

"No one asked me before"

Addressing the Needs of
Black and Minority Ethnic
Carers of Older People
in Edinburgh and the Lothians

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Action research supplements the detached academic observer from one discipline with a multi-disciplinary team of practitioners working together in a process of mutual learning. It is characterised by concern for institutional functioning, monitoring of policy implementation and the views of major constituent groups. It generates replicable learning tested against past experience and current practice. Action research produces research conclusions at the appropriate point in a policy process, rather than waiting until the bitter end. It is fundamentally about collaboration and dialogue.

(From 'Managing Sustainable Development' by Carley and Christie, Earthscan, 1992)

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Introduction

The project originated when the Scottish Ethnic Minorities Research Unit approached LREC (Lothian Racial Equality Council), with the offer to co-fund a worthwhile research project. LREC recommended a proposal by VOCAL (Voice of Carers across Lothian), a voluntary carer-led organisation, which aims to raise awareness and represent the needs and interests of carers in Lothian. The initiative stemmed from a perception that little had been done to identify and support minority ethnic carers who were likely to share common difficulties with white carers in addition to encountering specific difficulties associated with their ethnic origin.

Attention was focused on minority ethnic carers of older people as little work has been done in Lothian or indeed, Scotland to address their needs. Although the minority ethnic population is younger than the mainstream population, both the numbers and the proportion of older people from these communities are expected to continue to rise in the foreseeable future. Consequently, the proportion of carers looking after them is also predicted to increase.

It was felt that a systematic study on the needs of this particular group of carers which had previously not been identified would benefit the future planning of services by Lothian Health and the Social Work Departments in Edinburgh and the Lothians. One of the main aims of the project was to uncover gaps in service provision and reveal ways in which existing services could be tailored to meet the needs of minority ethnic carers. Both departments were thus approached for representation on the project.

Two voluntary organisations which supported older people in the minority ethnic communities were also invited to participate. These were the Edinburgh Chinese Elderly Support Association (ECESA) and MILAN (Senior Welfare Council) which works with the Bangladeshi, Indian, Mauritian and Pakistani communities. The collaboration of these organisations was sought because of their key involvement in the area and the need to raise the profile of the project within the minority ethnic communities, thus facilitating access to carers. Lothian Race Equality Council was also represented in the project to contribute expertise in countering racial discrimination and promoting equal opportunities.

The research was undertaken by the Scottish Ethnic Minorities Research Unit (SEMRU) in collaboration with the organisations named above. The Unit is a collaborative venture between Heriot Watt University in Edinburgh and Glasgow Caledonian University. Its primary function is to promote and carry out applied and policy-orientated research on the position of minority ethnic groups and the incidence of racism and racial discrimination in Scotland.

It was determined from the outset, that the research would be action-oriented with the findings forming the basis of a development phase which would lead to specific initiatives to support carers of older people in the minority ethnic communities. This had implications for the way in which the research was carried out. Firstly, all the key organisations identified above were represented on the steering group to allow for the input of different interest groups and to ensure that the output of the project would contain useful information for the planning of future services. Secondly, it was recognised that the very act of identifying carers and conducting interviews on their caring role with them would be, in many cases, the first step in raising their awareness of their rights as carers to formal support. Thirdly, an important component of the methodology was the organisation of focus groups consisting of carers to validate and discuss some of the results obtained in individual interviews. It was intended that in the development phase of the project, these focus groups would form the basis of carer support groups.

In order to contextualise the project in the current climate of welfare provision, the report opens with a literature review, *Community Care Policies in Relation to Minority Ethnic Carers*. The next section, *Research Aims, Questions and Methodology*, defines the scope of the project and details the research process. The findings of the study are presented in the following six sections, *Characteristics of Carers in the Sample*, *Characteristics of the Cared for*, *The Nature of Care, Social Work and Community Services*, *Knowledge and Use of Health Services* and *Other Essential Forms of Support*. This is followed by *Focus Group Discussions with Asian and Chinese Carers*. The penultimate section, *Conclusions* draws together the key issues revealed by the research and, the report concludes with *Summary of Recommendations*.

A Note on Terminology

Diverse terms are frequently used to describe minority ethnic communities: "black", "ethnic minorities", "black and minority ethnic groups" and "minority ethnic groups" or "minority communities". In this report, the author has chosen to use "minority ethnic", while recognising that other terms may be equally valid.

The term "Asian" has been used to collectively describe those people who were born in Bangladesh, India or Pakistan and their descendants. Similarly, the term "Afro-Caribbean" has been used to describe those of African origin who were born in one of the Caribbean Islands and their descendants born in the UK. Both terms are used in the awareness that the peoples to whom they are applied may themselves neither define their identity as such nor share a common culture.

1. Community Care Policies in Relation to Minority Ethnic Carers

"I don't know how to get help for him... I would like him to stay in a nursing home but he cannot communicate in English."

Community care policies have irrevocably altered the nature of health and welfare provision. The Government White Paper Caring for People (1989) and the ensuing legislation, the NHS and Community Care Act (1990) resulted in significant changes in the way health and social work provision were perceived and implemented. The aim was to "...enable people to live in their own homes or in a homely setting in the community, wherever possible, and to promote independence and choice." (Scottish Office, 1994). This policy has resulted in the closure of hospital beds, reduced the length of time in hospital and encouraged the development of early supported discharge. Social work departments have also been encouraged to develop services which would support the care of people in their own homes wherever possible.

A significant policy goal for community care users is clearly stated in the 1986 Audit Commission report, Making a Reality of Community Care, which called for "the adjustment of services to meet the needs of people rather than the adjustment of people to meet the needs of services." This emphasis on services to be responsive to need necessitates that services be planned through local consultation and mechanisms established for receiving user feedback. It also requires that proper assessments of need are carried out and that community care users are offered a choice in the forms of support made available to them. Ultimately, any assessment of the effectiveness of the policy demands an evaluation of the extent to which "community" has been conceptualized in inclusive terms.

This chapter considers the minority ethnic dimension in community care, the new recognition of carers in general and the needs of minority ethnic carers in particular. It begins by discussing the founding principle of community care to provide needs-led services for all sections of the community. It then considers the political and social context in which practical decisions are made about prioritising needs in the face of limited resources and the danger that minority ethnic communities may be marginalized if decisions are taken solely on the principles of market efficacy. It is suggested that policy decisions should also consider the legislation provided by the Race Relations Act and the principle of equity of access. Next, the increased importance of the voluntary sector since the split of purchasing and providing services in health and social work departments is considered, along with the ability of minority ethnic communities to access and use those services. Having thus set the context, the increased importance of the role of carers in general, and minority ethnic carers in particular is considered. The chapter concludes by drawing attention to the importance of identifying and addressing the needs of minority ethnic carers.

1.1 The Minority Ethnic Dimension in Community Care Policy

The White Paper Caring for People states that:

"...people from different cultural backgrounds may have particular needs and problems. Minority communities may have different concepts of community care and it is important that service providers are sensitive to these variations. Good community care will take account of the circumstances of minority communities and will be planned in consultation with them."

This recognition that services may have to be adjusted to the needs of people in minority ethnic communities is a major departure from the "colour blind approach", in which the same service is provided to people irrespective of their ethnicity. The "colour blind" approach is

limited in not recognising the particular difficulties faced by people in the minority ethnic communities in accessing and using services and by default, accepts the white experience as the norm (Atkin and Rollings, 1993). Particular factors which may have to be considered in providing a culturally sensitive service include differences in linguistic ability, dietary needs, the requirement to maintain segregation between the sexes, fear of racial discrimination and other religious and cultural differences. The importance of planning services in consultation with minority ethnic communities to ensure their accessibility and appropriateness cannot be under-estimated.

However, the danger that lies in highlighting the needs of people solely in terms of their minority ethnicity is that the considerable diversity within and between minority ethnic communities may be obscured. Although minority ethnic communities may share a common political and social disadvantage stemming from their minority status, the extent of this disadvantage is affected by a plethora of factors, not least of which is the degree of economic success which has been achieved by a particular community. Similarly, the needs of individuals within a minority ethnic community are influenced by a variety of factors which include their age, gender, education, social class, personal attitudes and experiences. The recognition of diversity along both these dimensions is not only a challenge to the planning and provision of community care services but essential if services are to be truly responsive to need.

1.2 Establishing Priorities in Community Care and Minority Ethnic Communities

Community care policy assumes a level playing ground in which services are led by needs and provided through contractual procedures according to market efficacy. However, people in the minority ethnic communities who are disadvantaged in political, social and economic terms and subject to racial discrimination are not equal players. Particular differences in their needs have often not been recognised: much empirical evidence documents the inaccessibility and inappropriateness of community and health services with respect to people in these communities (Walker and Ahmad, 1994; Aksham, Henshaw and Tarpey, 1995).

An important factor which mitigates against the provision of needs-led services for minority ethnic communities is the issue of cost in providing specialised services for relatively small numbers of people. Where continuing tight restraints on public expenditure result in financial issues dominating the agenda, the needs of minority ethnic groups may be "squeezed out". As Craig and Rai point out (1996, p.128):

"without state direction or intervention, there is little evidence that market mechanisms alone are likely to meet the needs of small, unpopular or poor groups of service users, or of those whose needs may be more difficult to identify or meet"

Thus, policy decisions in planning, purchasing and commissioning services must be based on principles other than market efficacy if the needs of minority ethnic communities are not to be marginalized. Other considerations which should be included in policy decisions are the requirements of the Race Relations Act for local authorities and the principle of equity of access for health authorities.

1.2.1 The Race Relations Act

The Race Relations Act (1976) makes it unlawful for local authorities to discriminate either directly or indirectly on racial grounds in the provision of goods, facilities and services. Direct discrimination occurs when a person is treated less favourably on racial grounds than another and may result in losses such as missed job opportunities or access to services. Indirect discrimination is defined as the imposition of conditions or requirements which,

while not apparently discriminatory in themselves, have the effect of lowering the proportion of people from certain ethnic groups who are able to access services or qualify for jobs.

In addition to an obligation not to discriminate, local authorities also have a positive duty to ensure that they function in such ways as to eliminate unlawful racial discrimination and promote equality of opportunity between people from different ethnic groups. In relation to care in the community, this necessitates the planning, providing and delivering of services which are appropriate, accessible and responsive to all sections of the community, including the specific needs of minority ethnic groups.

1.2.2 Equality of Access

The National Health Service is committed by the Patient's Charter to respect privacy, dignity and religious and cultural beliefs. The good practice guide published by the Scottish Office (1994), Access to Health Care by the Ethnic Minorities also reminds those concerned with the provision of health services that one of the founding principles of the NHS is to provide all sections of the community with equal access to appropriate health care and treatment and that "the avoidance of racial discrimination is central to achieving this" (Scottish Office 1994: 9)

Both health and social services are thus committed to recognising the needs of people in the minority ethnic communities in the policy agenda despite limited resources. However, in practice, the extent to which such needs are prioritised will depend on how far political will is exerted in recognising and meeting those needs.

1.3 The Role of the Voluntary Sector

One of the fundamental changes resulting from the 1990 NHS and Community Care Act was the restructuring of health and social work departments which separates purchasing and provider functions. Caring for People described the responsibilities of the social work department in terms of an "enabling authority" charged with ensuring the delivery of services through the development of a purchasing and contracting role and operating according to principles of market efficacy. Thus, instead of merely providing services, social work departments would become purchasers and care managers who prepare local community care plans, arrange care packages and carry out assessments on individual need. The voluntary and private sector would compete against each other to provide services in a mixed economy of care.

The increased importance of the voluntary sector in providing community care services calls for an assessment of the extent to which minority ethnic communities may access and use these services. The general unsuitability of mainstream voluntary service provision by these communities has been well documented (Atkin and Rollings, 1993; Patel, 1990). Unfortunately, there has been no systematic investigation on a nation-wide basis into the steps taken by voluntary organisations to provide more accessible and appropriate services for minority ethnic groups since the introduction of the 1990 NHS and Community Care Act.

However, eight years ago, the Scottish Council of Voluntary Organisations (SCVO) conducted an investigation into race equality in the Scottish voluntary sector (MacLeod 1988). This year SCVO carried out an investigation based on a sample of 120 organisations to measure the extent of progress made in this area by the voluntary sector since the study (McIntosh 1996). It concluded that although the principle of equal opportunities is currently more widely understood (68.9% of the sample now have Equal Opportunities policies as opposed to 59% previously), there was little reason to be optimistic about the way organisations are actively implementing policies in such a way as to benefit minority ethnic communities.

Among the findings, two are worth drawing particular attention to: firstly, only 21% of the organisations in the survey had used outreach strategies to establish links with minority ethnic communities and secondly, only 23.5% had made use of positive action measures which are legally sanctioned to increase access to services by people in these communities.

1.4 Minority Ethnic Voluntary Organisations

In the light of evidence which suggests that mainstream voluntary organisations in general and those in Scotland in particular are not currently equipped to meet the service requirements of the minority ethnic communities, the importance of minority ethnic voluntary organisations filling the gaps in service provision is clear. Atkin and Rollings (1993) found that because these organisations are locally-based small organisations and largely staffed by people from the communities they serve, they seem better able to design services which meet individual needs.

However, the vulnerability of these organisations which depend on short-term funding for their existence has also been highlighted (Patel, 1990). A conference organised by SCVO on community care and the minority ethnic communities in Scotland in 1993 raised concerns which were related to limited resources and the ability of small minority ethnic voluntary organisations to compete on equal terms with large well-established white voluntary organisations in a contract culture. As Atkin (1996:151) points out:

"Access to funding is related to access to the political structure, and to the knowledge and information within which bids can be framed to meet the ideas that are currently in favour."

Minority ethnic organisations which are not represented politically and which lack the political acumen to bid for contracts may be marginalised and their very existence threatened, unless the importance of their role is given due recognition.

1.5 New Recognition of Carers

The change in emphasis for services to be delivered in the home or in "a homely setting" has also led to a new recognition of the role of carers. This has culminated in the passing of the Carers Recognition and Services Act in Parliament in 1995 making 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 look after. Further, the legislation gives local authorities the discretionary power to provide services which are identified as required by the assessment. Policy and practice guidance issued by the Scottish Office in association with the Act emphasises the importance of ensuring that assessment is equally available to all members of the community. Specifically, the guidance states that

"Authorities should also ensure that carers from black and minority ethnic backgrounds, whose first language is not English, can participate in the assessment (para 23)."

Much has been written on the nature of informal care in the past decade (Qureshi and Walker, 1989; Twigg, 1992) which evidences the heavy costs of caring in financial, emotional and physical terms. Finch (1989) found that care in the community increasingly resulted in care provided by the family. The General Household Survey on Informal Carers (Green, 1985) also provided vital information on the extent and pattern of care-giving in the community which was updated in 1990.

Organisations such as Carers National Association, Carers Impact and VOCAL (Voice of Carers Across Lothian) have campaigned to push carer issues onto the policy agenda and lobbied for support for those providing informal care. In recognition of the pressures on carers, the

King's Fund published "Carers Needs: A 10 Point Plan for Carers". This plan is based on seven identified needs of carers: information, respite and sitter services, emotional support and counselling, support in a crisis or emergency, practical help, health care and education and training. The recommendations in the document have been endorsed by Edinburgh and the Lothians Joint Planning Partners and acknowledged in the strategic document *Towards 2000: Developing a Strategy for Caring in the Lothians* which provides a policy framework to improve the quality and effectiveness of services for carers

One of the most fundamental elements which characterises informal care is that it takes place within the context of an existing relationship with the cared-for. Thus, discussions with and about carers are inextricably bound to the person they are providing care to and it is difficult to consider one without the other. The disability movement has argued that the prioritisation of carers on the policy agenda takes place at the expense of treating disabled people as individuals in their own right and does little to promote their independence and autonomy. However, as Twigg and Atkin (1994) argue, to focus solely on disabled people, ignoring those who provide care to them is also unacceptable. Not only are carers entitled to services in their own right but the welfare of those to whom they provide care depends on a large extent on the continued well-being of the carer. Thus, both the needs of carers and the people they look after need to be incorporated in public policy.

1.6 Minority Ethnic Carers

Many research studies carried out in England have focused on the experiences of minority ethnic carers (Begum, 1992; Coles, 1990; Kalsi, 1993; Lambeth Social Services, 1990; London Borough of Camden, 1990; McCalman, 1990; Sage and Sangavi, 1992; Walker and Ahmad, 1994). Consultations with carers from multi-racial backgrounds have also been documented (Birmingham Social Service 1992; Black Carers Forum, 1992)¹. These studies report the many problems which minority ethnic carers share with white carers as well as their particular difficulties. They also reveal that the former have tended to have their needs overlooked in community care planning. Some of the problems which have been revealed by the studies include low awareness of services, inaccessibility and inappropriateness of existing services and a fear of racial discrimination. However, thus far, the needs of minority ethnic carers in Scotland and the extent to which their needs have been met have not been considered in depth.²

Widespread uncertainty and ignorance about the needs of minority ethnic carers persists. Myths such as "they look after their own" prevail in spite of accumulating evidence that traditional family ties are being broken down due to factors such as geographic dispersal of relatives in search of employment, economic pressures and changing values. Unless attention is drawn to the needs of minority ethnic carers, those who control resources and services may continue to be unaware of the extent of unmet need which exists. Additionally, moves which are taken to increase service uptake among people in minority ethnic communities may not succeed unless prior investigations into service requirements have been carried out. It is thus promising that the Carers' strategic document *Towards 2000* acknowledges the particular difficulties faced by minority ethnic carers in accessing services and proposes to address the issues raised by this research project and respond constructively to its recommendations. In the next chapter, we will discuss the research aims, questions and methodology.

1. A few useful handbooks for professionals working with minority ethnic carers have also been compiled (Yee and Blunden, 1995; Yee, 1996).
2. Chakrabati and Cadman (1995) included a small sample of 9 carers in their study which mainly focused on the needs of minority ethnic elders in Tayside.

2. Research Aims, Questions and Methodology

"No one has asked us whether we needed this before."

This section describes the research aims and questions and defines the scope of the project. It also details the methodology employed by the research.

2.1 Research Context

The purpose of the research was to investigate the needs of minority ethnic carers of older people, who had been perceived as receiving little formal support. More specifically, the focus of the project was carers of older people in the "visible minority communities", that is, those whose skin colour marked them as distinctly different from the majority white population and who were thus most likely to be victims of racial discrimination. However, it was also recognised that these groups may suffer from indirect discrimination, that is, the failure on the part of the public sector to accommodate their specific needs in the planning and provision of services. This concentration of the study was not intended in anyway to discount the needs of white minorities such as the Jewish and Polish communities, but rather to carry out a comprehensive assessment of the needs of this particular group of carers and the services available to them.

It was further decided to focus on the needs of minority ethnic carers who were looking after people over the age of 50. This age was chosen for two reasons. Firstly, it has been recognised that the onset of age related diseases occurs earlier in the minority ethnic communities, due to ill-health and poor social and economic conditions. Secondly, the minority ethnic projects working with older people, including the two who participated in the project, tend to cater to those who are aged 50 and above. The geographical focus of the project was confined to the Lothian region, which included the city of Edinburgh which has the largest minority ethnic population as well as Mid, East and West Lothian.

The research has been motivated by the recognition that while all carers may have common needs such as the need for information and support in a crisis or emergency, it is essential to recognise the particular needs of those caring within the minority ethnic communities. It is also necessary to distinguish the needs of those who are caring for older people as opposed to those caring for other groups such as those with learning difficulties or mental health problems although older people may suffer these difficulties too. It is hoped that this analysis of needs will constitute the first step in the planning and provision of appropriate and accessible services to minority ethnic carers.

2.2 Research Aims

The specific aims of the research are as follows:

1. To identify service needs and preferences for service delivery
2. To identify barriers to services and examine the extent of direct and indirect discrimination in accessing existing forms of carer support
3. To identify gaps in current service provision and make specific recommendations for changes in current service delivery patterns
4. To inform the process of future planning and consultation

2.3 Research Questions

The following questions were addressed:

1. What is the nature and extent of informal care-giving for minority ethnic carers of frail and elder people in Lothian?
2. What specific factors influence the experience of informal care giving for these carers?
3. What are the differences/similarities for this particular group of carers in relation to the position of white carers?
4. Is existing service provision adequate and suitable for minority ethnic carers?

2.4 Identification of Carers

The number of carers identified and invited to participate in the project was informed by an estimate of the total number of minority ethnic carers of older people in Lothian and by the 1991 Census figures for people above the age of 50 in the relevant minority ethnic communities.

2.4.1 Estimate of the total number of minority ethnic carers of older people in Lothian

The General Household Survey (Green, 1985) estimates that one adult in seven (14%) is an informal carer. "Carers" are defined as people who were looking after, or providing some regular service for a sick, handicapped or elderly person living on their own or in another household. Adults are defined as those above the age of 16.

The 1991 Census states the following population figures in Lothian:

White	714,020
Black Caribbean	228
Black African	710
Black other	531
Indian	1370
Pakistani	3270
Bangladeshi	331
Chinese	2231
Other groups (Asian)	1161
Other groups (Other)	2158
Total	726,010

The total minority ethnic population stands at 11,990, that is 1.65% of the total population and the total number in the minority ethnic population above the age of 16 in Lothian is 9,782. However, Lothian Racial Equality Council and other organisations which work with minority ethnic groups believe these figures to be significantly under-enumerated. The figures given should therefore be treated with caution.

Applying the finding of the GHS 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 was provided for, the GHS found that 90% of carers were looking after someone aged above 45. Although the present study is restricted to carers of those above the age of 50, given the absence of available data on the proportion of carers who are caring for people above this age, we will apply this proportion to the population of 1397 minority ethnic carers. This results in a figure of 1257 carers who are looking after dependents aged 45 and above.

However, it would be misleading not to make adjustments for the younger age of the minority ethnic communities in comparison to the white population, due to immigration patterns. The percentage of people who are above the age of 45 in the white population in Lothian is 36.85% while the percentage of those in the minority ethnic population is 11.26%. We can adjust the figure of 1257 previously obtained to allow for the younger age profile of the minority ethnic population by making the following calculation:

$$\begin{aligned}
 & 1257 \times \frac{\text{Percentage of people above 45 in the minority ethnic population}}{\text{Percentage of people above 45 in the white population}} \\
 & = \frac{1257 \times 11.26}{36.85} \\
 & = 384
 \end{aligned}$$

This gives an estimate of 384 carers of people who are currently looking after someone aged above 45 years in the minority ethnic communities in Lothian. It should be emphasised that this is, at best, a conservative estimate given the believed under-enumeration of Census figures and the earlier onset of age-related diseases in the minority ethnic communities. Further, any estimate of the current population of minority ethnic carers is set to increase over time as the number of older people in the minority ethnic population increases.

2.4.2 Proportion of those above 50 in the minority ethnic communities

Every effort was made in this study to reflect the proportions of each of the minority ethnic communities in Lothian within the group of carers interviewed. Since data on the number of carers in each of the minority ethnic communities was not available, the numbers of people over 50 in the minority ethnic communities, as recorded by the 1991 Census, were used as a basis to estimate the target proportion of carers to be interviewed from each minority ethnic community. The assumption made was that the proportion of those above 50 who are dependent on informal care is likely to be the same in each of the minority ethnic communities. The breakdown of those above 50 in each of the minority ethnic communities is given below:

Numbers of People Above 50 in Lothian

Ethnic group	No Above 50	Percentage
Afro-Caribbean	107	10.6
Bangladeshi	23	2.2
Chinese	273	27.2
Indian	165	16.5
Pakistani	358	35.7
Other Asian	76	7.6
Total	1002	100

2.4.3 Carers in the Sample

Guided by the estimate of the total number of carers of older people in the minority ethnic communities and the number of older people in each of the minority ethnic communities, a total of 45 carers were identified and interviewed in the four months allocated to field work. Approximately half of these carers were in touch with MILAN and ECESA, either directly or through the services provided to the people they were caring for, thus ensuring that some feedback was received on the appropriateness of current service provision. However, an important component of the remit of the researcher was to identify carers who were not in touch with either of these organisations. This was to ensure a more complete picture of the experiences of minority ethnic carers in the population at large. It should be borne in mind that since approximately half of the carers were identified through minority ethnic organisations, there is a possible bias towards a higher uptake of services in the study than is generally reflective of minority ethnic carers in Lothian.

The breakdown of carers included in the sample by minority ethnic community is given below:

Ethnic Group	No of carers	Percentage
Afro-Caribbean	2	4.4
Bangladeshi	3	6.7
Chinese	15	33.3
Indian	8	17.8
Pakistani	15	33.3
Other Asian	2	4.4
Total	45	100

Comparing the breakdown of carers by ethnicity in the sample against the Census data in 3.2 we find that the proportion of Bangladeshi, Chinese and Indian carers is slightly over-represented while the proportion of Pakistani carers is slightly under-represented. The proportion of Afro-Caribbean and other Asian carers are noticeably under-represented. This reflects the researcher's difficulty in identifying carers in the latter two communities. This sample is statistically reliable with regard to the minority ethnic population in Lothian as a whole but less reliable for some of the smaller communities. Carer responses are thus considered as a whole rather than disaggregated into each minority ethnic community.

2.5 Methodology**2.5.1 Launch of the project**

Representatives from Lothian Heath, the four Social Work Departments in Edinburgh and the Lothians and voluntary organisations who worked with minority ethnic communities were invited to the launch of the project which was held in Cathay Court, a sheltered housing project designed for older people in the Chinese community. This was to raise the awareness of service providers of the project and to obtain their cooperation in facilitating access to carers.

2.5.2 The questionnaire

In designing questions which aimed to assess carers' need of available services, an important consideration was the likely possibility that carers would not have heard of some or all of the services on offer. Thus, questions which aimed to assess needs in certain areas were followed by questions which aimed to elicit carers' interest in using services which were related to that need. For example, questions which elicited carers' ability to take breaks from caring were followed by questions which aimed to elicit carers' interest in respite services. Further, services were referred to in functional terms, rather than by the terms they are generally known by. Thus, rather than asking carers "Would you like the person you are looking after to go to a lunch club?", the question which aimed to elicit this information was "Would you like the person you are looking after to go to a place where s/he could have lunch with other people on a regular basis?" Similarly, instead of asking the carer "Would you make use of respite services?", we asked the carer, "Would you make use of a service where the person you are looking after could stay for a few days to give you a rest?"

2.5.3 Working with interpreters

It was anticipated that gathering information from carers would require working with a team of interpreters who were collectively conversant with the range of languages used by them, familiar with the aims of the project and who would be available for the duration of the study. In order to ensure that interpreters were clear about their role and consistent in the use of terminology, a briefing and training session was held. The session detailed the purpose of the project, areas covered in the questionnaire, key terminology and provided some training in the process of interpreting. It was emphasised to all present that in their role as interpreters, they were to enable carers to speak for themselves rather than speak for them.

Of the 9 members of the team, 2 were from the Lothian Interpreting and Translation Service and 7 were members of the Asian and Chinese communities. The latter were chosen for their ability to facilitate access to carers. The pool of interpreters included both male and female interpreters for the Asian and Chinese communities. When interviewing Asian female carers, only female interpreters were used.

2.5.4 Pilot Study

A pilot study was carried out in which the process of eliciting data from the questionnaire was tested with two carers, one English speaking and one through working with an interpreter. Since this did not reveal any major problems, after a few minor adjustments, the main study commenced.

2.5.5 Contacting carers

Carers were identified through the cooperation of MILAN and ECESA and by outreach work with community leaders, women's groups and professionals in medical and social work departments, including those who themselves belonged to minority ethnic communities. Information leaflets were printed in English, Mandarin, Urdu, Bengali, Gujarati, Punjabi and Hindi providing information on who may be seen as an informal carer of an older person, the aim of the project and how to get in touch with the researcher. In many cases, carers were identified by professionals who were providing services to those in receipt of care. The anticipated method of identifying carers through "snow-balling", that is, through carers who were already identified and interviewed achieved only limited success. This may be due to the isolation which carers often experience by virtue of their caring responsibilities or to a reluctance to pass on the names of friends or relatives without knowing their willingness to be interviewed.

2.5.6 The interviews

Almost all the interviews were conducted in the homes of the carers. The advantage in doing so was that the carer did not have to make alternative care arrangements during the time of the interview. A disadvantage of this decision was the possibility that in some cases, the carer was inhibited by the presence of the person they were caring for. However, it was felt that on balance, the advantage of interviewing carers in the home outweighed the disadvantage because it minimised inconvenience to the carer.

Interviews generally lasted from one and half hours to two hours. Often, the interview session was halted to allow for the continuity of caring, such as checking on the older person, getting a drink for them or taking him or her to the toilet.

2.5.7 Analysis of the data

Data from the questionnaires was collated and analysed on the computer with the Statistical Package for Social Sciences (SPSS). Preliminary results were distributed to members of the steering group who fed back comments to the researcher and requested more information on certain aspects.

2.5.8 Focus Groups

Two focus groups were organised, one with Chinese carers and one with Asian carers. The purpose of the focus groups was to:

- validate the research findings of the interviews
- obtain more useful information for service planners and providers.
- test out the appropriateness of some of the recommendations
- obtain a consensus of opinion among carers who had been individually interviewed
- form the basis of carer support groups

More details on the arrangements for the focus groups are given in Sections 9. The next 8 sections will present and discuss the findings from the interviews with individual carers.

3. Characteristics of Carers in the Sample

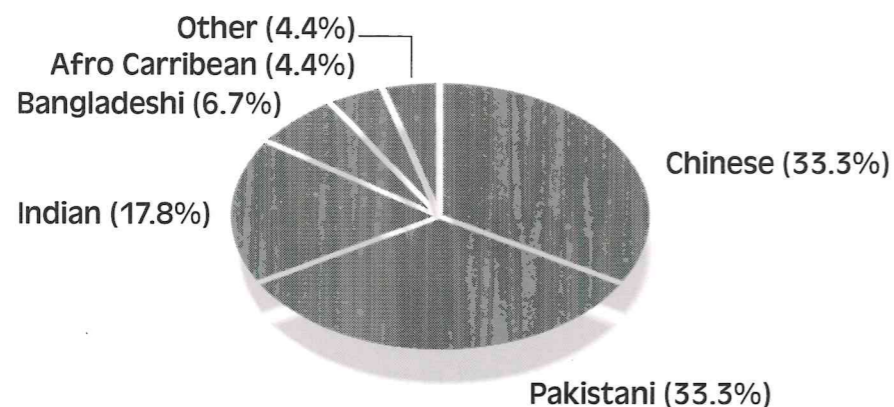
"I forget myself, who I am, because I have to look after him every minute, every second."

This section provides a description of the 45 carers in the sample, that is, their ethnic origin, gender, age, the languages they speak, their marital status, number of children and occupation. It also describes carers' evaluation of their own health, their financial circumstances and the number of older people they look after. Finally, it considers how caring has affected their work or studies and their lives.

3.1 Ethnic Origin

A third of the carers interviewed were of Pakistani origin and a third of Chinese origin. 17.8% of the carers interviewed were of Indian origin. Other ethnic groups which were represented in smaller numbers were the Afro-Caribbean, African, Afro-Asian and Bangladeshi communities.

Figure 1: Ethnic Origin of Carers



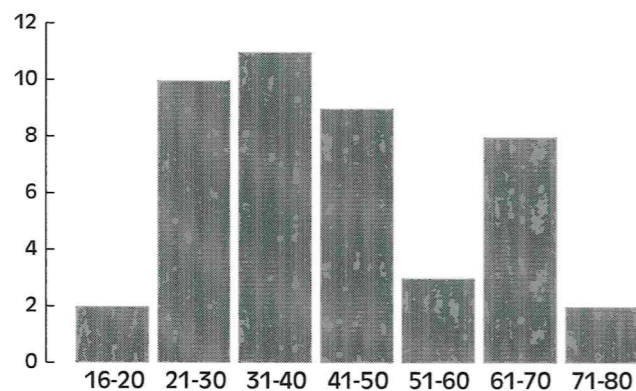
3.2 Gender

About three quarters (75.6%) of the carers were women and a quarter (24.4%) were men.

3.3 Age

The peak age for caring was 31-40 years, with about a quarter (24.4%) falling in this age group. Another quarter of the sample (26.6%) consists of a relatively young group of carers between 16-30 years. This provides a contrast to an older group of carers (17.8%), between the ages of 61-70 years.

Figure 2: Age of Carers



3.4 Languages Spoken

As we would expect, the main languages spoken by carers reflect the ethnic composition of the sample. These are Punjabi, Urdu, Cantonese and Hakka. About half of the carers (53.5%) were able to speak English while the remainder (46.7%) were not.

3.5 Marital Status of Carers

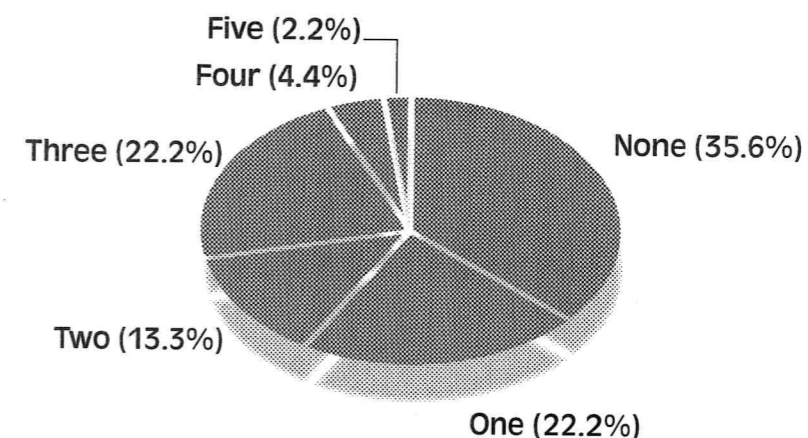
88.9% of carers interviewed were married.

3.6 Number of Children Under 16

In addition to looking after an older person, nearly two-thirds (64.4%) of the carers were looking after children who were under the age of 16.

As Figure 3 shows, 28.8% of carers had three or more young children.

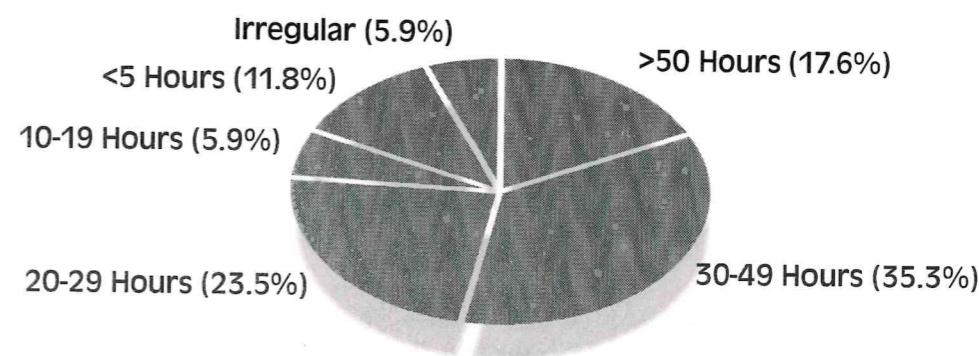
Figure 3: Number of Carers with Children Under 16



3.7 Occupation

60% of the carers were not working or studying. About a third (35.6%) held a paid job. As Figure 4 shows, the number of hours spent working by carers in employment varied from less than 5 hours per week to more than 50 hours per week. More than half of the carers (58.8%) who were in employment worked between 20 - 49 hours a week.

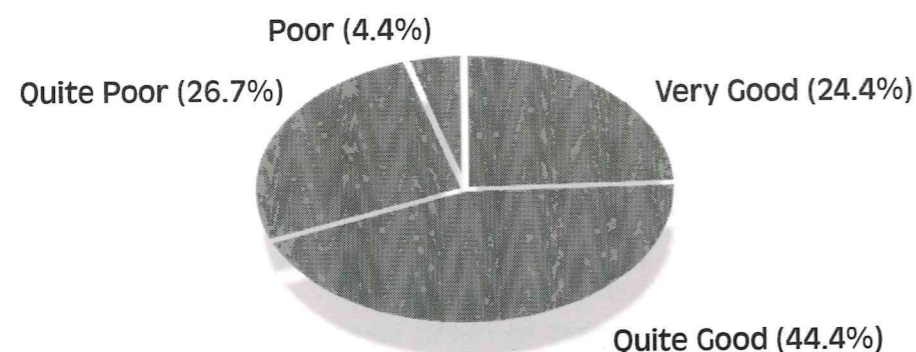
Figure 4: Number of Hours Worked by Employed Carers



3.8 Evaluation of Health

Two thirds of the carers (68.8%) perceived their health to be either very good or quite good. About a quarter of the carers (26.7%) rated their health to be quite poor and the remainder (4.4%), very poor.

Figure 5: Carers' Evaluation of Their Own Health



The carers who reported that they had poor health suffered from a wide range of diseases, both physiological and psychological, much of which was extremely debilitating. One carer said:

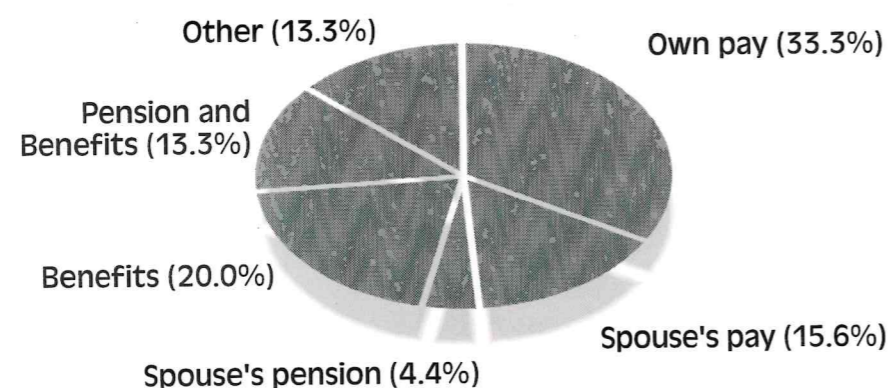
We are physically and mentally exhausted. It has taken its toll. We have to look after her all the time.

Diseases which carers suffered from included cancer, cardio-vascular problems, thyroid and kidney-related problems, migraine, diabetes, arthritis and backache.

3.9 Financial Circumstances

A third of the carers received their main income from their own employment. For a fifth (20%) of the carers, the main income came from benefits. Other sources of income for carers were from their husband's pay, his pension or a combination of his pension and benefits.

Figure 6: Carers' Main Source of Income



3.10 Number of Older People who were looked after by Carers

Just above two-thirds of the carers (68.9%) were looking after people who were living with them: 57.8% were looking after one person and 11.1% were looking after two persons. In addition to caring for older people, 2 carers in the sample were also caring for a child with mental health problems while another was caring for a child with learning difficulties.

3.11 Effect of Caring on Carers' Life

Carers replied in a variety of ways when asked how their caring responsibilities had affected their life. 4 carers spoke positively of caring as part of a good relationship:

Quite happy looking after him. We have been married for 40 years.

I enjoy doing things for him, I stay with him all the time.

4 carers emphasised familial obligations and a sense of duty:

Don't have time for myself but it is my duty, so I do it. If I had a choice, I wouldn't do it. Affects social life, concentration at school, affects a lot of things.

2 carers spoke of how their lives had been profoundly changed when they first assumed the task of caring:

It has affected my marriage, my husband is not here. I came from abroad to look after my mum since 1989. I have only been back home once.

10 carers spoke openly of the physical and emotional strain they were currently experiencing:

I am so tired and fed up. I just want to run away from it all.

11 carers described ways in which caring had restricted their social life and movements:

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.

What kind of life do I have? ... I have no chance to go out anywhere on my own.

7 carers said that caring had not affected their lives, but went on to qualify their responses, suggesting that it was more likely that they had made the mental and practical adjustments which were necessary:

Not to any extent. Grandchildren and children used to look after her. I was working full time. Used to go over and make dinner after work. It was tiring. Once she needed 24 hour care, I had to put her in the nursing home, I had to work.

3 carers spoke about how caring had affected their work (see Section 3.12) while the remaining 4 said caring had not affected their lives at all.

3.12 Impact of Caring on Employment

About half of the carers (48.9%) reported that their work or studies or their chances of taking up employment had been affected in some way by the responsibilities of caring for an older person:

I gave up a full time job. I have lost confidence. Before, I was oozing with it, there was nothing I could not do. Now I avoid people where before I used to seek them out.

Big changes, I closed up my shop and began to lease rooms in the house to guests.

Those who had been working or studying had either given up work, changed jobs, reduced their working hours or been prevented from working longer hours than they would have done. Those who had not been working had been prevented from taking up employment or studying:

My husband is in Pakistan, I would like to bring him over, but I don't have enough money to support him here. I would like to work more hours so that he can come here. But mum comes first.

Caring for her takes up a lot of time. I would like to work, quite hard when there is a family to support and just one person working. But this holds me back.

3.13 Extent of financial dependence of cared for on carer

31.1% of the carers financially supported the older people they were looking after while 37.8% did not. 28.9% of carers partly supported the people they were looking after.

Key findings

- Three quarters of the carers in the sample were women.
- The peak age of caring was between 21- 40 years.
- Nearly half of the carers were not able to speak English.
- More than a quarter of the carers had a minimum of three young children.
- About a third of the carers rated their health as either very poor or quite poor.
- Just over a third of the carers were in paid employment.
- Nearly half of the carers had their work or chances of taking up employment affected by caring for an older person.
- 20% of carers were entirely dependent on benefits.
- More than two-thirds of the carers were looking after someone who was living with them.
- Almost a third of the carers financially supported the people they were looking after

Discussion

One of the most striking findings of the study was the diversity which existed between individual carers: carers came from a variety of cultural backgrounds, spoke a variety of languages, ranged from the young to the old and were equally likely to be working or not working. All of these factors affect their attitude towards caring, the nature of the caring relationship and the care that they give to older people. In turn, tending to an older person impacts on the choices which are available to the individual carer. The nature of care is thus influenced by the carer who is in turn changed in some way by the care he or she provides.

Many carers in this sample come from cultural backgrounds which place a strong emphasis on the care of elderly people. Asked how caring for her mother has affected her life, one carer replied:

I don't put it that way. She is my mum, (my life has been affected) the same as looking after me has affected her life. It's my duty as her daughter. It's my obligation as her child.

However, the tradition of caring for relatives in old age often competes with financial pressure and geographical dispersal of relatives in search of employment. Changing values also determine how carers perceive their caring responsibilities:

It's something we do, but times are changing for women in the community.

I was brought up here. My priorities are with my wife and children, I have to live with that.

The conflict between what is expected and what is possible, or the cost at which it is possible, is one which many carers and the people they are looking after keenly feel. This conflict in expectations across generations has been more generally observed with reference to the changing family structure in minority ethnic communities (Cameron et al 1989; Fenton, 1987).

Another characteristic which differentiates the minority ethnic carer in this sample from others in the indigenous population is their greater tendency to be living with the cared for: 69% of carers in this study were living with the person they were caring for against the 4% found in the General Household Survey on Informal Care. This would suggest that the cared for are more likely to benefit from continuous care than their counterparts in the white population. However, the flipside of this coin is that the carers who live with them may probably be more in need of services which allow them breaks from caring.

It is worth noting that the peak age of caring of 21- 40 years in the minority ethnic communities in this sample is relatively low in comparison to that of the peak age of 45-64 years which was found in the General Household Survey. This may be reflective both of the generally younger age of the minority ethnic communities and of the earlier onset of age-related diseases in these communities as has been described by studies on minority ethnic health (Bhalla and Blakemore, 1981; Fenton, 1988). The younger age at which age-related diseases begin among people in minority ethnic communities would suggest that their carers spend more years caring than other carers.

This sample population of carers also shows the existence of an older group of carers between the ages of 61-70. Many of these people are themselves in poor health, in need of care and without the familiar support structures of the countries from which they have migrated. The difficulty that these people have in caring for someone else is often increased

by their inability to speak English, and so access external forms of support.

Also worthy of note is the large proportion of minority ethnic carers who are women (75.6%). Many of these women are young, and having married at an early age, are looking after young children. Indeed, 29% of carers in this sample are looking after three or more children under 16. The added responsibility of tending to one or more older persons with different needs can be overwhelming. Further, since many of these women are housebound, they are isolated from information and services which would have eased the task of caring for an older person. On the other hand, those carers who are in employment and have young children can also face unbearable pressure in coping with competing demands on their energy and time.

The economic deprivation faced by many minority ethnic carers should also not go unrecognised. Half of the carers in this sample (48.9%) have had their chances of taking up work or their ability to work restricted and a fifth are entirely dependent on benefits:

I cannot work any more for money, I have to depend on benefits. I used to work in a Chinese restaurant as chef in my husband's business.

In addition, 31% of the carers financially support those they look after. Caring for an older person who is in poor health incurs additional expenditure; many minority ethnic carers struggle with the financial burden of providing adequate care.

Minority ethnic carers then share with white carers the added responsibilities of looking after an older person and all that this entails. However, they also face particular difficulties which are associated with the condition of the people they are carrying for and with belonging to a minority culture in a predominantly white population. In the next section, we will consider the characteristics of the people who are receiving care.

Recommendations

The four Social Work Departments in Edinburgh and the Lothians should build on established race equality strategies to:

1. Develop and provide training
 - a) To community care assessors:
 - to assist them in the consideration of the ethnic origin of carers, their age, gender, the languages they speak, the number of young children they have, their health and their financial circumstances (Section 3.1- 3.9)
 - in working effectively with interpreters (Section 3.4)
 - b) To interpreters in key areas such as community care assessments (Section 3.4)

4. Characteristics of the Cared For

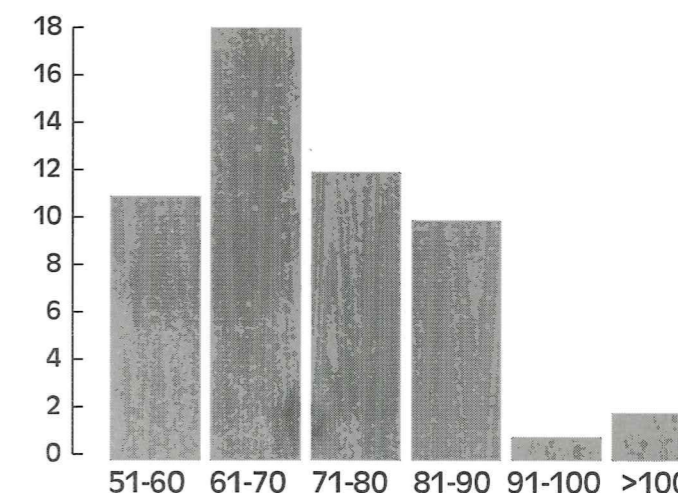
"He is very weak, very tired. He can't walk too far, it's like he is carrying a hundred pounds of rice."

This section describes the extent of the dependency of the cared for on the carer by detailing their condition. A total of 54 people were cared for by the 45 carers in the sample. We consider the age of the people being looked after, their gender, the languages they speak, where they live in relation to the carer and the extent of their physical and mental difficulties.

4.1 Age

More than three quarters of the cared for (75.9%) were between the ages of 51 and 80, with the largest group (33.3%) in the 61-70 age range.

Figure1 : Age of the Cared For



4.2 Gender

70.4% of the cared for were female and 29.6% male.

4.3 Ethnic Origin

The ethnicity of the cared for reflected that of the carers since most of the carers in the sample were looking after relatives who belonged to the same ethnic group. Thus, the minority ethnic groups in which the number of cared for was largest were the Chinese, Pakistani and Indian communities, at 37%, 33.3% and 16.7%, respectively. The other older people who were cared for came from the Afro-Caribbean, African, Afro-Asian and Bangladeshi communities.

4.4 Languages Spoken by Cared For

As in the case of the carers, the languages spoken by the cared for reflect their ethnic origin. The main languages spoken by the cared for are Punjabi, Cantonese, Urdu and Hakka. However, a much smaller percentage of those receiving care were able to speak English (16.7%) than those providing care (53.5%). 6 of the people being cared for only spoke languages which were not commonly spoken even within the minority ethnic communities: these were Hindi, Pushtu, Sudanese, Tosai and Waitao.

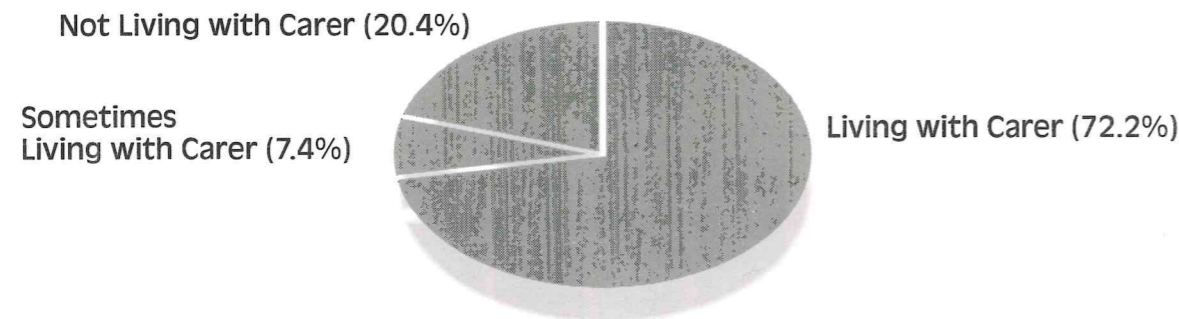
4.5 Relationship of the Cared for to the Carer

More than a third of cared for (35.2%) were parents of the carer while a fifth (20.4%) were parents-in-law. About a quarter (24.1%) were being looked after by their spouse. Other older people were receiving care from their grandchildren or other relatives. Only two were being looked after by friends or neighbours.

4.6 Where the cared for were living

72.2% of the cared for lived with their carer. Of the 11 others who were not living with the carer, 4 were living with family in another household, 3 were living in nursing homes and 4 were living on their own in another household (including 3 who lived in sheltered housing). 4 of the older people sometimes lived with the carer who was interviewed and sometimes lived with other family members in different households.

Figure 2: Living Arrangements of Cared For



4.7 Physical and Mental/Psychological Difficulties

In order to estimate the extent of their caring responsibilities, carers were asked about the physical and mental difficulties which the people they were looking after suffered from. The eight areas in which carers were asked about the physical functioning of the people they were looking after were: holding or picking things up; reaching or stretching; eating or drinking; seeing; hearing; speaking; walking and continence. With respect to mental or psychological difficulties that the older people may be suffering from, carers were asked whether they demonstrated the following behavioural patterns: difficulty in following a conversation; difficulty in recognising people; tendency to ask the same questions; depression; tendency to become easily confused and tendency to become easily angry or aggressive.

As Table 1 shows, the majority of people being looked after (96.3%) were suffering from at least one physical difficulty, with 61.1% suffering from at least one physical difficulty and at least one mental difficulty.

Table 1: Difficulties which cared for were suffering

	No	Percentage
No physical or mental difficulties	2	3.7
Physical difficulty only	17	31.5
Mental difficulty only	2	3.7
Physical and mental difficulties	33	61.1
Total	54	100.0

4.8 Physical difficulties experienced by the Cared for

77.8% of the cared for had difficulty in more than one area of physical functioning. As Figure 4 shows, 50% had difficulties in a minimum of three areas.

Figure 4: Difficulties in Physical Functioning

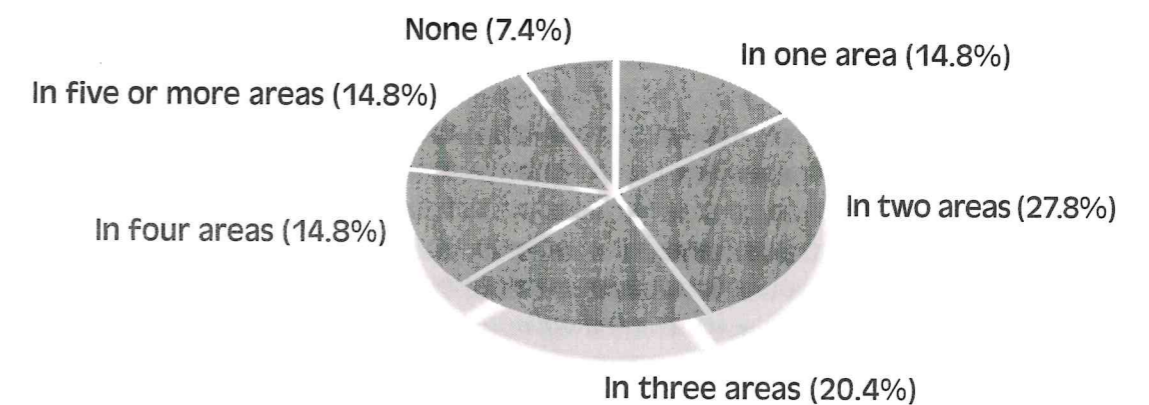


Table 2: Physical difficulties experienced by the Cared for

Difficulty	Difficulty		No difficulty		Sometimes	
	No	%	No	%	No	%
Holding/picking up	26	48.1	18	33.3	10	18.5
Reaching/stretching	20	37.0	26	48.1	7	13.0
Eating/drinking	3	5.6	51	94.4		
Seeing	24	44.4	30	55.6		
Hearing	14	25.9	38	70.4	2	3.7
Speaking	6	11.1	47	87.0	1	1.9
Walking	43	79.6	11	20.4		
Continence	16	29.6	35	64.8	3	5.6

As Table 2 shows, 79.6% of the cared experienced mobility difficulties. Many carers elaborated that this meant that the older people were not able to get things for themselves, such as food or drink from the kitchen or to walk far.

Nearly half of the cared for (48.1%) experienced difficulty in holding or picking up things and more than a third (37%) found it difficult to reach or stretch for things. One 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."

44.4% of the cared for had problems seeing, even with the use of glasses. The degree of difficulty in seeing ranged from having very weak eyesight or watery eyes to being registered blind or partially blind. A quarter (25.9%) had difficulty in hearing. 6 older people who were being looked after had problems speaking and 3 had difficulty eating or drinking. One person was unable to speak or hear.

29.6% of the people who were receiving care suffered from some form of incontinence. Carers who were looking after people who had this difficulty described associated problems, such as the latter not being able to go out or be far from a toilet or having to change clothes frequently.

4.9 Mental/Psychological difficulties experienced by the Cared For

61.1% of the cared for experienced a mental or psychological difficulty in at least one of the six areas described in Table 3 and more than a third (35.3%) had difficulty in at least two of these areas. A large proportion of those receiving care (42.6%) suffered from depression. 29.6% got confused easily and the same proportion got easily angry. In many cases, the target for the aggression would include the carer. One carer said of her mother, "I am her biggest enemy." Others would ask the same questions repeatedly (22.2%) and about the same proportion had difficulty following a conversation (20.4%).

Table 3: Mental/Psychological difficulties experienced by the Cared For

	Difficulty		No difficulty		Sometimes	
	No	%	No	%	No	%
Following conversation	11	20.4	40	74.1	3	5.6
Recognising people	8	14.8	46	85.2	-	-
Repeating same questions	12	22.2	39	72.2	3	5.6
Depression	23	42.6	23	42.6	8	14.8
Confused easily	16	29.6	31	57.4	7	13.0
Easily angry	16	29.6	30	55.6	8	14.8

5 of the people being looked after displayed classic symptoms of dementia, such as difficulty in putting clothes on due to getting confused over which to put on first, misplacing objects and wrongly accusing others of theft, or being forgetful with water and gas taps. One carer described her husband as having had "two attacks on his mind" and having forgotten his powers of speech.

4.10 Diagnosis of diseases

Carers were also asked whether the people they were caring for had been diagnosed and what the diagnosis was. Carers' ability to report the diagnosis precisely varied. 4 of the older people being cared for had cancer, 7 had experienced a stroke and 1 had Parkinson's disease. 10 older people suffered from diabetes and 14 from some form of arthritis. 10 had various problems associated with the heart while 6 had high blood pressure. 2 of the women being looked after had problems with their womb. Often, the people being looked after were said to have been diagnosed as suffering from more than one of these conditions, for example as having diabetes and angina or cancer and arthritis.

Key findings

- A third of the cared for were between 61-70 years.
- 70% were female.
- Less than a fifth were able to speak English.
- Just over 70% were living with their carer.
- Approximately 60% had both physical and mental difficulties.
- Half of the cared for had difficulties in a minimum of three areas of physical functioning.
- More than 40% suffered from depression.

Discussion

Certain characteristics of the older people in minority ethnic communities receiving care in this study are worth noting: 61% suffered from at least one physical difficulty and one mental difficulty, half had difficulties in physical functioning in at least three areas and 43% were suffering from depression. All of these factors suggest a heavy dependence on informal care within minority ethnic communities. Carers who look after one or more people who have difficulties in physical functioning in several areas and who are also depressed carry a particularly heavy burden.

However, the older person who is receiving care in the minority ethnic community is also likely to be disadvantaged in one more respect, the inability to speak English: 83% of the cared for in this sample were unable to speak English. This restricts the ability of the older person to communicate with others outside of his or her community, resulting in a heavier reliance on the carer and the community for social activities and entertainment. It also inhibits those who are less physically disabled from obtaining essential services such as going to the doctor or the hospital unaccompanied, thus increasing their dependence on the carer.

Another factor which is worthy of note is the large proportion of women who are receiving care. Cultural expectations on the role of women, including those relating to female seclusion among Muslim communities, result in a large percentage remaining within the confines of the home (Blakemore and Boneham, 1994). This restriction in social mobility makes them more dependent on other members of the family for services or formal support which necessitate contact with the wider community.

One characteristic of the cared for in this study which contrasts against that found by the General Household Survey is worth drawing attention to: the greater likelihood that they are likely to be related to the carer. In this study of 45 carers, only 2 were providing care to people who were not related to them against the 20% found by the national survey. The fact that carers in the minority ethnic community are more likely to be related to the cared for than those in the general population of carers suggests an element of choice in the latter who have chosen to care for neighbours or friends which is less likely to be present in the former. Without the ability to choose, the psychological burden of caring is increased. This lack of choice is perhaps especially worth noting with respect to the high proportion of married women who are 'duty-bound' to provide care to their parents-in-law.

Summarising this section, it has been noted that many characteristics of older people in the minority ethnic communities increase the task of caring for them. In the next section, the nature of the care which is provided is considered.

Recommendations

The four Social Work Departments in Edinburgh and the Lothians should build on established race equality strategies to:

1. Develop and provide training to community care assessors to alert them to the particular difficulties experienced by minority ethnic older people and their reliance on informal care (Section 4.4, 4.8 and 4.9)

5. The Nature of Care

"It is the same as in white families, when it comes down to the crunch there is only one person carrying the can."

This section considers the responsibilities undertaken by carers, the number of hours per week they spend on caring and the length of time they have been caring. It also considers the extent of informal support available to carers, how they would cope in crisis situations and their ability to take time off. It concludes by describing the aspects of looking after one or more older persons which carers find most difficult to cope with.

5.1 Caring Responsibilities

The large majority of carers were involved in monitoring the condition and safety of the people they were looking after (96.3%) and keeping them company (92.6%). More than four-fifths of the carers (83.3%) also carried out household chores for the cared for, such as cooking, shopping or washing clothes. Other responsibilities included entertaining the cared for by taking them out, for example, to see friends (70.4%) and providing medical support, such as taking them to the doctor or giving them medication (64.8%).

A lower percentage of carers were involved in providing practical help such as household repairs and gardening (57.4%) and doing paperwork, such as paying bills and filling up forms (40.7%). This reflects the predominantly female population of main carers and the traditional division of labour within households. 38.9% were also involved in interpreting for those receiving care who were not able to speak English. This lower percentage is also reflective of the greater tendency of the men in many minority ethnic households to be more fluent in English

More than a third of the carers (35.2%) were involved in personal care such as bathing, dressing and combing hair. The same proportion (35.2%) were involved in providing physical help with walking, climbing up or downstairs or getting in or out of bed. Others reported that they had in the past been involved in providing personal care and physical help to the people they were looking after and may be called upon to do so in the future.

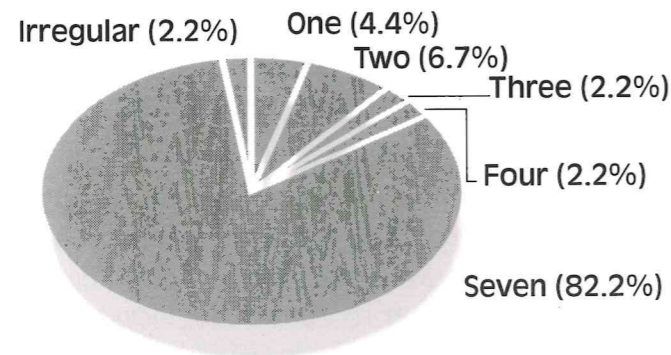
Table 1: Caring Responsibilities

	Care given		Not needed		Sometimes needed	
	No	%	No	%	No	%
Personal Care	19	35.2	34	63.1	1	1.9
Physical Help	19	35.2	32	59.3	3	5.6
Paperwork	22	40.7	31	57.4	1	1.9
Household chores	45	83.3	8	14.8	1	1.9
Practical Help	31	57.4	23	42.6	-	-
Keeping company	50	92.6	4	7.4	-	-
Entertaining	38	70.4	15	27.8	1	1.9
Medical Support	35	64.8	18	33.3	1	1.9
Keeping an eye	52	96.3	2	3.7	-	-
Interpreting	21	38.9	32	59.3	1	1.9

5.2 Time Spent on Caring

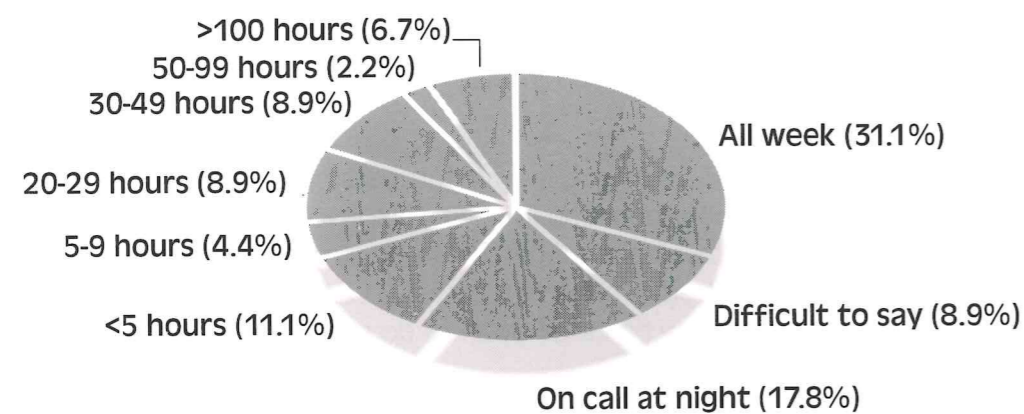
More than four fifths of the carers (82.2%) said that they provided care 7 days a week. This reflects the large proportion of carers living with the people they were caring for.

Figure 1: Days a Week Spent on Caring



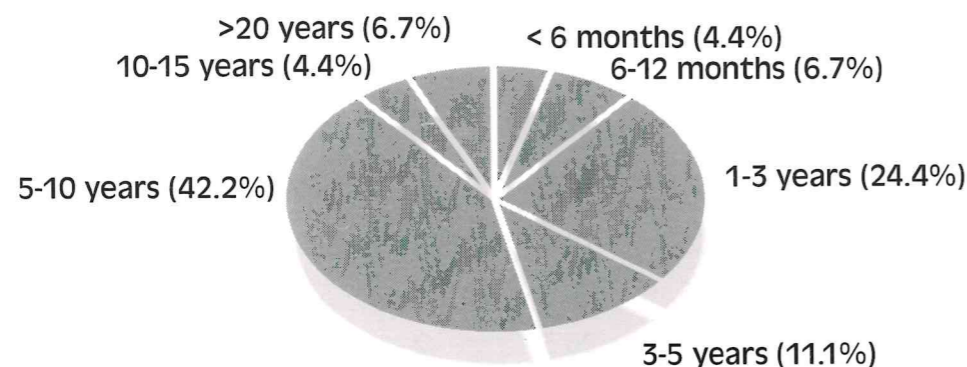
Asked how many hours of care they provided a week, 31.1% of the carers reported that they provided continuous care all day long.

Figure 2: Time Spent on Caring



More than half of the carers (53.5%) had been looking after the older person for more than 5 years.

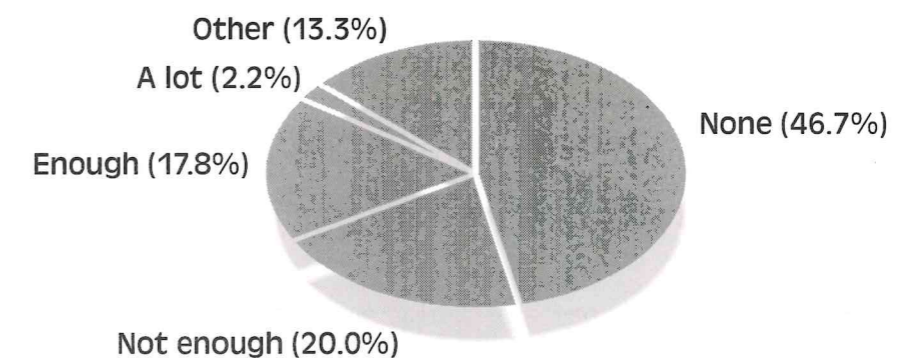
Figure 3: Length of Time as a Carer



5.3 Time off from providing care

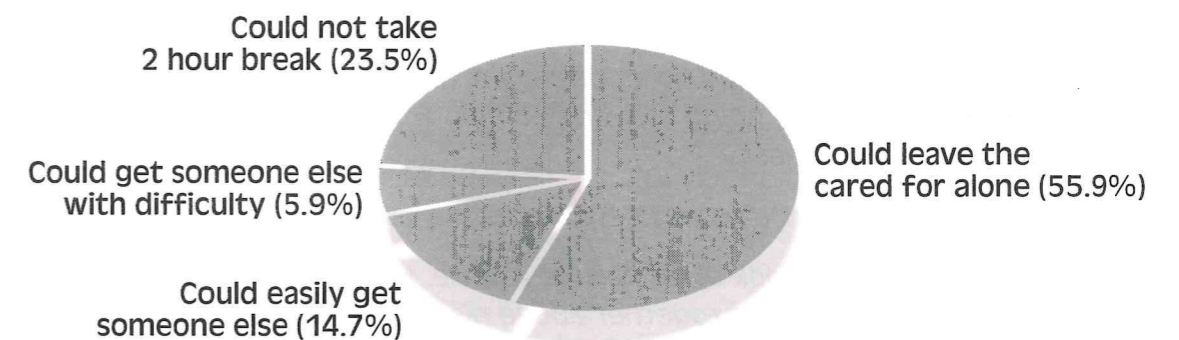
Nearly half of the carers (46.7%) reported that they had no time off from caring. 20% that they had not enough time off while 17.8 carers said that they had enough time off. Only one carer said that she had a lot of time off. The remaining 6 carers responded in ways which suggested that they had difficulty with the concept of "having time off". At least a few of these carers perceived caring to be such an integral part of the relationship that they had with the person they were looking after that they could not conceive of "time off".

Figure 4: Time off from Providing Care



Since twenty hours of care a week has been recognised as a significant proportion of time spent on caring (as in the General Household Survey), carers who spent at least this amount of time on care were asked about their ability to take time off. Figure 5 shows that as many as 23.5% of the carers reported that they would not be able to take two hours off. Not surprisingly, a larger percentage, about a third (35.3%) of the same group of carers, would not be able to take two days off. Predictably, the same group of carers found it more difficult to take a week off from caring than to take two days off, with as many as 44.1% reporting that they would not be able to take a week off.

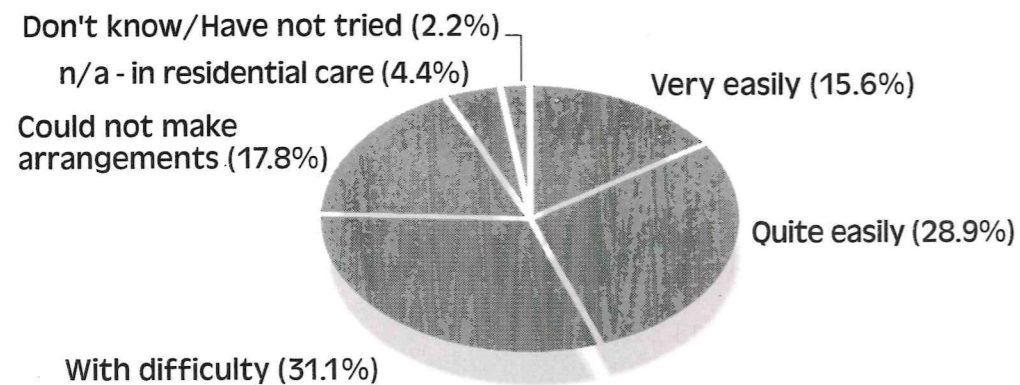
Figure 5: Ability to Take a Two Hour Break



5.4 Crisis situations

Carers' ability to make alternate arrangements in case of emergencies, during which they would be unable to provide care due to a sudden illness or accident, varied greatly from being able to do so easily to not being able to do so at all. 28.9% said that they would be able to do this quite easily against the 31.1% who reported that they would be able to do this with difficulty.

Figure 6: Ability to Arrange Alternative Support



14 carers spoke of turning to members of the family or particular relatives in times of crisis:

Would ask relatives to come around. In times of need, family would rally around.

6 carers mentioned the presence of family but suggested that this would be difficult to arrange or limited:

The two other daughters would have to take over. Just hope that they will.

Brother in the States would come and look after her.

4 carers did not know what they would do but hoped that others would be able to help:

Hope people at MILAN would be able to help.

7 carers said that they had no idea what would happen if they were suddenly unable to provide care:

Nobody to look after her- our son and daughter are far away. I never think about this. When it happens, I will think about it. Our son and daughter have to work. Can you think for us?

I don't know what I would do. I don't want to think about it. All sorts of things could happen, going to work, coming from work. I don't know what I would do, to be honest.

7 carers responded in ways which suggested the lack of appropriate alternatives:

Will get children to look after her for a while. Hope it doesn't happen (said while clasping his hands together above his head in a gesture of prayer).

Don't know if there is such a service (residential respite care, mentioned in the last question). I can send him there. Give me the address. It would be very useful.

3 carers said they had never thought about it. This did not apply to the 3 carers who were looking after someone in residential care. Only one carer said he would contact the Social Work Department.

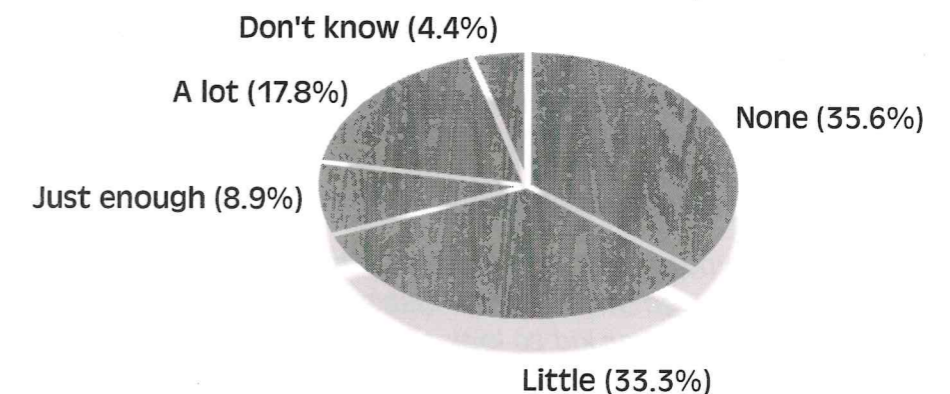
5.5 Presence of Informal Support

44.4% of all the cared for were looked after by a sole carer, that is, someone who was solely responsible for the care of the person/s that they were looking after. The caring arrangements for the remaining 55.6% are diverse, with the most common arrangement being the support of one or more people who were not living with the carer or the cared for (22.2%).

5.6 Family Support

A third of the carers (33.3%) reported that they had little family support and about another third (35.6%) said that they had no support at all (35.6%).

Figure 7: Amount of Family Support



5.7 Difficulties experienced in caring

Carers were asked what they found most difficult to cope with. Responses to this varied greatly, revealing practical difficulties, the complexities of the caring situation and the nature of the relationship between the carer and cared for. 2 found everything difficult. 6 carers found certain aspects of providing personal care particularly difficult:

Giving her a bath. Need two people to be there, to hold each arm, put her clothes on. To wash her hair, her body.

I myself find it difficult to take a bath. When I have to take him into the bathroom with me, it is very, very difficult.

4 carers described other practical difficulties:

I don't know how to get help for him. I applied for him to stay in Cathay Court but there is no one to look after him there. I would like him to stay in a nursing home, but he cannot communicate in English. He doesn't get breakfast or lunch, only biscuits or bread, he gets no food until 4 o'clock in the evening. I am worried that he is also lonely.

It's difficult to take him to the hospital or go to the doctor because of transport problems

3 carers spoke of the emotional strain:

Difficult to say no. When I do, I feel guilty and resentful. I find it difficult not to get angry. When I was on holiday, I had to take both of them out on separate days.

Seeing my mother physically and mentally ill.

4 carers responded in terms of difficulties in inter-personal relationships:

When people become old, they are like child, you know what I mean? Must have heart like this (stretching out both arms).

Her incessant enquiring about everything that goes on with everybody. Can't rely on her for anything, for moral support or affection.

Another 2 carers spoke of differences in values:

Her being old with different values and living in the same home. I try to avoid clashes.

4 other carers responded in terms of a combination of emotional and practical difficulties:

I can take everything, but I can't take the verbal abuse. It is a problem taking her out, difficult for me to take her out because I can't push. Mum has not been out for 4 months.

6 carers spoke of being restricted in what they could do:

I get tired, I don't go out anywhere, always in the house. I never go out, never have the time to go out with my husband, don't like to leave her alone. Just like a kid, another kid to look after.

Trying to find time for myself, for what I would like to do for myself. Sometimes its hard to cope with financially.

2 other carers spoke of the responsibility:

Mainly all the duties falling on one head. If there was someone else, I could share the duties..

3 carers spoke of how they coped:

Just pray when I have difficulties, I pray a lot.

Never think of that. If there is an obstacle, I try to overcome it, look for another means. Don't allow myself to get depressed or tired. I organise my shifts to fit in with her appointments.

9 carers reported that they did not find anything particularly difficult.

5.8 Difficulties in Accessing Services

The difficulties which carers had in accessing services and their desire to use services were made apparent by the requests made of the researcher. Among the requests were help with accessing home helps, meals on wheels, transport to the lunch clubs and information on how to get a walking stick and a wheelchair, how to enrol for home tuition or English classes, how to get a taxi-card, how to apply for a grant for a house extension and the location of the nearest general practitioner. The researcher tried to assist directly and through referrals to VOCAL, MILAN and ECESA but was limited by time constraints in what she could do.

Key findings

- More than a third of the carers provided personal care such as bathing and dressing.
- The same proportion provided physical help in walking or climbing up and down stairs.
- More than a third of the carers acted as interpreters for the people they were looking after.
- Over four fifths provided care 7 days a week.
- Just under a third provided continuous care all day long.
- More than half had been caring for more than 5 years.
- Nearly half reported that they had no time off from caring.
- 24% of the carers who provided more than twenty hours of care a week reported that they could not take a two hour break, 35% reported that they could not take two days off and 44% that they could not take a week off.
- Nearly half of the carers would either only be able to make alternative arrangements with difficulty or not be able to make them at all in the event of an emergency.
- 44% of the cared for were looked after by a sole carer.
- About two thirds of the carers reported that they had either little or no family support in caring for the older person/s.
- Carers shared similar difficulties as white carers in providing personal care and physical help, and like them, experienced emotional stress, interpersonal difficulties in the caring relationship, social restriction and time pressure.
- Carers also experienced particular difficulties which were related to the heavy dependence of those they provided care to and difficulties in accessing appropriate forms of support.

Discussion

Like other carers, the extent of care provided by those from a minority ethnic background is directly related to the severity of the disability of the people they are looking after. We have already noted in the discussion in Section 2, that certain characteristics of those receiving care in these communities make the task of caring for them particularly difficult. Indeed, more than a third of the minority ethnic carers in this sample are involved in two of the most strenuous aspects of care-giving, that of providing physical help (for example, with walking or getting out of bed) and personal care (for example, bathing and dressing). These aspects are particularly difficult for the older group of carers, some of whom are themselves frail and in poor health.

Where the carer and the older person care being cared for are not of the same sex, and the older person is either a parent or parent-in-law, the difficulties in providing personal care are more than physical: they involve the crossing of socially acceptable boundaries. While this also poses difficulty for many white carers, the minority ethnic carer may be torn between two cultural expectations: one, that she/he provides care to older people and two, that distance between the sexes is maintained:

Daughter-in-law is not supposed to clean father-in-law when he has dirtied himself.

The intimate nature of these tasks makes them difficult to delegate, even if support were available, which is rarely the case.

Other aspects of caring which take on an added significance within the minority ethnic communities are those which require the ability to speak, write or read English. One such area is obtaining medical services, such as arranging appointments with the doctor or accompanying the older person to the hospital. Another area is dealing with paperwork, such as applying for benefits, filling up forms and paying bills. Minority ethnic carers who are in this situation often have to rely on other members of the family, friends or people working in voluntary organisations to help them in these matters. Information and support workers who work in minority ethnic voluntary organisations will readily testify to the great demand for their services in these areas.

The high proportion of minority ethnic people who suffer mental health problems is also worthy of attention, particularly those who suffer from depression. Prolonged contact with someone who is suffering from depression can be extremely wearying. It may also be difficult to cope with or to obtain relief from, particularly since in many cases, the depression may have been brought about by social isolation and economic deprivation.

It is clear then that many minority ethnic carers face particular difficulties in caring for older people and accessing external support. Unaware of this, many service providers have accounted for low uptake by pointing to the existence of an extended family network and claiming that they look after their own (McFarlane, 1989). In this context, the high proportion of people who are looked after by a sole carer (42.2%) in the sample is noteworthy, and adds to the accumulating evidence in the literature which questions the existence of the extended family and its ability to adequately support those who are frail and disabled (Baxter, 1989; Cameron et al, 1989; McCalman, 1990).

Further evidence which belies the veracity of a supportive family network is found in the ability of individual carers to take time off from caring: nearly half said that they had no time off from caring. Among those who were providing more than twenty hours of care, over a fifth said that they would not be able to take two hours off, more than a third reported that they would not be able to take two days off and 44% that they would not be able to take a week off. This suggests that a substantial proportion of minority ethnic carers routinely manage entirely on the strength of their own resources. Weakening the belief of the family network even further, is the evidence that many carers in this sample cannot rely on family support even in times of crisis.

Many of the experiences of minority ethnic carers of looking after older people will be familiar to white carers: the frustration of being restricted from career advancement or taking up employment, the competing demands of caring for children and older people, the

strenuous tasks of providing personal care and physical help, the torment of seeing loved ones in pain and the sense of loss when people they are providing care to undergo changes in personality. However, what may not be familiar to white carers are the particular difficulties of obtaining appropriate forms of external support which minority ethnic carers are confronted with. The next section will discuss the use and appropriateness of current community services and identify gaps in provision.

Recommendations:

The four Social Work Departments in Edinburgh and the Lothians should build on established race equality strategies to:

1. Consult with minority ethnic carers:
 - to develop personal care services which are sensitive to their cultural requirements (Section 5.1)
 - to develop a sitter service which will be flexible to their respite needs (Section 5.3)

Lothian Health should build on measures to increase race equality by:

1. Setting standards for patient records which clearly identify ethnic minority origin and any related requirements, particularly the need for language support (Section 5.1).
2. Provide a training programme
 - for staff to work effectively with interpreters (Section 5.1).

Lothian Health should work collaboratively with the four Social Work Departments in Edinburgh and the Lothians to:

1. Develop an adequate and appropriate crisis support mechanism by consultation with minority ethnic carers (Section 5.4)

6. Social Work and Community Services

"What will they do? What am I going to tell them? I don't know what services they offer. I don't have the confidence to phone them. I would like a lot of help but I don't know who to ask."

This section considers carers' current use of community services and their satisfaction with the services provided. It also identifies existing community services which carers would like to use and their preferences for service delivery. Finally, it identifies gaps in current service provision and describes the nature of carers' contact with Social Work department.

6.1 Uptake of services by carers and cared for

31.1% of the carers used at least one of the services which were provided by Social Work Department, voluntary organisations and community education. 68.9% of carers did not use any of these services. Of the 54 who were cared for, 55.6% used at least one of the services which were provided by Social Work Department or voluntary organisations or community education. 44.4% of the cared for were not using any of the services. The proportion of people from minority ethnic groups who are using these services in the sample are in part a reflection of the sampling process: part of the remit of the researcher was to identify carers who were in touch with MILAN or ECESA as well as those who were not. It is likely that the proportion of minority ethnic carers in Lothian who are using services is significantly lower than this study has found since those who are in contact with voluntary organisations are likely to be more aware of available services than those who are not.

The reasons most commonly given for not using services were a lack of knowledge of their availability and how to access them:

Don't know how to apply.

Never been offered them, not sure if we are entitled to them because she is living with us.

One carer said that she had asked her health visitor for a home help and someone to give her grandmother-in-law a bath and was told she could not get them because she lived in a large household. A few carers said that they did not need any services.

6.2 Domiciliary Support

This section considers carers' use and interest in using domiciliary services, that is, home helps, meals on wheels, sitter services and personal care services.

6.2.1 Home Help Services

6 carers were currently receiving the services of a home help. Of these, 2 were very satisfied with the service, 3 were quite satisfied and 1 was very dissatisfied. 6 other carers had discontinued the service. Positive comments on the service included:

Good help, no complaints.

It's free, it provides company. Mum's main problem is loneliness.

It gives her a break and provides relaxation.

Negative comments on the service included the number of changes in home helps,

dissatisfaction over the limitations of the duties of home helps and the cost:

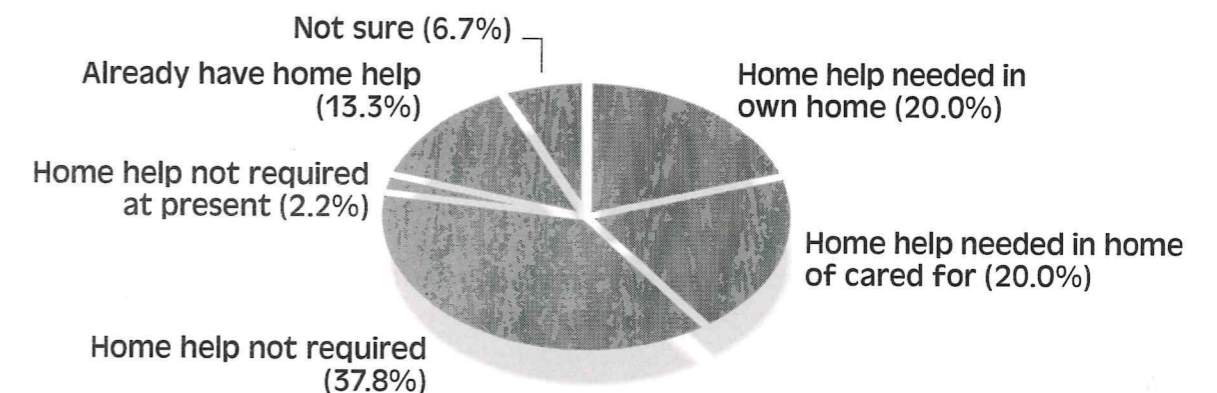
Different ladies came, I had to keep showing them how to make tea our way. They always used the phone to find out where they were going next. I also got a call from the supervisor that they were to do nothing for me, no ironing, no shopping.

I used to have a home help but she would only do mother's room, not the rest of the house. Mum's room is small, I can do that on my own. So I stopped her.

She was quite good but I had to stop it when I got charged for it. Couldn't afford it.

40% of the carers who are currently not receiving the service said that they would like someone to help them with household chores either in their house or in the house of the person they were looking after. 37.8% of carers did not need this. Of 3 carers who were not sure, 2 said it depended on whether they would have to pay for it.

Figure 1 Carers' Need for Home Help



6.2.2 Meals on Wheels

Only 4 of the 45 carers were currently receiving the meals on wheels service for the person they were looking after. Of the 4 who had experience of the service, 2 were quite satisfied, 1 was quite dissatisfied and 1 was very dissatisfied. Carers who were satisfied with the service said:

It relieves the burden of looking after my wife. At the moment, we get it three times a week. I would like it more often.

It is the food we eat.

Those who were dissatisfied or who had discontinued the service gave the following reasons:

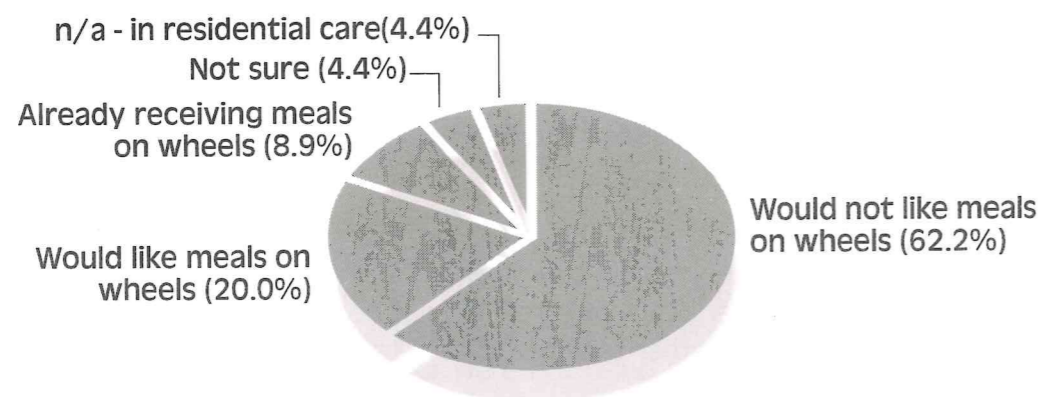
Too much ajinomoto (monosodium glutamate), also it is not suitable for grandmum because it is too hard to chew, and not suitable for mum because of her diabetes.

Didn't think it was halal.

About a fifth of the carers (20.0%) who are currently not receiving this service would like the service to be provided while 62.2% would not. 2 carers were not sure. The choice of food

carers preferred reflected their ethnicity. Thus, Chinese carers expressed a preference for Chinese food and Pakistanis and Indians, Asian food. In addition, the Muslims required food to be halal while 2 carers required it to be vegetarian to comply with religious requirements. Two said their wish to obtain the service depended on whether it would be provided free.

Figure 2 Need for Meals on Wheels



Many carers did not want to use the service because they preferred to cook themselves. Apart from this, the main reason given for not wanting to use the service was a feeling that the food would not meet the requirements of the person they were looking after:

He cannot take fatty foods, has to be careful with sugar content. He cannot take eggs.

Her requirements are not easy to meet. She needs fresh food, mostly fish.

We cannot eat their sort of food, we eat more fish and chilli.

Carers' views on the service indicate that not only do they prefer food which is similar to their normal meals but they are also concerned that the meals should be appropriate for the health of the people they are caring for.

6.2.3 Sitter Service

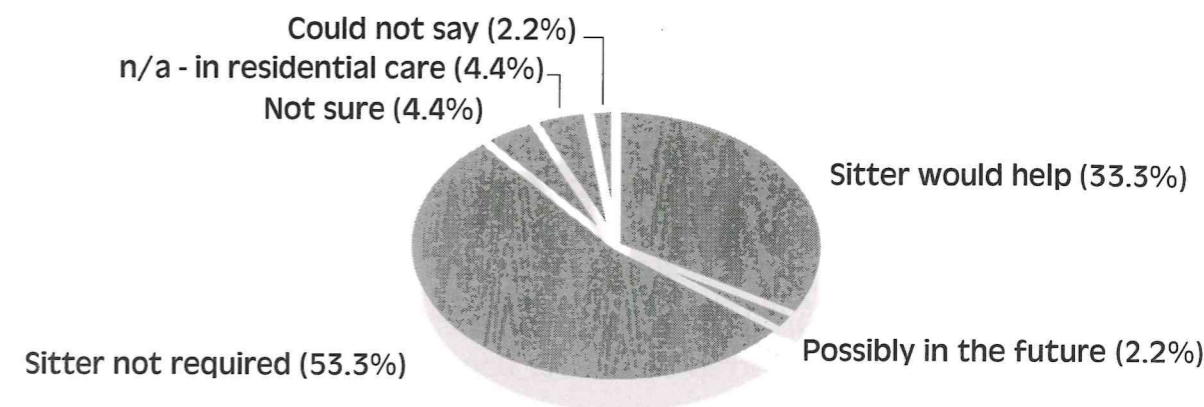
None of the carers were using a sitter service. A third of the carers (33.3%) expressed a desire for someone to come in from time to time and be with the person they were looking after to give them a rest. Many of them strongly emphasised that it was necessary for such a person to be able to speak the same language as that of the person they were looking after:

Someone who can speak Punjabi, wouldn't be any use otherwise.

Someone she knows, would not trust anyone to be with her, someone she can talk to, confide in. If this person were to come a few times and win her trust, then I could go out alone.

About half of the carers (53.3%) said that they did not need this. Among the reasons given were that they were generally able to either leave the cared for alone for a while, get someone to take their place or that they were reluctant to leave him or her with someone else.

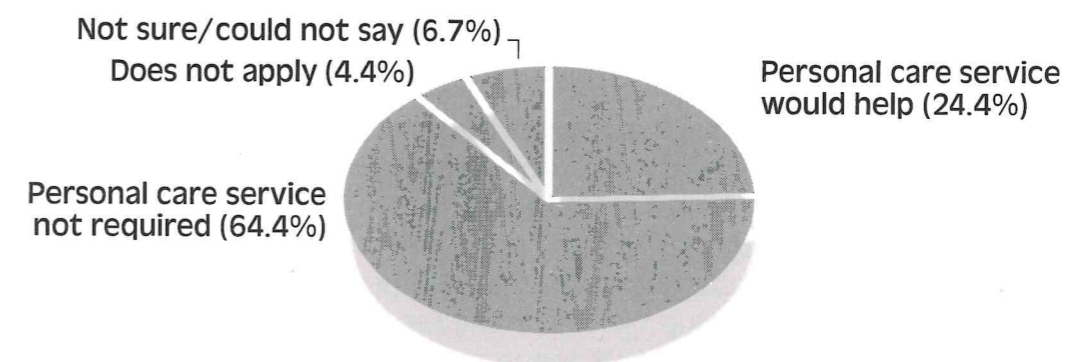
Figure 3 Carers' Need for Sitter Services



6.2.4 Personal Care

Only one carer in the sample was receiving the services of bath nurses with whom she was satisfied although she would have preferred male nurses to tend to her father-in-law. About a quarter of the carers (24.4%) said that they would like someone to help them with providing personal care.

Figure 4 Carers' Need for Personal Care Service



4 carers expressed a need for help with bathing, while 4 other carers would like someone to take the person they were looking after out:

I would like someone to come and take her out, she gets tired of sitting at home, I have asked friends at church.

Someone to take him for a walk, for a hair-cut. When he tried to do this himself, he collapsed on the road.

2 other carers would like someone to come in to give the person they are looking after massages.

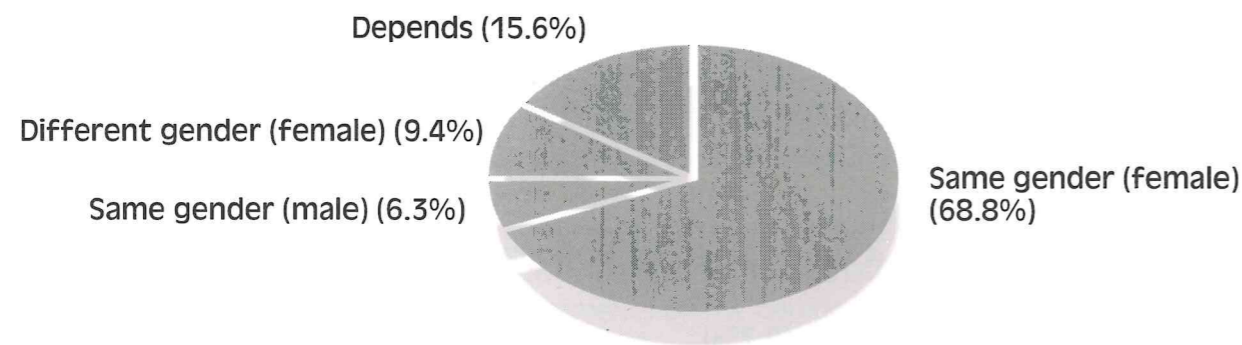
6.3 Preferences for Domiciliary Service Delivery

32 carers (71.1% of the sample) were either receiving domiciliary support of some kind or expressed an interest in receiving it in the future. The preferences of these carers for the gender, ethnicity and languages spoken by those who provide these services are considered below.

6.3.1 Gender

Just above two thirds of the carers (68.8%) who were either receiving domiciliary services or who expressed an interest in these services expressed a preference for the person to be the same sex as the cared for. 3 carers who were looking after older men expressed a preference for home helps to be female, citing reasons such as suitability for the task and a greater sense of security within the home. 2 carers expressed the need for male nurses to help with bathing. 3 carers made the distinction that it was important for the person involved to be of the same sex as the cared for if personal care was provided but preferable for the person involved to be female if involved in household tasks.

Figure 5 Preferred Gender for Domicillary Help

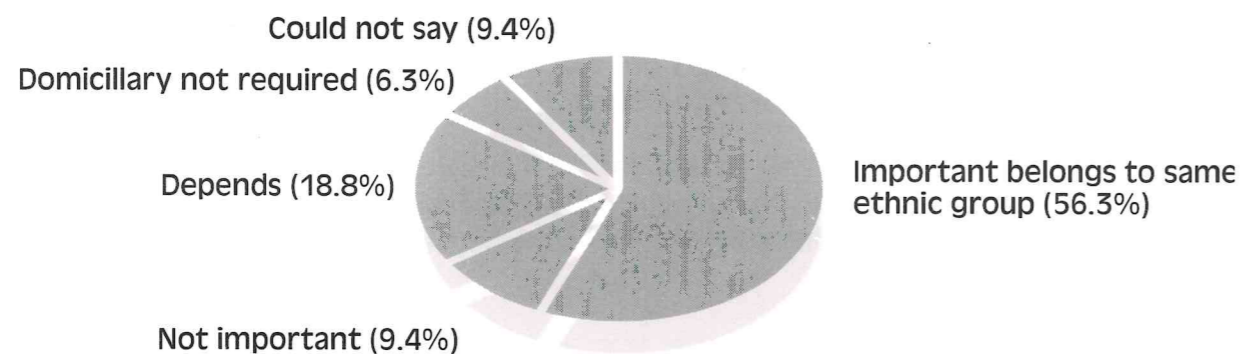


6.3.2 Ethnicity

More than half (56.3%) of the carers who were receiving domiciliary services or who expressed a desire for such services preferred the person involved to be of the same ethnic group, most commonly citing the increased ability to communicate with the cared for and themselves. 6 carers made the distinction that it was not important for home helps to belong to the same ethnic group but important for those who provided more personal services to the cared for, such as befriending services, to be from the same group. One added that a home help who was the same ethnic group as she was (Chinese) would be able to buy her the groceries she needed. 3 thought it was not important.

Interestingly, 2 carers expressed a preference for people providing domiciliary support not to belong to the same ethnic group. One said that familiarity would breed contempt in the case of a home help while another said that her Pakistani husband would feel less embarrassed if the person who helped him with bathing was white.

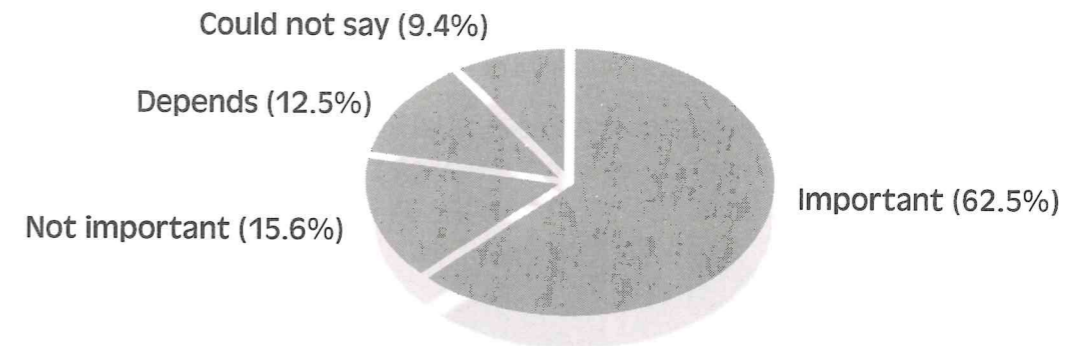
Figure 6 Preferred Ethnicity of Domicillary Help



6.3.3 Ability to speak the same language

62.5% of the carers who either received domiciliary services or expressed interest in receiving them for the person they were looking after preferred the person providing such services to speak the minority ethnic language. Of the 5 carers who did not think that this was important, 2 carers cited their own ability to speak English while 2 others cited the ability of the people they were looking after to speak English. 4 carers made the distinction that it was not important for those providing home help services to speak the same language but important for those who provided a befriending or sitter service.

Figure 7 Domiciliary Help's Ability to Speak Same Language



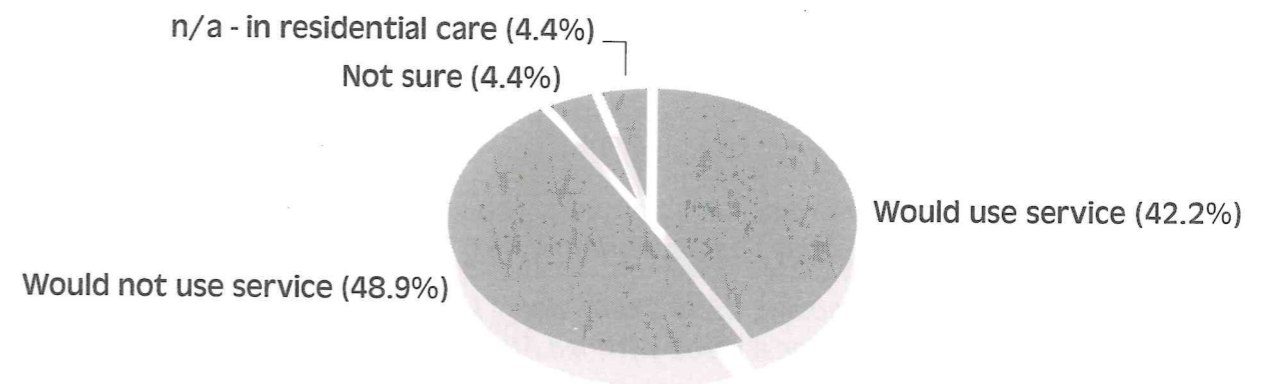
6.4 Support outside the home

This included crisis support, residential respite care and long-term residential care.

6.4.1 Crisis Support

The concept of a service which carers could use in the event of an emergency which prevented them from carrying out their caring activities was new to almost all the carers interviewed. Indeed, as the responses in Section 3.5 indicate, many carers had never thought about what would happen in a crisis situation should they not be able to provide care. It is thus surprising that without much knowledge of the form of such a service, as many as 42.2% of carers positively responded to the use of such a service against the 48.9% who did not. On the other hand, this finding is consistent with the finding that a substantial proportion of carers would not be able to rely on family members even in the case of an emergency (Section 3.5).

Figure 8 Need for Residential Emergency Services

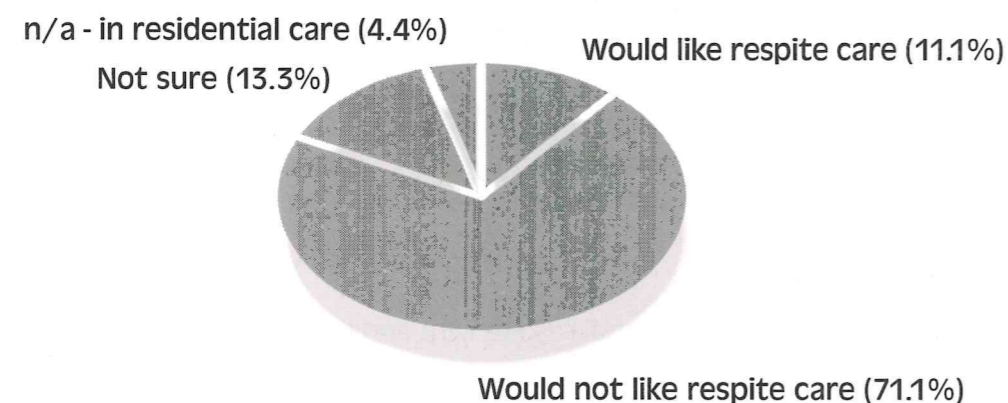


All the carers who responded positively said that it would be important to them that the people whom they were looking after receive the food they were used to and be able to communicate with staff and other users of the service. Among the main reasons carers gave for not requiring this service was the unwillingness of the person they were looking after to leave the home and the presence of family or friends who could be counted on in the event of an emergency.

6.4.2 Residential Respite Care

The concept of residential respite care was completely novel for almost all the carers and had to be explained to them. None of the carers had ever used such a service. It is thus not altogether surprising that 71.1% of the carers said that they did not wish the person they were looking after to be sent to a place for a week or ten days to give them a rest. 5 carers would welcome this opportunity for a break while 6 were not sure.

Figure 9 Preference for Residential Respite Care



The most common reason (given by 11 carers) for not wishing to send the people they were looking after somewhere else to be looked after was the unwillingness of the latter to go:

My husband 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.

She would never accept it.

10 carers had personal reasons for not wishing to use the service:

I would not go anywhere without her. Also, I don't have any place to go without her. Even if I go to the mosque, my heart is always at home.

We always go for holidays together, otherwise I would be worrying about him.

7 carers had concerns about whether the people they were looking after would be able to communicate with others:

Because she won't be able to speak to anyone, she would feel completely miserable, she would feel that I had abandoned her

Depends if Gujeratis are looking after them, don't know if they would like it. They went to Fort William for a week with MILAN.

5 carers explained their reluctance in terms which could be directly related to cultural beliefs:

We are very conservative, if she goes for a couple of weeks I have to go as well.

My mother has a daughter and a son. When people don't have children, they go to nursing homes.

4 carers mentioned that they could leave the people they were looking after to stay with other members of the family if they wanted to go away. Other responses given by carers were that more information was required, that it depended on the person who was being looked after, that food would be a problem and that they did not know of any such service.

6.4.3 Long-Term Residential Care

Only three carers were looking after people who were staying in nursing homes. Of these two were positive about the service provided:

It's small, run like a home. Care is good, they have organised activities, good meals. They take them out to various places, shopping, get people into recreational things. She's not isolated by being black, she's pals with the others.

She gets good Chinese meals. It was difficult for her to communicate with the staff at first, but she can now communicate through sign language. She would prefer Chinese staff.

One carer was not satisfied with the quality of care which his mother received:

Mother has to be fed, but only the family will do this. Also, it would be better if she had Chinese food.

However, on discussing it with his friends, he had resignedly come to the conclusion that the standard of care in all nursing homes was similar.

In response to whether carers would consider sending the person they are looking after into long-term residential care, 71.1% responded negatively. One of the most common reasons given was the latter's unwillingness to go:

He wouldn't like it, he likes to sleep in his own bed, in his own home.

If you take her away from her son, it would be the end of her world. She likes to be in the family unit, feel wanted.

Other carers, mainly Asian, explicitly mentioned cultural and religious beliefs:

98% I would not send her there, our culture stops us from doing this.

We want to go to heaven, when we look after her, we are all the time getting blessings.

Other reasons given for not considering residential care were personal choices:

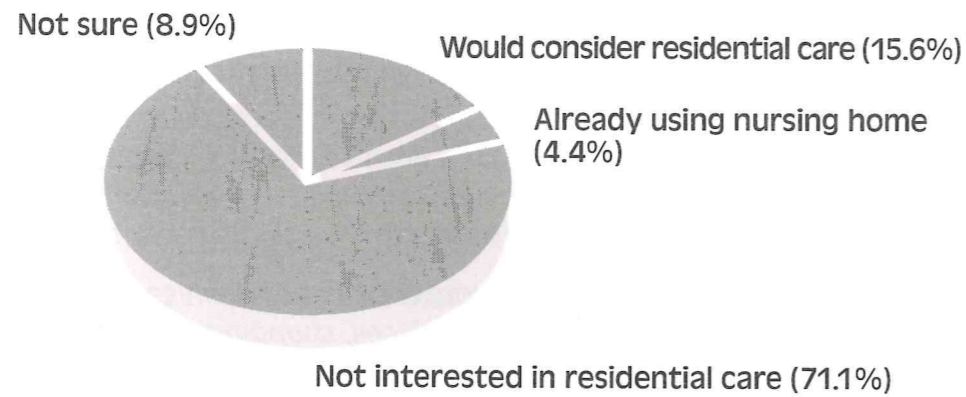
We would like to enjoy life together. We are very happy together.

If I am here, why should she go?

Other responses were that it depended on the person they were looking after and whether the person they were caring for could communicate with others.

Of the 7 carers who reported that they would consider using the service, two said that in the event of their death, the person they were looking after would have to stay in a nursing home. Two other carers responded that they would consider sending the person they were looking after into residential care if their condition worsened.

Figure 10 Interest in Long Term Residential Care



6.5 Voluntary Sector Day Care Provision

This section describes the satisfaction of carers who attended the MILAN and ECESA day care centres as well as of those who did not attend themselves but were looking after older people who did. Satisfaction levels were generally very high for both the day care centres.

8 carers were attending one of the two day care centres together with the person they were looking after. One carer attended the centre alone because his wife was unable to go due to ill health. Of these, 7 were very satisfied with the service provided, mostly for social reasons:

All of my friends are there.

A lot of people of the same age to talk to in my language.

One carer was quite aggravated with some confusion which had arisen which resulted in his benefits being reduced when he had approached one of the organisations for assistance in applying for a grant and this had coloured his view of the day care service. 2 carers had stopped going to the day care centre, 1 because he could not leave his wife who felt too ill to come and the other because of a disagreement with those who were running the centre.

19 carers were looking after older people who attended one of the two day care centres on their own. Of these, 14 were very satisfied with the service provided for the cared for by the centre and 4 were quite satisfied. Carers expressed satisfaction with the day care centres, mostly because of the opportunity it afforded for social interaction for those they were looking after:

They get tired sitting at home. Gives them an opportunity to get out.

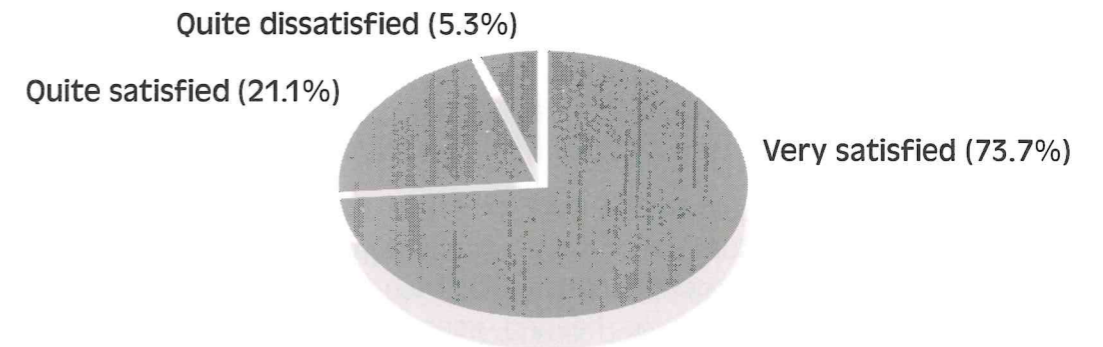
A lot of Chinese people there, someone reads the news out.

One carer expressed dissatisfaction that those attending the day care centre could not easily go to the office for information and felt that those running the service should provide more practical information and assistance to service users, many of whom could not read English. A few carers who were looking after people who attended both day care centres expressed concerns over the food served in the clubs:

The food is not suitable for diabetes, too starchy. Very sweet. People who are starving will eat what is in front of them, send sugar levels rising.

A few other carers expressed disappointment with the lack of transport arrangements which made it difficult or impossible for the people they were looking after to attend the day care centre. 4 of the cared for had stopped going to the centre, one because of a language barrier (she spoke a different language from the others who attended the club), one because she was in mourning, one because she was too ill to go and one because of a disagreement with those who ran the centre.

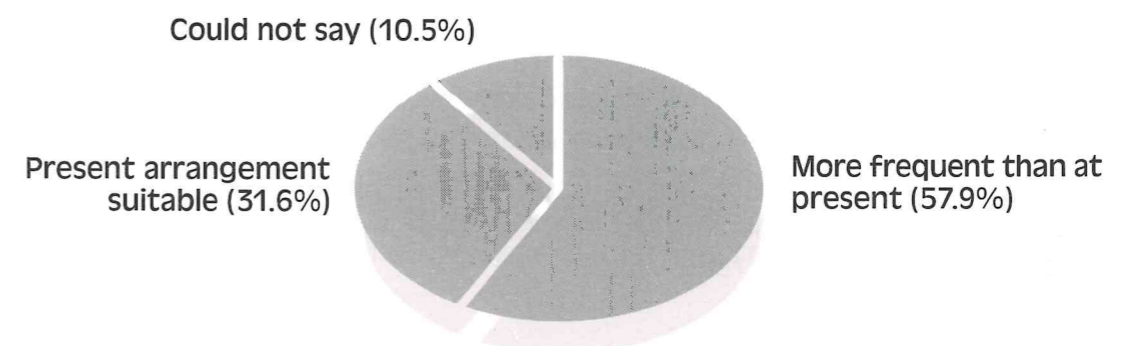
Figure 11 Carers' Satisfaction with Day Care Centre



People generally attended the day care centre once a week, with a few Chinese carers reporting that they, and the people they were looking after, went to the centre less frequently in the winter because it was too cold. Of the 19 carers who were looking after older people who were attending a day care centre, 11 would like the service to be run more frequently than the present weekly arrangement. 6 thought that the present arrangement was sufficient while 1 carer said that it depended on the preference of the person who was using the service. One carer who would like to go more often had concerns about the affordability of the meals and was worried about leaving her husband alone. She added that if she could get someone to be with him, while she was absent, she would then be able to go.

With regard to whether the day care centre hours should be extended, 6 thought that they should while 11 of the 19 carers thought the present length of two to three hours was sufficient. One of those who would like the club hours extended suggested that activities such as music classes or physical education be organised.

Figure 12 Carers' Preference for Frequency of Day Care Service



24.4% of the carers in the sample would like the people they are looking after to attend a day care centre. All those who expressed a desire for the service thought that it was important that at least some members of staff and some users of the day care centre spoke the same language as the person they were looking after. Those who wished the people they were looking after to go to a day care centre expressed concern that the food served should be culturally familiar as well as compatible with the dietary requirements of the person they were looking after:

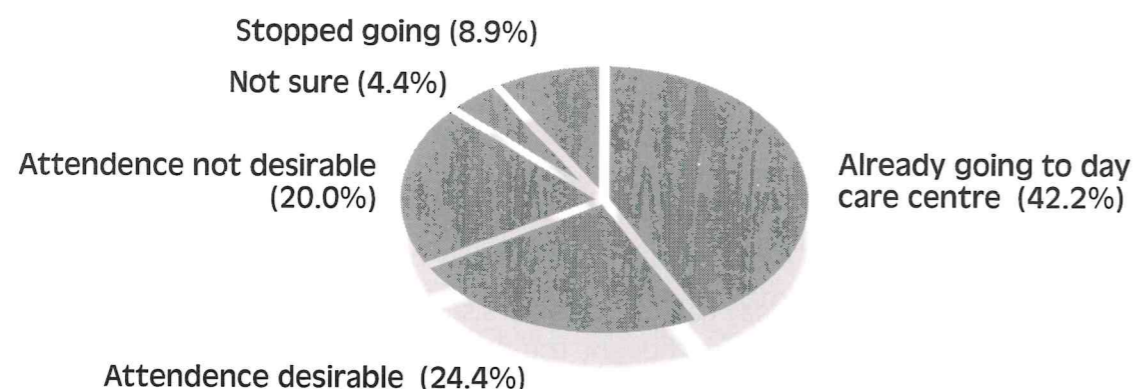
Must have vegetarian food. Should not contain fat because of his heart disease.

Should be Pakistani food and should also be suitable for diabetes.

Many carers who wished the person they were caring for to go to a day care centre also stressed the importance of suitable transport arrangements. Other facilities which carers wished at the centre were accessible toilets, staff who would help the older people to move about if necessary and for some Asian carers, separation between men and women.

9 carers said that they would not like the person they are looking after to attend a day care centre while 4 were not sure. Among the reasons given were an unwillingness on the part of the latter to attend and/or difficulty in using such a service because of health conditions such as incontinence, frailty or hearing impairment. One carer explained that her grandmother-in-law was unable to go out at all due to her mobility difficulties and the location of their flat in an upper tenement.

Figure 13 Carers' Need for Cared For to Attend Day Care Centre



6.6 Other services

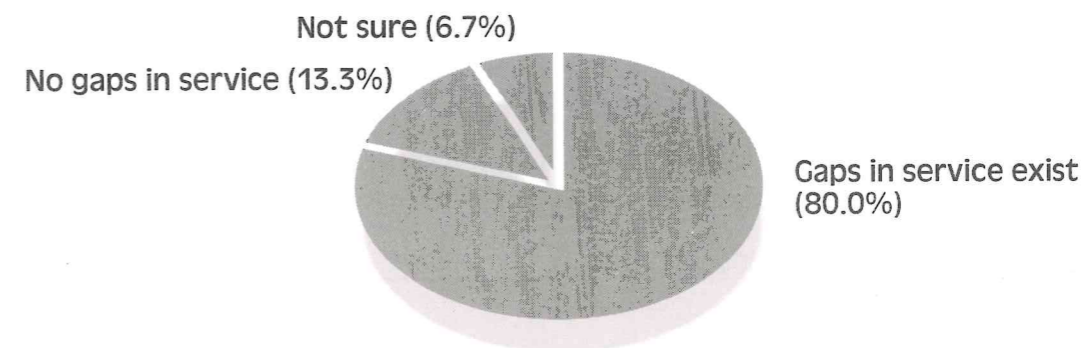
10 carers made use of other services. Of these, 5 used the services of other minority ethnic voluntary organisations and 2 had used mainstream carers' agencies to obtain information and advice. One received help from social work department with picking up her children from school. The other services were a privately employed home help and tuition in English at home.

Four of the cared for made use of other services provided by other minority ethnic voluntary organisations. One, who was Afro-Caribbean, made use of a mainstream voluntary organisation to meet other retired men.

6.7 Gaps in Community Service Provision

80% of the carers felt that there were gaps in service provision which if filled would make it easier for them to care for older people. 3 carers did not know what was available and thus did not feel they could articulate what would make it easier to care for the older person. 6 carers felt that they were receiving all the services they required.

Figure 14 Carers' Perception of Gaps in Services



Among the gaps in service provision cited were currently existing services such as home helps, meals on wheels, befriending schemes, sitter services, bath nurses and physiotherapy. However, carers also expressed a desire for other domiciliary services not currently available. These included someone to take the person out, to give them a massage, and a support worker for themselves who could provide them with information on existing services and how to access them. The need for more financial support to adequately care for someone who was in poor health and housebound was also felt: some of the carers found it difficult to meet the cost of obtaining appropriate food, transport costs to obtain medical support and heating bills

6.8 Contact with Social Work Department

Only about a quarter of the carers interviewed (24.4%) had contact with Social Work Department against the three quarters (73.3%) who had no contact. Among those who had contacted the Department, seven had met with positive responses. These included three who had got home helps and one who had got help with settling a disabled relative into a special school. One had made contact with the Department through a referral from the general practitioner of the person receiving care and had been allocated a place in a nursing home. Another carer was receiving support from the Department in the form of help with the mortgage on her house and part instalment of the car. Yet another, working as a district nurse, described both her experience of receiving support from Social Work Department at the point of sending her mother to a nursing home and her continued contact very positively:

Social worker gave me a list of nursing homes. Worked out the finances. It was easy for me because I know who to go to, what I was asking for, I know the system, so we didn't have any major problems. They visited her at the home a few times, sometimes planned, sometimes unplanned. There were meetings between the social worker, myself and the nurse who is working there. They keep me informed of what's happening to her and how they are dealing with it.

This contrasts with the experience of another carer who received some support after her grandmother had been discharged from hospital but expressed disappointment that it was only for a limited period:

Hospital contacted Social Work Department. They got her equipment, bath chair, bed handles and a high chair. The social worker came out two or three times to see if the equipment was suitable. We didn't have any more contact after that.

Another instance of a carer receiving only limited support may be found in the experiences of a carer who received the services of a home help shortly before the interview with the researcher took place and expressed great satisfaction with her. However, she continued to face difficulty in giving her husband a bath and did not know that she could request for support in this area or that Asian meals on wheels were available.

Another carer, who was looking after both her in-laws and had three young children described her experience thus:

I rang up Social Work Department to find out about getting house extension because it is really crowded after the children come back from school. It would have been great to have a box-room. We haven't heard from them. But (previously) they had got us a wheelchair, sliding doors for the bathroom and a ramp for the house.

Two others who expressed dissatisfaction with the Department recounted their experiences:

A lady came to the house after three weeks. It was a long procedure, many forms. Then a man came and checked, said he would send an estimate. It's 3 or 4 months since then, but we have not heard from them. 4 or 5 times my husband called them, they said they can't decide whether to give it or not (grant for a toilet downstairs)

I tried to get bath aids and a toilet seat for my father-in-law; I got a bottle for urine. Felt they didn't give me enough help at all.

Two other carers had contacted the Department for benefits. One had asked for carers' allowance over the phone but was told he didn't qualify because he was a student while the other was awaiting the outcome of an application.

Among those who had not contacted the Department, 19 did not know what it was:

Don't know. Just getting on with my life. It's only now that I am realising what's on offer, that's why, now that I can see what other people can do for my mum.

Don't speak English, don't know why I should contact them

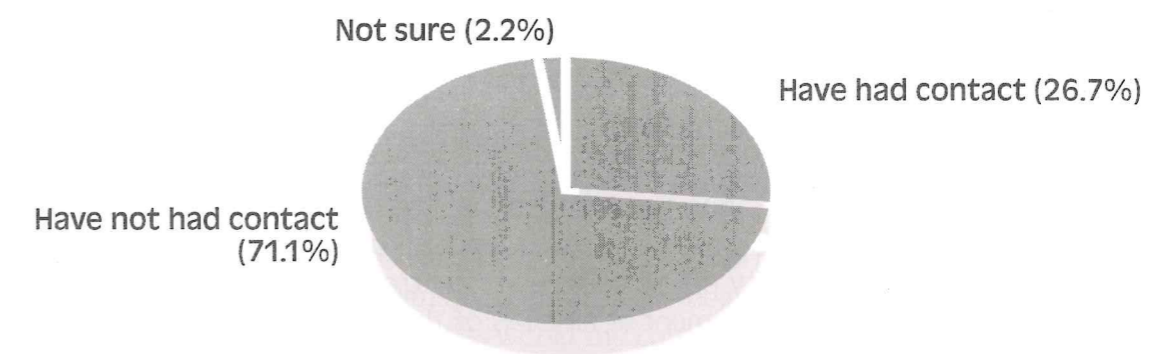
9 carers responded that they did not need the services:

Our needs are not so bad that we have to go down that avenue. Not sure if it's available.

The need hasn't arisen. We sort of manage. Try and manage the best we can.

One carer said that both his sister and brother had contacted the Department without getting any service, so he had not bothered to apply. Three did not explain why they had not been in contact with the Department.

Figure 15 Carers' Contact with Social Work Department



Key findings

- About 70% of the carers did not use any of the services provided by Social Work or voluntary organisations. The main reasons given for not using the services were lack of information on their availability and difficulty in accessing them.
- A small number of carers were using home helps and meals on wheels services or were looking after people living in nursing homes. Satisfaction levels with these services varied.
- About 40% of the carers expressed an interest in using home helps and 20% in using meals on wheels.
- A third of the carers expressed an interest in a sitter service and a quarter in personal care services, including bathing, massage and taking the cared for out of the house.
- Among carers who expressed an interest in domiciliary support, more than two thirds expressed a preference for the person to be of the same sex as the cared for. More than half would like the person to belong to the same ethnic group and about two thirds would like the person to speak the same minority ethnic language.
- 42% of the carers reported that they would use a crisis support service in the event of an emergency.
- About 40% of the carers were looking after people who attended the day care service provided by MILAN and ECESA. Satisfaction levels of these services were generally high.
- Nearly a quarter of the carers expressed a desire for the person they were looking after to attend a day care centre.
- Other services which carers and the people they were looking after used were mainly provided by minority ethnic voluntary organisations.
- 80% of the carers felt that there were gaps in service provision, which if filled, would make the task of caring easier.
- Only a quarter of the carers had been in contact with Social Work department.

Discussion

The study clearly shows that the current low uptake of social work and community services cannot be attributed to lack of interest or need on the part of minority ethnic carers. Instead, the evidence demonstrates that many minority ethnic carers do not know about existing services and have difficulty accessing them. This is similar to the findings of other studies on minority ethnic carers (Sage and Sangavi, 1992; McCalman, 1990). In order to narrow the gap between current unmet need and service uptake, a pro-active stance by Social Work Department is clearly required. This may take a variety of forms: translation of available services in the relevant minority ethnic languages, the dissemination of appropriate promotional material demonstrating the willingness of the Department to serve the multi-racial population in which it is based, outreach work through minority ethnic voluntary organisations and other minority ethnic community centres and the active recruitment of minority ethnic people for employment at all levels of the Department.

Investigations into the provision of social work services to minority ethnic people has often been conceptualised in terms of knowledge and use and has rarely considered the quality of the services delivered (Atkins and Rollings, 1993). The findings in this study with regard to service provision are thus worth noting because it suggests that many of the services currently available are not suitable to the needs of minority ethnic carers or of the people they look after. With regard to domiciliary support, minority ethnic carers have clear preferences for service delivery related to the gender, ethnicity and ability of those in contact with the people they are caring for to speak the same language. They also wish the cared for to receive appropriate food. Some of these preferences have already been taken on board by the City of Edinburgh Social Work Department in their recruitment of home helps from minority ethnic communities and the availability of culturally familiar food in the meals on wheels service. These are laudable steps in the right direction and should be emulated by the other Social Work Departments in the Lothians, if they are not already in place. It is important that these measures to make services ethnically sensitive are extended to other services such as sitter services, personal care services and residential care. In order to increase service uptake, it is also vital that the current ethnically sensitive services are widely publicised in the minority ethnic communities as many of the carers in this study were unaware of their availability.

However, the findings suggest that further fine-tuning of the services is required. With regard to the home help service, the evidence suggests that in deciding the duties which home helps may be reasonably expected to undertake for minority ethnic older people, some consideration should be given towards relieving the burden of the large percentage of carers who live with them and provide continuous care for them. Turning to the meals on wheels service, we have seen that although it is important that food is culturally appropriate, it is also essential to the carer that it is nutritionally suitable for the person receiving care.

The evidence in the study also shows that thus far, most of the available services are targeted towards the older people in the minority ethnic communities. Although the importance of services such as meals on wheels, home helps, lunch club and day care provision in supporting carers indirectly cannot be under-estimated and some of the older carers may themselves directly benefit from these services, a gap in service provision to carers clearly exists. In particular, none of the carers in this study were familiar with, or had experienced any form of service which offered them a break from caring. This lack of knowledge of respite services among minority ethnic carers has also been documented in other studies (Cole, 1990; McCalman, 1990). The importance of appropriate respite care

provision should clearly not be under-estimated in the light of the evidence in Section 5.3 which shows the inability of a substantial proportion of minority ethnic carers to take time off from caring. One form of respite which the evidence suggests is likely to be attractive to the minority ethnic carer is the provision of domiciliary sitter services by staff who are able to speak the language of the cared for. Other initiatives in this area should consider the provision of culturally sensitive residential respite care for minority ethnic groups either in separate locations or as part of the services offered by selected existing centres.

The ability to meet specific requirements may partly contribute to the relatively high uptake of services provided by MILAN and ECESA. Both agencies are staffed by people from within the Chinese and Asian communities respectively, who speak the languages spoken by the people in the communities which they serve. Both organisations have premises which are located in areas which are densely populated by their target service users and operate pro-actively to promote their activities within the community. Both offer food which is culturally familiar as well as arrange transport to facilitate attendance. Both organisations also organise talks on topics of interest, such as health-related matters, as well as English classes. At MILAN, the practice of gender separation among some communities is respected by the presence of a screen which divides the hall in two while at ECESA, certain items of news and forthcoming events are always read out in Chinese. Both organisations thus provide service-users with opportunities for social interaction and participation in activities which are likely to be useful and of interest within a safe and familiar setting.

The important role that voluntary organisations like MILAN and ECESA play in their communities extend beyond direct service provision. Both agencies also provide practical information and offer guidance in the areas of benefit rights and access to mainstream services. This latter function is particularly valuable in the light of the low level of awareness of the role of the Social Work Department among many minority ethnic people and the current lack of preparedness of many mainstream organisations to cope with their needs. In addition, staff in these organisations play an important role in raising the awareness of white service providers and mainstream agencies to the specific needs of minority ethnic carers, and where necessary, challenge examples of bad practice.

However, judging from service users' comments, both organisations could improve current service provision in two respects. The first is in the important area of transport provision: not all those who would like to attend the day care centres are currently doing so because of the lack of adequate transport. This applies not only to those who live within Edinburgh but also those who live outside the city. The second area is in the suitability of the food which is provided to those who attend the day care centres: many have expressed concern that although the food is culturally appropriate, it is sometimes not suitable for those who are in poor health. Both clubs may benefit from consultation with dieticians.

It is clear that these, and other minority ethnic voluntary organisations should be adequately supported in the continued provision and expansion of their services. Support may include financial support, resource provision, the provision of suitable premises for service expansion and staff development and training. Improved collaboration between minority ethnic organisations and mainstream organisations such as Social Work Department and other voluntary organisations is also necessary in order to increase the uptake of both services specifically targeted to the minority ethnic communities as well as appropriate mainstream services.

While this study shows that the vast majority of minority ethnic carers look after older people within a domestic setting, the importance of planning for care to be provided within

an institutional setting should not be under-estimated. It would be misleading to use the current numbers of people who are receiving residential care as indicators of demand for these services. On the contrary, the fact that a small number of minority ethnic people are using mainstream services which are not culturally familiar to them and which have not been designed to meet their needs points to the potential demand for ethnically sensitive services. Service providers need look no further than the popular day care services and the full-occupancy rates of the sheltered housing project for the elderly Chinese in Cathay Court for concrete evidence that minority ethnic carers and the people they look after will use non-traditional services if their social and cultural needs are taken into account in the planning of such services.

Thus far, we have considered the low uptake of existing services and how these may be tailored to meet the cultural requirements of minority ethnic carers. However, consideration should also be given to the provision of new services which are in line with the preferences stated by carers in this study. One such service would take older people out of their homes to places of interest and/or accompany them to obtain medical services. This service could be offered either in small groups or an individual basis. Other carers requested financial support to adequately carry out the task of caring while others expressed an interest in services such as aromatherapy and massage for the people they are looking after.

Recommendations

The four Social Work Departments in Edinburgh and the Lothians should build on established race equality strategies to:

1. Consult with minority ethnic carers:
 - to ensure that existing services, in particular home helps and meals on wheels are appropriate, accessible and responsive to religious customs, dietary needs and personal requirements (Section 6.2.1 and 6.2.2).
 - to develop a sitter service which will be flexible to their respite needs (Section 6.2.3).
 - to develop personal care services which are sensitive to their cultural requirements (Section 6.2.4).
 - to increase day care provision and develop residential services which take into account the expressed preferences of carers that the people they look after are able to communicate with staff and other users and receive the food that they are accustomed to (Section 6.5, 7.6.3, 7.7.1 and 7.7.2).
2. Collaborate with minority ethnic and mainstream voluntary organisations to undertake outreach work to establish contact with isolated minority ethnic carers (Section 6.1 and 6.8)
3. Set targets to increase the employment:
 - of minority ethnic people at all levels, particularly in the areas of service planning, community care assessments and the provision of services of a personal nature. Positive action programmes should be developed to meet these targets (Section 7.6.2 and 7.6.3)

- of minority ethnic staff providing domiciliary support, taking into account the expressed preference of a substantial proportion of minority ethnic carers that domiciliary support staff be as the same gender and ethnicity of the people they provide care to and that they speak the same language (Section 6.3).
4. Support ECESA and MILAN in their day care provision and associated transport arrangements for minority ethnic carers and the people they look after through a commitment to adequate long-term funding (Section 6.5)

Lothian Health should work collaboratively with the four Social Work Departments in Edinburgh and the Lothians to:

1. Develop an adequate and appropriate crisis support mechanism by consultation with minority ethnic carers (Section 5.4 and 6.4.1).
2. Develop and provide a programme of training with VOCAL to existing community organisations already serving Edinburgh and Lothians' minority ethnic populations to. This would
 - raise awareness of carer issues, encourage a holistic approach to client assessment and develop an effective referral system for specialist advice/information on carers' issues and needs (Section 6.1).
3. Investigate the feasibility of establishing a jointly funded post of Minority Ethnic Carer Worker. This post could act as a catalyst for operational and policy development within the unitary authorities, ensuring that minority ethnic carers needs are recognised and integrated within mainstream services. Specifically, this would
 - act as a focal point for minority ethnic carers' issues, provide opportunities for enhanced consultation with carers to develop, monitor and evaluate both existing and new services and ensure more effective dissemination of information (Section 6.1).

Organisations in the voluntary sector should:

1. Regularly assess and monitor the extent to which their services are accessed and used by minority ethnic carers and the people they look after.
2. Take positive action and measures to develop services appropriate to the needs of minority ethnic carers by outreach work and pro-active contact.
3. Ensure equal opportunities policies are in place and regularly monitored with regard to employment, staff training and education on all aspects of equality.
4. Ensure that all conditions of grant in terms of service agreements or purchasing agreements are fully complied with, particularly in relation to the needs of minority ethnic carers.
5. Work in conjunction with Lothian Health and the four Social Work Departments in Edinburgh and the Lothians to ensure a coordinated approach towards the development of appropriate services for minority ethnic carers.

7. Knowledge and Use of Health Services

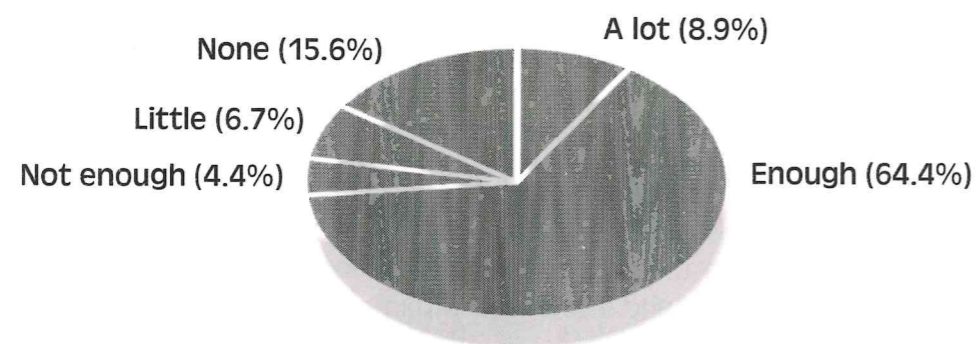
"He (general practitioner) is not aloof. He listens to her even when he doesn't understand."

This section begins by considering carers' perception of their knowledge of the condition of the people they are tending. It then goes on to consider carers' knowledge of, use and satisfaction with available health services. It ends by describing their preferences for service delivery.

7.1 Carers' Perception of Own Knowledge of Condition of Cared for

Nearly two thirds of the carers (64.4%) felt that they had sufficient knowledge of the condition of the cared for. Just over a quarter (26.7%) felt that they had either not enough, little or no knowledge of the illness of the person.

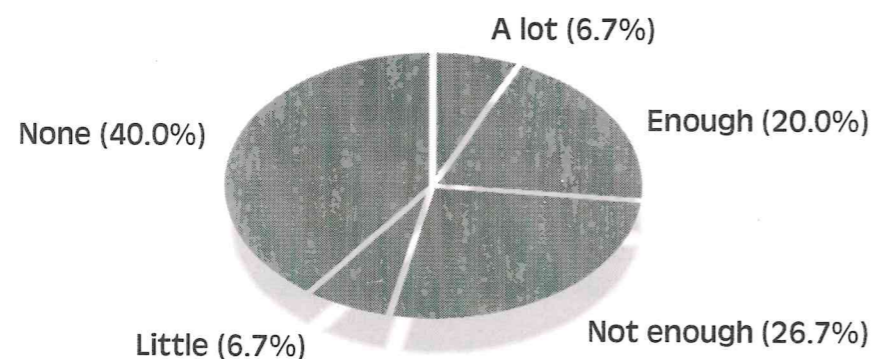
Figure 1: Knowledge of Cared For's Condition



7.2 Carers' Knowledge of Health Service

Slightly more than a quarter of the carers (26.7%) felt that they had either a lot of information or enough information about available health services. This contrasts with 33.4% of carers who felt that they had little or not enough information and 40% who have no information at all on the health services available.

Figure 2: Information about Health Services



7.3 Use and Satisfaction level of Health Services

This section describes the use of the health services by the cared for and the satisfaction of the carer with these services.

7.3.1 General Practitioner

93.3% of the carers were looking after at least one older person who had seen a general practitioner in the last year. Of these, 35.6% of the carers were very satisfied with the general practitioner and 44.4% were quite satisfied. Among the reasons carers gave for being satisfied were the level of care with which the general practitioner treated people, his/her familiarity with the condition of the person, willingness to make house visits in the case of the physically disabled and overall interest and helpfulness:

She's very nice, explains everything. She checks properly, she listens properly. The whole family goes to her, she is more than a doctor.

He has been looking after her a long time, he knows all about her.

He always makes home visits, he's been coming for 25 years, he talks to him very nicely.

2 carers attributed their satisfaction to the fact that the general practitioner was able to speak the same language as the patient. One of them said:

He's an Indian doctor. Makes a big difference in communicating problems.

4 carers highlighted communication problems despite being either very satisfied or quite satisfied with the general practitioner:

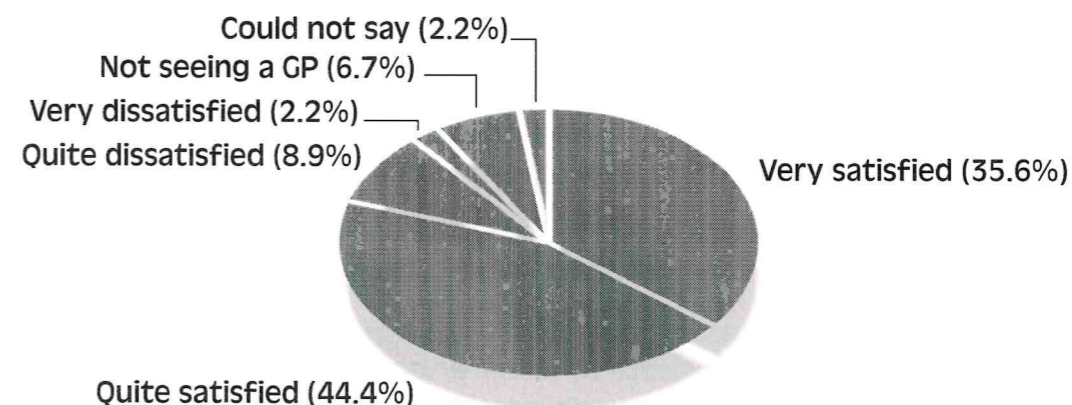
She's happy with him, he's not aloof. He listens to her even when he doesn't understand.

4 carers were quite dissatisfied with the service provided by the general practitioner and 1 was very dissatisfied. Among the reasons given were the following:

I expected more information on what was available, what sort of quality of life she could expect, he just prescribed medicines for her.

She hasn't had any check-ups for two years, no angiograms or blood tests. The doctor at the outpatient clinic had carried out tests for her and referred her to the GP for future tests.

Figure 3: Satisfaction with General Practitioner



7.3.2 Outpatient Department

Of the 22 carers who were looking after older people who had been to an outpatient department in the last year, 5 were very satisfied while 12 were quite satisfied. Among the reasons given for being satisfied with the service were:

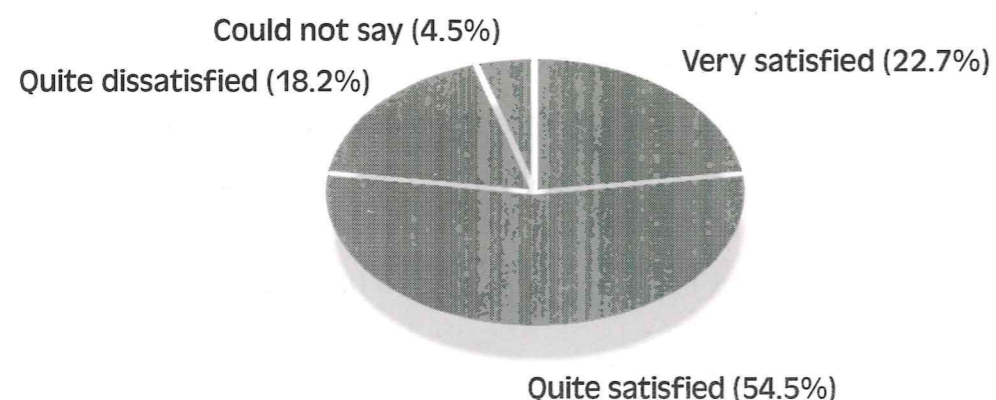
Really helpful doctors and nurses, they give you all the information you need.

There's a taxi service to take her there and back.

We are dealt with promptly.

The doctor speaks my language.

Figure 4: Satisfaction with Outpatient Department



4 carers were quite dissatisfied and 1 was unable to say. Among the reasons given for dissatisfaction were the lack of language support:

They phone home when they find out she can't speak English.

One carer, working as a staff nurse, said that it was difficult to evaluate the service because she felt that professionals tended to follow lines of enquiry which were based on racial stereotypes:

As soon as people see you, they start stereotyping the disease you might have. They ask you whether you come from South of the Sahara or North of the Sahara. If you say you come from the South, you can see the fright in their eyes (at the haematology clinic).

7.3.3 Day Hospitals

Only 2 of the cared for had attended a day hospital. Both were mainstream centres and their experiences provide an interesting contrast:

She enjoyed it although she was the only Asian. There was a doctor available there, we could communicate by letter or phone without going in. Staff tried to help with interpreting, so did passing doctors and nurses.

The health visitor suggested the day hospital. He went for 6 or 7 months once a week and then stopped. Language barrier, also there were very old people there, other people who were ill, he felt depressed.

It is noteworthy that both older people were open to attending a mainstream service despite the inability to communicate in English, although in one case, this eventually contributed to him discontinuing attendance. Both accounts illustrate the importance of supportive, understanding staff in maximising access to mainstream services and in making them appropriate. They also point to the potential demand for the service among people in the minority ethnic community.

As discussed in Section 6.1.5, although day care provision was unfamiliar to most carers, almost a quarter of the carers (24.4%) responded positively to a service which provided care during the day for the people they were looking after.

7.3.4 Community Nursing

13 carers (28.9% of the sample) were looking after older people who were using at least one other service, in addition to the general practitioner and the day hospital. These included chiropody, occupational therapy, physiotherapy, psychiatric community nursing and the services of health visitors and a minority ethnic mental health worker. Only one carer was looking after someone who received the services of a bath nurse. Of these carers, 8 carers were very satisfied with the services which the cared for received while 5 were quite satisfied. Among the reasons given for satisfaction with the service were:

I got a lot of information from her (minority ethnic mental health worker) ... She leads us to other people, gives me a lot of information, she can build up a life for us.

She (physiotherapist) is understanding, she would try to communicate with her in spite of language problems.

These comments say much about the value placed by carers on home visits by appropriate professionals as well as the information and support gained over time through an on-going relationship.

7.4 Hospital Admission and Discharge

19 carers (42.2% of the sample) were looking after older people who had been admitted into hospital in the last year. At the point of discharge, 5 of these carers received a lot of information and support and another 5 received enough information and support. In contrast, 9 carers received either little or no information and support at the point of discharge. One carer said she got a lot of information but no support.

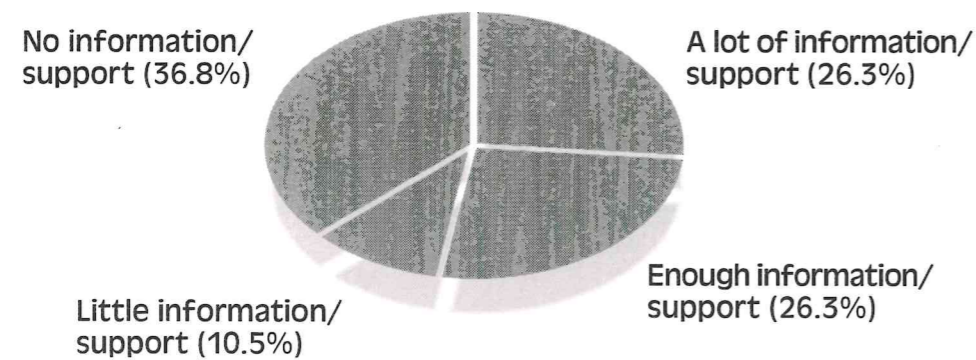
When asked what kind of information and support they would have liked to have received, carers said they would have liked:

More information on diet, how much exercise to do. We need communication in our own language, we can't read leaflets.

Someone to visit father.

Someone to take her out two or three times in her wheelchair.

Figure 5: Hospital Discharge Arrangements

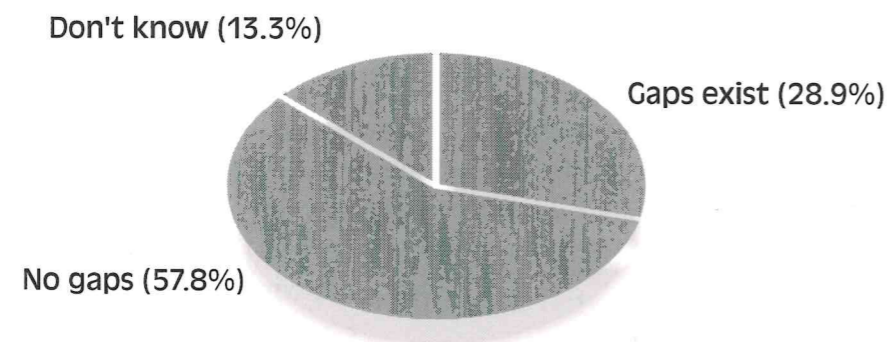


7.5 Gaps in Medical Support

As shown in Figure 6, more than half of the carers (57.8%) did not feel there that were any gaps in the medical support of the people they were looking after. Among these, one carer explained that she got a lot of support from the general practitioner. Another mentioned the support she received from a health visitor and a third explained that her mother was receiving alternative medicine and aromatherapy from a minority ethnic voluntary organisation.

13 carers (28.9%) felt that there were gaps in service provision which if filled, would help them care for the older person. Among these, 4 would like someone to visit the person they were looking after in their homes. Other services which carers thought would be beneficial included assistance with getting aids and adaptations, access to interpreting services, physiotherapy, massage, the administration of certain medical tests and financial help with the provision of a special diet. Significantly, 6 carers said that they did not know about health services which were available and thus could not answer this question.

Figure 6: Perceived Gaps in Medical Support



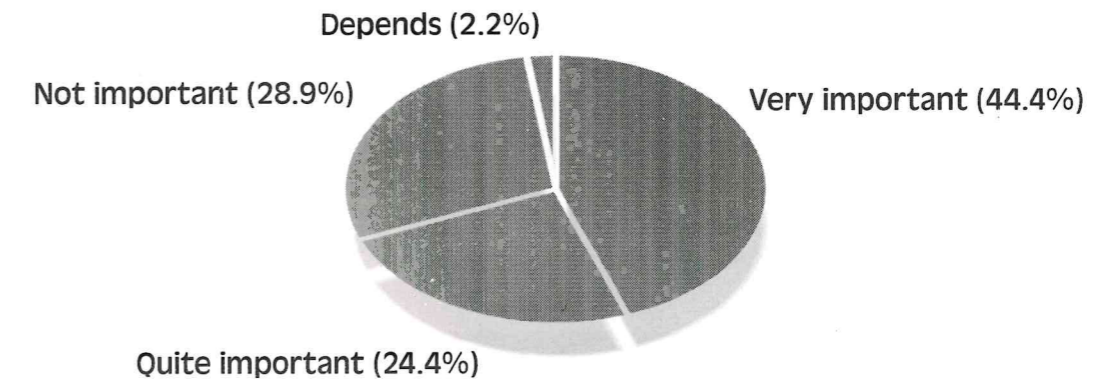
7.6 Preferences for Service Delivery

This section reports the importance that carers assigned to the gender and ethnicity of the professionals providing treatment and/or support. It also describes the importance placed by carers on the ability of professionals to speak the language of the cared for.

7.6.1 Gender

44.4% of the carers felt that it was very important for professionals to be the same gender as the person they were looking after, 24.4% quite important and 28.9% not important. One carer said that if the professional was male, the arrangement would be acceptable if his mother knew the person in question.

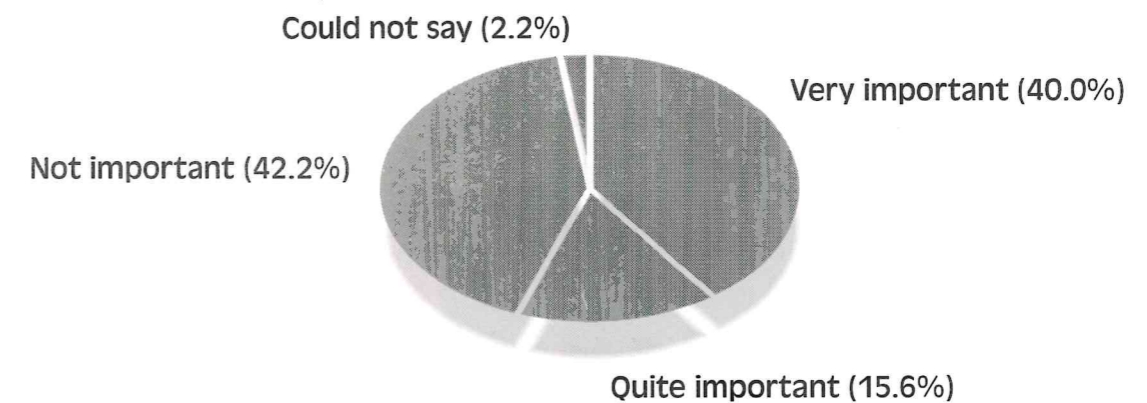
Figure 7: Gender of Professional



7.6.2 Ethnicity

Almost the same proportion of carers felt that it was very important for professionals to belong to the same ethnic group (40.0%) as those who felt that it was not important (42.2%). 15.6% felt that it was quite important. Many carers expressed their preference for the professional to belong to the same ethnic group in connection with the ability to communicate in the same language. One carer said that it was only important in relation to whether or not there was an interpreter present: if there was an interpreter present, it was not important.

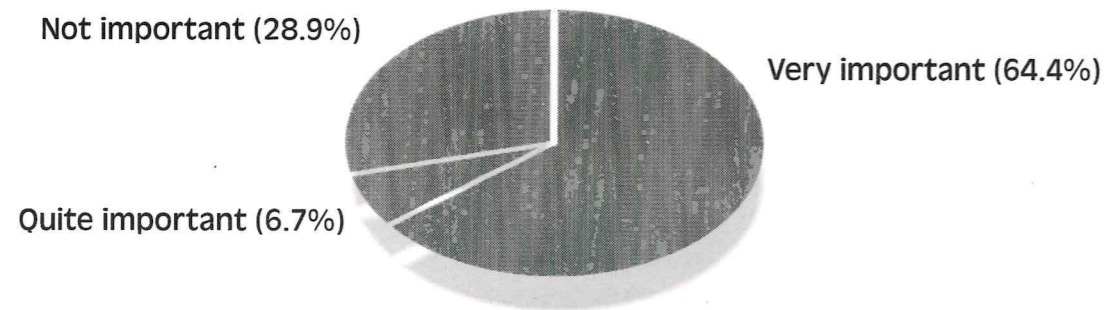
Figure 8: Ethnicity of Professionals



7.6.3 Ability to speak the language of the cared for

64.4% of the carers felt that it was very important for professionals to speak the same language as the cared for while 28.9% felt that it not important. Among the 13 carers who said that it was not important, 5 said that this was because they could speak English, 5 said that the people they were looking after could speak English while 2 said that someone else who could speak English would usually be around. One carer said it depended on whether an interpreter was available.

Figure 9: Language Ability of Professionals



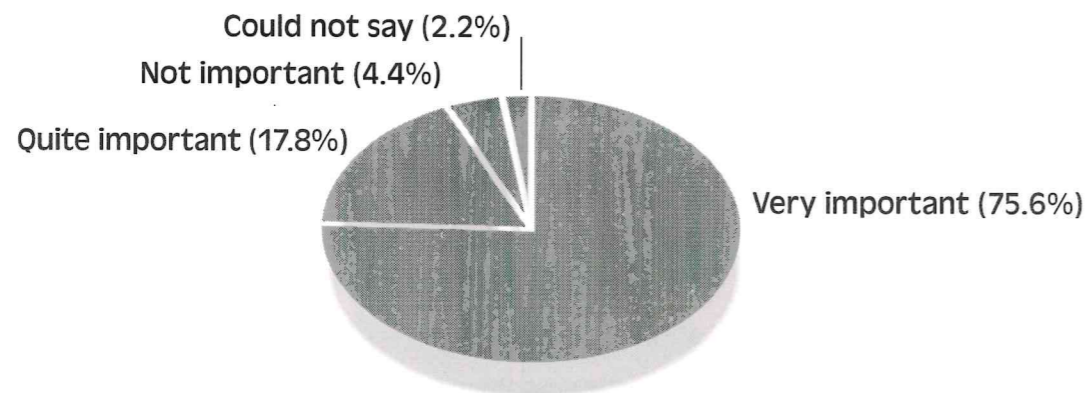
7.7 Preferences for service delivery for the cared for outside the home

This section considers the importance which carers assign to the cared for receiving the type of food she or he is accustomed to and the importance of their being in contact with people from the same ethnic group when outside the home. This has implications for placement of minority ethnic people in day hospitals, long-stay wards and nursing homes.

7.7.1 Cared for's Access to Usual Food

About three quarters (75.6%) of the carers felt that it was very important that the cared for receive the type of food that they were accustomed to while 17.8% felt that it was quite important. Only 2 thought that it was not important.

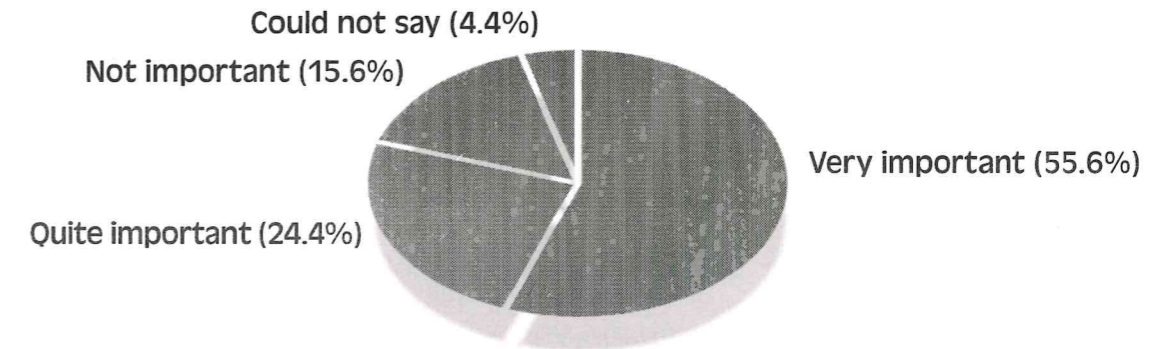
Figure 10: Cared For's Access to Usual Food



7.7.2 Contact with other people from the same ethnic group

More than half of the carers (55.6%) felt that it was very important for the person they were looking after to be with others from the same ethnic group when they were not at home. 24.4% felt that it was quite important. 7 carers felt that it was not important. One said that the older person she was looking after did not like to have social contact with anybody and another said that it depended on the older person.

Figure 11: Contact With Others of Same Ethnicity



Key findings

- About two thirds of the carers felt they knew a lot about the health of the cared for.
- Only a quarter felt they had enough knowledge of the health services available.
- Most carers are satisfied with the services of the general practitioner and the outpatient department.
- Less than 30% of the carers have received community nursing services but those who have are satisfied with them.
- Only half of the carers looking after older people who have been recently discharged from hospital received sufficient information and support.
- More than two thirds of the carers felt that it was important that the people they were looking after were in contact with professionals of the same gender and who spoke the same language.
- More than half of the carers considered it important that the professional who was in contact with the person they were looking after was from the same minority ethnic group.
- Most carers felt that it was important that the people they were looking after receive the type of food that they were accustomed to.
- Four fifths of the carers considered it important that the people they were looking after were in social contact with people from their own ethnic group when they were outside the home.

Discussion

Of all the health services available, the general practitioner is probably the first port of call when carers and those who they look after are confronted with health problems. Certainly, this study found that almost all of the cared for were in touch with a general practitioner. One of the most striking findings of this part of the study was the high level of satisfaction which most carers felt with the services received from the general practitioner. Judging from the comments made, this satisfaction may be attributed to the high degree of professionalism and care with which patients were treated.

However, it is also noteworthy that 39% of all carers in the sample acted as interpreters when the person they were looking after were seeing a doctor (see section 5.1). The use of carers for this purpose places an additional responsibility on them and necessitates their presence at appointments, often requiring those who are working to take time off from work:

She does not get language support, the doctor does not arrange for an interpreter so I have to leave work to go.

It is also an infringement of the patient's right to confidentiality and denies him/her a professional and impartial service. Guidance associated with implementing the NHS and Community Care Act and *Access to Health Care by the Ethnic Minorities: A Guide to Good Practice* emphasises the importance of using interpreting services where appropriate in providing an equitable service to patients from a minority ethnic background. Interestingly, a recent study of primary health care provision for elderly people in minority ethnic communities also found considerable dissatisfaction with the use of family members as interpreters among general practitioners (Pharoah, 1995).

Significantly, when asked how important it was to them that professionals should be able to speak the language of the person they were looking after, nearly two thirds of the carers said that it was very important while most of the remainder explained that either they or the person they were looking after were able to speak English. Effective communication with the general practitioner is not only important in terms of the quality of the consultation with the person being cared for but also in connection with referrals to other services. The latter is particularly important when we consider the low awareness of available health services among minority ethnic people (40% of the carers felt that they had no knowledge at all about health services). The onus then, must be on health staff to undergo adequate training in working with interpreters and to make provisions for interpreting where this is required. This applies not only to general practitioners but to all health professionals whose work brings them into contact with non-English speaking minority ethnic people.

The low level of awareness of existing services suggests that minority ethnic carers are not tapping into the full benefits of community nursing. This is supported by the finding in the current study that only 29% of the carers were using community nursing services. Responses from those who have received such services clearly show that they have benefited from advice, practical help, referrals to other agencies and increased awareness of available services. Many of the responses also indicate that the opportunity which community nursing provides for a personal rapport to be created on an individual basis outside of an institutional setting is a particularly beneficial and supportive one.

It is also worth noting that 29% of the carers felt that there were gaps in service provision which, if filled, would enable them to provide better care for the person they are looking after. This in itself may not arouse concern but if it is weighed in the light of the other finding that a substantial proportion of minority ethnic carers felt that they have no knowledge of available health services, then it is difficult not to come to the conclusion that they are insufficiently equipped with the required knowledge to identify gaps in medical support. Indeed, this view is supported by the carers who replied that they could not answer this question without knowing the range of available services.

One important mechanism which would help ensure that carers receive sufficient support within the home is in the area of discharge arrangements for those who have been admitted to hospital. Only half of the carers in this study felt that they had received sufficient

information and support on discharge to enable them to adequately care for the person in their homes. Again, the need for language support to allow effective communication is particularly important. Any arrangements made for post-discharge support for the patient and the carer should also consider the domestic circumstances of minority ethnic carers, particularly those with young children or others to care for, in addition to the older person. The level of support should be tailored to the needs of the individual patient and carer: where the older person is heavily dependent on their carer and/or they have a long term disability, it is important that adequate arrangements are made with both Social Work Department and with community nursing. Although this would constitute good practice for all discharged patients who are likely thereafter to be reliant on informal care, it may be argued that this is especially important in the case of minority ethnic people and their carers since these groups are much less likely to independently access community nursing services and the services provided by the Social Work Department (See discussion in Section 6.6)

Health promotion staff too have an important role to play in raising the awareness of minority ethnic carers and ensuring that they have access to available services. In this respect, the involvement of bilingual staff has often been advocated (Baxter, Poonia, Ward and Nadirshaw, 1990; Begum, 1992; Bhatnagar and Ineson, 1994). Although the terminology which has been used to refer to such staff has been varied, for example, community health educators, health liaison workers, link workers etc., their perceived role shares many similarities. Briefly, it has been suggested that the presence of bilingual staff would be beneficial for the minority ethnic communities: they would play an important role in facilitating access to health services by minority ethnic people, act as advocates when required and make referrals to other health professionals. In addition to reducing inequalities in health service access, such workers would also be in a position to provide informed input into the planning and purchasing of specialised services for minority ethnic groups and for the development of other appropriate initiatives by health staff in meeting the particular needs of these groups. It is interesting to note that an initial evaluation of a recent initiative by Greater Glasgow Health Board to employ community health educators to provide information on cancer, cancer screening and diabetes for Asian and Chinese women has been very positive (SEMUR, 1995).

Another initiative which would support minority ethnic carers in caring for older people in their homes would be an increase in the number of community nurses from multi-cultural backgrounds. This view is supported by the finding in this study that more than half of the minority ethnic carers felt that it was important for professionals to belong to the same ethnic group. This finding may be closely linked to the desire to communicate effectively, but it may also be argued that community nurses from the same cultural background would have a better appreciation of some of the psychological aspects involved in providing care to an older person within a minority ethnic setting, such as the power dynamics within the family structure and the pressure to conform to cultural norms.

It should also be noted that more than two thirds of the carers felt that it was very important for professionals to belong to the same gender. In practical terms, this points to the need for staff to elicit and take into account the preference of the patient with regard to the preferred gender of the doctor/nurse. This is particularly important where there is a possibility that the professional and the

patient may be of different genders and may reduce unnecessary discomfort and embarrassment on the part of the patient.

Turning now to the importance which carers assign to the food provided for those in their care, we note that almost all the carers felt that it was important that the cared for receive the food they are accustomed to. Many carers spoke of having to bring food into the hospital because the food served was not suitable. The key requirements are for compliance with the cultural and religious requirements of users, such as the provision of halal food or vegetarian food. However, carers have also expressed the importance of food being suitable for the health condition of the person they are looking after. Thus, in order to meet the dietary requirements of older people in the minority ethnic communities, sufficient care must be taken to ensure food provision is planned to meet cultural and religious requirements and is nutritionally appropriate for older people.

The finding that four fifths of the carers felt that it was important that the people being looked after should be in contact with other people who belonged to the same ethnic background has obvious implications for the appropriate placement of minority ethnic older people in day hospitals and long-stay wards in hospital. It strongly suggests that where possible, they should be placed so that they have social contact with other users from the same minority ethnic background. Such placement would ease the alienation which many older people would feel in being the only minority ethnic person among white users or users from other minority ethnic groups who neither speak the same language nor share the same culture. The evidence suggests that if services took account of this preference, minority ethnic carers and the people they look after would be much more likely to use them.

Recommendations

Lothian Health should build on measures to increase race equality by:

1. Setting standards for patient record systems which clearly identify ethnic minority origin and any related requirements, particularly the need for language support (Section 7.3.1 and 7.6.3).
2. Establishing mechanisms with appropriate community organisations to ensure that minority ethnic carers are consulted in the planning and development of health services.
3. Providing a training programme
 - a) For staff to:
 - Increase awareness of race and cultural issues and the specific minority ethnic needs highlighted in this report (Section 7.6 and 7.7).
 - Work effectively with interpreters (Section 7.6.3).
 - b) For interpreters in key areas such as doctor-patient consultation and hospital discharge arrangements (Section 7.4).
4. Establishing the development of bilingual health liaison workers as part of an information strategy to facilitate the access of health services to minority ethnic people, act as advocates when required and make referrals where necessary (Section 7.2, 7.6.2 and 7.6.3).

5. Devising a strategy to improve the placement of minority ethnic people in day hospitals and long-stay wards taking into account their preference to be in contact with other users from the same minority ethnic group (Section 7.7.2).
6. Ensuring that minority ethnic patients receive food that complies with their health, religious and cultural requirements and provide confirmation to their carers (Section 7.7.1).
7. Establishing an on-going system to monitor the satisfaction of minority ethnic carers and the people they look after, regularly review policy and indicate to all staff where changes in service planning, purchasing and delivery are required.

Lothian Health should work collaboratively with the four Social Work Departments in Edinburgh and the Lothians to:

1. Develop an information strategy for minority ethnic carers which effectively publicises the services and forms of support which are available, including the interpreting service (Section 7.2).
2. Improve the arrangements at the point of hospital discharge for information provision and support and for liaison between community nursing and social workers (Section 7.4).

8. Other Essential Forms of Support

"We don't get any information. Nothing, we never filled the form."

This chapter considers the need for other essential forms of support for carers which include the need for information, carer support groups, equipment, financial assistance and suitable housing.

8.1 Availability of Information

This section describes where carers currently get information and their need for more information. It then considers where carers would like to see information and the form in which they would like information disseminated to them.

8.1.1 Where carers get information

Asked where they get information which helps them with their caring responsibilities, more than a quarter of the carers (26.7%) reported that they did not receive any information at all:

Nowhere, don't know where to get it.

Other carers described a variety of sources which are given in Table 1. 5 carers mentioned more than one source. Of the sources of information carers had recourse to, the most common were minority ethnic voluntary organisations such as MILAN and ECESA and through friends. Another of the more common sources of information was the general practitioner and/or the surgery, with two mentioning a district nurse and a health visitor. Other sources of information were community leaders, the media, leaflets and the library. Two carers had been in touch with mainstream organisations such as the Family Advice and Information Resource (FAIR) and VOCAL and one with the Advisory Bureau. Two carers who were nurses had the benefit of professional knowledge. Only one carer mentioned the Social Work department.

Table 1: Where carers get information

	No
Minority ethnic voluntary organisations	6
General practitioner/surgery	6
Friends	6
Community leaders	4
Media	3
Library/leaflets	3
Hospital	2
Mainstream organisations	2
Professional knowledge	2
Social Work Department	1

8.1.2 Carers' Need for information on financial assistance and services

As Figures 1-3 show, more than three quarters of the carers expressed a need for more information on financial benefits that they may be entitled to, services provided by Social Work Department and health services.

Figure 1: Need for Information on Benefits

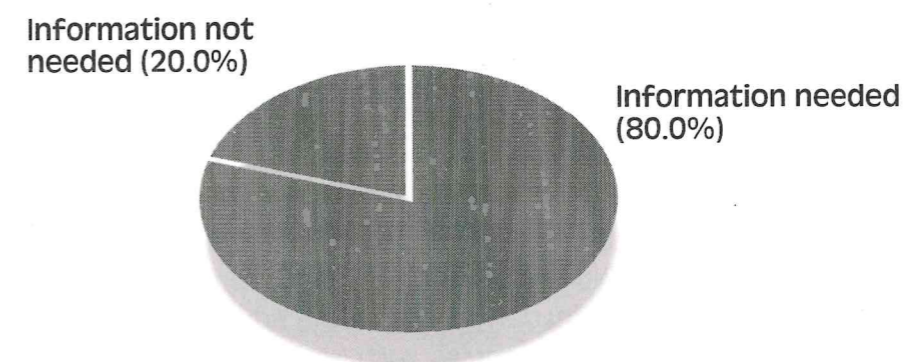


Figure 2: Need for Information on Social Work Department

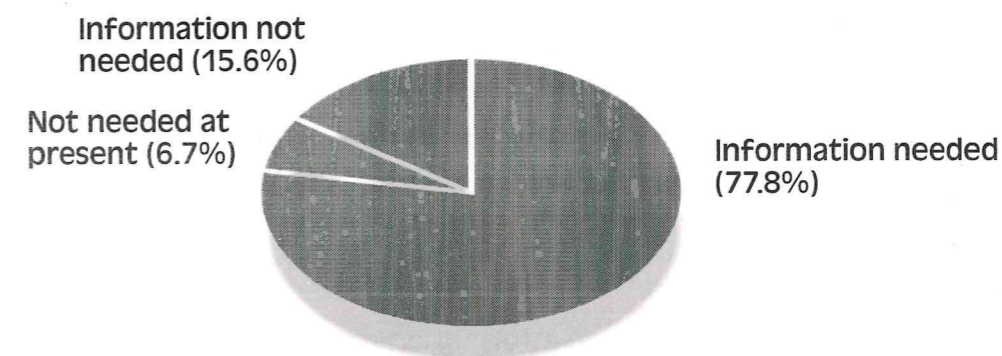
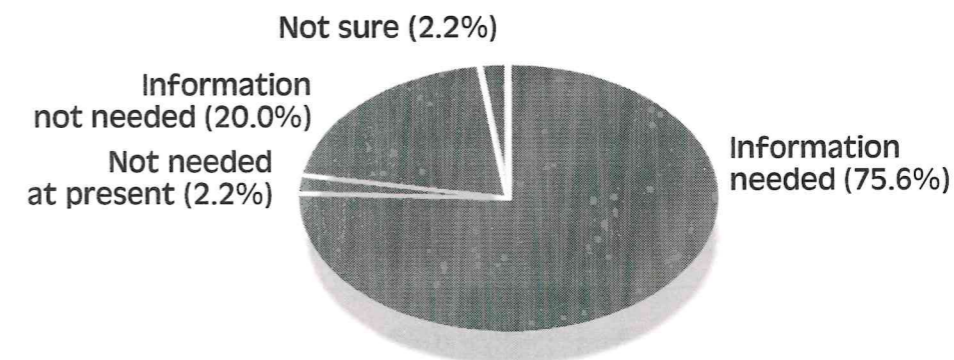


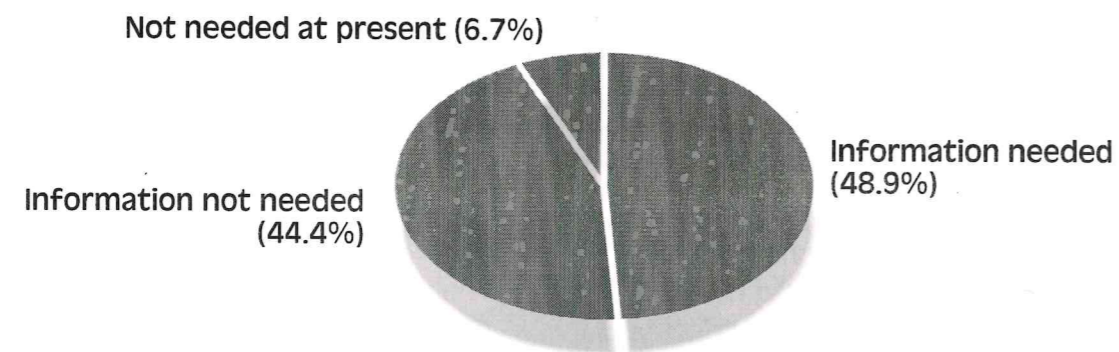
Figure 3: Need for Information on Health Services



8.1.3 Carers' Need for information on practical tasks

Nearly half of the carers (48.9%) would like information on practical tasks such as lifting techniques.

Figure 4: Need for Practical Information



8.1.4 Where carers would like to see information

91.1% of the carers would like at least one of the above kinds of information. These carers suggested a number of places in which information could be made available to them: 48.8% of the carers would like to have information posted to the house. Other places that carers commonly requested were community centres such as MILAN and ECESA, the doctor's surgery and religious centres. A few carers suggested more than one place.

Table 2: Where carers would like to see information

	No	Percentage
religious centre	3	6.7
community centre	8	17.8
post to the house	22	48.8
doctor's surgery	8	17.8
other	8	17.8

8.1.5 Forms in which carers would like to see information available

56.1% of carers who would like to have more information would like written information in English while 46.3% would like to have written information in the mother tongue. 5 carers expressed a desire for information to be available in forms which would be accessible to them as well as to the person they were looking after, most commonly in the form of leaflets in English and the mother tongue. One carer said that an effective form of disseminating information would be through talks given at community centres such as MILAN and ECESA. Some carers would like to see information available in more than one form.

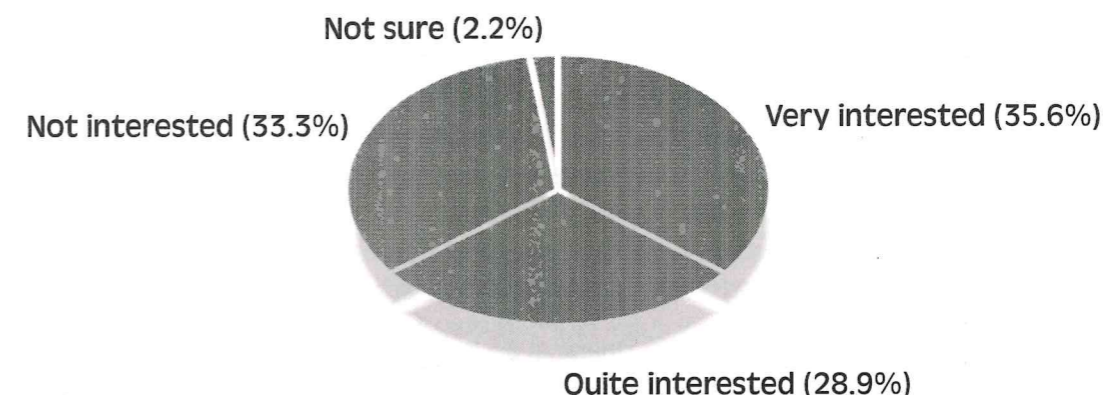
Table 3: Forms in which carers would like to see information available

	No	Percentage
Leaflets in English	23	56.1
Leaflets in mother tongue	19	46.3
Audio cassette in mother tongue	3	7.3
Videotape in English	2	4.9
Videotape in mother tongue	4	9.8
other	1	2.4

8.2 Interest in Carer Support groups

35.6% of the carers were very interested in meeting with other carers to exchange information and support, 28.9% quite interested and 33.3% not interested.

Figure 5 Carers' Interest in Carer Support Groups



Of the carers who were interested in meeting with other carers, 7 would require the services of a sitter while they attended meetings.

8.3 Need for Equipment

64.4% of the carers felt that the older person they were looking after was not in need of any equipment either because they already possessed what was required or because their condition did not require its use. More than a third of the carers (35.6%) do not have equipment which would make caring for the older person easier for a variety of reasons. As Table 4 shows, one of the main reasons is a lack of knowledge of what is available, what type of equipment to get or how to get it. One carer asked the researcher how she could get a walking stick for her mother and another how she could get a wheelchair. Often, there is not a single factor but a few factors which combine to hinder the carer from getting what is required, for example, the equipment being too expensive and the carer not knowing if the cared for is entitled to it and if so, who to contact. One carer expressed dissatisfaction over the poor quality of the hearing aid which her mother had received from the hospital and said that her highest priority was to save enough money to buy her a more effective hearing aid.

Table 4: Reasons for lack of useful equipment

	No
Didn't know it was available	3
Don't know what type	4
Don't know how to get it	5
Too expensive	4
Other	8

8.4 Financial Assistance to Carers

42.2% of the carers reported that they had sought financial assistance for their caring responsibilities while 57.8% had not. Of the 19 who had sought financial assistance, 10 had succeeded in obtaining it, 5 had failed to obtain it while 3 were awaiting the outcome of an application.

Organisations which facilitated successful applications included MILAN, ECESA, the Benefits Agency and the Advisory Bureau. One carer had obtained £500 for heating, bed and clothing during a financial crisis with the help of a health visitor. Carers were often not clear what they had received but in a few cases offered to show the researcher written notification. Other benefits which carers received for themselves and/or those they were caring for included Invalid Care Allowance, Disability Living Allowance, housing benefits, a budgeting loan, attendance allowance and income support. A few carers said that they had only received these forms of financial assistance after years of caring.

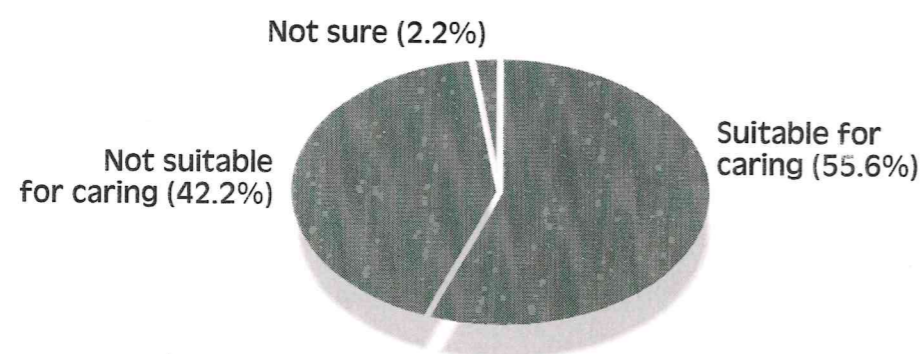
Among those who had failed to receive the financial assistance they had sought were three carers who had contacted Social Work department for extensions to the house. Two others who also did not get the assistance they sought were someone whose mother had not qualified for disability living allowance and a carer who had not obtained a carer's allowance because he was a student. One carer said that she would have liked to study but was afraid of losing her carers' allowance and income support.

8.5 Suitability of housing conditions for caring

Half of the carers (53.3%) felt that the house that the cared for was living in either with or without them was suitable for their caring responsibilities. Among those satisfied with the housing conditions were 6 carers who lived in the Cathay Court sheltered housing project with the people they were looking after. Among the reasons given for being satisfied with the scheme were the suitable size of the apartments, adequate heating and the presence of the warden in the event of emergencies. One carer in his seventies who was looking after his mother who was more than 100 years old also expressed satisfaction at being able to live next door to his mother while still maintaining his privacy.

Also among those who felt that the cared for were living in suitable accommodation was a carer whose mother had difficulty in walking and was living in a first floor flat in council housing. Her mother had originally been allocated a ground floor flat but this proved unsuitable as she was racially harassed by children in the neighbourhood. She felt that her mother was better off on a first floor flat because it was less accessible to the children who had been harassing her.

Figure 6: Suitability of Housing Conditions



42.2% felt that the accommodation was not suitable for caring for the older person. 11 felt that they would have to move while the remainder felt that home adaptations were required. Of those who felt they would have to move, 6 carers faced difficulty in looking after older people who had difficulty getting into and out of apartments which were not on the ground floor, and in some cases up several flights of stairs. This lack of access seriously inhibited the ability of carers to take the people they were looking after out, as well the ability of the older people to go out by themselves. The effect of this was virtual imprisonment of the older person in many cases, and the carer who felt that s/he was unable to go out without him/her.

For the remaining 5 carers who felt that they would have to move, 3 cited overcrowding in the present accommodation and problems with going up and down stairs. The remaining 2 carers were looking after people in spacious accommodation. Of these, one carer felt the house was too big for her father who lived by himself. The other carer felt although the house that she and her mother-in-law lived in with the rest of the extended family had two rooms downstairs, one of which could have been used by her mother-in-law, these were needed to maintain segregation between the sexes when receiving both male and female visitors.

The remaining 9 carers required adaptations to be made. Of these, 4 required an extra toilet to be made downstairs to make it easier for the older person to access and because of problems with continence. 3 required an extra room downstairs for the person they were looking after. Among these carers, was a woman whose husband had not seen their upstairs bedroom for 6 years. She herself had been sleeping with her husband in the lounge of their house in that time because he needed to be looked after at night. Another carer explained that when male visitors came to the house she could go into the kitchen but her mother-in-law had no other place to go but upstairs, which she found difficult to do.

Other adaptations which were required by carers for the people they were looking after were an entry door phone, light switches and cupboards at lower levels, a ramp to facilitate access into a ground floor flat and a shower to be added to an existing bathroom. Two carers had problems with heating: one lived in a flat without central heating while the other had difficulty paying his heating bills.

Key findings

- More than a quarter of the carers reported that they did not receive any information at all.
- Over three quarters of the carers requested information on financial assistance they may be entitled to, social work services and health services.
- More than half of the carers requested information to be posted directly to the house.
- Nearly half of the carers would like information printed in their mother tongue.
- Nearly two thirds of the carers were either very interested or quite interested in meeting other carers to exchange information and support.
- More than a third of the carers felt that they lacked equipment which would lighten the task of caring.
- Just over 40% of the carers had sought financial assistance for caring.
- Nearly half of the carers felt that the house they were living in was not suitable for caring.

Discussion

Minority ethnic carers, like white carers, clearly have a need for information which would enable them to provide adequate care. Asked where they got information from, many of them cited their general practitioner, friends and minority ethnic agencies, including MILAN and ECESA. Significantly, more than three quarters of the carers expressed a need for more information on financial benefits which they may be entitled to, services provided by Social Work Department and health services. This desire for more information would suggest that carers do not feel that they have enough information on benefits and services which would make caring easier. About half of the carers in the sample expressed a preference for information to be posted directly to the house. This is not surprising given the isolation and lack of freedom experienced by many carers and is also indicative of a strong desire for information. Other places where carers expressed a desire for more information were their general practitioner's surgery and community centres such as MILAN and ECESA, suggesting their current reliance on these sources of information.

Asked about the form in which they would like to see information available, more than half of the carers expressed a desire for written information in English, reflecting the finding that about half of the carers were able to speak English. Nearly half expressed a desire for written information in their mother tongue. A small number of carers expressed a desire for more information in the form of audio cassettes and videotapes in the mother tongue, probably reflecting an inability to read as well as a need for visual representation of the services on offer. This suggests the need for a strategy for disseminating information takes into account the diversity of languages which carers speak, their literacy rates and their lack of familiarity with existing services.

The desire for more information and support may form part of the motivation for joining carer support groups, in which a third of carers were very interested and another third quite interested. This finding shows that minority ethnic carers share with many white carers the desire to meet with other carers to share experiences, exchange information and support. Part of this information may well include practical tasks, such as lifting techniques, which nearly half the carers would like information on. The demand for minority ethnic carer support groups is attested by the popularity of the support groups for Asian and Chinese carers of children with learning difficulties in the MELD (Minority Ethnic Learning Disability) project in Lothian and by the growth of other carer support groups elsewhere (Baxter et al 1990; Yee, 1995). The finding that some carers who were interested in attending meetings reported that they would require sitter services also points to the need for respite services.

Difficulties in accessing services also apply in the area of obtaining appropriate equipment, with more than a third of the carers in the current study (35.6%) reporting that they lacked equipment which would lighten the task of caring. Barriers which prevent them from getting the equipment include lack of knowledge of what is available, what type of equipment to get, how to get it and the cost of such equipment. This applies to even the most common forms of equipment, such as walking sticks and wheelchairs, which would obviously improve the quality of life of both the carer and the person receiving care. Much of the equipment which has been obtained has been through referral from the general practitioner or through Social Work Department after hospital discharge. It is clear that much more proactive work has to be done in this area if minority ethnic people are to be supported in their caring role through the use of appropriate equipment.

Minority ethnic carers also face difficulties in obtaining financial assistance when they require it. The present study revealed that 42% of carers had sought financial assistance for

their caring responsibilities. It is worth noting that many of these carers had used the services of minority ethnic voluntary organisations such as MILAN and ECESA to facilitate access to benefits. However, in spite of the substantial costs incurred in providing special diets, heating and transport for medical services, some carers had failed to obtain this assistance when they required it, notably those who had applied for grants for house extensions. The frustration which results from the inability to obtain carers' allowance while studying full-time is also one which many minority ethnic carers are likely to share with white carers.

Carers of older people from minority ethnic backgrounds, like other carers, would like the people they are looking after to be suitably housed: they would like for them to live in housing which is affordable, easy to access and move around in, has adequate space and heating and is adapted to meet the needs of their physical or mental disabilities. Nearly half of the carers in the current study did not feel that the housing conditions of the people they were looking after were suitable for caring for them. The study shows that in addition to the housing needs of white carers, minority ethnic carers have other needs, such as the need to protect the people they are caring for against racial harassment. Other housing needs may be attributed to their particular culture, such as washing and bathing habits and the need to maintain segregation between the sexes outside of the family. Minority ethnic carers' preference for the person they are looking after to be in social contact with people from the same minority ethnic group may also impact on their housing needs.

An important factor which has to be considered when considering the housing needs of minority ethnic carers of older people is the likelihood that minority ethnic-headed households live in poorer than average housing: they are more likely to live in overcrowded conditions (the 1991 Census figures for Scotland show that minority ethnic households are 11 times more likely to be living in crowded residences than the white majority) and to lack basic amenities. At least part of the overcrowded conditions may be attributed to the higher likelihood of minority ethnic carers living with the older people they are providing care to. Further, minority ethnic people often face difficulty in applying for housing due to lack of familiarity with the system and language barriers. This would indicate that this particular group of carers and the people they look after may be particularly in need of support in accessing suitable housing or arranging for the present accommodation to be adapted.

Seen in this context, the sheltered housing scheme for elderly Chinese at Cathay Court is an example of good practice in meeting the needs of a particular community. Apart from providing warm, adequate accommodation for older Chinese people, it also provides them with a safe and familiar social environment. It is also worth noting that the carers in this sample who lived in Cathay Court had all benefited from domiciliary support in some form. This may be accounted for by their access to existing services through information which they had obtained from each other, the warden and staff from ECESA. The evidence in this study on carers who live in the sheltered housing project bears testimony to the acknowledgement by the White Paper Caring for People (Department of Health, 1989) that housing is a vital component of community care and is often the key to independent living (para 3.5.1).

Recommendations:**Social Work Department should:**

1. Facilitate the establishment of carer support groups for minority ethnic carers of older people (Section 8.2).

Lothian Health should work collaboratively with the four Social Work Departments in Edinburgh and the Lothians to:

1. Develop an information strategy for minority ethnic carers which
 - ensures that they and the people they look after receive the financial assistance that they are entitled to (Section 8.1 and 8.4)
 - effectively publicises the services and forms of support which are available, including the availability of the interpreting service (Section 8.1)
 - takes into account the diversity of minority ethnic languages, the literacy rates of minority ethnic carers and their expressed preferences for information dissemination (Section 8.1.3 and 8.1.4).
2. Develop a strategy ensuring that minority ethnic people and their carers who require appropriate aids, adaptations and equipment are supported in accessing them (Section 8.3).
3. Collaborate with housing authorities in developing a strategy for housing frail and disabled minority ethnic people and their carers (Section 8.5)

9. Focus Group Discussions with Asian and Chinese Carers

This section gives an account of the arrangements which were made to conduct the Asian and Chinese carer groups and reports the discussions. It also evaluates the focus groups in the light of the objectives which were outlined in Section 2.5.8 and considers the contribution of the discussions to the research findings described in the preceding chapters.

9.1 Preliminary arrangements

The researcher liaised with representatives from Pilmeny Development Project and ECESA to set up convenient times, dates and venues for the focus groups for Asian and Chinese carers respectively. The Asian carers met at Lorne Social Work Centre which was close to the MILAN premises while the Chinese carers met at the sheltered housing project at Cathay Court in which some of them lived.

Carers were informed about the purpose of the meeting and those who were able to come and interested in attending were asked if they required sitter services. 5 Chinese carers required sitter services and this was arranged by paying ECESA volunteers to act as sitters. A few Asian carers felt uncertain about taking taxis on their own so a minibus driven by an Asian driver who was already known to a few of them was arranged to pick them up from their homes. Arrangements were also made for appropriate refreshments to be provided and for carers to be reimbursed for travelling expenses.

9.2 Attendance at the focus groups

7 carers attended the Asian carers' focus group. The focus group for Chinese carers was attended by 8 carers, 7 of whom had been participated in the survey and 1 who had heard about it by word of mouth and who expressed interest in being present. One carer had to leave after the first half of the discussion to prepare and take food to his mother who had been admitted into hospital since appropriate food was not available.

9.3 Language Support

Both groups required different language support arrangements. In the focus group for Chinese carers, only one carer in the group was able to speak English. To allow the discussion to proceed largely uninterrupted in Chinese, the services of two interpreters were used. The researcher addressed the group through one interpreter who also kept the group focused while the second interpreter kept the researcher informed of the ongoing discussion.

The Asian carers focus group was more varied in their linguistic abilities: a few carers spoke English fluently in addition to speaking Punjabi or Urdu. Others were Punjabi or Urdu-speaking and varied in their ability to understand English. The meeting was thus conducted in a mixture of these languages, with the English-speaking carers intermittently switching to Punjabi or Urdu, the latter two languages being mutually intelligible. Two interpreters were also present for this group. The researcher led the meeting with the assistance of one interpreter who translated the researchers' English into Urdu and translated the Punjabi or Urdu contributions from the group into English for the researcher. The second interpreter facilitated the discussion by translating any English contributions into Punjabi for the benefit of those who were not English-speaking.

9.4 Focus Group Discussion

Discussion in the focus group concentrated on: experience of current services; interest in using other services; contact with the Social Work Department; hospital discharge arrangements; information dissemination; financial assistance and the future development of carer support groups.



Asian Carers sharing experiences and exchanging information

9.4.1 Home Help Service

Satisfaction among those who were receiving the home help service varied from those who were very satisfied to those who were so dissatisfied that they had stopped the service. Those who were satisfied with the service said that the tasks were well-performed while those who were dissatisfied complained about the lack of adherence to specific times and limitations in the range of tasks which the help would perform.

9.4.2 Meals on wheels

Many of the Chinese carers present had experienced the meals-on wheels service and had discontinued it because they found it lacked taste and it contained too much monosodium glutamate. In contrast, Asian carers were not familiar with the service and requested information on the service.

9.4.3 Day Care Centres

Carers who attended the day care centre were generally satisfied with the opportunity afforded for social interaction. Chinese carers showed an interest in the provision of transport particularly in winter but were concerned that they would have to pay for it. Asian carers felt that the provision of transport was crucial for attendance at the day care centre and that they would not be able to attend without it.

9.4.4 Respite Services

Carers in both groups were not using any respite services and responded enthusiastically to the prospect of using services which would afford them a break from caring. Both groups wanted to know about the form such services would take and were told this could include both sitter services as well as residential care for those they were looking after.

9.4.5 Interpreting Services

Carers in both groups emphasised the importance of interpreting services, particularly those who were not able to count on family members to interpret for them. The Chinese

elderly who lived in the sheltered housing project in Cathay Court had arrangements with interpreters made for them by the warden for medical appointments. The only Chinese carer present who was able to speak English said she was heavily burdened by requests from her mothers' friends to interpret for them. An English-speaking Asian carer reported that she was forced to interpret for her mother-in-law at the doctor's although she did not personally want to be there. Carers who had used interpreting services for medical appointments complained that it was not always possible to arrange them for the times when it was required. None of the carers seemed to be aware that it was the responsibility of medical staff to ensure the presence of an interpreter when necessary.

9.4.6 Other Services

Asked whether there were any other forms of external support they would like to receive, some Asian carers requested help with transport for medical appointments. One Chinese carer suggested trips to places of interest to relieve the monotony of caring while another suggested help with getting prescribed medicines from the chemist.

9.4.7 Contact with Social Work Department

None of the Chinese carers knew about the role of Social Work Department or had been in contact with them although some of them had experienced services provided by them, such as meals on wheels or the home help service. This was because these services had been accessed for them either through ECESA or the warden at the sheltered housing project. In contrast, some of the Asian carers were familiar with the role of the Department and a few had directly contacted the Department for services such as home helps and applications for grants for extensions to the home.



Taking a break ...Chinese Carers and group facilitators share views over refreshments

9.4.8 Hospital Discharge Arrangements

Carers in both groups were looking after people who had been admitted into hospital in the last year. Asked whether they had received enough information and support at the point of discharge, responses varied. Those who responded positively were asked about the kind of information they had received and replied that they had been informed about future appointments. None of the carers in either group had been visited at home or referred to anyone else. Asked whether interpreters had been present at the point of discharge, carers in both groups responded negatively. One carer said:

It would have been good to know what they had done to her and whether the operation was successful.

The same carer complained that she had been forced to administer insulin injections herself although she was uncertain how to do this because she could not get anyone to come to the house. At least two Asian carers felt that the perception among hospital staff was that they had supportive extended families and did not require any help:

They say you have big families, everyone is going to help you, so you don't need help. But in many cases, the Asian families keep their head down.

9.4.9 Information Dissemination

Opinion varied as to preferred forms of information dissemination in the two groups. Some Chinese carers expressed a strong preference for information in Chinese to be posted to the house. Some Asian carers too expressed a desire for written information in the mother tongue. However, carers in both groups said that this would be of limited value due to illiteracy. Other forms in which information could be disseminated could be either through videotapes or through word of mouth.

9.4.10 Financial Assistance

Chinese carers who were receiving benefits had accessed them through ECESA. One carer reported that he had only come to know about his right to Invalid Care Allowance (ICA) when he was interviewed for the project. Some carers expressed uncertainty about what they were currently receiving and what they were entitled to. Asian carers were told that they could come to either MILAN or Pilmeny for help with completing and sending off forms.

9.4.11 Future Development of Carer Support Groups

Both focus groups showed considerable potential for development into future carer support groups: carers spontaneously shared information on their caring experiences and exchanged information on the problems they were currently facing as well as strategies which they had used to overcome particular difficulties. Participants from both groups responded enthusiastically to the idea of carer support groups and suggested activities such as talks by professionals on health and services provided by the Social Work Department and trips to places of interest.

9.5 Evaluation of the Focus Groups in relation to other findings

It was felt that both focus groups were successful in fulfilling the objectives for which they had been organised. Firstly, research findings from the individual interviews on certain key areas were validated. Secondly, more information was obtained for service planners and providers in areas in which it had been requested, namely on service use and hospital discharge arrangements. Thirdly, a consensus of opinion was obtained in some areas from carers who had been previously interviewed individually. This was valuable for the testing of some of the recommendations for their appropriateness in terms of the needs of two groups of carers. Finally, the seeds for the development of two future carer support groups were sown.

Additionally, the focus group discussion revealed interesting differences between the two groups of carers which were related to service use, their contact with Social Work Department and the need for language support. Importantly, it was also felt that carers in both focus groups had benefited from obtaining an increased awareness of their rights to external support and more information on the services which were currently available.

10. Conclusions

"It's only now that I am realising what's on offer...only now that I can see what other people can do for my mum"

The study clearly shows an area of unmet need among minority ethnic carers of older people. This is likely to increase as the current relatively young minority ethnic population ages unless measures are taken to address them. As in other studies of a similar nature which have been carried out elsewhere in the country, this study demonstrates a low awareness of existing services among minority ethnic carers as well as the inaccessibility and inappropriateness of current service provision to these carers' needs. Worthy of special attention is the lack of services which are specifically targeted towards the minority ethnic carer, including the availability of suitable respite services.

Insofar as their particular needs have not been identified and thus not accommodated in the planning and provision of services, these carers have suffered the effects of indirect racial discrimination. The study provides evidence of preferences of service delivery which clearly highlight the limitations of the 'colour-blind' approach. It is clearly important that Lothian Health and the four Social Work Departments in Edinburgh and the Lothians build on measures to meet these requirements, taking into account the gaps in service provision which have been revealed. Service providers may also be guided by the expressed preferences of minority ethnic carers in tailoring existing services to meet specific needs. The importance of designing services which take into account such preferences should not be under-estimated in the light of evidence which shows that minority ethnic carers discontinue services which they need should these prove inappropriate to their requirements.

While the needs of minority ethnic carers, like those of carers in general, are closely linked to those of the people they look after, it is important that they are considered in their own right, an opportunity which is legitimised by the passing of the Carers Recognition and Services Act. As with other carers, some of their needs may coincide with those of the cared for while others may be in direct conflict. Sensitively designed and conducted community care assessments would be alert to the potential for both consensus and divergence in service requirements between these two groups of users.

Furthermore, assessments should be carried out in full awareness of existing race equality strategies and cultural pluralism. This may be facilitated by prioritising increased service uptake among minority ethnic carers and the people they tend to, conducting staff training programmes in racial awareness and increasing the recruitment of people from these ethnic origins. However, conducting thorough assessments of need are in themselves futile unless there is also a whole-hearted commitment to providing culturally sensitive services.

Although much may be achieved at little or no cost through increased awareness and sensitivity among staff, the provision of certain required services is likely to involve additional expenditure. In the face of limited resources, ultimately, the extent to which the needs of minority ethnic carers and the people they tend to are prioritised in the political agenda will depend on the extent to which the communities they belong to are recognised and prioritised in community care policies.

The recent approach to needs-led services in community care is an opportunity which should not be missed to provide appropriate services to minority ethnic carers and the people they care for as well as ensuring that existing services are attuned to their particular cultural requirements. Many aspects of community care policy potentially facilitate sensitive

provision to minority ethnic people: the split between purchaser and provider functions of the health and social work departments and the enabling role of the latter create the opportunity to contract culturally sensitive services, while the emphasis on consultation in planning services could also ensure that appropriate and accessible services are designed for minority ethnic carers and the people they care for. It is hoped that Joint planners in Lothian will continue to build on measures to increase race equality by seriously considering the recommendations which follow.

Summary of Recommendations

The four Social Work Departments in Edinburgh and the Lothians should build on established race equality strategies to:

1. Consult with minority ethnic carers:
 - to ensure that existing services, in particular home helps and meals on wheels are appropriate, accessible and responsive to religious customs, dietary needs and personal requirements (Section 6.2.1 and 6.2.2).
 - to develop a sitter service which will be flexible to their respite needs (Section 6.2.3).
 - to develop personal care services which are sensitive to their cultural requirements (Section 6.2.4).
 - to increase day care provision and develop residential services which take into account the expressed preference need of carers that the people they look after are able to communicate with staff and other users and receive the food that they are accustomed to (Sections 6.5, 7.6.3, 7.7.1 and 7.7.2).
2. Develop and provide training:
 - a) To community care assessors
 - to assist them in the consideration of the ethnic origin of carers, their age, gender, the languages they speak, the number of young children they have, their health and their financial circumstances (Section 3.1-3.9).
 - to alert them to the particular difficulties experienced by minority ethnic older people and their reliance on informal care (Section 4.4, 4.8 and 4.9)
 - in working effectively with interpreters (Section 3.4 and 5.1).
 - b) To interpreters in key areas such as community care assessments (Section 3.4 and 5.1).
3. Set targets to increase the employment:
 - of minority ethnic people at all levels, particularly in the areas of service planning, community care assessments and the provision of services of a personal nature. Positive action programmes should be developed to meet these targets (Section 7.6.2 and 7.6.3)
 - of minority ethnic staff providing domiciliary support, taking into account the expressed preference of a substantial proportion of minority ethnic carers that domiciliary support staff be of the same gender and ethnicity as the people they provide care to and that they speak the same language (Section 6.4).
4. Provide support to minority ethnic carers by:
 - Supporting ECESA and MILAN in their day care provision and associated transport arrangements for minority ethnic carers and the people they look after through a commitment to adequate long term funding (Section 6.5).

- Facilitating the establishment of carer support groups for minority ethnic carers of older people (Section 8.2).
5. Collaborate with minority ethnic and mainstream voluntary organisations to undertake outreach work to establish contact with isolated minority ethnic carers (Section 6.1 and 6.8)
 6. Regularly review policy and indicate to all staff where changes in service planning, purchasing and delivery with respect to the needs of minority ethnic carers are required.

Lothian Health should build on measures to increase race equality by:

1. Setting standards for patient record systems which clearly identify ethnic minority origin and any related requirements, particularly the need for language support (Section 5.1, 7.3.1 and 7.6.3).
2. Establishing mechanisms with appropriate community organisations to ensure that minority ethnic carers are consulted in the planning and development of health services.
3. Providing a training programme
 - a) For staff to:
 - Increase awareness of race and cultural issues and the specific minority ethnic needs highlighted in this report (Section 7.6 and 7.7).
 - Work effectively with interpreters (Section 5.1 and 7.6.3).
 - b) For interpreters in key areas such as doctor-patient consultation and hospital discharge arrangements (Section 7.4).
4. Establishing the development of bilingual health liaison workers as part of an information strategy to facilitate the access of health services to minority ethnic people, act as advocates when required and make referrals when necessary (Section 7.2, 7.6.2 and 7.6.3)
5. Devising a strategy to improve the placement of minority ethnic people in day hospitals and long-stay wards taking into account their preference to be in contact with other users from the same minority ethnic group (Section 7.7.2).
6. Ensuring that minority ethnic patients receive food that complies with their health, religious and cultural requirements and provide confirmation to their carers (Section 7.7.1).
7. Establishing an on-going system to monitor the satisfaction of minority ethnic carers and the people they look after, regularly review policy and indicate to all staff where changes in service planning, purchasing and delivery are required.

Lothian Health should work collaboratively with the four Social Work Departments in Edinburgh and the Lothians to:

1. Plan appropriate, coordinated services which are targeted to the needs of minority ethnic carers by:
 - developing an adequate and appropriate crisis support mechanism by consultation with minority ethnic carers (Section 5.4 and 6.4.1).
 - developing a strategy ensuring that minority ethnic people and their carers who require appropriate aids, adaptations and equipment are supported in accessing them (Section 8.3).
 - developing and providing a programme of training with VOCAL to existing community organisations already serving Edinburgh and Lothians' minority ethnic populations to raise awareness of carer issues, encourage a holistic approach to client assessment and establish an effective referral system for specialist advice/information on carers' issues and needs (Section 6.1).
 - investigating the feasibility of establishing a jointly funded post of Minority Ethnic Carer Worker. This post would act as a catalyst for operational and policy development within the unitary authorities, ensuring that minority ethnic carers needs are recognised and integrated within mainstream services. Specifically, this would: act as a focal point for minority ethnic carers' issues; provide opportunities for enhanced consultation with carers to develop, monitor and evaluate both existing and new services, and ensure more effective dissemination of information (Section 6.1)
2. Develop an information strategy for minority ethnic carers which
 - ensures that they and the people they look after receive the financial assistance that they are entitled to (Section 8.1 and 8.4)
 - effectively publicises the services and forms of support which are available, including the availability of the interpreting service (Section 8.1)
 - takes into account the diversity of minority ethnic languages, the literacy rates of minority ethnic carers and their expressed preferences for information dissemination (Section 8.1.3 and 8.1.4).
3. Improve the arrangements at the point of hospital discharge for information provision and support and for liaison between community nursing and social workers (Section 7.4).
4. Collaborate with housing authorities in developing a strategy for housing frail and disabled minority ethnic people and their carers (Section 8.5)

These recommendations should be considered by the Strategic Development Group for Carers in Edinburgh and its equivalents in Lothian in the planning of services and progress monitored regularly.

Additionally, the following recommendations have been included for consideration by organisations in the voluntary sector based on the findings of section 6.1.

Organisations in the voluntary sector should:

1. Regularly assess and monitor the extent to which their services are accessed and used by minority ethnic carers and the people they look after.
2. Take positive action and measures to develop services appropriate to the needs of minority ethnic carers by outreach work and pro-active contact.
3. Ensure equal opportunities policies are in place and regularly monitored with regard to employment, staff training and education on all aspects of equality.
4. Ensure that all conditions of grant in terms of service agreements or purchasing agreements are fully complied with, particularly in relation to the needs of minority ethnic carers.
5. Work in conjunction with Lothian Health and the four Social Work Departments in Edinburgh and the Lothians to ensure a coordinated approach towards the development of appropriate services for minority ethnic carers.

References

- Ahmad W, Kernohan E and Baker M** 1989 Patients' choice of general practitioner: influence of patients' fluency in English and the ethnicity and sex of the doctor *Journal of the Royal College of General Practitioners* 39/321: 153-55
- Aksham J, Henshaw, L and Tarpey, M** 1995 *Social and Health Authority Services for Elderly People from Black and Minority Ethnic Communities* London: HMSO
- Atkin K and Rollings J** 1993 *Community Care in Multi-Racial Britain: A critical view of the literature* London: HMSO
- Atkin K** 1996 An opportunity for change: voluntary sector provision in a mixed economy of care In W Ahmad and K Atkin (eds) *"Race" and Community Care* Buckingham: Open University Press
- Audit Commission** 1986 *Making a Reality of Community Care* London: HMSO
- Baxter C, Poonia K, Ward L and Nadirshaw Z** 1990 *Double Discrimination* London: King's Fund/Commission for Racial Equality
- Baxter C** 1989 *Cancer Support and the ethnic minority and migrant work communities* London: CancerLink
- Begum N** 1992 *"Something to be Proud of ..."* London Borough of Waltham Forest: Race Relations and Disability Unit
- Bhalla A and Blakemore K** 1981 *Elders of the Minority Ethnic Groups All Faiths for One Race (AFFOR): Birmingham*
- Bhatnagar A and Ineson A** 1994 *Health and health care: the needs of women of Bangladeshi and Pakistani origin in Edinburgh* Nari Kallyan Shangho/Lothian Health Promotion Department
- Black Carers Forum** 1992 *What do Black People Say?* Gloucester: Black Carers Forum
- Blakemore K and Boneham M** 1995 *Age, Race and Ethnicity: a comparative approach* Buckingham: Oxford University Press
- Blakemore K** 1982 Health and illness among the elderly of minority ethnic groups *Health Trends* 14/3: 68-72
- Cameron E, Badger F, Evers H and Atkin K** 1989 Black old women, disability and health carers in M Jeffreys (ed) *Growing Old in the Twentieth Century* London: Routledge
- Chakrabati M and Cadman M** 1995 *Survey of Needs of Minority Ethnic Elders and Carers for Social Work Support in Tayside* Glasgow: University of Strathclyde
- Cmnd (849)** 1989 *Caring for People* London: HMSO.
- Coles J** 1990 *The Needs of Elderly Black People, Carers and People with Disabilities* London: Lambeth Social Services
- Craig G and Rai D** 1996 Social security, community care - and "race": the marginal dimension. In W Ahmad and K Atkin (eds.) *"Race" and Community Care* Buckingham: Open University Press

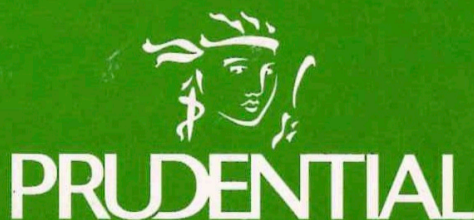
- Department of Health** 1989 *Caring for People: Community Care in the Next Decade and beyond* London: HMSO
- Fenton S** 1987 *Ageing Minorities: Black People as they grow old in Britain* London: Commission for Racial Equality
- Fenton S** 1988 Health work and growing old: the Afro-Caribbean experience *New Community* 14/3: 426-433.
- Finch J** 1989 *Family Obligations and Social Change* Cambridge: Polity
- General Household Survey** 1990 *Carers in 1990* London: HMSO
- Green H** 1988 *General Household Survey 1985: Informal Carers* London: HMSO.
- Griffiths K** 1992 *Reports of Consultations with Asian and Chinese Carers from 1991-1992* Birmingham: Birmingham Social Services
- Kalsi K** 1993 *Asian Elderly Carers: Their needs in the London Borough of Greenwich* London: Greenwich Social Services
- Kings' Fund Centre** 1989 *10 Point-Plan* London: King's Fund Centre
- Lambeth Social Services** 1993 *The Care Needs of Asian Older People in Lambeth: Working in Partnership for racial equality* London: Lambeth Social Services
- Lothian Regional Council** 1995 *Towards 2000: Developing a Strategy for Carers in the Lothians* Lothian Regional Council
- MacLeod L** 1988 *Irrespective of Race, Colour or Creed?* Scottish Council of Voluntary Organisations
- McCalman J** 1990 *The Forgotten People* London: King's Fund Centre
- McFarlane M** 1989 *"We look at the Walls": a report on mental health services in Lothian and the needs of minority ethnic communities* Edinburgh Association of Mental Health
- McIntosh G** 1996 *Beyond a Paper Exercise? Black and Minority Ethnic Communities and the Scottish Voluntary Sector* Scottish Council of Voluntary Organisations
- Patel N** 1990 *A "Race" Against Time: Social Service Provision to Black Elders* London: Runnymede Trust
- Pharoah C** 1995 *Primary Health Care for Elderly People from Black and Minority Ethnic Communities* London: HMSO
- Qureshi K and Walker A** 1989 *The Caring Relationship* Basingstoke: Macmillan
- Sage J and Sangavi C** 1992 *An Equal Voice: The Needs of minority ethnic elders and carers in the Medway Towns* Medway and Gillingham Race Equality Council
- Scottish Ethnic Minorities Research Unit** 1995 *Interim Evaluation Report on Asian and Chinese Women's Health Project: Fook Hong/Sehat* Scottish Ethnic Minorities Research Unit
- Scottish Office** 1994 *Access to Health Care by the Ethnic Minority Communities: A Guide to Good Practice* Scotland: HMSO
- Twigg J and Atkin K** 1994 *Carers Perceived* Buckingham: Open University Press

- Twigg J** 1992 *Carers: Research and Practice* London: HMSO
- Walker R and Ahmad W** 1994 Windows of Opportunity in Rotting Frames: care providers' perspectives on community care and black communities *Critical Social Policy* 40: 46-69
- Wright C** Language and communication problems in an Asian community *Journal of the Royal College of General Practitioners* 33: 101- 4
- Yee L and Blunden R** 1995 *General Practice and Carers: Scope for Change?* London: King's Fund Centre
- Yee L** 1996 *Improving Support for Black carers: a source book of information, ideas and service initiatives* London: King's Fund Centre

Why this Report?

- Both the number and proportion of older people in minority ethnic communities is increasing. Consequently, the number of minority ethnic carers of older people is also set to rise.
- Minority ethnic carers face particular difficulties over and above those experienced by white carers.
- Many of the existing services which carers can use are either inaccessible or inappropriate to the specific needs of minority ethnic carers. Minority ethnic carers have clear preferences for services which would support them in their caring responsibilities and would use services which accommodate them.
- The needs of minority ethnic carers in Scotland have not been identified before and have therefore not been accommodated in the planning and provisioning of health and social work services.
- Planners and providers of health and social work services have a legal duty to offer services which are accessible and appropriate to all sections of the community, irrespective of ethnic origin.
- Carers from minority ethnic communities are affected by additional problems such as poor housing and higher unemployment. Social and healthcare services have a central role to play in countering social injustice.

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