Accessibility and equity of health and social care services: exploring the views and experiences of Bangladeshi carers in South Wales, UK

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Abstract

There is a paucity of information regarding the extent and nature of caring provided by minority ethnic communities. The proportion of older people from these communities will dramatically increase in the next 20 years, which will be accompanied by increasing health and social care needs and an increased demand for carers. A qualitative, exploratory study was conducted to identify the health and social care needs of informal carers, who were caring for a dependent adult from a Bangladeshi community in South Wales, UK. This paper focuses on Bangladeshi carers' access to formal support services provided by the statutory, private and voluntary sectors to assist them with their caring responsibilities. The findings are based on data collected using face-to-face, focused interviews with 20 Bangladeshi carers. Purposive and snowball sampling were used to recruit the sample. The data were analysed using thematic content analysis. The dimensions of accessibility and equity of quality of care were drawn upon to aid understanding of the findings. Bangladeshi carers faced a number of barriers in accessing health and social service provision, which impeded uptake of these services. Additionally, there was evidence of inequity in service provision. Recommendations for improving the accessibility of health and social care services are proposed, which may assist in promoting more equitable services for carers from the Bangladeshi community.

Keywords: accessibility, carers, ethnicity, formal support, inequity

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Introduction and background

In Wales 17% of the population are currently aged 65 or older and this is predicted to rise to 18% by 2011 and to 20% by 2016 (National Assembly for Wales (NafW) 2002). The proportion of older people from black and minority ethnic communities is predicted to significantly increase over the next two decades (Karlsen & Blanchard 2002), which will lead to increasing health and social care needs and increased demand for carers (Karlsen & Blanchard 2002).

In Wales, 16% (360 000) of the adult population are estimated as being carers (Perry *et al.* 2001), who are defined under the Carers & Disabled Children Act 2000 section 1 as being 'individuals aged 16 or over who provide or intend to provide a substantial amount of

care on a regular basis for another individual aged 18 or over'. It is acknowledged that this figure may be an underestimate (Perry *et al.* 2001).

There is a paucity of information regarding the extent and nature of caring provided by minority ethnic communities. The latest census incorporated a question on caring that helps to address this shortfall. Published census figures identify 28 355 people in the study area (Office for National Statistics (ONS) 2001) who provide unpaid care but do not distinguish between different minority ethnic groups.

The under-representation of ethnic groups in general population surveys has been addressed in the study of *Ethnic Minority Psychiatric Illness Rates in the Community* (Sproston & Nazroo 2002). Part of the study explored ethnic differences in caring (for someone other than a

child) and its association with health, and focused on five of the main minority ethnic groups in England (Bangladeshi, Black Caribbean, Indian, Irish and Pakistani), which included a general population White group as a comparison (Nazroo & Sproston 2002).

Of the total sample of 4281 people, 650 were Bangladeshi. The findings identified similar levels of caring being provided across the ethnic groups. Seventeen per cent of Bangladeshi men and 19% of Bangladeshi women were providing care to an adult compared with 15% and 23% of men and women from the White group, respectively (Karlsen & Blanchard 2002). Similar levels of psychological morbidity were found in carers from the ethnic groups, although poorer physical health was identified in the Bangladeshi and Pakistani carers compared with carers from White or Irish groups (Karlsen & Blanchard 2002). Gender differences with regard to psychological and physical morbidity among carers could not be explored due to insufficient numbers (Karlsen & Blanchard 2002).

There is considerable research evidence suggesting that people from minority ethnic communities experience health disadvantage (Smaje 1995, Nazroo 1997, Acheson 1998, Johnson *et al.* 2000). Recent health and social care policies explicitly refer to the need for health and social care providers to respond to ethnic diversity (NHS Ethnic Health Unit 1996, Department of Health 1997, NafW 2000, 2002, WAG 2005).

The Welsh Assembly government is committed to improving the health and well-being of carers and launched the *Caring about Carers – A Strategy for Carers in Wales: Implementation Plan* in 2000 (NafW 2000). A number of measures have been implemented to support carers, including the Carers & Disabled Children Act 2000 and the Carers' Special Grant scheme. The former enables local authorities for the first time to provide services directly to carers, whilst the latter is aimed at promoting the development of flexible and innovative services to support carers, primarily through the provision of breaks from caring (Naf W 2001).

However, service provision for carers in Wales is patchy with a lack of strategic direction (Apsitis & Jones 1999). Services tend to be ethnocentric, attempting to change ethnic communities in line with Western values rather than trying to understand them (Atkin 1992). There appears to be a stereotype that large extended families in these communities will contribute willingly and without question to caring (Murray & Brown 1998). However, Blakemore (2000) reports that families are not as supportive to older people as they were due to changes in family structures and residence patterns.

Limited information is available concerning family obligations and community care for minority ethnic groups and there is a lack of research in terms of both qualitative studies on the experiences of black and minority ethnic carers and also large-scale information sources (Ahmad 1996, Atkin & Rollings 1996).

In the study area 2.2% of the population define themselves as belonging to an ethnic group other than White (ONS 2001), which is an increase from 1.6% in 1991 (Office of Population Censuses and Surveys 1991). The study area has the third highest population of non-White ethnic minorities in Wales, of which the largest minority ethnic community is the Bangladeshi community (ONS 2001). Although the minority ethnic population is not extensive compared with some UK cities, it is increasing and current health policy emphasises the need to provide more equitable services for disadvantaged groups (NafW 2001a, WAG 2005).

Small-scale projects (Baruah 1997, Colton & Roberts 1997, Kahn 1998) have been conducted with the local black and minority ethnic population, which have focused on access to services and users' experiences regarding the quality of services. Colton & Roberts (1997) found that the Bangladeshi subsample who were interviewed (n = 54) reported poorer health compared with the total sample (n = 140) and more long-standing illness.

The survey (n = 189) conducted by Baruah (1997) focused on black and minority ethnic women's access to services. The findings highlighted a low level of awareness and uptake of public services especially of social services. Two-thirds of all respondents did not know what kind of help social services offered. To date limited information is known about Bangladeshi carers' awareness and knowledge of formal support services and this research sought to address that shortfall.

Methods

The aim of the study was to identify the health and social care needs of Bangladeshi carers, who were caring for a dependent adult. Specific objectives were to:

- obtain detailed accounts of carers' health and social care needs; and
- develop recommendations to inform planning of future health and social care provision for the Bangladeshi community.

In order to meet the aim and objectives a qualitative, exploratory study was conducted. Exploratory qualitative research is conducted when a new or underexplored area is being investigated and is designed to uncover the various ways in which a phenomenon is manifested (Polit & Hungler 1999). Accessing the sample proved challenging as Bangladeshi carers did not use local voluntary and statutory carers' groups and there were no carers' groups provided specifically for minority ethnic carers. Bangladeshi carers were therefore

hidden within their community. A research assistant recruited from the local Bangladeshi community sensitively gained access to carers through using a combination of purposive (Burgess 1984) and snowball sampling (Bowling 2002). Purposive sampling was used to identify an initial carer and thereafter snowball sampling was employed, which involved asking one carer to nominate another and so on until the sample of 20 carers was recruited. Each carer knew only of one other carer whom they could nominate. It is acknowledged that snowball sampling has its limitations and may lead to the recruitment of participants from similar backgrounds. However, it is an appropriate sampling strategy for accessing hard-to-reach or hidden populations (Bowling 2002).

Approval was gained from the local research ethics committee and informed consent was obtained from all participants. Written consent was not always obtained because of literacy issues. However, as the interviews were tape-recorded verbal consent was recorded. A verbal explanation as to the purpose of the study was given and written information was also provided in English and Bengali. Although the language used mainly by participants was Sylheti, there is no written format of this language, therefore written information was translated into Bengali.

Data were collected between January and August 2002 using individual, focused interviews (Merton *et al.* 1956, Bryman 2001) and normally conducted in the participants' homes. The focused interview comprised mainly open-ended questions, enabled participants to talk freely about the issues on the topic guide derived from the literature and to raise additional issues of concern. The following topics were explored: accounts of their experiences of caring and perceptions of their caring role; the effect of caring on their lives; exploring their health and social care needs; and awareness and uptake of local resources and sources of support. The interviews were conducted in the participants' preferred language which was English, Bengali, or Sylheti or occasionally a combination of these languages.

The interview tapes were transcribed and where appropriate translated into English. To ensure the accuracy of the translation, a professional translator independently translated a sample of the interviews. The interview data were thematically analysed by initially coding the data, then identifying categories and key themes (Bowling 2002). Analysis of the data commenced as soon as data were collected and all members of the research team analysed the transcripts in order to verify the coding and categorisation of the data, which facilitated interrater reliability. The categories were confirmed by the data or extended as data emerged which did not fit existing categories. The data

were then considered in the light of existing literature. Three key themes were identified: the cultural context of caring, the experience of caring, and formal support for carers. This paper addresses findings from the latter theme and specifically focuses on the accessibility and equity of formal support services for Bangladeshi carers. Issues related to the appropriateness and acceptability of formal support services have been discussed elsewhere (Merrell *et al.* 2005).

Findings and discussion

The findings are based on the analysis of data from 20 Bangladeshi carers who were caring for 22 care recipients, as some carers were caring for more than one dependent. Most of the carers also had childcare responsibilities. The majority of carers were female (n = 16), all were Muslims and their ages ranged from 16 to 62 years. The age of the care recipients ranged from 26 to 80 years. Ten were cared for by their spouses, a further 10 by their sons, daughters or granddaughters, and two were cared for by their parents. Six carers were educated in the UK and could speak and read English, whilst 14 carers had immigrated to the UK. Of these 14 carers, two had good spoken English, four could speak a little English and eight could not speak English. All those who were educated in the UK were between 16 and 26 years of age. In order to protect participants' identity their words are attributed using the letter C to denote carer followed by a number from 1 to 20 which reflects the number of participants in the sample.

Accessibility of formal support services

Understanding of Bangladeshi carers' views regarding the accessibility of formal support service was informed by drawing on Maxwell's (1984) dimensions for assessing the quality of care. In this context accessibility is the extent to which services are accessible to carers from the local Bangladeshi community and incorporates carers' awareness and knowledge regarding existing service provision. While there are different interpretations of the concept of equity (Pereira 1993, Black 1994) for the purposes of aiding understanding of the data, equity refers to whether there is equal treatment for equal need (Smaje & Le Grand 1997) and specifically whether Bangladeshi carers receive equitable services.

Accessibility

Three key issues were identified which influenced carers' access and use of service provision. These were information and knowledge regarding existing services,

sources of information, and language barriers to accessing mainstream services.

Knowledge of existing health and social service provision

The majority of participants had limited knowledge and awareness of health and social services available to assist them in their caring responsibilities:

- ... they are not aware where one should go. Like me, I don't know myself and if there are any organisations or if there are any I don't know myself. (C16, p. 4)
- ... but as a carer to have the leave of somebody taking on charge as opposed to myself, I really don't think there are any. I mean to be honest with you. (C17, p. 6)
- ... no one has approached us about these things. We do not know about these facilities ... that if you're having difficulties like this, there is assistance like this. I do not know. (C18, p. 6)

Two carers reported that they were unaware of local services, because they did not need any formal support and therefore had not sought any information. Of the minority of carers who were aware of local services, this did not of itself result in accessing these services. As one carer reported when asked about accessing services:

... I'm aware of all the services that may be available. But first of all I didn't feel confident to use the services, secondly I haven't heard of any of our community members who use the services ... so I don't know how to get access to the services. (C9, p. 6)

It therefore seems that additional barriers to accessing services are that some carers do not feel confident about doing this and that these services may not be acceptable to all members of the Bangladeshi community.

Of those interviewed only one carer was in receipt of support from social services and one other carer reported that her dependent relative had been assessed by social services. Carers seemed unclear regarding the role and function of the social services department, which was often confused with the Department of Social Security. A lack of awareness of social service provision was identified by Murray & Brown (1998) in their inspection of community care services for Black and ethnic older people in eight Local Authorities with high minority ethnic populations in England. Awareness of social service provision in the local area under study has not improved since 1997 when Baruah found that two-thirds of respondents in a survey (n = 189) of Black and minority ethnic women did not know what kind of help social services offered. However, confusion over the role and function of social services departments is also apparent in the White majority population.

Three carers were receiving support from district nursing and community psychiatric nursing services, whilst none reported receiving any support from the health visiting service. It was also apparent that carers had limited knowledge and information regarding other service provision, such as housing grants, aids and adaptations.

Most of the carers interviewed were in receipt of general welfare benefits such as child benefit, state retirement pension and income support. However, there was less awareness of financial benefits specifically available for carers:

To be honest I never think of that, there might be anything for me to look after my mum. This is the first time I came to know. If there is any I don't know. (C9, pp. 8–9).

... well I don't get any benefits for caring for him at all, I am not aware of any such benefits. (C10, p. 4)

Only two of the 20 carers interviewed reported being in receipt of Disabled Living Allowance, and a further four had applied for this allowance but had been refused. One carer had applied many years previously for the Attendance Allowance, which had been refused and had not re-applied, even though the condition of her relative had deteriorated. Bowes & Dar (2000) and Bowes & MacDonald (2000) have also identified that older South Asian people and their carers have limited knowledge of services, especially social services and welfare benefits. Similarly, Vernon (2002) found in a sample of 28 Asian people with disabilities that they lacked information about entitlements and services, and knowledge of how to access services even though they were all fluent in English or in British sign language.

Understanding the complex welfare benefits system is challenging and this becomes even more so when the situation is compounded by an inability to speak or read English as reported by this carer:

... and if they could get a person like yourself (the interviewer) you know who's able to work in DSS, and explain it, and these situations. They can't, you know, these people, most of these Asian people they cannot write, they cannot read English, at all whatsoever so they do need, somebody there to be Asian supporters ... (C12, pp. 10–11)

It is likely that not all the carers interviewed were claiming benefits to which they were entitled and as a result were experiencing financial hardship. As there was a low level of knowledge regarding health and social care provision and welfare benefits, sources of information were explored.

Sources of information

Without exception all the interviewees reported being in regular contact with their general practitioner and that general practitioners and hospital doctors were the main sources of information:

AA How do you get information about services at the moment? From the doctor,

AA What about leaflets, newspaper or TV No, just doctors. (C10, p. 7)

Well I don't get any information. When I go to the doctors, the GP gives me medication, then we can understand. Thereafter the big, bigger psychiatric doctors, they send us to. (C16, p. 3)

However, the information provided was primarily focused on the medical needs of the care recipient and their carers. Attendance at the general practice surgery and the hospital provided opportunities to disseminate information about service provision and welfare benefits available for carers. Of the four carers in receipt of community nursing or social services only one cited these services as sources of information, therefore other health and social care professionals were not viewed as sources of information.

The next most frequently mentioned source of information was word of mouth:

Well other people who are getting benefit at the moment from them, from word of mouth. (C16, p. 7)

AA ... so how do you receive information?

I know ... from people's talk. (C13, p. 11)

Word of mouth has the potential to be an effective way of disseminating information regarding service provision for carers throughout the local Bangladeshi community. Indeed, Murray & Brown (1998) in their inspection of community care services provided by Social Services Departments identified that word of mouth was the most effective way of providing information to Black elders.

As most carers reported being in regular contact with their general practitioner, it would seem that this could be an accessible and acceptable venue for disseminating information specifically targeted at carers. In order for the information to be accessible to all Bangladeshi carers, it may need to be in audio or video format to account for the varying degrees of literacy in English and Bengali and the fact that some ethnic languages have no written form, for example, Sylheti.

Bedi & Gilthorpe (1995) identified that video programmes achieved the highest level of popularity and usage with the Bangladeshi community in Birmingham. Similarly in a survey of 436 participants from community minority ethnic groups primarily reflecting the Asian communities in Coventry, video tapes were the preferred means of information dissemination (72%) followed by videos coupled with leaflets (Coventry Health Information Forum 1991). Although videos are

initially costly to produce, if they are developed in consultation with the target audience and take into account their beliefs and values, then it is likely to be a more effective way of delivering health information in the long term (Coventry Health information Forum 1991).

The carers interviewed did not have the time or resources to seek out information, therefore information needs to be easily accessible at venues which carers frequently attend. Alternative venues for disseminating information could usefully be explored, for example, the local mosques and Asian grocery stores, as carers frequented these stores on a regular (often daily) basis. Sadler *et al.* (1998, 2001) effectively delivered a cancer education programme for Asian Americans provided by bilingual and bicultural undergraduate students in Asian grocery stores and via religious sites and cultural events.

By disseminating information through local venues where Bangladeshi people often frequent, the level of knowledge regarding health and social care provision for carers may rise throughout the Bangladeshi community and through word of mouth be disseminated widely.

Language barriers to accessing mainstream services

The inability to speak, read and write English was an over-riding problem in gaining access to mainstream services, and this was age and gender related. All the male carers interviewed could speak some English and this was irrespective of their age. Other studies have indicated that South Asian men are more able to communicate in English than South Asian women (Nazroo 1997, Johnson et al. 2000, Gerrish 2001). However, the ability to speak English was closely associated with the age of female carers. Of the 16 female carers interviewed, 11 reported that they either could not speak English or were able only to converse a little. All five female carers who could speak English well were aged between 16 and 26 years. Johnson et al. (2000) in their health and lifestyle survey (n = 4452) of Black and minority ethnic groups in England identified that older Bangladeshi women (aged 50 and over) had the lowest levels of ability in English and were least likely to be economically active.

The language barrier was therefore a particular concern for the older female carers interviewed, as indicated in this statement from a female carer in her 50s:

I do go to the doctors, but I find it difficult since I am not good in English, and unable to communicate properly. I take my children to translate, and sometimes take my husband he can speak a little bit of English, but not too much. Language is a major barrier for me to access mainstream services. (C2, p. 3)

Language difficulties therefore resulted in some carers having to rely on children or other relatives to act as interpreters. Placing the burden of interpreting on children has been viewed as inappropriate (Gerrish *et al.* 1996, Henley & Schott 1999). In one instance the carer was reliant on her dependent relative who had mental health problems for information regarding his condition and progress, as she was unable to communicate with the healthcare professionals.

None of the carers reported that health or social care professionals had utilised professional interpreting services and there seemed an over-reliance and expectation that family members would act as interpreters, despite interpreting services being available within the Trust. Gerrish (2001) reports similar findings in her study of the interactions between district nurses and South Asian patients and their carers. She found that district nurses rarely utilised professional interpreting services and that carers' needs, who were often women and unable to speak English, were inadequately addressed.

A reliance on children and other relatives to act as interpreters resulted in delays in seeking medical advice:

... then about 6–7 pm in the afternoon, I got [relative's name] I rang him and said can you call the emergency doctor for me, my son keeps saying he's burning inside, for the last few days ... Then later [relative's name] rang the doctors and they said take him down. ... Then [relative's name] came from work and took him down. About 7, after 7 ... From there, they sent him to [hospital name] then came home for prayers and left him in hospital. (C4, p. 10)

Carers who were unable to read and write English were reliant on children, other relatives and friends to help them complete application forms; for example, for claiming welfare benefits and for aids and adaptations to the house. Once the application had been submitted several carers reported that because of language difficulties they were unable to pursue the claim:

... I did apply for disability allowance but I have not heard from them, nothing yet. I applied by seeking help from other people. I applied through social services. My son helped fill the form, but I can't speak English so I can't chase it up where it is, I could explain myself better if I could speak. (C6, pp. 6–7)

Being reliant on children and other relatives to act as interpreters resulted in delays in responding to correspondence, sometimes resulting in hospital appointments being missed. Additionally, the inability to pursue welfare benefits claims resulted in financial hardship.

For those carers who were able to communicate in English considerable time and energy was expended in acting as interpreters and advocating on behalf of their dependent relatives. This was particularly difficult for carers who were in full-time employment and had additional caring responsibilities:

... I have to take her down to doctor, hospitals, and if they need any translating, to the hospital. I have to always be there, ring for her and speak to everybody on behalf of her, speak English, and she has difficulty reading English as well, ... so she can't communicate, with anybody, you know, so it's always, I have to be there. (C12, p. 2)

The carers interviewed faced a number of challenges in gaining access to mainstream services which raised additional issues with regard to equity in service provision which is now considered.

Equity in service provision

From analysing the data there was evidence that Bangladeshi carers experienced inequity in service provision. None of the carers reported being offered an opportunity to have their needs assessed, although this is a requirement under the Carers & Disabled Children Act 2000. Holzhausen (2001) found in her national survey of 2215 carers that carers from minority ethnic groups were less likely to have been assessed (41% compared to 50%) but were more likely to be on a waiting list to be assessed (19% to 7%) than White carers. As the response rate from minority ethnic groups was only 3%, and the questionnaire was distributed through carers' groups and organisations, the situation for minority ethnic carers may be bleaker than the findings indicate.

As many of the older female carers interviewed could not speak English, a comprehensive needs assessment could not be conducted without the use of professional interpreting services or reliance on family members to act as interpreters.

None of the carers reported that professional interpreting services had been offered or provided. Carers may prefer family members to act as interpreters rather than professional interpreters, and this is an area in need of further research, but the important issue is that carers and care recipients are provided with a choice and that their preferences are met. The inability to speak English should not be a barrier to appropriate, effective and equitable care (Gerrish 1999, 2001).

It was identified that service providers relied upon children to act as interpreters and yet this has been strongly criticised (Gerrish *et al.* 1996, Henley & Schott 1999, Gerrish 2001). Placing this burden upon children is seen as inappropriate and can result in tensions in family relationships, especially where a child and parent or grandparents are involved (Ahmad 1996). The availability of professional interpreting services and 'Language Line' (a telephone interpreting service) needs to be widely disseminated throughout the local Bangladeshi community.

Carers reported a lack of understanding of the Bangladeshi culture by service providers, especially in relation to the Department of Social Security: ... because there is no Bengali people that you can talk to ... I mean who can you explain these sort of things? I mean if there was an Asian person, who can break down into details, and the way I'm explaining to you, because it's easier ... I mean you know, when you go in DSS, and there isn't I mean every single person there is an English person, and they don't understand, and they try not to understand it ...

AA What? To understand the culture?

The culture and the situation, they should look into it more, I find they don't ... I find they, are very uncaring people up there. (C12, p. 10)

A lack of understanding of other cultures can lead to the stereotyping of minority ethnic groups, which results in differential practice being delivered (Murray & Brown 1998, Davies & Bath 2001, Burr 2002). All public authorities have a statutory duty to investigate discriminatory practice and promote racial equality. Ensuring that all health and social care workers are culturally proficient through the provision of appropriate education and training can reduce the occurrence of discriminatory practice (Lindsey *et al.* 2003).

Few carers were in receipt of support from health and social care providers. This should not be interpreted as meaning that there were low levels of need. It has been shown that Bangladeshi men and women report significantly worse levels of general health including particularly high levels of diabetes, stomach ulcers, heart disease and headaches/migraine (Johnson et al. 2000). Carers reported having health problems such as diabetes, arthritis and gastric ulcers but relegated their needs as the needs of the care recipient and other family members took priority. McGarry & Arthur (2001) reported a similar finding in their qualitative study of the experiences of older carers. However, McGarry & Arthur (2001) identified that this was an issue for carers who were aged over 75 years when it is anticipated that carers are at greater risk of health problems. In this study the carers' ages ranged from 16 to 62 years, with the majority aged between 41 and 62 years and therefore were experiencing health problems at a much younger age.

As it is known that Bangladeshi carers have poorer physical health compared with carers from White or Irish groups (Karlsen & Blanchard 2002), it could be anticipated that the uptake of services would be greater if based on the level of need. Yet as the findings indicated, only four carers were in receipt of formal support provided by community nursing and social services and none reported being in receipt of support from voluntary services.

It is acknowledged that some carers may not avail themselves of support services, especially those which relate to direct, personal care because there was a perception that these services would be unable to meet their cultural and religious needs. However, the findings indicated that most of the carers interviewed were unable to exercise a preference, as they were unaware of the availability of health and social services to assist them with their caring responsibilities.

In order to ensure that equal opportunities policies are being implemented and identify any inequalities in service provision, there is a need for all health and social care providers to routinely record essential information regarding, for example, ethnic origin, language spoken and religion (Hansen & Hempel-Jorgansen 2001). This need was recognised with the launch in July 2005 of a Practical Guide to Ethnic Monitoring in the NHS and Social Care, which stresses the importance of ethnic monitoring to ensure that services are 'equitable and appropriate for patients, service users, communities and staff' (Department of Health et al. 2005, p. 6). The guide recommends the routine collection of data on ethnic origin (using standardised codes compatible with the 2001 Census), religion, diet and language. Karlsen & Nazroo (2002) also recommend the recording of sensitive indicators of socioeconomic position to reveal the significant contribution which this factor makes to the relationship between ethnicity and health. This would provide essential information on, for example, patterns of service uptake, which can be used to inform initiatives aimed at ensuring more equitable provision of health and social services for Bangladeshi and other minority ethnic carers.

Conclusion

Bangladeshi carers' awareness of and access to formal support services have been discussed applying the dimensions of accessibility and equity (Maxwell 1984). The carers interviewed received limited support from health and social care providers. However, low levels of uptake of services were not indicative of low levels of need.

Communication difficulties as a result of language barriers significantly impeded awareness, access and uptake of health and social services, especially social services. Yet the provision of communications support to service users by the NHS and Social Services Departments is not an optional extra, but a requirement under the Race Relations (Amendment) Act 2000 and the Human Rights Act 1998 (Department of Health *et al.* 2005). The findings indicated that the language barrier was age and gender related and that there was underutilisation of professional interpreting services. However, it is unclear as to whether this was because of a lack of awareness of these services, insufficient resources or whether carers preferred to rely on family members to

act as interpreters. The perception that services were unable to meet cultural and religious needs also influenced the accessibility and uptake of service provision. It is hoped that the routine collection, analysis and reporting of ethnicity data will inform decision-making in the NHS and Social Services Departments, to ensure that they are fair employers and that services are equitable and accessible to all.

Some carers reported a lack of understanding of the Bangladeshi culture by service providers, especially in relation to the Department of Social Security. However, all health and social care workers need to be culturally proficient, through the provision of appropriate training, to ensure that equitable care is being provided. This, however, has implications for the provision of cultural diversity training, the extent and nature of which is an underexplored issue in Wales.

As Bangladeshi carers were hidden within the local community the findings suggest the need for an outreach link worker who is able to advocate on behalf of individuals but also for the Bangladeshi community as a whole as there was evidence of inequity in service provision. Since completion of the study a part-time community development worker for Asian carers has been appointed by the Social Services Department. Although the NHS is based on the principles of equal access and equal treatment for all, the findings identified that the Bangladeshi carers interviewed faced many challenges in accessing mainstream services and that inequity in service provision resulted in their health and social care needs being inadequately addressed. It is incumbent upon health and social care providers to ensure that services are accessible and that equitable services are provided if the disadvantage experienced by Bangladeshi carers is to be addressed.

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