were quantitative with sample sizes ranging from 157 to 1643 and eight were qualitative with participant numbers ranging from 19 to 76. Interviews and surveys were the most common methods employed.

Participant characteristics

Numbers of ethnic groups participating in the research ranged from one (Merrell *et al.* 2006, Lai & Surood 2008) to eight (Scharlach *et al.* 2006). Reflecting the countries where the studies were undertaken, the ethnic groups of carers most commonly studied

were: White, Black African, Black Caribbean and Asian groups from the Indian subcontinent (Indian, Pakistani, Bangladeshi) and American Asian (Far East Asian, e.g. Chinese and Korean). In the majority of cases, participants were caring for older people, but Fazil *et al.* (2002) focused on carers of children with disabilities. Carer participants were in a variety of age groups, but the vast majority were over 30 years old [minimum specified 16 years (Merrell *et al.* 2006) and maximum 86 (Hubert 2006)]. Social care services investigated included day care; respite services; personal care; social worker support; and unspecified social services and support services for carers or the person they cared for.

Although some studies compared minority ethnic groups with the White majority, this was rare, making it difficult to specifically say whether the barriers identified were specific to, or at least more common among minority ethnic carers than White carers.

Study quality

Using the Kmet *et al.* (2004) scales, study quality was found to be variable with scores ranging from 5/20 for the qualitative studies to 22/22 for the quantitative ones. Overall, quantitative studies scored more highly than qualitative ones (Tables 1 and 2). The quantitative studies consistently performed well in terms of describing their research questions and rationale for their methods, but they performed less well in

Table 1 Kmet *et al.* (2004) quality ratings for the quantitative studies

Study	Cassado *et al.*	Giunta *et al.*	Lai and Surood	Li	Townsend and Kosloski
Question/objective sufficiently described	2	2	2	2	2
Study design evident and appropriate	2	2	2	2	2
Method of subject/comparison group selection or source of information/input variables described and appropriate	2	2	2	2	2
Subject characteristics sufficiently described	1	2	2	1	2
If intervention and random allocation were possible, were they described	N/A	N/A	N/A	N/A	N/A
If intervention and blinding of investigators were possible, were they reported	N/A	N/A	N/A	N/A	N/A
If intervention and blinding of subjects were possible, were they reported	N/A	N/A	N/A	N/A	N/A
Outcome and (if applicable) exposure measures well defined and robust to measurement	1	1	2	2	1
Sample size appropriate	2	2	2	2	2
Analytical methods described/justified/appropriate	2	2	2	2	2
Estimate of variance is reported for the main results	2	2	2	1	2
Controlled for confounding	1	2	2	2	1
Results reported in sufficient detail	2	2	2	2	2
Conclusions supported by the results	2	2	2	2	2
Total score	19/22	21/22	22/22	20/22	20/22

Yes = 2, Partial = 1, No = 0 or not applicable (N/A). Total maximum possible scores therefore can vary.

Table 2 Kmet *et al.* (2004) quality ratings for the qualitative studies

Study	Fazil *et al.*	Hensel	Hepworth	Hubert	Merrell *et al.*	Netto	Neufeld *et al.*	Scharlach *et al.*
Question/objective sufficiently described	2	2	1	2	2	2	2	2
Study design evident and appropriate	1	2	1	2	2	1	2	2
Context for the study clear	2	2	1	2	2	2	2	2
Connection to a theoretical framework/wider body of knowledge	1	2	1	1	1	1	2	1
Sampling strategy described, relevant and justified	1	1	0	1	2	2	2	1
Data collection methods clearly described and systematic	1	1	1	1	1	1	2	2
Data analysis clearly described and systematic	0	0	0	1	1	0	2	2
Use of verification procedure(s) to establish credibility	0	0	0	0	2	0	2	2
Conclusions supported by the results	1	2	0	1	2	2	2	2
Reflexivity of the account	1	0	0	1	0	1	1	1
Total score	10/20	12/20	5/20	12/20	15/20	12/20	19/20	17/20

Yes = 2, Partial = 1, No = 0.

Table 3 Barriers potentially affecting carers from any ethnic group

Barriers	Barriers reported in
Attitudinal	
No perceived need to use services, e.g. rely on informal support	Casado *et al.* (2011), Giunta *et al.* (2004), Hubert (2006), Scharlach *et al.* (2006), Hensel *et al.* (2005)
Attitudes, e.g. shame, pride, wanting to be together, congruence with personal beliefs	Hensel *et al.* (2005), Hubert (2006), Lai and Surood (2008), Li (2004), Neufeld *et al.* (2002)
Reluctance to involve non-family members	Casado *et al.* (2011), Fazil *et al.* (2002), Li (2004), Scharlach *et al.* (2006)
Unwillingness of the cared-for person and the wider family to use services	Fazil *et al.* (2002), Netto (1998), Hepworth (2005)
Dissatisfaction/concerns with service quality, mistrust of services	Hensel *et al.* (2005), Lai and Surood (2008), Scharlach *et al.* (2006)
Practical	
Cost	Casado *et al.* (2011), Giunta *et al.* (2004), Hepworth (2005), Neufeld *et al.* (2002), Scharlach *et al.* (2006)
Availability of services (e.g. timing and funding restrictions)	Casado *et al.* (2011), Li (2004), Townsend and Kosloski (2002), Scharlach *et al.* (2006), Hepworth (2005)
Low awareness or lack of information about services	Hensel *et al.* (2005), Hubert (2006), Merrell *et al.* (2006), Netto (1998), Scharlach *et al.* (2006)
Administration, e.g. bureaucracy, paperwork, communication with service and waiting lists	Lai and Surood (2008), Li (2004), Scharlach *et al.* (2006), Townsend and Kosloski (2002)
Lack of transport to service	Giunta *et al.* (2004), Lai and Surood (2008), Neufeld *et al.* (2002)

terms of describing their samples and outcome measures. The qualitative studies generally explained the rationale for their approach well, but the methods and data analysis tended to be less well described. Relationships with theoretical frameworks and researcher reflexivity were also often less well articulated. However, there was no discernible relationship between quality ratings and study findings.

Barriers

Despite a wide and inclusive search, few studies investigating minority ethnic carers' satisfaction with social care were identified, although more highlighting perceived barriers were found. These barriers were a mixture of structural and attitudinal ones. Few made direct comparisons within studies between

Table 4 Culturally specific barriers

Barriers	Barriers reported in
Practical	
Language barriers	Casado *et al.* (2011), Fazil *et al.* (2002), Hensel *et al.* (2005), Hubert (2006), Lai and Surood (2008), Li (2004), Merrell *et al.* (2006), Netto (1998), Neufeld *et al.* (2002), Scharlach *et al.* (2006)
Practical and attitudinal	
Ethnic matching: wanting staff matched to their ethnicity	Hensel *et al.* (2005), Fazil *et al.* (2002), Giunta *et al.* (2004), Netto (1998)
Concerns about cultural and religious appropriateness, e.g. meeting religious and dietary needs, insensitivity to religious and cultural needs	Casado *et al.* (2011), Hensel *et al.* (2005), Hubert (2006), Lai and Surood (2008), Li (2004), Merrell *et al.* (2006), Netto (1998), Scharlach *et al.* (2006), Hepworth (2005)

the perceptions of minority ethnic carers and majority White carers.

Initial narrative analysis of the findings suggested that some barriers were potentially common across ethnic groups and some specific to certain minority ethnic groups. It was therefore decided to divide the barriers into two categories. One included barriers potentially relevant to all ethnic groups and the other category more specific to minority ethnic groups.

General barriers – not ethnic or culturally specific
Obstacles or difficulties described in this section are potentially relevant to all carers and are not unique to minority ethnic groups. Commonly reported barriers here were grouped into two types: attitudinal (e.g. not seeing the need for services, reluctance to involve outsiders and pride or shame) and practical barriers (e.g. low awareness of services and lack of information, cost and service availability) (Table 3).

Culturally specific barriers
The barriers described here are more explicitly related to carers' culture or ethnic group. These too are a mixture of attitudinal and practical and include language barriers and concerns about cultural or religious appropriateness of services. Not having services provided by people of the same ethnic group was also seen as a barrier by some carers (Table 4).

Comparison of the findings from the qualitative and quantitative studies suggested similar findings with both approaches. However, some barriers identified in the qualitative studies were not highlighted in the quantitative findings. Lack of awareness and insufficient information arose as clear barriers in the qualitative studies, but not in the quantitative ones. For example, both approaches identified language as a possible issue, but only the qualitative research identified low awareness and

lack of culturally appropriate services. With both approaches, some carers reported not seeing 'the need' for services, but the qualitative studies also reported that some carers or those they cared for simply did 'not want services'. These themes overlap, but are also slightly different.

Satisfaction

Very few satisfaction studies were identified and there were no clear patterns in satisfaction with social care. Some minority ethnic groups expressed satisfaction with some services. For example, Hepworth (2005) reported that the South Asian carers interviewed were satisfied with support groups, whereas Hensel *et al.* (2005) found that South Asian carers were satisfied with carers' centres, but dissatisfied with others, e.g. social workers and respite. The minority ethnic carers in Hubert's (2006) study were largely satisfied with day care and respite, but less satisfied with support from social workers.

The paucity of studies investigating satisfaction and their diversity in participants, service focus and findings made comparison of the qualitative and quantitative studies difficult. Both methods identified both satisfaction and dissatisfaction with services. However, the qualitative studies suggested reasons for satisfaction such as 'caring' staff and receiving emotional support (Box 1).

Discussion

This review set out to identify and summarise the available research evidence for satisfaction and barriers to social care service use among carers from minority ethnic groups. Disappointingly, few of the studies directly compared minority ethnic carers' perceptions with majority White carers' perceptions, making it difficult to identify perceptions confined to

Box 1 Satisfaction with social care

Satisfaction	
Minority ethnic (mostly Caribbean and Indian) carers: mostly satisfied, e.g. with day care (day centre staff described as 'caring' and 'respectful of cultural and religious differences') and respite; almost all described it as 'good', but less so with social workers	Hubert (2006)
South Asian carers: satisfied with support groups, benefitted from emotional and social support, information sources and active involvement gave them purpose and sense of achievement. They spoke 'positively' about befriending schemes	Hepworth (2005)
South Asian carers: carers' centre provided by voluntary sector 'positively regarded'	Hensel *et al.* (2005)
Hispanic carers more satisfied than White carers with respite	Townsend and Kosloski (2002)
Dissatisfaction/low satisfaction	
South Asian carers: low satisfaction with respite, home carers, social services, e.g. social workers 'poor' or 'unsatisfactory', respite 'poor'. Local authority day centre 'poor'	Hensel *et al.* (2005)
African American carers: less satisfied than White carers with day care	Townsend and Kosloski (2002)

particular ethnic groups or to compare perceptions of White majority carers with minority ethnic carers. This is important as it may serve to reinforce the impression that the experiences of minority ethnic carers are unique and always different from those of the White majority, whereas, given their role as carers, there are likely to be many experiences in common (Hubert 2006). If the experiences of all carers are to be improved, it is essential that common barriers are recognised and addressed.

Our review suggests that reasons carers give for not using services may apply to many ethnic groups, including White majority carers. The reasons offered may be a reflection of both how health or disability problems are perceived by different ethnic groups and who their members perceive to be responsible for caring and how it should be supported.

Reasons include low awareness of services and having insufficient information; not perceiving the need for services; a sense of duty; bureaucracy; concerns over finances and reluctance on the part of the care recipient. This conclusion is supported by comments both from authors of some included studies (Hubert 2006, Scharlach *et al.* 2006) and from other research (Winslow 2003, Brodaty *et al.* 2005, Yeandle *et al.* 2007, Giuntoli & Cattan 2012). For example, Hubert (2006, p. 266) emphasised:

Many of the issues discussed above are not confined to people from Black or minority ethnic groups, but are relevant to all carers….

Yeandle *et al.* (2007, p. iv) reported:

Our interviews with ethnic minority carers raised some issues about the skills of paid care workers, especially where service users spoke languages other than English, and about culturally appropriate provision. In general, however, common issues were more important than differences.

These similarities in barriers to accessing services should not be underestimated. The development of personal budgets in England may improve access to care and support by enabling carers from minority ethnic groups (and everyone eligible) to have greater choice in how this is provided, where and by whom (Newbronner *et al.* 2011).

A recent study (Giuntoli & Cattan 2012) has some parallels to the findings of our review. These authors investigated how older migrants (which, in the UK context, are only a small part of minority ethnic carers), including older people and their carers, would like to receive and access services, and found that participants' expectations could be categorised as 'abstract' high standards and 'pragmatic' expectations. Abstract standards included high standards of good practice, cultural understanding and responsiveness to individual expectations. These were common to all ethnic groups, but there was not always similarity across ethnic groups about how these expectations should be met. Dignity was a central expectation common to all ethnic groups. 'Pragmatic' expectations were culturally specific expectations of practices that migrant older people and carers associated with maintaining dignity in old age. Furthermore, these differences could not always be explained as an outcome of different cultural backgrounds, but were frequently associated with life experiences and personal characteristics (Giuntoli & Cattan 2012).

This is not to say that there are not some barriers to services that are specific to minority ethnic groups or that some aspects of being from minority ethnic groups do not compound barriers for these carers. For example, minority ethnic carers may be less likely to seek out information about services, which may then result in them being less likely to be aware of services. Reasons for not seeking out services include:

a perception that care for kin is the family's responsibility, the information may not be provided in a culturally appropriate way or, because of the stigma associated with illness and disability or asking for help for themselves, they avoid admitting needing it (Williams & Johnson 2010). In addition, if majority group carers feel that information is lacking or that poor communication with services prevents them from using services, then the situation is likely to be even more challenging for minority ethnic carers. Other characteristics, such as not wanting to involve non-family members in caring, may be more significant in some cultures, but are likely to apply across both majority and minority groups. Furthermore, it is well recognised that poverty and racial inequalities may compound the difficulties minority ethnic groups experience in accessing services (Ahmad & Atkin 1996, Adamson et al. 2003) and may mean that they are less able to afford services or other solutions relevant to disability or frailty.

Research suggests that there are many common experiences to carers across all ethnic groups and carers from diverse ethnic groups can identify both positive and negative aspects of their role (Scharlach et al. 2006). However, differences, for example, in motivations for caring, adaptation to their role and the use of social support may influence perceptions of services. Parveen et al. (2011) distinguished between extrinsic and intrinsic motivations for caring and reported that Asian (British Indian, Pakistani and Bangladeshi) carers in their study were more often extrinsically motived by a sense of obligation or duty, while the White British carers adopted the role for more intrinsic reasons such as emotional attachment to the care recipient. The White British carers in their study were generally willing to provide care as it was part of 'their nature' (Parveen et al. 2011, p. 869). For Asian carers, their willingness arose from fulfilling their cultural and religious duty, whereas the White carers' willingness was due to reluctance to have their relative placed in an 'institution'. Although these perceptions may differ with the carers' generation or cohort and may change over time, findings such as these may help explain some different attitudes to service provision.

If carers feel that they have no choice and are extrinsically motivated, this may influence expectations of support from services.

There were some commonly identified barriers in our review that were specific to minority ethnic group carers such as language and not taking up services because they were not perceived as likely to be appropriate to their culture or religion. Related to this was the finding that some minority ethnic participants wanted service providers to match their ethnic background to foster cultural and language similarity. Language differences are clearly a barrier relevant to many aspects of service provision starting from information about services, knowing what support is available, applying for services and, finally, service provision itself. Clearly, this is an important subject and research needs to investigate at what point in the process of accessing services that language is a barrier and how. However, translating information is only the first step. As Moriarty (2012) has pointed out when referring to services for older minority ethnic people, translating information leaflets into different languages is insufficient to change the situation – outreach services should also be developed so that minority communities know what services are available. Other research (Manthorpe et al. 2012) has shown that social care staff highlight the challenges of providing culturally sensitive services partly because of their inadequate knowledge but also because of the difficulties they face in involving minority ethnic communities in designing and providing services.

Furthermore, it may be that highlighting language difficulties may be a relatively easy answer for carer participants to give in response to interview questions about barriers to services as it is part of popular, easily accessible discourse (Nunkoosing 2005, Funk et al. 2010). Arguably, such answers are easier to give and less emotive than suggesting that services are culturally inappropriate or of poor quality. This deserves investigation.

This review has highlighted the dearth of literature relating to satisfaction with social care among minority ethnic carers, despite their increasing numbers and growing role in supporting people with long-term conditions. Too few studies were identified here to allow clear patterns to be identified and it was not possible to say if any ethnic groups were less or more satisfied than any other. This suggests a clear need for further research, especially given large-scale recent quantitative survey data (e.g. Health and Social Care Information Centre 2013), which reveal that some minority ethnic groups are less satisfied than White British users with publically funded social care in England. There are several potential reasons for these lower satisfaction ratings. Such reasons could include minority ethnic service users receiving less satisfactory support than others, but these are not the only possible explanations. For example, it seems likely carers' cultural background with shared values and beliefs may influence understandings of satisfactory care and how they perceive and complete satisfaction surveys. Carers from minority ethnic groups may respond differently to satisfaction questionnaires from the majority; for example, participants may tend to give less favourable responses even when receiving the same standards of

care as those of the majority. This may be a reflection of differences in the way questionnaire items are interpreted or of different expectations (Mead & Rowland 2009). These issues deserve further exploration. Similarly, expectations of services and perceptions of what satisfaction with services means may be influenced by carers' cultural background. Although not all authors agree (see Linder-Pelz 1982), many authors make the commonsense assumption that satisfaction reflects fulfilment of users' expectations (Williams *et al.* 1998), but the link between user/carer experience and expectations and satisfaction ratings remains unclear (Bjertnaes *et al.* 2012, Bowling *et al.* 2013). With a few exceptions (e.g. Bowling *et al.* 2013), researchers investigate user and carer experiences and expectations separately and fail to discuss how they may interrelate. This omission makes it difficult to determine the impact of expectations on satisfaction. For example, people with high expectations are more likely to be disappointed, while those with low expectations may have their expectations exceeded, which in turn may influence their experiences of services. In addition, prior experience, whether positive or negative, is likely to influence expectations. All these factors may well affect minority ethnic carers differently from carers from majority ethnic groups.

Limitations

Limitations of included research studies

The studies included in this review were of variable quality and there were some common limitations. For example, all were cross-sectional and therefore could not offer information about the dynamic nature of caring. The quantitative studies generally scored well in terms of their quality, but the qualitative studies were often less well described. Frequently, details of data analysis were lacking and the findings were presented in insufficient detail to be reassured of the strength of the evidence. However, quality ratings did not appear to be related to study findings, but given the diversity of methods, participants and services investigated, this is perhaps not surprising.

Furthermore, many of the studies relied on interviews, but it has been suggested that it is unwise to rely solely on interviews in research with carers because answers given in interviews may represent their attempts to cope by constructing meaning of their experiences. The findings may be more a reflection of broader social and cultural ideals, rather than a reflection of experiences (Funk *et al.* 2010). The inclusion of other methods of data collection by researchers could modify this limitation.

Limitations of the review

Only research studies published in English were included, meaning that some relevant papers may have been omitted and in the event, all included studies came from either the UK or North America. This decision over language was partially pragmatic (CRD 2009), but, clearly, this may have meant that some potentially relevant non-English language studies were not identified. As our search strategy did not specifically include all UK minority groups, some studies may have been omitted; however, terms for the larger minority groups were utilised as were broader terms covering all minority groups.

Many studies could not be incorporated in the review because it was not possible to separate carer responses from other participants' responses or because the study investigated both health and social care and it was not possible to determine to which service participants were referring. Therefore, some potentially useful information was not synthesised.

Overall, the paucity of relevant studies, particularly in relation to service satisfaction, limits the conclusions that can be drawn. For example, having more pertinent literature should have made it possible to identify if barriers to services are more distinct to specific ethnic groups.

Strengths

This study had several strengths in being focused on a defined participant group providing some specific answers. We achieved the review's aim of identifying and summarising the main perceived barriers for minority ethnic carers in accessing social care support, but there was insufficient evidence to answer whether there are ethnic-related differences in satisfaction with social care. However, we have been able to highlight the similarities across groups.

Clearly, most of the findings of these qualitative studies are unlikely to be generalisable to all carers because of their small sample sizes, but they can be viewed as 'transferable' (Leninger 1994) because of their overall similarity of findings in similar context and circumstances.

Implications of the findings and conclusions

The findings of this review have implications for both social care and support and for research. More research is needed that directly compares different ethnic groups' perceptions of barriers to accessing social care. This would make similarities and differences between groups clearer. Further research inves-

tigating preferences for different types of care may help elucidate the barriers. For example, preferences for in-home versus out-of-home respite have been shown to vary by ethnic group (Moriarty *et al.* 2011, Phillipson *et al.* 2014), suggesting that diverse groups' preferences should be explored. Service funders and providers need to recognise both the barriers to services which are common to most carers and those barriers more specific to minority ethnic carers. For example, a plea for more information (loosely defined) about services is common to all groups, but perhaps greater attention should be given to information content and terminology to ensure that it is seen as relevant to carers. The fact that carers from many ethnic groups do not recognise themselves as carers (Molyneaux *et al.* 2011) may be particularly true of minority ethnic groups (Williams & Johnson 2010), so also needs to be addressed here. However, perceptions of care-giving and attitudes to services are likely to be fluid as these cultural groups change and adapt in relation to the surrounding culture, which itself is also subject to change.

Future research should be designed to allow greater understanding of the dual impact of ethnic group and other characteristics such as gender or migrant status on access and satisfaction with services. For example, in the UK, carers are more often female than male (Office for National Statistics 2013) and this twofold impact of gender and ethnic group deserves more investigation, especially given that men and women may respond to caring differently (Pinquart & Sörensen 2006).

Conclusion

Work remains to be done in understanding and addressing differential access to services for carers from minority ethnic groups. Carers' support services should involve carers from both minority and majority ethnic groups in service design and delivery. Carer involvement may increase the chance that the service will be seen as suitable and relevant to carers' needs. At the local level, services designed with carers' input may be more likely to fit the local demographic profiles allowing for potentially greater personalisation. Similarly, as Vickers *et al.* (2012) suggest, carers should also be involved in designing research to improve its practical relevance and verifiability.

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web-site.