'I forget myself': the case for the provision of culturally sensitive respite services for minority ethnic carers of older people

Gina Netto

Abstract

Background The aim of the study was to investigate the need for, use of and preferences for respite services among minority ethnic carers of older people. It was anticipated that the similarities which these carers share in caring for a person from a minority group far outweigh the differences arising from their particular ethnic origin.

Method Interviews were conducted with 45 minority ethnic carers of older people in the Lothian region of Scotland. A detailed qualitative analysis of their need for respite services and preferences for service delivery was undertaken, the results of which have implications for other minority ethnic carers of older people in the United Kingdom.

Results The findings suggest that many of these carers would be open to the use of respite services which would allow them a break from caring. Their need for respite services is evidenced by several factors including certain characteristics of those they look after and the lack of support from other members of the family. The low uptake of respite services by these carers may be accounted for by a general lack of awareness of the availability of these services as well as clear preferences for service delivery which are currently not being met.

Conclusions Existing policies in the United Kingdom provide a firm foundation for a pro-active approach which recognizes the particular isolation experienced by minority ethnic carers and addresses the current low uptake of services. Respite services which are currently available could also be made more appropriate to the needs of these carers by accommodating differences in linguistic ability, dietary needs, gender sensitivity, and other religious and cultural differences.

Keywords: respite services, minority ethnic carers, access, appropriate services

Introduction

Respite and sitter services have an important role to play in ensuring the continued mental and physical well-being of informal carers who support frail and disabled older people in their own homes. These services allow carers to take a break for a period from anything from a few hours to several weeks at a time. While carers take short breaks, the cared for receive residential respite care either in a National Health Service (NHS) facility such as a hospital ward or a residential respite facility. Alternatively, home respite services allow the carer to send the person who is receiving care to live with another family or to remain within their own home to be cared for by another person.

Research into the knowledge and use of community services among minority ethnic people has shown a low awareness and uptake of respite services. This raises several interesting questions: What are the factors which contribute to these carers' lack of awareness of these services? Do certain cultural values make respite services appear unattractive to carers? Would older people in these communities consent to being looked after by paid carers? Are carers in these communities so well supported by a family network that the use of respite services is rendered unnecessary? If not, are the services which are available appropriate to their needs? The relevance of these questions to service planners and providers is made clear in the context of the United Kingdom's rapidly ageing population of minority ethnic people and the number of informal carers who will support them.

This paper describes part of a qualitative study whose purpose was to investigate the needs of minority ethnic carers of older people, to evaluate the appropriateness of current services to these carers' needs and to uncover any existing gaps in service provision. The study considered the experiences of carers from minority ethnic communities as a whole rather than disaggregated into particular communities. The rationale for doing so, in full awareness of the considerable diversity which exists between them, lies in the understanding that the similarities which these carers share in caring for a person from a minority group and in dealing with the cultural insensitivity of current service provision far outweigh the differences arising from their particular ethnic origin. Our focus here is on the need for, use of and preferences for respite services. First, we will explore carers' attitudes to caring, which suggest that they would be open to using respite services, and
we point to particular factors which contribute to their low awareness of these services. Second, we will consider the need for respite services by considering the particular circumstances of carers, the cared for and the nature of care. Third, we will describe carers’ current use of and interest in different forms of respite care and their preferences for service delivery. Finally, we will suggest how current respite services can be made more appropriate and services developed to meet these carers’ needs.

The study

The geographical focus of the study was the Lothian region of Scotland, which consists of Edinburgh and surrounding areas. However, the findings have applicability for the planning and provision of respite services for minority ethnic carers of older people in other parts of the United Kingdom. The 1991 Census records the total minority ethnic population in Lothian as 11,990 of which the total number of adults above the age of 16 was 97,822. Applying the finding of the General Household Survey (GHS) on informal carers that one adult in seven is an informal carer to the minority ethnic population, we would expect 1,397 minority ethnic carers in these communities. In analysing whom care is provided for, the GHS found that 90 per cent of carers were looking after someone above the age of 45. Applying this proportion to the population of 1,397 minority ethnic carers would result in an estimate of 1,257 carers who are looking after someone above the age of 45. However, it would be misleading not to make adjustments for the younger age of the minority ethnic communities in comparison with the white population as a result of migration patterns. The percentage of white people above the age of 45 in Lothian is 36.8 per cent whereas the percentage of people from a minority ethnic background who are above the same age is 11.2 per cent. Accordingly, to allow for the younger age profile of the minority ethnic population, the figure of 1,257 carers previously obtained can be adjusted (1,257×11.2/36.8) to give us an estimate of 384 carers in the Lothian region who are looking after someone above the age of 45.

A detailed qualitative study was carried out on 45 carers who were identified using the same definition of ‘carers’ as in the GHS, that is, adults who are looking after or providing some regular service for a sick, handicapped or elderly person living either with them or in another household. Table 1 provides a breakdown by ethnicity. The sample approximately reflects the minority ethnic composition in Lothian as shown in Table 2, except for under-representation of the Afro-Caribbean and other Asian communities as a result of the difficulty in identifying carers from these communities. The sample is statistically reliable for the minority ethnic population in the area as a whole.

Methods

Half of the carers were identified through minority ethnic voluntary organizations for older people which participated in the study and the other half by outreach work. In many cases, carers were identified through health professionals who were providing services to those whom they were looking after. Interviews, lasting 1½–2 hours, were carried out with individual carers, mostly in their homes and using interpreters where necessary.

Attitudes towards caring

Many carers in this sample came from cultural backgrounds which place a strong emphasis on the care of older people. Asked how caring for her mother has affected her life, an African carer in her forties replied, ‘I don’t put it that way. She is my mum, [my life has been affected] the same as looking after her affected her life. It’s my duty as her daughter. It’s my obligation as her child.’

However, the tradition of caring for older people often competes with financial pressures and changing values. Said an Indian carer with three young children who had been caring for her grandfather-in-law and both her parents-in-law until the death of both the older men and who was now caring for her mother-in-law, ‘It’s something we do, but times are changing which place a strong emphasis on the care of older people. Caring for her takes up a lot of time. I would like to work, it is quite hard when there is a family to support and just one person working. But this holds me back.’

Asked what was the most difficult thing she had to cope with, a Chinese carer who had grown up in the United Kingdom and was looking after her mother-in-law, who had spent most of

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afro-Caribbean</td>
<td>2</td>
<td>4.4</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>3</td>
<td>6.7</td>
</tr>
<tr>
<td>Chinese</td>
<td>15</td>
<td>33.3</td>
</tr>
<tr>
<td>Indian</td>
<td>8</td>
<td>17.8</td>
</tr>
<tr>
<td>Pakistani</td>
<td>15</td>
<td>33.3</td>
</tr>
<tr>
<td>Other Asian</td>
<td>2</td>
<td>4.4</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black Caribbean</td>
<td>228</td>
<td>1.9</td>
</tr>
<tr>
<td>Black African</td>
<td>710</td>
<td>5.9</td>
</tr>
<tr>
<td>Black, other</td>
<td>531</td>
<td>4.4</td>
</tr>
<tr>
<td>Indian</td>
<td>1370</td>
<td>11.4</td>
</tr>
<tr>
<td>Pakistani</td>
<td>3270</td>
<td>27.2</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>331</td>
<td>2.7</td>
</tr>
<tr>
<td>Chinese</td>
<td>2231</td>
<td>18.6</td>
</tr>
<tr>
<td>Indian</td>
<td>8</td>
<td>0.7</td>
</tr>
<tr>
<td>Other groups (Asian)</td>
<td>2158</td>
<td>17.9</td>
</tr>
<tr>
<td>Total</td>
<td>11,990</td>
<td>100.0</td>
</tr>
</tbody>
</table>
her life in Hong Kong, replied, 'Her being old, with different values and living in the same house. We try to avoid clashes.' Asked the same question, a male Indian carer who had married a white woman and who was the sole carer of his mother responded, 'Clash of cultures. What is expected of me. I was brought up here. My priorities are with my wife and children, I have to live with that.' These comments illustrate the particular difficulties related to differences in cultural values and perceptions of family obligations which might be encountered by carers who have grown up in this country and who are looking after first-generation immigrants.

Low awareness of respite services

The attitudes described above suggest that many minority ethnic carers would not be adverse to taking breaks from their caring responsibilities and would be willing to explore the use of services which would enable them to do so. It is thus worth reflecting on why their awareness of services is so low. One obvious factor is their lack of recognition of their status as 'carers', a phenomenon which is also widespread in the general population of carers. This is hardly surprising, as the use of 'carers' is a socio-political construct whose currency is much more closely tied into rights to practical support than to the feelings and relationships which motivate care-giving; the word 'carer' has no equivalent in any of the minority ethnic languages spoken in the area.

Further, three-quarters of the carers were women, reflecting the gendered pattern of caring in the general population. As many of them are housebound, they are isolated from information and services which could have eased the burden of caring, a pattern which has also been found in the mainstream population. However, in the minority ethnic communities, this isolation is exacerbated by the inability of many to speak English: in the sample this amounted to nearly half of all carers (46.5 per cent; 21/45). This, combined with an overall lack of familiarity with the range of health and welfare services which are available, contributes to their low awareness of respite services.

Need for respite services

The need for respite services is related to the particular characteristics of minority ethnic carers and those they care for, as well as the extent to which caring responsibilities are shared.

Characteristics of carers

One of the main characteristics of the carers in this sample that points to the strong need for respite care is the tendency for caring for an older person to be combined with child care. This trend arises from the heavily gendered nature of caring as well as the younger peak age of caring of 31-40 years, which is considerably younger than the peak age of 45-64 years found in the GHS study. More than a quarter (27.8 per cent; 13/45) of the sample were looking after three or more young children under the age of 16. This can result in considerable tensions and in compromises having to be made. A Punjabi carer in her thirties with children under the age of 16 who was solely responsible for looking after her physically disabled mother-in-law and shared the care of her grandmother-in-law with a sister-in-law said, 'So many things I would like to do with my husband and children are restricted. I feel like I have missed out on my freedom, not spent time with my own children.'

The greater likelihood of carers to be living with parents and parents-in-law in the same, rather than a separate household also suggests that these carers would welcome breaks from caring. These living arrangements differ from those found in the GHS, which revealed that a higher percentage of carers look after a parent or parent-in-law living in another household than one who lives in the same household. The living arrangements associated with informal care in the minority ethnic communities mean that care-giving is a daily activity for more than 80 per cent of the carers (37/45). Even when the carer is living with an older person who is not heavily reliant on care, difficulties associated with differences in inter-generational views can arise. A Chinese carer in her thirties who had three young children had this to say of her hearing-impaired mother-in-law who lived with them: 'Because we can't communicate, the tension builds up. She doesn't understand how we bring up our children and it is difficult to make her understand.'

Like white carers, these carers too experience physical and emotional stress, limited social activity and difficulty in taking breaks from caring. Significantly, more than a quarter of the carers (26.7 per cent; 12/45) rated their own health as quite poor, with many complaining of tiredness and stress. A Pakistani woman in her sixties, who herself had diabetes and high blood pressure, and had undergone three eye operations, had this to say about caring for her husband, a dementia sufferer in his seventies: 'I forget myself because I have to look after him every minute, every second.' The ability to take breaks from time to time would greatly contribute to the continued ability of carers to support those they care for.

Characteristics of the cared for

Many mental and physical characteristics of the cared for directly correlate with their reliance on informal carers, pointing to the desirability of allowing the latter time away from their caring responsibilities. A total of 54 older people were receiving the care of the 45 carers in the sample. As many as 50 per cent (27/54) of them had difficulties in a minimum of three areas of physical functioning. Among these areas, mobility difficulties were most commonly experienced (79.6 per cent; 43/54). Said one Chinese carer of her husband who is in his sixties and who had suffered a stroke, 'He is very weak, very tired. He can't walk too far, it's like he is carrying a hundred pounds of rice.' Other common difficulties were
holding or picking up things (66.6 per cent; 36/54) and reaching or stretching for things (50 per cent; 27/54). An Indian carer elaborated that this meant that her grandmother-in-law 'has to be given everything', another that her mother-in-law would eat 'if food is placed in front of her, she needs a basin of water to wash her hands'. As many as half (50.6 per cent; 31/54) of the older people who were being cared for also suffered from depression, which in many cases seemed difficult to alleviate as it was likely to have been brought about by social isolation or economic deprivation.

More than a third of the carers (35.2 per cent; 19/45) were undertaking two of the most strenuous aspects of care-giving, that is, personal care, such as bathing and dressing, and providing physical help in walking or climbing up and down stairs. Describing the difficulty she experienced in bathing her grandmother-in-law in her nineties, a Punjabi carer said, ‘Two people need to be there, to hold each arm, put her clothes on, to wash her hair, her body’. The higher incidence of long-standing illness among people identifying themselves as Bangladeshi, Black Caribbean, Indian and Pakistani than in the white groups as reflected in the 1991 Census suggests that the reliance on informal care in these communities for long periods may be more prevalent than in the white population. Over half of the carers (53.5 per cent; 24/45) in this sample had been responsible for the care of an older person for more than 5 years. This means that carers have to be able to sustain their ability to care over a long period, again pointing to the desirability of allowing them breaks to nurture themselves.

**Extent of informal support**

Carers’ need for respite services is directly related to their ability to share the responsibilities of caring with other members of the family or supportive friends. This study found that more than a third of the carers (35.6 per cent; 16/45) received no support at all from other family members. Said an Indian carer who was looking after her blind mother-in-law, ‘It’s the same as in white families, when it comes down to the crunch there is only one person carrying the can’. In fact, given the prevailing myths of supportive extended families in the minority ethnic communities, one of the important findings of this study is that the proportion of sole carers in these communities is, in fact, larger than the proportion of sole carers in the general population, which the GHS recorded as less than a quarter (23 per cent).

Dispelling the myth of the supportive family network further and underlining the need for respite services, nearly half (46.7 per cent; 21/45) reported that they had no time off from caring. A Pakistani carer who shared the care of her physically disabled grandmother who was recovering from stroke with her mother said, ‘We are physically and mentally exhausted. It (caring) has taken its toll. We have to look after her all the time.’ Their exhaustion had led them to send the old woman who had been living with them to other relatives a week before the interview took place but they had already received complaints from them about the difficulty of looking after her.

**Use and preferences for respite services**

In the light of evidence which suggests that many of these carers carry a heavy burden of continuous care, it is of concern that none of them had ever used a respite service either in the form of sitter services or residential respite care, although both services are available in the area. As we have already established that the lack of uptake of respite services cannot be attributed to lack of need, it is worth exploring whether currently available services are appropriate to the particular needs of these carers.

**Sitter services**

Many of the carers were familiar with sitter services though not in relation to older people. When asked whether they would use such a service, a third of the carers (33.3 per cent; 15/45) responded positively. However, many of them strongly emphasized that it was necessary for the sitter to be able to speak the same language as that of the person they were looking after. A fairly typical comment in this regard was, ‘It must be someone who can speak [language], wouldn’t be any use otherwise’. Confirming this, when asked how important it was for staff to be able to speak the same language, nearly two-thirds of the carers (62.2 per cent; 28/45) responded that it was either very important or quite important, with others adding that they or the people they looked after could speak English. Gender matching was also important, with more than two-thirds (68.8 per cent; 31/45) reporting that they would prefer staff to be the same sex as those they were looking after.

**Residential respite care**

The concept of residential respite care was completely novel to all of the carers and had to be explained to them. Seventy-one per cent of them reacted negatively to the service. The most common reason given for not wishing the people they were looking after to go somewhere else to be looked after was the unwillingness of the latter to go. Said a Gujarati woman who was herself suffering from breast cancer, of her husband, ‘He would not stay. He does not like to stay in hospital, he gets upset and angry. I am the only one who can control him.’ A Chinese carer who could not leave his wife alone even for a few hours, said simply, ‘She would not go’.

Other reasons given for not using the service were personal. Said a Chinese carer of her husband, ‘We would like to enjoy life together. We are very happy together.’ A few carers explained their reluctance in terms which could be directly related to cultural beliefs. For example, a Pakistani carer offered the following explanation, ‘We are very conservative, if she goes for a couple of weeks, I have to go as well.’

Other carers had concerns about whether the person they
were looking after would be able to communicate with others. An African carer said of her mother, 'Because she wouldn't be able to speak to anyone, she would feel completely miserable, she would feel that I had abandoned her'. When carers were asked how important it was to them that those whom they were looking after were in social contact with people of their own ethnicity outside their home, 80 per cent (36/45) reported that it was either very important or quite important, many explaining that it allowed them to relate to others. This strongly suggests that where possible, sensitive placement of minority ethnic people with others who can speak the same language would go a long way towards easing the alienation they would feel in being the only minority ethnic person among white users or users from other minority ethnic groups who do not speak the same language.

Another strong preference connected to service delivery outside the home was the cared for's access to the food they were used to consuming, with almost all the carers reporting that it was either very important or quite important (93.4 per cent; 42/45). Further exploration of what would be acceptable revealed that this meant that food had to be culturally familiar, and meet any religious requirements as well as the dietary requirements of the health condition of the cared for. For example, for an Indian carer, this meant that her husband 'must have vegetarian food. It should not contain fat because of his heart condition.'

Home respite services

Carers' preferences for the person they are caring for to be with others of the same ethnic origin and to receive the food they are used to consuming strongly suggest that they would welcome home respite services which would allow the older people to be cared for either in their own home or in the home of a family from the same minority ethnic group. These services would enable the carer to take a break comfortable in the knowledge that those they were caring for were well looked after in a culturally familiar setting. Such services could well be developed in collaboration with minority ethnic community-based organizations with a health remit.

Conclusion

We have argued that the attitudes of minority ethnic carers towards caring suggest that many would welcome the opportunity to take some time off from their caring responsibilities. We have also attempted to account for their low awareness of respite services. The strong need for respite services is indicated by several characteristics of minority ethnic carers and those they look after as well as the extent of informal support they receive. The finding that none of the carers were in fact using these services suggests either a lack of knowledge of them, their lack of appropriateness, or both.

It would appear that a pro-active approach which recognizes both the isolation which is commonly experienced by carers as well as the particular cultural isolation of those in the minority ethnic communities is required to address the current low uptake of services directly aimed at the minority ethnic carer. As it is common even for carers in the mainstream population not to perceive themselves as such, a crucial element of this process is raising the awareness of carers in the minority ethnic population of their status and their rights to be supported. Health professionals who are in contact with older people whose health suggests that they may be reliant on informal care have an important role to play in this regard.

However, awareness-raising of carers' rights to services would be meaningless in the absence of appropriate services for the carer and the cared for. The study clearly demonstrates the limitations of the colour-blind approach in which services are directed towards the needs of the majority white population. Particular factors which would have to be taken into account in providing a culturally sensitive respite service include differences in linguistic ability, dietary needs, gender sensitivity, fear of racial discrimination, and other religious and cultural differences. In addition, the preference for domiciliary services for respite care as indicated by the evidence of this study is worth noting. The evidence also suggests that, for longer periods, the development of home respite services would be an attractive option.

The pro-active approach suggested above would be most effectively developed within a policy framework which takes cognisance of the particular needs of minority ethnic communities in relation to health and welfare services. In the United Kingdom, recognition of this has already been documented in the White Paper Caring for people (1989) which explicitly advocates that service providers should be sensitive to variations in need of people from different cultural backgrounds and plan services in consultation with them. The NHS is also committed by the Patient's Charter to respect the privacy, dignity, religious and cultural beliefs of patients whose welfare is closely related to that of their carers. Additionally, the Carers Recognition and Services Act (1995) makes it a duty for local authorities to carry out an independent assessment of the needs of carers in addition to those of the people they are looking after, and policy and practical guidance emphasize the importance of ensuring that assessment is equally available to all members of the community. Cumulatively, these policy statements provide a firm foundation for giving priority to the needs of minority ethnic carers in the provision of health care. However, the extent to which such policies are implemented will inevitably depend on how far political will is exerted in recognizing and meeting those needs.

Acknowledgements

This study was initiated by Voice of Carers Across Lothian (VOCAL) in collaboration with SEMRU (Scottish Ethnic Minorities Research Unit), Lothian Racial Equality Council,
Lothian Health, the City of Edinburgh Council and ECESA and MILAN, which serve minority ethnic older people in the area. The research was made possible through part-funding by SEMRU and the fund-raising efforts of VOCAL. I am also grateful for comments related to this paper by Professor Moira Munro, Stewart Green and Mary Netto.

References

3 Netto G. 'No one asked me before': addressing the needs of black and minority ethnic carers of older people in Edinburgh and the Lothians. Edinburgh: SEMRU/VOCAL, 1996.

Accepted on 12 November 1997