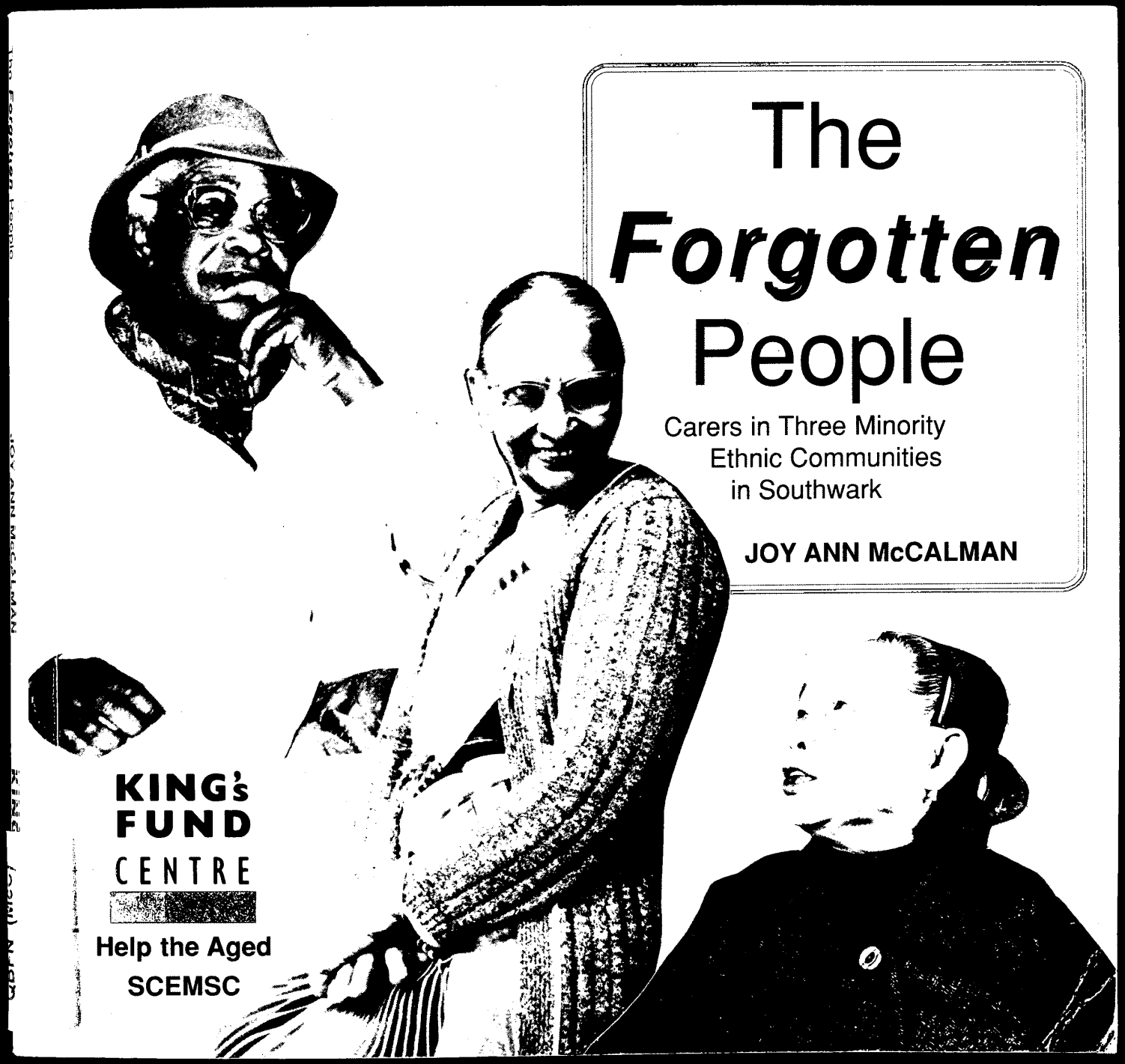

The *Forgotten* People

Carers in Three Minority Ethnic Communities in Southwark

JOY ANN McCALMAN

KING's FUND CENTRE

Help the Aged

SCEMSC

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ACKNOWLEDGEMENTS

Finding people to be interviewed for this research project was difficult as there was no specific organisation for minority ethnic carers. There was also little information about where they lived from statutory or voluntary organisations.

But we received enormous help from individuals associated with caring organisations in Southwark who submitted names and addresses of carers they knew.

Among those who helped were managers of statutory and voluntary day care centres, luncheon clubs, neighbourhood community centres and other caring organisations, including Age Concern Southwark, Southwark Alarm Scheme, Crossroads, Carers National Association Southwark, and Carers' Group Area 5 Southwark.

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Design, sub editing & typesetting:
Derek Heptinstall, Positive Publications,
84 Dowanhill Road,
London SE6 1SY 081 698 5716

Typing:
Joy Ann McCalman
Dorothy Aofolagu
Ruth Page

Carers Unit
King's Fund Centre
126 Albert Street, London NW1 7NF Tel: 071-267 6111

Contents

FOREWORD

The research described in this book was carried out in the London Borough of Southwark during 12 months in 1988 and 1989. Its first purpose was to discover the tasks, difficulties and situation of carers in three minority ethnic communities; Afro-Caribbean, Asian and Vietnamese/Chinese. Secondly, it aimed to reach conclusions and make recommendations on improvements to community care services.

The sponsoring organisations were concerned that so little was known about minority ethnic carers. A few community organisations had things to say about their members or users, but we knew of no attempts to seek out carers from minority communities, and no documented findings about their circumstances. For the first time this report gives us a glimpse into the reality of caring in three different minority ethnic communities in London. Previously there existed only an overall commitment to a multiracial approach to community care based on an uninformed awareness of needs. This research presents evidence from carers themselves.

Hopefully, Joy Ann McCalman's book will encourage all those concerned with community care to think how they can provide support for minority ethnic carers as a part of a range of improvements in support for all carers. *The Forgotten People* is relevant to planners and service managers in every health and social services authority. Voluntary and community organisations should draw on it to inform themselves in preparation for consultations with statutory agencies.

The practical steps that statutory, voluntary and community organisations can take are set out in the list of recommendations in the final chapter.

Although the book will be a useful starting point for dialogue in Southwark, it does not constitute a systematic audit of services, and its conclusions were drawn up with a wider audience in mind. Future work on the subject should encompass larger numbers of carers and should review service policy and provision which this research was unable to do. This book remains a unique beginning.

We hope that these research results will draw attention to the reality of life for carers in the minority ethnic communities who have been largely forgotten. Service planners and providers, in particular, should ensure that these, and other carers, are remembered in the new arrangements for community care planned for 1991.

Martin Bould, Carers Unit, King's Fund Centre
Dr Ann Hodgson, Help the Aged
Mabel Carter, Standing Conference of Ethnic Minority Senior Citizens

CHAPTER ONE

Introduction

1 Background

"The policy of successive governments has been to promote community based services allowing the reduction of long-stay care provisions. This is generally considered better in most situations. It is also most economical in many cases: a frail elderly person living in their own home with day and domiciliary support would typically cost public funds £135 per week, the same person would cost about £295 per week in National Health Service geriatric ward". (Audit Commission Report - *Making a Reality of Community Care* 1986 p.1)

The total cost of caring at home is, of course, much higher than that given by the Audit Commission report because the majority of services provided by statutory bodies are heavily underpinned by the work of informal carers such as relatives, friends and neighbours. (1)

These carers are at the centre of current debates about the future development of community care. For many years their problems have been hidden from public view.

Only now is it being recognised that they are in the front line of community care and that without them, welfare services could not cope with the work that would be needed. Two key policy documents - the Griffiths Report on community care and the White Paper *Caring for People* - have advocated increased support and practical help for carers.

The subsequent legislation proposed in the NHS and Community Care Bill will require community care agencies in the 1990s to make major changes in assessment procedures, planning and delivery of services and targeting of resources to meet greatest need. Agencies developing and implementing plans for supporting carers will be able to draw on a large body of research and examples of many practical initiatives which show what carers need and how they can be helped.

Unfortunately in discussions about support services, carers in minority ethnic communities have tended to be overlooked - these are *The Forgotten People.*

A recognition that carers in minority ethnic communities were losing out in recent community care developments led to

the research described in this report. The research aimed to discover the extent to which services were meeting the needs of minority ethnic carers. The report helps to establish their specific needs as well as showing those they have in common with other carers.

By exploring the experiences and needs of carers from minority ethnic communities, *The Forgotten People* challenges assumptions common among organisations which support elderly people and their carers. Its findings clearly show that no longer should services be denied on the grounds of low take up or lack of need of services among minority ethnic communities.

2 Origins of the project

The origins of the project evolved from the concerns of three organisations; the Standing Conference of Ethnic Minority Senior Citizens(SCEMSC), the King's Fund Carers Unit, and Help the Aged.

SCEMSC aims to address the needs of older people in all minority communities including Asian, African, Caribbean, Chinese, Vietnamese, Latin American, Cypriot, and Middle Eastern.

The organisation has 300 member groups, most of them providing day activities, housing and help at home for minority ethnic elders. SCEMSC had already identified carers as an area which needed more work, and was seeking to do more through projects funded by special grants.

Through this research, SCEMSC wished to identify the current needs of carers and elders and to draw them to the attention of health and social services in Southwark, London and nationally. It was hoped that the project might lead, directly or indirectly, to community initiatives to meet these needs.

The King's Fund Carers Unit was set up in 1986 to produce information for carers and training materials for professional workers. In 1987 it agreed to sponsor two projects (involving one-sixth of its budget) specifically for the minority ethnic carers. This project was one: the 'Asian Carers' project in Leicester, with SCOPE and Voluntary Action Leicester, was the other. Both projects recognised that the issue of carers was still at an early stage of development in minority ethnic communities. Both were intended to help the King's Fund, local organisations, and others with a concern for carers, learn more about the needs of black communities.

Help the Aged is a national charity dedicated to improving the quality of life of elderly people in the UK and overseas. It pursues this aim by raising and granting funds for community- based projects, housing and overseas aid. Carers and minority ethnic elders are groups whose needs have for too long remained ill-defined and unmet. Help the Aged supported this project because more needed to be learned about the the needs of minority ethnic carers and it was hoped that a community

initiative, such as a self-help scheme, could be launched.

3 Design

Designed to last one year, the project was located in the London Borough of Southwark because:

- SCEMSC - which housed the project - had a number of active groups in the borough, representing a range of minority ethnic communities including Afro-Caribbean, Asian, Chinese and Vietnamese organisations which were willing to assist in the research

- The office of SCEMSC is based in Southwark and had developed strong links with statutory and voluntary agencies which could give the project a solid foundation

- The projected growth of the minority ethnic elderly population in Southwark. The following information was provided by SCEMSC at the beginning of the project -

"Approximately 25.5 per cent of householders in the borough are headed by a person from the New Commonwealth and Pakistan. The major communities are of Afro-Caribbean, Asian, African and Turkish Cypriot origin. The 1981 census estimated that there are approximately 1,200 minority ethnic elders, mainly West Indians, but substantial numbers of Asian and Cypriot elders. Additionally, Southwark has been the destination for a lot of secondary migration by the Vietnamese/Chinese community adding to an increase in the size of that community's elderly population already settled in the borough."

According to SCEMSC the projected numbers of ethnic minority elders are:

	1981	1986	1991
Asian communities	220	350	520
Afro-Caribbeans	750	1500	2600
Mediterraneans	400	620	940
Chinese etc	30	50	90

- No data was available on carers of minority ethnic elderly relatives.

4 Aims

The project's aims were:

- To identify and work with carers of elderly people from the Afro-Caribbean, Asian and Vietnamese/Chinese communities

- To identify gaps in support services provided by statutory agencies

- To assess and produce information material for carers in different languages

• To identify areas for developing self-help groups or schemes

This project had two main phases :

Phase One : Talking to Carers of Afro-Caribbean, Asian and Vietnamese/Chinese elderly, discovering their needs and presenting recommendations in a report.

Phase Two : Defining how best these needs could be met, identifying statutory and voluntary organisations commitment to these carers, and educating the general public by the dissemination of information on the project's findings.

5 Project workers

The project was staffed by one full time research and development worker and one part-time secretarial and administrative assistant.

6 Steering committee

A steering committee was set up to support and give advice to the researcher. Its members represented SCEMSC's member groups within Southwark from the communities already mentioned, the local authority, the Health Service, welfare organisations for elderly people, and local voluntary organisations. The committee also agreed the methodology, final draft of questionnaire and all reports on the project. A list of the steering committee's members can be seen on page 79.

7 Methodology

● PRELIMINARY WORK

Prior to the appointment of the researcher, SCEMSC informed all relevant member groups, Health Service, voluntary, and welfare organisations about the project. The steering group met and defined its role before the researcher commenced work.

● PILOT SCHEME AND INTERVIEWS

A pilot scheme, using two carers from each community was carried out to test the questionnaire. Changes were then made before other carers were interviewed. The same questionnaire was used for each community. Interviews with carers were conducted either in their homes or at community centres they visited. Information on the project for the Asian and Vietnamese/Chinese communities was translated in Gujarati, Bengali, Urdu, Vietnamese and Chinese. The researcher was also accompanied by interpreters when carers did not speak English.

● AGE DEFINITION

Recognising that minority ethnic people may age earlier than the rest of the population, the project decided not to keep to 65 years of age as a definition of an elderly person. Therefore a starting point of 55 years of age was chosen although in a few cases ages had to be estimated. In fact ten of the 36 people interviewed were recorded as being between 55 and 65 years of age.

● RECORDING INFORMATION

Much of the information was given in anecdotal form, but all results from the questionnaires were manually tabulated as the numbers interviewed were relatively small. The outline work programme for the 12-month project is given in Appendix Two, page 80.

8 Finding and interviewing carers

It was decided that 20 carers from each of the three communities would be interviewed. This number proved very difficult to find due to:

- The Isolation of Carers

At the time of this project the Southwark council had not started ethnic record keeping.

Social services and housing departments could not identify carers of minority ethnic communities in their areas.

Many carers from the Afro-Caribbean community did not belong to organisations because most of their time was spent between work and caring.

- Time allocated for interviewing

The time allocated to each community was very limiting as it did not allow a relationship to be established.

There was also not enough time to fully discuss the questionnaire with carers.

- Interviewing problems

Although the questionnaire was examined by representatives from each of the communities, some carers felt that many of the questions were too personal and did not wish to answer them.

Some carers who did not speak English were unwilling to talk to interpreters they did not know.

Others who were unwilling to talk on a one-to-one basis, spoke as members of a group to the researcher.

It is customary in the Asian community for sons and daughters to live with their relatives and look after them without outside intervention as this is sometimes viewed as a sign of failure.

Some families might not have wished to speak to the researcher because they were embarrassed by the fact that their elderly relatives were living on their own.

9 How the researcher was received

The majority of carers who spoke to the researcher and her interpreters were eager to speak of their experiences, feelings and hopes for the future. The information received was tabulated and written in an anecdotal account.

10 Numbers interviewed

Unfortunately, time did not permit the researcher to complete the last two aims of the project - to produce information for carers in different languages and to identify areas for developing self-help groups or schemes. Neither was she able to interview the 60 carers defined in her brief. Thirty four were interviewed for the main research comprising 13 Afro-Caribbean, eight Asian and 13 Vietnamese/Chinese carers. Six others were interviewed for the pilot scheme.

11 Presentation of the book

A summary of the research methods and findings is given in Chapter Two. Following this are chapters presenting the detailed findings about carers in the Afro-Caribbean, Asian and Vietnamese /Chinese communities. Each of these chapters has sections entitled:

INTRODUCTION
CARERS AND RELATIVES
WORK OF CARERS
KNOWLEDGE AND USE OF SERVICES
NEEDS OF CARERS AND RELATIVES
COMMENTS

Chapter Six has a case study (real names not used) from each of the communities showing how the problems affect individuals. The final two chapters discuss the issues and list the recommendations for community and voluntary organisations, health services, social services and research organisations.

The term "minority ethnic" has been used to cover the range of black and other communities. Other terms like "Afro-Caribbean", "Asian" and "Vietnamese/ Chinese" are defined at the beginning of the chapters allocated to them. It is anticipated that *The Forgotten People* will be consulted by people with different backgrounds and interests. This book has been designed for ease of reference and every attempt has been made to avoid repetition. But some duplication was necessary because some readers will only want to refer to selected chapters.

Readers wishing to obtain a photocopy of the questionnaire should contact the King's Fund Carers Unit at the address at the front of the book, price £3.

References
(1) Caring for People(HMSO 1989), para 8.11 (p.63): "Their (ie carers') total input was greater than the combined inputs financed from central and local government."

CHAPTER TWO

Summary of the research methods and findings

1 Despite the emphasis placed on the importance of carers by successive government statements on care in the community, there is no clear understanding of the needs of carers in minority ethnic communities, and very limited responses from service providers.

2 A research and development worker was employed for one year to interview carers in Afro-Caribbean, Asian and Vietnamese / Chinese communities in Southwark.

3 Considerable difficulties were experienced in finding carers for the interviews. Thirty-four were interviewed for the main research report and others took part in pilot interviews and group discussions.

4 Age and gender: approximately 62 per cent of all carers interviewed were women and 38 per cent men. Sixty two per cent were aged over 40. Seventeen per cent of all carers looked after two elderly relatives.

5 Over 80 per cent of their elderly relatives were aged over 60.

6 Ability to speak English: The percentages of carers who spoke English were; Afro-Caribbean (100 per cent), Asian (50), Vietnamese/Chinese (23).

7 Similarly, all elderly relatives of the Afro-Caribbean carers spoke English. Percentages for the other groups were; Asian (50 per cent), Vietnamese/Chinese (not available).

8 Employment: approximately 26 per cent of all carers were in full-time employment, nine per cent worked part-time and another 12 per cent were at school or on training courses. The remainder were full-time carers. All carers devoted a substantial amount of their time to caring.

9 Relationship to elderly people: All elderly relatives being cared for were closely related to their carers. Of these, approximately 26 per cent were mothers, 21 per cent husbands, 18 per cent fathers, 13 per cent wives, seven per cent each mothers-in law and grandmothers, five per cent grandfathers and three per cent step-mothers.

10 Approximately 77 per cent of all elderly relatives lived with their carers and the remainder lived alone. Of these 15 per cent were couples.

11 Ailments of elderly relatives in all three groups varied widely although about 62 per cent of the Afro-Caribbean elderly relatives suffered from diabetes and associated conditions like blindness or failing eyesight. In the other two communities it was difficult to highlight common illnesses, but approximately 26 per cent had severe difficulties in walking or were unable to walk.

12 Approximately 62 per cent of carers provided some aspects of personal care such as bathing or dressing whilst approximately 71 per cent provided physical help such as lifting or walking. Ninety per cent deal with all paperwork/financial matters and the remainder sought help from relatives or their community workers. All carers provide practical care, and their help in the giving of medicines varied according to the types of medicine prescribed.

13 Time devoted to caring varied but the majority of carers (74 per cent) spent over 11 hours per day caring for their elderly relatives. The figures below show the hours per day spent caring for relatives by all carers:

HOURS	21-24	16-20	11-15	5-10	TOTAL
CARERS	11	1	13	9	34

14 Number of years caring: Fifty per cent of all carers had been caring for two to five years. Eighteen per cent each had been caring for six to ten years and six to 12 months. Nine per cent had been caring for 11 to 15 years and approximately three per cent each had been caring for 16 to 20 years and over 20 years. This shows that a considerable part of carers' lives is spent caring as 15 per cent had been undertaking this role for over 11 years and 82 per cent had been caring for over two years.

15 The majority of carers received help from family members closest to them. These included the carers' spouses, children, sisters, brothers, and in the Vietnamese/Chinese communities, parents and grandparents. Many carers had young children who, naturally, could only give them limited help. Many carers, especially in the Asian and Vietnamese/Chinese communities, had no other relatives than their immediate families in Britain. Five carers had no relatives in Britain and therefore received no help.

16 All three communities expected carers to provide continuous care for their elderly relatives. Hence shared caring with formal care services was seldom considered. A small number were able to get periods of rest but a large majority could get no-one to relieve them. To add to the difficulties, some elderly relatives objected to having a new carer even for a short time. This research showed that only approximately 23 per cent of carers had a holiday within the

previous four years. Twenty three per cent had not had a holiday since they began caring while nine per cent had had one between ten and 20 years before. Forty four per cent could not remember when they last had a holiday.

17 Difficulties experienced by carers included difficulty with physical tasks, lack of communication due to language barriers, their own poor health, heavy caring duties, financial difficulties and emotional stress.

18 Services: the study looked at what services were available to give carers a break. The majority of elderly people took advantage of community day centres/luncheon clubs. Only 21 per cent used social services day centres.

19 Services providing longer breaks such as council-run Holidays for the Elderly and the Disabled Elderly were generally not known.

20 Of the services provided in the home, home help was the most known. However it would appear that this service was limited to elderly carers. Only one young carer had been offered this service but could not use it because she could not communicate with the home help in English.

21 Aids and adaptation services were used by 15 per cent of the elderly relatives.

22 Meals on wheels were only used by approximately three per cent of the elderly relatives. Those who were aware of this service were not happy with the meals provided.

23 Apart from the GP and the community nursing services, all other services provided by the National Health Service were little known and not used.

24 Of all the advice and information services, welfare rights was the most known and used service.

25 Voluntary agencies were rarely known. Only the Citizen's Advice Bureau had been heard of in the Asian and Vietnamese/Chinese communities.

26 In most cases carers were unable to say whether services were suitable to their needs because they did not know about them or use them.

27 Racism was not felt to be a factor by most carers when they tried to obtain services. Others felt they did not know whether they had encountered it. However, one Afro-Caribbean carer did feel that she was encountering racism. Three Asian families had reported racial abuse and threats made to them and their families on the housing estate where they lived.

28 Carers' needs were numerous and varied. These included education on health, diet, and caring as well as help with day-to-day life in a predominantly white society. Other needs included the breakdown of language barriers, access to information and

services, physical help with caring, relief care for their elderly relatives, links with social services, health and volunteer services, adequate housing, an emergency help line and adequate financial means.

29 The needs of elderly relatives varied according to their disabilities and position within their families. For example, those whose physical needs were being met by their carers, expressed the need for faculties they had lost such as seeing or walking. Those who lived alone and had to look after themselves when their carers were absent, asked to be near their carers or wanted them to fulfil more of their physical needs.

30 Housing: seventy nine per cent of all carers lived in accommodation rented from the council or Housing Trusts. Twenty one per cent lived in their own accomodation. Approximately 21 per cent of those who lived in council housing had applied for a transfer. One carer who applied for a specially-adapted flat for his elderly relative was offered what he considered unsuitable accomodation which he refused. The rest were awaiting replies.

31 Benefits: approximately 64 per cent of the elderly relatives received a pension. The remainder were not of pensionable age. Seven per cent received Mobility Allowance, 15 per cent Attendance Allowance, 53 per cent Housing Benefits, 23 per cent Income Support, seven per cent Invalid Care Allowance and five per cent received no benefits.

32 Health: the majority of carers descibed their health as being satisfactory, fair or good. However, they admitted feeling tired and suffered from a number of stress-related medical problems.

33 The main conclusions are presented in Chapter Eight, page 72. In summary they are, firstly, that minority ethnic carers have similar experiences of caring as all other carers, though they often had more severe problems such as poverty, housing and racism. Secondly, existing services were not getting through to minority ethnic carers or meeting their needs. Take up and awareness of services are low among all carers but among minority ethnic carers they appeared even lower. The research also showed that language was a big barrier for some carers.

To overcome these problems, what are required are better procedures and a new management approach rather than large amounts of money. The work of minority ethnic community organisations provide encouraging examples of the way forward for services.

CHAPTER THREE

Afro-Caribbean Carers

INTRODUCTION

1 Background

The Afro-Caribbean community is Southwark's largest minority group comprising half of the borough's minority ethnic population. (1) Its people, formerly called West Indians, originate from islands stretching from South East Florida to North East Venezeula as well as from coastal regions in Central and South America. These people, like those throughout Britain, migrated from former British colonies where English is the first language and French Patois the second in some islands.

In Southwark, the majority of Afro-Caribbeans are from Jamaica, Dominica and St Lucia. Many are Christians, belonging to churches such as the Roman Catholic, Anglican, Methodist and Pentecostal. Their cultures vary widely according to their country of origin.

Many who came to Britain during or just after the Second World War are now in, or approaching, their retirement years. They now face the reality that they will never be able to return to the land of their birth to enjoy their retirement years as they had planned.

At present a majority of elderly Afro-Caribbeans in the borough live alone. Even those fortunate enough to live with relatives or to be cared for by friends, bemoan the fact they will not be able to spend their "last days at home".

2 Contacting carers

Finding carers proved to be no easier in the case of the Afro-Caribbean community than in the other minority ethnic groups. Churches and Afro-Caribbean organisations were contacted by post and by telephone but almost all of them were unable to help as the majority of their elderly members lived alone.

A survey was held in Peckham Rye on two consecutive days in order to locate carers but this exercise also proved fruitless. Everyone who spoke to the researcher said they did not care for an elderly person at home and did not know of anyone who did. Some even questioned whether there was a significant number of elderly people in

Carers found it difficult to take a break of more than two days at a time. Many had not had a holiday for more than a year.

Southwark who needed care from others.

However, a total of 15 carers looking after 15 elderly relatives were located through a cross section of organisations including day centres, tenants associations and black organisations. Two were interviewed for the pilot scheme and the remaining 13 for this report. Of the latter, one carer looked after both parents whilst two carers - a young son and daughter - together cared

for their father. Their roles were seen as joint carers, hence they were included in this research as two carers.

The answers given by carers for the pilot scheme are not tabulated in this report. However, they have been included in the summary.

3 Difficulties

Although all carers were visited in their homes, many were very apprehensive at first to speak to the researcher. Some asked if she was working for social services while others felt that some of the questions were too personal. A few were also reluctant to answer questions on finance.

Although it was generally felt that the project was important, many also believed that Southwark Social Services would ignore any recommendations made by it.

There was some difficulty in establishing who the carer was when more than one person was caring for the same elderly person and when two elderly people were seen as caring for each other.

So it was decided for the purposes of this project that " the carer " would be the person who carried out the majority of tasks. For example, at one interview where both daughter and husband were found to be caring for an elderly woman, the interview was with the daughter as she was also "keeping an eye" on her elderly father.

CARERS AND RELATIVES

4 Carers

GENDER AND AGES

Age	21-30	31-40	41-50	51-60	71-80	Total
Male	1	1	2	0	1	5
Female	1	2	1	3	1	8

WHERE THEY LIVED

Camberwell	3
Dulwich	1
Herne Hill	1
Newington	1
Peckham	6
Forest Hill	1

(Borough of Lewisham)

LANGUAGE

All carers spoke, read and wrote in English only. Their elderly relatives also spoke English.

MARITAL STATUS AND CHILDREN

Carers	Male	Female
Single	1	1
Married	3	6
Divorced	1	1
With children	6	4
Without children	1	2
Children at home	2	4
Children not at home	2	2

EMPLOYMENT STATUS

Carers	Full Employ.	Part-time	Retired	Total
Male	4	0	1	5
Female	4	3	1	8

Those in full employment were only able to maintain their jobs because of the help they received from other relatives, friends and social services.

Some carers worked flexi-time and others did shift work in order to facilitate their caring role. Two worked in the evenings when other relatives and, in some cases, children were at home. Both had also reduced their working hours in order to provide better care. All carers with jobs, stated that they had to work in order to maintain themselves and their relatives as social security benefits were inadequate. Both retired carers supplemented their incomes by renting a room in their houses.

In cases of emergency - for example, acute illness - carers have had to use holiday entitlements to care for their relatives.

Carers in part-time employment also stated that their career advancement had been hampered by their inability to work full time.

HEALTH

Descriptions of their health by carers were:

Good	8
Satisfactory	2
Fair	3

VISITS TO GP

Fortnightly	1
Monthly	4
Bi-monthly	2
Only when ill	6

COMPLAINTS AND ILLNESSES

Ten suffered from medical complaints such as:

Hypertension	4
Bronchitis	2
Arthritis	2
Depression	2
Headaches	2
Failing eyesight	1
Back pain	1
Diabetes	2
Painful leg	1

Five carers had two illnesses and four had one. One carer had three ilnesses but three had none.

No one took tranquilisers, sleeping tablets or anti-depressants. Six took medication.

5 Relatives

RELATIONSHIP TO CARERS

In the Afro-Caribbean community, carers tend to care for someone who is closely related to them. Contrary to the general assumption that women do most, if not all, the caring, nearly half of those interviewed were men. It is customary in the Afro-Caribbean community that the first child takes on the responsibility of caring for his or her parents. In the absence of the first-born child, it is not unusual to find the first grandchild or unmarried daughters caring for grandparents. The relationship of relative to carer was:

Elderly Relatives	Carers	
Number	Male	Female
Mothers 3	2	*1
Step-Mother 1	1	0
Mother-in-Law 1	0	1
Grandmother 1	0	1
Wife 1	1	0
Fathers 3	*1	3
Husbands 3	0	3
Total 13	*5	*9

* Father is being cared for by both son and daughter. One daughter who cares for both her parents is counted twice in the above table.

WHERE THEY LIVED

Of those being cared for, two lived away from their carers. However, one lived less than two miles away and the other less than three miles. Both elderly relatives had services at hand in case of an emergency. For example, one was an elderly woman residing in private church accommodation adapted for elderly people with a warden who made periodic checks to ensure that tenants were safe and well. The woman's flat was also equipped with a bell to enable her to summon help. The other, an elderly man, was a member of the Southwark Alarm Scheme.

The carers of both these elderly relatives visited them about three times daily. Another elderly woman had her own self-contained flat on the ground floor of her step-son's home. This woman has not been included in the category of those elderly relatives who lived alone as she received constant support from her step-son's family.

AGES

	61-65	66-70	71-75	76-80	Total
Male	1	3	0	2	6
Female	1	1	2	3	7

AILMENTS

The ailments of the elderly relatives were varied and inter-related. For example, many with diabetes also have failing eyesight or are totally blind and those with strokes (cerebral vascular accidents) also had hypertension.

Most of the elderly relatives suffered from more than one ailment, the highest recorded number for one person being five. The ailments and conditions and the number of people with them were:

Diabetes	8
Failing Eyesight or Total Blindness	7
Arthritis	5
Stroke (CVA)	3
Hypertension	2
Painful joints especially knees	2
Constant Body Pains	2
Incontinence	2
Memory Loss/Dementia	1
Amputation of Limb	1
Asthma	1
Hay fever	1
Gas - Indigestive Ailment	1

WALKING

Walked unaided	3
Used aids such as sticks, crutches, Zimmer frames and /or assistance from their carers	9
Unable to stand or walk	1

DRESSING

Dressed themselves	7
Supervised and required help occasionally	4
Unable to dress themselves	2

EATING

Fed themselves	7
Slow at eating and must be encouraged	6

CONTINENCE

Continent	6
Occasional accident on account of not being able to get to the toilet in time	5
Completely incontinent	2

SHOPPING/SOCIAL EVENTS

Went out during the day to places which were near home	1
Enjoyed going out occasionally with their carers	2
Preferred to stay at home and had to be encouraged by carers to leave their homes	10

- Social Events did not include churches or day centres

WORK OF CARERS

6 Time and help given

● TIME SPENT WITH RELATIVES

Nine carers spent 11 - 15 hours a day with their elderly relatives while the remaining four spent five to ten hours. The majority of these hours were in the day when most tasks needed to be done. Nevertheless, three carers did provide care during the night, varying from help with turning in bed and toileting to a hot snack.

All carers have had to provide care during the night in cases of emergencies such as in a hypoglycaemic attack or the worsening of an illness. In some cases carers had to sit with relatives unable to sleep.

● PERSONAL CARE

Eight of the 13 carers provided some aspect of personal care including:

Bathing - 6 carers
Cutting Nails - 6 carers
Washing - 3 carers
Dressing - 3 carers
Feeding - 2 carers
Shaving - 2 carers
Using the toilet - 2 carers

● PHYSICAL HELP

Ten carers provided physical help which, in this research, was defined as help with getting in and out of bed, with walking, and climbing stairs inside and outside the home.

Varying degrees of physical help were identified. For example, carers helped their blind elderly relatives with walking outside the home. Similarly, assistance with climbing stairs was confined to help with leaving and entering their homes and getting to and from the bathroom and toilet.

One elderly relative who was unable to stand or walk, had to be carried by her son to her bedrooom.

● HELP WITH PAPERWORK/ FINANCIAL MATTERS

Twelve of the 13 carers attended to all paper work/financial matters on behalf of their elderly relatives. The other shared this task with her blind husband who liked to be kept informed of such matters. Acting as his eyes, she enabled him not only to make decisions but also to perform tasks he thought necessary.

● OTHER PRACTICAL HELP

All carers provided other practical help for their elderly relatives. This included the preparation of meals, shopping, laundry, house work, gardening and decorating.

● VISITS OUTSIDE THE HOME

All carers escorted their elderly relatives on trips outside the home. However, the majority of these are usually confined to visits to doctors, hospitals, day centres and churches when transport is provided.

Social visits by carers were very rare due to lack of private transport and elderly relatives' reluctance to leave their homes.

● COMPANY FOR RELATIVES

All carers sat with, read to, talked to and generally socialised with their elderly relatives. Some wanted more time to do this.

● GIVING MEDICINE

Giving medicines and treatment varied according to the illnesses of relatives. Of the ten carers performing this task, the most frequent job was preparing and sometimes administering insulin injections. Other forms of help with medication include the preparation and measuring of liquid potions. Ten elderly relatives also supplemented medication prescribed by doctors with that of herbal remedies. Two had also sought a second opinion on their illnesses from private doctors.

● SAFETY AT HOME

All carers generally keep an eye on their elderly relatives to ensure that they are warm and safe from household accidents.

7 Number of years carers have spent caring

	Years					
Carers	16-20	11-15	6-10	2-5	6-12	Total
Male	0	1	1	3	0	5
Female	1	0	2	4	1	8

8 Help from family

Eight carers received help from other family members who, in most cases, were those closest to them - for example, husband,wife, or children. Some brothers or sisters helped occasionally but did not seem to take full or part responsibility for caring. Other family members such as aunts, uncles, cousins, nephews and nieces sometimes visited but were not directly involved in caring. However, in one case where an elderly male carer looked after his wife, extra help was given by his nephew's daughter.

9 Rest and holidays

In the Afro-Caribbean community, it is assumed that someone caring for an elderly relative will do so until his or her elderly relative dies.

Shared caring was not often considered by the family unless the carer could not continue or had extreme difficulties.

This puts greater stress on carers as many are unlikely to have a rest of two

consecutive days or more at any time.

Few older Afro-Caribbbean people go away during their holiday periods. Those not born in Britain usually associated holidays with travelling overseas to their land of birth or to visit children who have settled elsewhere.

Of the carers interviewed, six were able to have a rest from caring for at least two days, while four could not and three had never tried.

All 13 elderly relatives could be left alone for varying lengths of time ranging from half an hour to all night depending on the circumstances of both carers and elderly relatives.

Four carers had no difficulty in arranging for someone to look after their elderly relatives while they were away on holiday, as members of their immediate family would usually cover for them.

Two found it fairly difficult to arrange because they also had responsibilities for young adult children who had commitments of their own. Four found it very difficult as they also had to care for young children. Three had never asked anyone.

Only one elderly relative objected to having another carer for a short period. The others would only agree if the new carer was known to them.

Only four carers had been on holiday during the previous year. For the remainder it had been at least three years since their last holiday.

Four could not remember when they last went away and one said it had been 20 years before.

KNOWLEDGE AND USE OF SERVICES

10 Community services

● PROFESSIONAL AND VOLUNTARY VISITS

Regular visits of at least once a month to carers and their elderly relatives from workers in statutory, voluntary and religious organisations were:

Monthly visits from their doctors	4
Daily visits from community nurses	5
Twice weekly visits from home helpers	4
Daily Meals on Wheels	1
Social worker	1
Health visitor	0
Voluntary agencies	0
Church ministers	7
Church members	8

● VENUES RELATIVES VISITED

Eleven attended church about once monthly, 11 attended day centres twice weekly (each totalling more than ten hours).

All who attended church enjoyed the fellowship and all who attended day

Most elderly relatives attended day centres - and enjoyed the companionship

centres, the companionship. Two who attended day centres also enjoyed the handicraft workshops and the social life. No one could think of anything they disliked about church or the day centres.

INFORMAL VISITS

All the elderly relatives received visits from relatives, friends and neighbours during the week. However, not many visited every

week. Those who visited daily or weekly are those closest to the carer.

CARE OUTSIDE THE HOME

	Known by 12
Luncheon clubs	
Day centres	12
Residential homes	12
Respite care	5
Holidays for the Elderly	11
Holidays for the Disabled Elderly	9

SERVICES USED

Services used by elderly relatives	
Luncheon clubs	0
Day centres	11
Residential home (for a short period)	1
Respite care (when husband was in hospital)	1
Holidays for the Elderly	3
Holidays for the Disabled	2

All those who used day centres were happy with them.

The elderly relative who once lived in a residential home, greatly disliked it because she "was not treated properly", the meals were poor - " mince every day " - there was no stimulation or activities, and she became homesick.

The elderly relative who was given respite care enjoyed her stay at the hospital.

Three enjoyed the holidays for the elderly. One who went on the holiday for the disabled elderly was dissatisfied. The carer complained that her mother had returned unkempt and had not been washed properly throughout the holiday period.

DOMICILIARY SERVICES

Carers knowledge of services available for their elderly relatives in their own homes were also tested. The results were:

	Known by 12
Home helps	
Meals on Wheels	12
Aids and Adaptation service	8
Southwark Alarm Scheme	3

Six carers and their elderly relatives used home helps. These included the two elderly relatives who lived alone, the elderly lady who lived in her self-contained flat, two elderly carers and one male carer who looked after his mother.

One elderly relative received Meals on Wheels and another had used the service in the past.

Three used aids and adaptations in their homes including Zimmer frames to aid walking and climbing stairs, rails, raised bathroom and toilet seats and commodes.

One elderly relative's home was connected to the Southwark Alarm Scheme.

All six carers receiving the the Home Help Service found it very useful but three would have liked an increase in the two hours a week allocation to enable them to provide better care.

The elderly relative who used the Meals on Wheels service was not very satisfied with the presentation of the food or its taste. However, as it was his only means of obtaining a hot meal at midday, he was prepared to continue to use the service until alternative arrangements could be made. The other elderly relative who once used this service was also not satisfied with it.

The three elderly relatives who used services providing aids and adaptations had found the equipment very helpful. So too had the elderly relative who had been given an alarm connected to Southwark Alarm Scheme.

However, seven elderly relatives and their carers did not use any of the services available to them in their homes. These services had never been offered and the carers believed they were not entitled to them because they were in employment.

11 National Health Service

● GENERAL PRACTITIONERS

All carers and their elderly relatives knew of GPs and visited them. This service was very helpful to 11 carers while two described it as being unsatisfactory. In one case this was because the doctor was reluctant to allow the relative to get a second opinion about her failing eyesight. The carer believed that the specialist was not treating the condition.

One carer was very dissatisfied with her GP because she said he refused to make house calls or examine her elderly relative even in an emergency. She said he preferred to prescribe medication for her relative based on the verbal history he received from the carer.

● COMMUNITY NURSING

The services provided by community nurses were known to 11 carers and five of their elderly relatives used them. Of these, four carers were satisfied with the services whilst one was very dissatisfied because the nurses who visit his elderly relative seemed to be very unreliable as they rarely kept appointments, and when they did, they were almost always late.

They also seemed to be always in a hurry and therefore spent very little time with his elderly relative. This carer has complained to the Health Authority and was told that due to cutbacks, the nurses' priority is now to provide care for elderly people who lived alone.

● CHIROPODY

Nine carers know of the chiropody service which was used by five of their elderly relatives. All were happy with the service they received.

● DAY HOSPITALS

The services provided by day hospitals were known to eight carers. At present two

elderly relatives attended. However, neither they nor their carers were satisfied with this service as it seemed as if no effective treatment was being prescribed.

● PHYSIOTHERAPY

Physiotherapy was known to six carers. Two elderly relatives used this service and both were satisfied with it.

● OCCUPATIONAL THERAPY, PSYCHIATRIC COMMUNITY NURSING, HEALTH VISITING AND SPEECH THERAPY

These services were known to five, three, four and five carers respectively. However, none of the elderly relatives used them.

● CONTINENCE ADVISER

Five carers had heard of this service and one elderly relative was under the care of an adviser. Her carer was dissatisfied with this service as the adviser has made only one visit for assessment and had not been in contact since. Meanwhile, the community nurse continued to supply incontinence pads while the cause of the condition remained untreated.

12 Services offering advice and information

● SOCIAL WORKERS

Social workers were known to six carers. One carer had contacted a social worker and she was hoping that the service would benefit her. Three other carers had had help from hospital social workers which they found very helpful when elderly relatives were discharged from hospital.

● WELFARE RIGHTS

Welfare rights was known to six carers. Three used the service and were satisfied with it.

13 Voluntary agencies

● CITIZENS ADVICE BUREAU

Six carers had heard of CAB. Three used the service and were very satisfied with it.

● AGE CONCERN

Age Concern was known to five carers of whom two had used the service and found it very helpful.

● HELP THE AGED

One carer had heard of Help The Aged. However, the service it provided was not known to carers.

DIAL-A-RIDE

The Dial-a-Ride service was known to five carers. One carer who had contacted the service for her elderly relative said she was very dissatisfied with it because the booking clerk was unhelpful and the service was late.

14 Suitability of services

Many carers found it difficult to answer the question about whether services offered to them were in keeping with their cultural and religious background. Of those who did answer, three said yes, and two replied no. Of the latter, one carer found it difficult to obtain information on financial support available to dependant elderly people. The other carer, whose elderly relative once stayed in a residential home, was unable to obtain adequate financial support to enable him to care for his relative at home. He wanted social services to provide help geared to the needs of carers instead of imposing services on them.

None of the carers who received services were able to obtain these through direct access to social services. All services were granted through intermediaries such as GPs, welfare rights workers, and on the request of hospital doctors when elderly relatives were discharged home.

At present, none of the carers knew who to approach for small grants to buy items such as carpets, washing machines, beds and other essential items to enable them to provide better care.

15 Experiences of racism while trying to obtain services

Although the majority of carers had experienced difficulties, 12 carers stated that they had not encountered racism while trying to obtain services on their own.

However, one carer felt she was subjected to racism from the housing department in Southwark in her efforts to obtain a housing transfer which she had requested four years before. According to this carer, the housing officer in her area had repeatedly told her that there was no accommodation available big enough to house her large family. She said that although she had reported large empty properties in the area these had been allocated to people who had not been on the waiting list for as long as she had.

This carer together with her elderly relative and young family lived in a flat on a housing estate.

The rooms were constantly cold and the walls affected by rising damp and covered with mildew. The carer believed that the death of her young child had been due to her living conditions.

She was depressed, still grieved for her child and felt helpless and lonely in her quest to provide a better home for her entire family.

Agencies had been approached, but none had helped.

NEEDS OF CARERS AND RELATIVES

16 Difficulties and needs

● DIFFICULTIES FOR CARERS

Three carers could not name any task in their caring which they found difficult. After caring for someone for many years, they felt able to solve the various problems which they encountered.

Those who had had difficulties stated the following:

- Having to leave their elderly relative alone at home for long periods
- Having to care alone in a severe or an acute attack of an illness
- Not being able to provide one's elderly relative with a room of her own
- Lifting
- Unable to extend personal care due to age and strength
- Unable to have their elderly relative live with them due to lack of suitable accomodation in either home
- Having to continuously travel to and from elderly relatives home several times during the day and night
- Maintaining two homes
- Coping with emotions on seeing their elderly relative helpless due to loss of memory and blindness and unable to do anything about it

● NEEDS OF CARERS

Four carers could not think of anything that would help them to provide better care. The others wanted:

- To obtain bigger and better accommodation for the entire family
- To be able to be relieved from caring for a couple of hours each day
- To be able to have a break from caring for at least two consecutive days at regular intervals
- Suitable accommodation so that the elderly relative can have his/her own room.
- Help with lifting
- Suitable adaptable dwelling for elderly relatives and family of carer
- Information on financial benefits available to the elderly relative and the carer
- Aids and adaptations to enable the elderly relative to move around the home
- More financial support
- An increase in home help time to those who receiving the service and its introduction to those who were not

● NEEDS OF RELATIVES

As the physical needs of the elderly relatives were being met by their carers, those who expressed a need focussed on the things they miss most, such as:

- To live with carer
- Companionship during waking hours
- Companionship at night for those living

alone
- Warmth
- To walk
- To walk without feeling pain
- To see
- Assistance to climb stairs

17 Housing

Of the 13 carers, seven lived in owner-occupied dwellings comprising one detached house and six terraced houses.

The remaining six carers lived in rented accommodation. Five of these are owned by Southwark Council and the remaining one by Lewisham Council. Of these, five were maisonettes and the other a flat. (Two carers shared a maisonette.)

One of the two elderly relatives living alone occupied a ground floor council flat. The other lived in a specially-adapted flat for the elderly owned by the Church.

Ten of the 14 dwellings had an adequate number of rooms. The four which did not were all owned by the council and three of the carers had tried to obtain larger and more suitable premises. Of these, only one was offered alternative accomodation which was considered unsuitable. The other carers were still waiting to hear. One carer did not apply for alternative premises because she and her mother and father were hoping to return to Jamacia in a year's time.

Aids and adaptations such as rails and bathroom and toilet appliances, were found in one council flat, one owner occupied house and the specially-adapted church flat. None were found in homes where the carers were not of pensionable age. However, many of the other carers wanted aids and adaptations.

18 Benefits

	No. of Elderly Relatives
Pension	10
Mobility Allowance	2
Attendance Allowance	4
Housing Benefits	3
Income Support	3
Invalid Care Allowance	2

Not all elderly relatives received benefits. Two received no financial benefits as one is not of pensionable age but relied on his wife who still worked.

The other was not entitled to any benefits having only recently arrived in Brtiain.

The number of benefits received were:

One benefit	received by	3
Two benefits		3
Three benefits		5

Nine of the carers supported their elderly relatives while four did not. Of the latter, two were elderly couples with one partner looking after the other. Two carers who lived with their elderly father shared all bills with him.

However seven carers found it

financially difficult to provide the care their elderly relatives needed. Of these, only two had approached various agencies for information on benefits.

COMMENTS

Contrary to the common belief that most carers are women, it would appear from this small sample of carers that in the Afro-Caribbean community men play a significant role in caring for elderly relatives.

Many carers had full-time or part-time jobs which meant that they found it difficult to find time for other activities in groups like community organisations. Hence the problem of finding carers for this project.

The fact that so few were unable to have a break from caring for two or more consecutive days and that more than half of those interviewed had not had a holiday for over a year, suggests that differing types of respite care are needed.

The best solution for everyone would be for means to be found to enable elderly relatives, to socialise more frequently outside their homes, allowing their carers time to relax.

Many carers found caring for their relatives, nearly half of whom were men, demanding. They also admitted to feeling tired and to having their social life curtailed. However, many found their work rewarding and their elderly relatives, an asset, as they provided them with companionship and the benefit of wisdom gained through experience.

For further discussion of these research findings, see page 64.

(1) Black and Other Minorities: Key Facts - Race Equality Unit, Town Clerks Department, London Borough of Southwark).

CHAPTER FOUR

Asian carers

INTRODUCTION

1 Background

In Southwark, the Asian community comprises of one eighth of the total minority ethnic population. Its people originate mainly from Pakistan, India, and Bangladesh. Others arrived in Britain from East Africa. Their languages are many and among these are Urdu, Hindi, Punjabi, Gujarati and Bengali. They are a religious people with religions such as Islam, Hinduism, Sikhism and Christianity. Many of these religions strongly influence the social and cultural patterns of their lives in Southwark and elsewhere in the United Kingdom.

2 Contacting carers

Finding Asian carers, as in the case of Afro-Caribbean carers, proved to be a difficult task. Contacts were made with Asian organisations and a temple in the borough. Individuals who worked with the Asian community were also contacted and spokespersons for the various groups promised to contact carers.

Information on this project was translated into three languages - Urdu, Bengali and Punjabi - and was disseminated to all the groups mentioned and associated individuals. The researcher was accompanied by an interpeter when visiting carers as many of them did not speak English.

Asian carers were contacted through several sources. For example, one carer was contacted through a day centre, four through an individual who worked with the Asian community on a housing estate, and five through an Asian voluntary organisation. Meetings with carers were also organised and held at a voluntary Asian organisation.

Ten carers looking after ten relatives were interviewed. The results of two of these were used for the pilot scheme and the remaining eight for this chapter. The conclusions of two meetings held with Asian carers were taken into account in the

sections on the needs of carers and elderly relatives and the recommendations were devised from information given by all carers, including the two on the pilot scheme.

Of the eight carers interviewed, only two cared for elderly relatives. The remainder cared for their husbands aged 55 and over but who had not yet reached pensionable age. Two of these appeared to be of pensionable age but because they have no adequate proof of their age, it was difficult to assess whether they qualified as elderly relatives.

3 Difficulties

It was discovered that the low number of carers who volunteered to be interviewed was due to many factors. The researcher was told by Asian women that the reasons were:

- The Asian community expected elderly relatives to be cared for by their families and any intervention from outsiders was seen as social disgrace.

- Questions in the questionnaire were too personal.

- Many of the carers did not speak English and would have been more cooperative if the questionnaires had been written and given to them in their own languages.

Other reasons were:

- Some carers, on hearing that the researcher was unable to obtain for them better housing and/ or adequate living conditions, felt that the interview was pointless.

- Others who lived apart from their relatives, feared that this would be seen as a social disgrace by the Asian community. This was of grave concern to some older Asian carers who were worried about their own well being if they should need help in the future.

Many of the carers preferred to speak to someone they knew so the researcher worked with interpreters who were known to the community.

Many of the interpreters were also part-time workers for organisations of which the carers were members, so many of them could only afford to give limited time.

To try to overcome this problem, one interpreter distributed copies of the questionnaire to Asian carers who also spoke English. Two of these were returned but they were incomplete and could not be used in the research.

The general impression gained by the researcher was that carers were not sure that she could be trusted with personal details of individual families despite the assurances of confidentiality that were given.

The researcher felt that more time was needed to gain the trust and confidence of the community before a project of this nature could be carried out satisfactorily.

The Asian community expect family members to care for elderly relatives without intervention - but carers do need support from community

CARERS AND RELATIVES

4 Carers

GENDER AND AGES OF CARERS

Age	21-30	31-40	41-50	51-60	61-70	Total
Male	0	0	0	1	1	2
Female	1	2	2	0	1	6

WHERE THEY LIVED

Camberwell	1
Peckham	2
Newington	5
Walworth	1
Outside Southwark	
Finsbury Park (Haringey)	1
	10*

* Includes two people in the pilot scheme.

LANGUAGE

The carers interviewed spoke the following number of languages:

Three languages	2 carers
Two languages	2
One language	4

All those who speak one language named Bengali as their first language. One named English, one Punjabi, one Urdu and one Chicheva as their first language. Four of their relatives could speak English.

MARITAL STATUS AND CHILDREN

Carers	Male	Female
Single	0	0
Married	1	6
Divorced	1	0
With children	2	6
Without children	0	0
Children at home	1	6
Children not at home	1	0

Of the seven carers who had children living at home, six had young children of school age. The other carer lived at home with his son and daughter-in-law who had young children of school age.

EMPLOYMENT STATUS

Six of the eight carers were homemakers while the remaining two were retired. All spent a substantial part of their day caring for their relatives. Seven received financial benefits and one was dependent on her husband's income.

HEALTH

Carers described their health as:

Satisfactory	3
Fair	3
Problematic	2

VISITS TO GPs

Fortnightly	1
Monthly	4
Only when ill	3

Five took medication,

COMPLAINTS AND ILLNESSES

Seven suffered from medical complaints such as:

Hypertension	1
Headaches	1
Diabetes	2
Frozen shoulder	1
Nervous disorder	1
Rheumatism	1
Tiredness	1
Heart attack	1
Body pains due to Lifting	1
Gastric problems	1
Chronic heart failure	1
Occasional pains in Chest and elbow	1

The number of illnesses per person were:

Three illnesses	1
Two illnesses	3
One illness	4

One elderly carer took Valium in order to sleep at nights.

5 Relatives

RELATIONSHIP TO CARERS

In the Asian community, it is customary that elderly relatives (mother and father) are looked after by their son and daughter-in-law. The eight carers interviewed were not typical as they included only two couples. However at the two meetings eight women stated that they were caring for their in-laws. Five of the women carers interviewed, did not have in-laws residing in Britain. The relationship of relatives to carers was:

Elderly Relatives	Carers	
	Number	Male	Female
Mother	1	1	0
Wife	1	1	0
Mother-in-law	1	0	1
Husbands	5	0	5
Total	8	2	6

WHERE THEY LIVED

As stated, seven of the the eight relatives lived with their carers The ninth lived in a ground floor bedsit. She was visited daily by her son who spent almost all day with her before returning home 17 miles away.

AGES

Gender	55	56-60	61-65	80-85	Total
Male	4	0	1	0	5
Female	0	1	1	1	3

AILMENTS

Many of the relatives who were very ill, needed a great deal of care. The condition of these relatives varied and most of them suffered from more than one ailment, the highest number for one person being four. Ailments and their frequency were:

Diabetes	2
Arthritis	2
Stroke(CVA)	2
Persistent body pains	1
Incontinence	1
Gastric problems	4
Speech disability	3
Depression	4
Failing eyesight	1
Swollen and painful legs	1
Difficulty in walking	1
Forgetfulness	1
Hypertension	1
Injured back	1
Severe back pain	1

WALKING

Walked unaided	2
Using aids such as sticks, crutches, Zimmer frames and/or with assistance from carers	5
Unable to stand or walk	1

DRESSING

Dress themselves	3
Needed to be supervised and required help occasionally	4
Unable to dress themself	1

EATING

Fed themselves	3
Slow at eating and must be encouraged	2

CONTINENCE

Continent	4
Occasional incontinence because they could not get to the toilet in time	3
Completely incontinent	1

SHOPPING/SOCIAL EVENTS

Enjoyed going out occasionally with their carers	4
Preferred to stay at home and had to be encouraged by carers to leave their homes	4

(This list does not include churches or day centres)

WORK OF CARERS

6 Time and help given

- **TIME SPENT WITH RELATIVES**
  Four carers spent 21 - 24 hours a day with their relatives and the remaining four spent 11 - 15 hours. The majority of tasks were done during the waking hours although five carers also provided care during the night. Then, their tasks varied from helping with toileting to sitting with relatives who could not sleep.

- **PERSONAL CARE**
  Four carers provided personal care of which the most common was bathing and shaving.

- **PHYSICAL HELP**
  Five carers provided physical care of which the most common tasks were help with walking and climbing the stairs.

- **HELP WITH PAPERWORK/ FINANCIAL MATTERS**
  Three carers dealt with all the paperwork and financial matters. One sought help from his daughter-in-law. The others who could not speak English asked their community worker to help.

- **OTHER PRACTICAL HELP**
  All carers provided practical help for their elderly relatives, including preparation of meals, shopping, laundering, housework, gardening and decorating.

- **VISITS OUTSIDE THE HOME**
  Carers also escorted their elderly relatives on visits. Like the Afro-Caribbean community, the majority of these were confined to visits to GPs and hospitals. Very few relatives visited day centres or luncheon clubs as there were none near their homes.

- **COMPANY FOR RELATIVES**
  All carers sat with, talked to and generally socialised with their relatives. However, two carers found this a depressing experience because their husbands could not speak and became frustrated and tearful because they could not respond.

- **GIVING MEDICINE**
  Seven carers gave medication varying according to their relatives' illnesses. The most frequent task was giving tablets. Two relatives took herbal remedies and one had approached a private doctor for a second opinion.

- **SAFETY AT HOME**
  All Asian carers, like those of the Afro-Caribbean community, generally kept an eye on their elderly relatives to ensure that they are warm and safe from household accidents.

7 Number of years spent caring

Carers	Over 20	11 - 15	2 - 5	6-12 months	Total
Male	1	0	1	0	2
Female	0	1	4	1	6

8 Help from family

All carers received help from other family members including carers' children, a sister, son, and daughter-in-law. But the majority of carers had very young children whose ability to help was obviously limited.

9 Rest and holidays

None of the carers had been able to take a rest of two or more consecutive days or had had a holiday since they started caring. This was due to lack of money and because the majority also cared for young children.

KNOWLEDGE AND USE OF SERVICES

10 Community services

● PROFESSIONAL AND VOLUNTARY VISITS

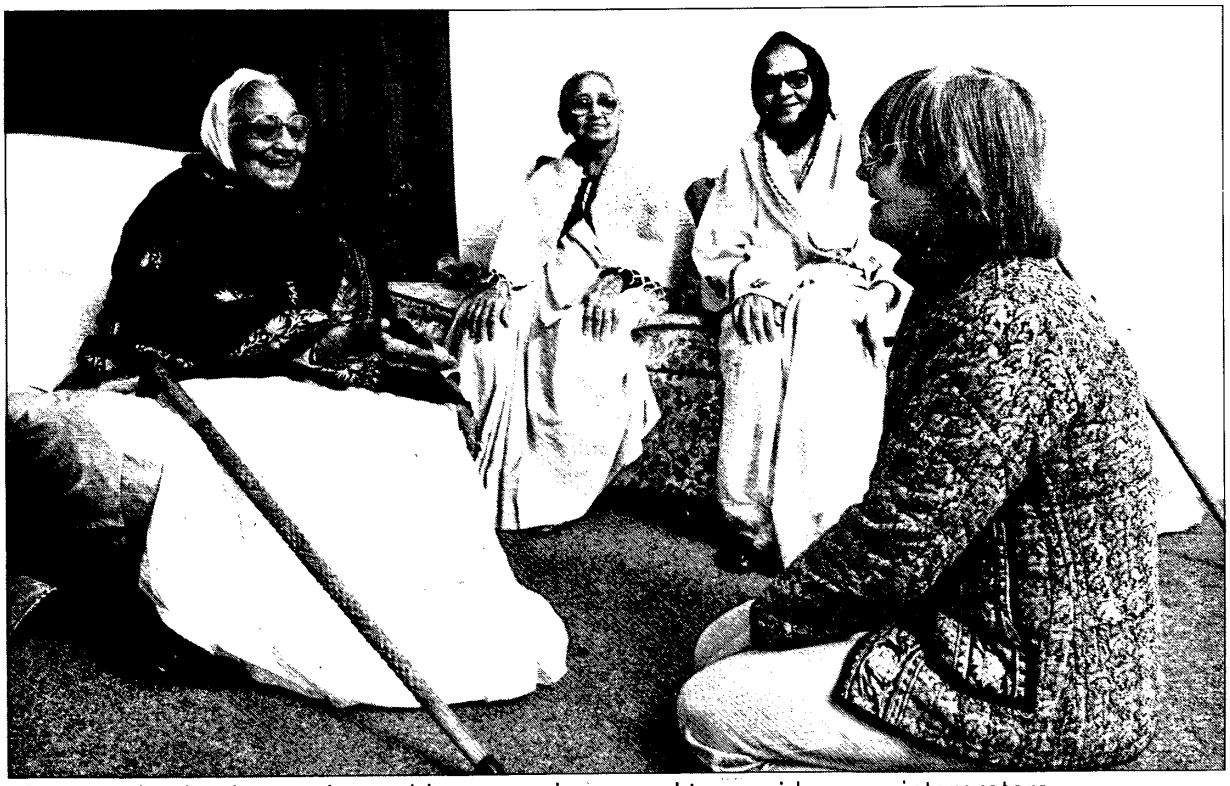
There were very few regular visits to carers and their elderly relatives from community services.

One carer received monthly visits from the community nurse. All relatives were visited by their GPs in an emergency. Other members of the community services were not known to carers.

● VENUES RELATIVES VISITED

Mosque (once or twice a year)	1
Day centre (twice weekly, totalling ten hours)	1
Community-based luncheon club (once a week, one to three hours)	1

All who attended these venues were happy to do so as they enjoyed socialising and the companionship of other people.



Communication is a major problem - services need to provide more interpreters

INFORMAL VISITS

Six of the carers did not have any other relatives apart from their immediate families in Britain. Their relatives received only occasional visits from friends and neighbours.

CARE OUTSIDE THE HOME

Almost all of the carers were unaware of many of the services provided in Southwark. Services known to them were:

Luncheon clubs	known by 3
Day centres	3
Residential homes	1
Respite care	1
Holidays For The Elderly	1
Holidays for the Disabled Elderly	1

SERVICES USED
One carer knew of all the services listed and their elderly relative had used the day centre and had been on a Holiday for the Elderly. This relative was very satisfied with the services she used. Among the others, only one relative attended a weekly luncheon club run by an Asian organisation.

DOMICILIARY SERVICES
Carers' knowledge of domiciliary services was also minimal. Services known were:

Home helps known by	2
Meals on Wheels	1
Aids and Adaptation Services	3

Among these, one carer had used the Home Help Service but no longer received it as she could not communicate with the home help. Three had been granted aids and adaptations comprising wheel chairs, a special air bed, bathroom and toilet appliances and rails, which they said were very helpful to them.

11 National Health Service

GENERAL PRACTITIONERS
All carers and their elderly relatives knew of and visited their GPs. This service was very helpful to all despite the difficult problem of communication.

COMMUNITY NURSING
Community nursing was known to one carer and was used by her relative. The service comprised a monthly health check and despite communication problems, both carer and relative seemed happy with it.

CHIROPODY
One carer knew of the chiropody service which was used by his elderly relative. Both were satisfied with the service they received.

DAY HOSPITALS
Two carers took their relatives to out-patients' appointments and were satisfied with the service they received.

SPEECH THERAPY
Speech Therapy was known to one carer whose relative had used it. However, this service had not helped the relative as he was unable to regain his speech.

OCCUPATIONAL THERAPY, PSYCHIATRIC COMMUNITY NURSING, HEALTH VISITING PHYSIOTHERAPY AND CONTINENCE ADVISER
None of these services were known to any carers or their relatives.

Although there was lack of communication between service providers and users, both carers and relatives appreciated what help they received and viewed it as someone taking an interest in their well-being.

12 Services offering advice and information

- **SOCIAL WORKERS**
  Hospital social workers were known to one carer who was given help by them when her relative was hospitalised.

- **WELFARE RIGHTS**
  Welfare rights workers were known to four carers who had consulted them and found them very useful. Carers had also sought and received information and advice from the community worker and workers of Asian organisations who also interpreted, wrote letters and accompanied them to business places.

13 Voluntary agencies

- **CITIZENS ADVICE BUREAU**
  One carer had used the services of CAB and found it helpful.

- **AGE CONCERN, HELP THE AGED AND DIAL-A-RIDE**
  None of the carers knew of these services.

14 Suitability of services

Many Asian carers could not say whether services were in keeping with their cultural and religious background because of their scant knowledge of services.

15 Experiences of racism while trying to obtain services

Carers did not feel that they had experienced racism in trying to obtain services. However four stated that they and their families were experiencing racism from members of the indigenous community who resided on the estate where they lived. It was reported that windows of Asian tenants were being smashed constantly, Asian children and adults were abused, and elderly women were afraid to walk through the estate at night. Although these matters were reported to the police and other agencies, they felt that nothing was being done to stop this harassment.

NEEDS OF CARERS AND RELATIVES

16 Difficulties and needs

- **DIFFICULTIES FOR CARERS**
  All carers felt that it was their duty to care for their relatives and had tried to cope the best way they could without help. However, many felt that they did not know much about the illnesses of their relatives and were unsure whether they were giving the

right care. This fear was compounded by the fact that they could not fully communicate with the GPs or other health and social services providers unless an interpreter was present, which was not always possible.

Other difficult tasks listed included:

Lifting
Having to look after both husband and children at the same time
Carrying shopping up four flights of stairs
Leaving relatives alone for long periods.

NEEDS OF CARERS AND

Carers requested the following help :

- Interpreters employed by the borough,in each department or place of importance

- A health visitor or nurse to visit and speak their language about their relatives' illnesses, prevention and treatment

- A helpline or someone who can be contacted for information and guidance

- A centre or activity unit for relatives especially those recovering from strokes, to help them recuperate

- Somewhere or someone to help stimulate relatives to take an interest in themselves and their surroundings especially when they are depressed and carers are unable to help them

- Financial reward for carers. One elderly carer looking after his wife had wanted to give his daughter-in -law some payment for her help to both his wife and himself. He applied for financial help from the social services department but was refused

NEEDS OF RELATIVES

Relatives were mainly concerned with inadequate living conditions and the limitations this placed on them. For example, some said they were cold, not because they did not have central heating, but because they could not afford to use it for longer than a few hours each day. One who had central heating was cold because there was no door to his sitting room.

Two relatives, one recovering from a stroke and the other with a heart condition, were confined to their flats for long periods because they could not climb stairs.

One man recovering from a stroke asked for an explanation of the after- effects. Many wanted to be pain free, feel warm, rehoused, to have repairs done to the flat. Two relatives who were unable to speak, could not express their needs.

17 Housing

Of the eight carers, five lived in council dwellings. One carer lived in rented

accommodation owned by a housing association, two in owner-occupied terraced houses, and one in a flat.

Three carers living on the same estate, were found to be living in very poor and inadequate housing. The approach to the flats was dirty, rooms were cold and unattractive and there were no lifts.

Two of the three carers living there felt that a change in accommodation was their prime concern and, in conversation, this seemed to take precedence over their caring role. The other carer was most concerned that the council repaired her flat as promised.

Requests for transfers to ground or first floor flats had been made by the two carers so they could cope better with their relatives' illnesses, but none had received favourable replies from the housing department despite GPs' letters and the community worker's representations.

18 Benefits

Benefits	Number of Relatives
Pensions	3
Mobility Allowance	1
Attendance Allowance	1
Housing Benefits	6
Income Support	5
Invalid Care Allowance	1

Three relatives received old age pensions. The remaining five, who were not of pensionable age, received other benefits.

One benefit received by	2
Two benefits	5
Five benefits	1

All carers supported the relatives financially from the family benefits they received.

COMMENTS

Half the carers interviewed lived on one housing estate and all were members of the Bengali community, so their problems, though not unique, were not necessarily typical of those of all Asian communities.

Despite the community's expectation that family members should care for their relatives without intervention from outsiders, it is evident that carers needed other support. But community services should be set up in consultation with the community and assessed to ensure that they are acceptable to users and appropriate to their values and norms.

Significantly, the research showed that the majority of carers interviewed did not have the immediate support of their extended family. But help by statutory or voluntary bodies should be provided sensitively. For example, provision of a home help from the same minority ethnic community overcomes some of the objections to outside intervention.

Further discussion is on page 66.

CHAPTER FIVE

Vietnamese/Chinese carers

INTRODUCTION

1 Background

The Vietnamese and Chinese communities are probably the most recent to reside in Southwark. Most people of both communities came originally from Vietnam, but a considerable number come from Hong Kong, Malaysia, China, Laos and Cambodia.

This project was primarily based on Vietnamese and Chinese communities from Vietnam. In Southwark there are about:

400 Vietnamese speaking refugees from Southern Vietnam

100 Vietnamese speaking refugees from Northern Vietnam

100 Chinese speaking refugees from Southern Vietnam and

1900 Chinese speaking refugees from Northern Vietnam

In Southwark, the Vietnamese and Chinese cultures are reflected within these communities and while Confucianism is the most popular religion, there are many Buddhists and Christians attending Roman Catholic, Anglican, Methodist and Pentecostal churches.

Members of both communities live side by side in Southwark and it is also common to find many Vietnamese-speaking Chinese and vice versa.

The communities are served by three community centres maintained by voluntary workers from the communities they serve. Two of these centres are based in Southwark and the other in Lewisham.

Those in Southwark are used by the Vietnamese and Chinese refugee communities. The centre in Lewisham is used by the Indo-Chinese community from Laos, Cambodia and Vietnam.

2 Contacting carers

Unlike the Afro-Caribbean and Asian communities, there was not much difficulty in finding carers of elderly relatives in these communities. This may have been because these communities are relatively small and there was more contact between community

Carers were younger than in the other two communities - and still adjusting to life in Britain

workers and individuals.

For this project, the community workers were contacted by post and in person to outline the aims and objectives of the project. In response, two of the community centres each allocated a worker who set up the interviews and acted as interpreter on all visits.

The third community centre translated the questionnaire in Cantonese/Mandarin and undertook to interview the carers themselves as they were unable to spare the time of a worker/interpreter.

Fifteen carers looking after 20 elderly relatives were interviewed. Interviews with two carers were used for the pilot scheme and the remainder for this part of the project.

3 Difficulties

Some carers who agreed to be interviewed, suddenly changed their minds as dates were being set for interviews. It was felt that this was because they were uncertain of what was being expected of them and of the outcome of the interviews.

To overcome this, more time was needed to explain to carers the aims and objectives of the project which might have gained their confidence. Unfortunately, there was not enough time left before the end of the project to do this so the wishes of the carers were respected.

Five elderly spouses whose partners appeared to be self caring were not interviewed as they did not fulfil the project's criteria of a carer.

CARERS AND RELATIVES

4 Carers

GENDER AND AGES

Carers	20 yrs & under	21-30	41-50	61-70	71-80	Total
Male	0	0	3	2	1	6
Female	3	2	1	1	0	7

WHERE THEY LIVED

Camberwell	11
Peckham	1
New Cross	1
(Borough of Lewisham)	

LANGUAGE

Of the 13 carers interviewed, three each spoke three languages, and ten, two languages each.

When two languages were spoken, these were Vietnamese and Cantonese. Those who spoke three languages named English as their third language. Ten carers named Cantonese as their first language and the remaining three named Vietnamese. Ten carers could read and write in their first language. Seven attended English classes.

MARITAL STATUS AND CHILDREN

Carers	Male	Female
Single	0	4
Married	6	3
Divorced	0	0
With children	6	3
Without children	0	4
Children at home	4	3
Children not at home	2	0

EMPLOYMENT STATUS

	Male	Female
Employment Training	0	2
Full-Time Employment	1	0
Home-Makers	1	3
Retired	3	0
Unemployed	1	0
At School	0	2
Total Carers	6	7

The male carer listed here as being a home-maker was unable to seek employment as he has been caring for his father since they both arrived in Britain as refugees. The other listed as unemployed was actively seeking employment as both his wife and children help to care for his elderly mother. Of the two female carers attending employment training at the community centre, one has had to give up full-time employment in order to care for her grandmother. The three women listed as home makers are financially supported by their husbands and care for young children at home.

HEALTH

Carers described their health as:

Good	7
Satisfactory	3
Fair	3

VISITS TO GPs

Their frequency of visits to the GP were:

Fortnightly	1
Monthly	2
Every six months	1
Only when ill	9

COMPLAINTS AND ILLNESSES

Three suffered from medical complaints including:

Headaches	3
Tiredness	3
Eye Strain	1
Hypothermia	1

One elderly carer took tranquillisers and two took medication.

5 Relatives

RELATIONSHIP TO CARERS

All of the carers looked after elderly relatives closely related to them. Many men in the Vietnamese/Chinese communities, like those in the Afro-Caribbean community, were found to be caring for elderly relatives. Grandchildren were also found caring for their grandparents. The relationship of

relative to carers was:

Elderly Relatives	Carers No.	Male	Female
Mothers	6	1	5
Fathers	4	2	2
Grandmothers	2	0	2
Grandfathers	2	0	2
Mother-in-Law	1	0	1
Wife	3	3	0
Total	18	6	*12

*Five carers each looked after two relatives.

WHERE THEY LIVED

In most Vietnamese/Chinese communities the extended family living in one unit is a normal feature of social life. However, this custom is not always followed in Southwark because of the shortage of adequate homes.Three of the 13 carers did not live with their elderly relatives. Two lived under two miles away and the other about four miles away. The elderly relatives who lived apart from their carers were all couples. All elderly relatives lived in the borough as well as 12 carers. The other carer lived just outside Southwark, in Lewisham.

AGES

	56-60	61-5	66-70	71-5	76-80	81-5	85+
Male	0	0	2	1	1	1	1
Female	2	1	4	1	2	1	1

Total males 6 Total females 12

AILMENTS

The ailments of the elderly relatives are varied and many suffer from more than one ailment, the highest being five. Ailments mentioned and their frequency were:

Diabetes	2
Arthritis	2
Stroke (CVA)	2
Persistent Body Pains	5
Incontinence	2
Haemorrhoids	1
Headaches	1
Depression	1
Failing Eyesight	1
Blindness	1
Difficulty in walking	8
Forgetfulness	1
Hypertension	1
Bronchitis	1
Frequency of Micturation (leads to incontinence)	1
Chronic obstructive airway disease	1
Difficulty in breathing	1
Hypothermia	8

WALKING

Walked unaided	10
Used aids such as sticks, and assistance from their carers	6
Bedridden	2

● DRESSING

Dressed themselves	6
Needed to be supervised and needed help occasionally	6
Unable to dress themselves	6

● EATING

Fed themselves	7
Slow at eating and had to be be encouraged	5
Difficulty in eating and needed a soft diet	6

● CONTINENCE

Continent	12
Occasional incontinence - unable to get to toilet in time	4
Completely incontinent	2

● SHOPPING/SOCIAL EVENTS

Enjoyed going out occasionally with their carers	8
Preferred to stay at home and have to be encouraged by carers to leave their homes	8
Bedridden	2

The majority of social events attended by the elderly relatives were organised by their community centres.

WORK OF CARERS

6 Time and help given

● TIME SPENT WITH RELATIVES

Seven carers spent 21 - 24 hours a day with their elderly relatives, one 16 - 20 hours, and the remaining five, five to ten hours. The majority of tasks were done during the waking hours, but six carers provided occasional night care.

● PERSONAL CARE

Nine carers provided some aspects of personal care of which the most common were bathing, washing and shaving. Many expressed having difficulty with these tasks which they said were awkward and time consuming.

● PHYSICAL HELP

Nine carers also gave elderly relatives physical help with walking, climbing the stairs indoors and toileting. These tasks were doubly difficult as many relatives did not have adequate walking aids.

● HELP WITH PAPERWORK/ FINANCIAL MATTERS

Three carers dealt with all paperwork and financial matters. Others sought the help of

their community workers at the centres they attended as they could not communicate in English.

- **OTHER PRACTICAL HELP**
  All carers provided practical help for their elderly relatives. This included preparation of meals, shopping, laundry, housework, gardening and decorating.

- **OUTSIDE VISITS**
  Eleven of the 13 elderly relatives were escorted by their carers on visits outside the home. The majority of these were to GPs and hospitals. Some relatives were encouraged to visit the community centres. Two relatives were bedridden and were only visited in an emergency by their GPs.

- **COMPANY FOR RELATIVES**
  All carers sat with, talked to and generally socialised with, their elderly relatives. This was shared by friends and visiting relatives.

- **GIVING MEDICINE**
  Eleven carers administered medication prescribed for their relatives' illnesses. The most frequent task was giving tablets. However, seven elderly relatives took herbal remedies but none had consulted a private doctor.

- **SAFETY AT HOME**
  All carers kept an eye on their elderly relatives and were aided by friends and other relatives.

7 Number of years caring

Carers	11 - 15	6 - 10	2 -5	6-12 mths	Total
Male	1	1	2	2	6
Female	0	2	3	2	7

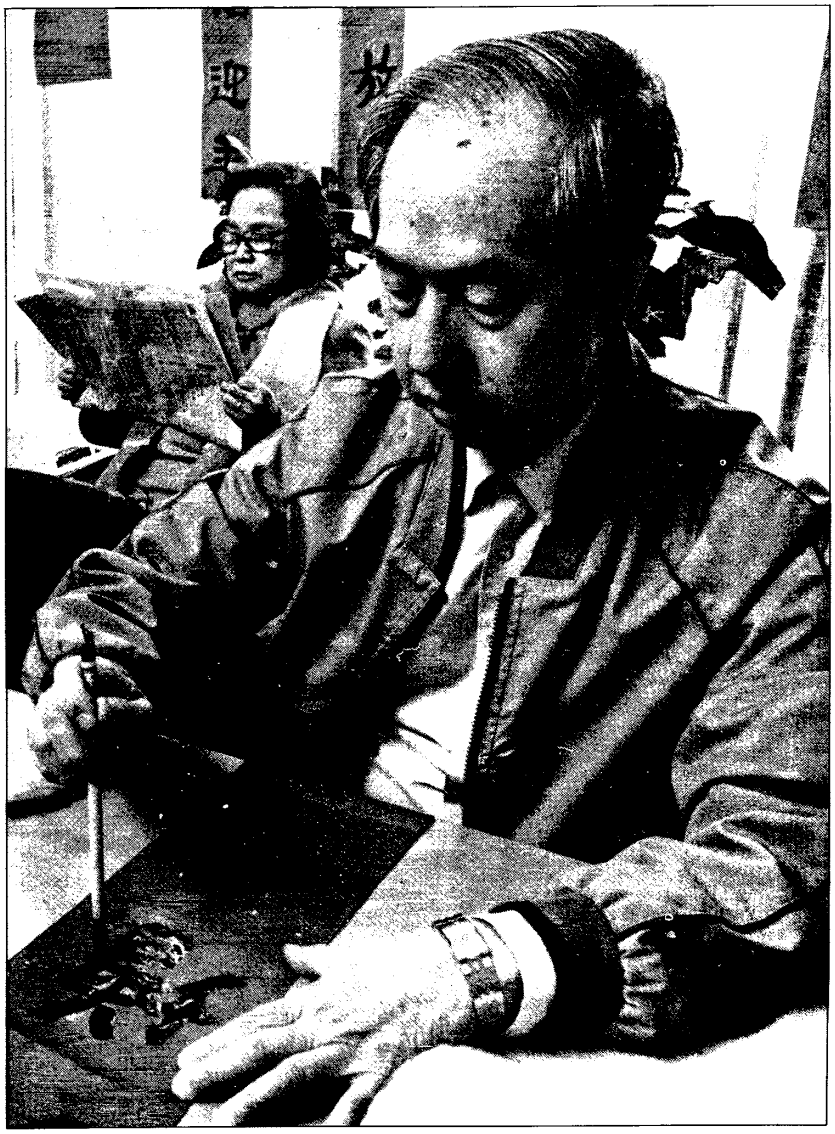
8 Help from family

Eight carers received help from other family members. These were usually relatives closest to the elderly relatives such as sons, daughters, daughters in-law and grandchildren. The five carers who did not receive help, had no close relative living in Britain.

9 Rest and holidays

Eight of the carers interviewed were able to take a rest of two or more consecutive days from caring. The remaining five could not because there were no other family members in Britain. Eleven of the elderly relatives could be left on their own or with their spouses. Three could be left for short periods and eight (four couples) for longer periods. Eleven carers could not remember when they last had a holiday. The remaining two had holidays six months and more than ten years before.

The Vietnamese/Chinese community is relatively new to Southwark and, being close knit, does provide some back-up



KNOWLEDGE AND USE OF SERVICES

10 Community services

● PROFESSIONAL AND VOLUNTARY VISITS

Six elderly relatives received frequent visits from their GPs. These visits were made on request as no GP visited routinely. Apart from these, one carer received monthly visits from a health visitor and another was visited by a social worker.

● VENUES RELATIVES VISITED

Of the 18 elderly relatives being cared for, only eight enjoyed going out.

Their visits were to:

Church or Temple	3 - regularly
Community-based Luncheon clubs	3 - once weekly for four hours 4 - once weekly for one to three hours 1 - three times a week for a total of ten hours

The five men and three women who attended these venues enjoyed the fellowship and the companionship of being with other people. However, one elderly male did not attend regularly because he did not know how to get there by bus. Each week he walked about three miles to visit the centre.

● INFORMAL VISITS

Five of the carers interviewed did not have any other relatives apart from their immediate families in Britain. In one household, the immediate family comprised the grandmother, grandfather (the elderly relatives) and grand-daughter - the carer. Hence, the occasional visits to these elderly relatives were limited to friends, neighbours and workers from their respective community centres . Other elderly relatives received daily visits from various members of their families.

● CARE OUTSIDE THE HOME

Almost all of the carers were unaware of many of the services provided in Southwark. Those they had heard of were:

Community centre luncheon clubs	known by 10
Day centres	3
Residential homes	1
Holidays For The Elderly	3

● SERVICES USED

Eight elderly relatives attended community-based luncheon clubs including two who

spent the day at the centres. One elderly relative had been on a holiday for the elderly organised by social services.

● DOMICILIARY SERVICES

Services known by carers were:

Home Helps	1
Southwark Alarm Scheme	1
Aids and Adaptation Services	1
Meals on Wheels	0

11 National Health Service

● GENERAL PRACTITIONERS

All carers and their elderly relatives knew of and used their GPs. They found the service very helpful despite the difficult problem of communication. Some carers expressed great admiration for their GPs' ability to communicate through sign language.

● COMMUNITY NURSING

This service was known to two carers whose elderly relatives had used it in the past. On both occasions, relatives were visited at home after they were discharged from hospital.

● CHIROPODY, DAY HOSPITAL AND PHYSIOTHERAPY

These services were each known to one carer but none had been used.

● PHYSIOTHERAPY

Not known to anyone.

● OCCUPATIONAL THERAPY, PSYCHIATRIC COMMUNITY NURSING, HEALTH VISITING, SPEECH THERAPY, PHYSIOTHERAPY

The services of the health visitor were known to two carers and have been very useful to their two elderly relatives. No-one knew of any of the other services.

● CONTINENCE ADVISER

Not known to anyone.

12 Services offering advice and information

● SOCIAL WORKERS

Social workers were known to five carers. Three had used their services and two had found them very helpful. The other carer said that although her social worker listened sympathetically to her problems, she did nothing to help her solve them.

● WELFARE RIGHTS

The work of Welfare Rights was known to four carers. The two carers who had used the service, had found it very helpful.

13 Voluntary agencies

- **CITIZENS ADVICE BUREAU**
  The CAB is known to two carers. One had used this service and found it helpful.

- **AGE CONCERN, HELP THE AGED AND DIAL-A-RIDE**
  None of these services were known to carers.

14 Suitability of services

All carers felt that they could not answer the question about the suitability of services because of their lack of knowledge of them.

15 Experiences of racism while trying to obtain services

Eleven carers did not feel that they had experienced racism in trying to obtain services. Two stated that they did not know.

NEEDS OF CARERS AND RELATIVES

16 Difficulties and needs

- **DIFFICULTIES FOR CARERS**
  Difficult tasks and problems experienced by carers were:

  • Bathing and washing - four carers had difficulties in coping with their bedridden relatives because of poor washing facilities in their flats

  • Dressing and lifting - highlighted by carers with bedridden elderly relatives

  • Toiletting - another problem for carers with bedridden and incontinent elderly relatives

  • Feeding - one carer found it difficult to get her elderly relative to take nourishment

  • Taking time off work - to take relatives to see the doctor

  • Communicating with GPs - not being able to speak English with the doctor caused difficulties for four carers

- Isolation - six carers felt isolated because they could not meet or communicate with a professional person about how to care for elderly relatives with specific medical problems and conditions such as diabetes, stroke, loss of appetite, depression, blindness, chronic obstructive airway disease leading to persistent breathlessness

- Social isolation - another carer felt isolated because she could not communicate with anyone - family, friend, nurse - on a daily basis

- Coping with housework - one carer found it difficult to care for an elderly relative and keep up with the housework

- Leaving relatives alone - leaving relatives for long periods was very difficult for two carers

- Travel - having to travel daily to elderly relatives' homes was a problem for one carer

- Anxiety - not being able to relieve the elderly relatives' anxieties on health problems

- Getting interpreters - having to arrange for an interpreter on visits to the doctor

- Clothes washing facilities - having to wash large amounts of soiled bed linen daily without a washing machine

NEEDS OF CARERS

Resolving problems on health care was the uppermost concern of the majority of carers as many of them felt isolated from the primary health care team (doctors, nurses, health visitors). Many felt that they were entrusted to care without adequate advice. Their main concern was to gain knowledge of caring for specialised illnesses and reassurance that what they were doing was right.

Another carer whose elderly relative has refused to eat, had sought advice on how to prepare soft but healthy and varied diets in order to tempt her relative to eat.

Many carers also sought advice on caring for relatives who complained of feeling cold despite living in centrally heated homes.

Those who were still trying to adjust to their new life in Britain needed help to understand the customs and culture of their host country.

Financial problems also featured prominently as many carers found it difficult to provide a substantial level of care on their income. Apart from pensions, many carers were unaware of the financial benefits available and did not know how to claim them.

An additional problem was that many elderly relatives and carers did not speak English very well. Many carers had learnt some English in Britain and could understand a little of what was said. However, many were reluctant to speak the

language for fear of making mistakes, and continued to attend English classes.

Help requested by carers was:

- Bilingual visitors who could give physical help with bathing, dressing and feeding elderly relatives as well as advice in doing these and other daily tasks

- Knowledge and means of obtaining financial allowances for the elderly relatives and carers

- Financial assistance to maintain a substantial level of care

- A wheelchair to enable elderly relative to sit out of bed

- Change in living accommodation from top to bottom floor of house with all rooms on one level

- To be able to talk to the doctor or a medical professional about treatment of illnesses of elderly relatives

- To have someone to accompany elderly relative to the doctor and speak on their behalf

- To have someone to sit with the elderly relative or visit when carer is out

- To be reunited with wife and children who are still in Vietnam

- Frequent visits from health visitors or persons who can advice on health matters and other facilities available for elderly relatives

- Volunteers who can communicate and act as companions to relatives living alone

- Specially-adapted flats for elderly relatives

- Knowledge and means of obtaining places in residential homes for elderly relatives who can no longer be cared for at home by carer

NEEDS OF RELATIVES

Although the project worker did speak to some of the elderly relatives through an interpreter, many of them did not express a need. Almost all the needs stated below were identified by the carers. These were:

- A variety of soft, wholesome and easily edible foods

- A wheelchair

- Permanent full-time care

- Appliances to enable a blind elderly person to be more independent in the home

- A comfortable chair

- To be able to feel warm in centrally heated dwellings

- To visit relatives in Vietnam
- Help in understanding the language, cultures, rules and regulations of the host country
- Special care and attention

17 Housing

All 13 carers lived in rented council accommodation. Four lived in terraced houses, five in maisonettes and four in flats, two of which were on the ground floor. There was adequate room in 11 of these dwellings but the other two were over-crowded and relatives had applied for larger premises. Many of their homes did not suit the elderly relatives because of the number of stairs, but no-one had applied for a transfer to other accommodation.

18 Benefits

	No. of relatives
Pension	12
Housing Benefits	12
Income Support	1
Attendance Allowance	1

One elderly relative received one allowance. Another received three. Eleven received two benefits each.Eleven carers supported their relatives and the remaining two were at school and were financially dependant on their relatives.

COMMENTS

Carers in this sample were married and younger than in the other two communities. Most carers had also been caring for a shorter period - under five years.

Both carers and elderly relatives were health conscious and saw their priority as being given information on health and care in terms of food, medicines and facilities.

With the Asian community, the Vietnamese and Chinese communities shared language difficulties and lacked knowledge of services. Their problems were compounded by the fact that the majority was still trying to adjust to their new life in Britain. In this situation it was only natural that they turned for help from their own communities. However, they cannot give all the practical help that is needed. But being relatively new to Southwark, these communities are closely knit and do provide some of the back-up services.

Many carers and their elderly relatives are still trying to adjust to British culture - and the weather. There is a language barrier, but their community workers were translating for them.

Although the community seemed to be a close one at present, there were signs of fragmentation, evidenced by the fact that close relatives were living apart from elders.

Discussion of the research findings is presented on page 67.

CHAPTER 6

Case studies

1 AFRO-CARIBBEAN CARER

'Give us the services that we want instead of dictating what should be available'

Mr Palmer is a divorcee who lives in a flat with his son. When his mother became ill with a stroke, he immediately moved into her masionette to look after her as he was the only close relative living in Britain.

The stroke severely disabled his mother, as she lost the use of her left arm and leg and could not stand. She also became incontinent and her speech was slurred.

After several spells in hospital after a heart attack and diabetes, his mother was eventually offered a place in a residential home. But because of "mince every day" and the lack of physical and mental stimulation, she pressed her son to take her home. After eight months, he gave in.

He was given the services of a home help twice a week and a community nurse who came twice a day to help wash, dress, check his mother's blood sugar level and put her to bed. Later, he was able to find his mother a twice-weekly place at an Afro-Caribbean day centre. However, due to the limited amount of financial help given, Mr Palmer could not afford to give up his job and sought the help of his daughter and son who were both at school.

This arrangement worked well during the school holidays when the children provided company for their grandmother while their father was at work. However, once school started, problems arose as it became apparent that his mother could not be left alone in the house for long periods due to her disabilities.

Mr Palmer then tried to employ a care assistant to be at home with his mother when he was at work. Financial assistance was sought to meet the assistant's wages but social services refused on the grounds that they did not provide such services for senior citizens. Although greatly disappointed, he employed and paid the wages of the care assistant out of his own income. However, the care assistant was unreliable and a replacement proved very difficult to find.

The community nurse also started to visit less frequently and not at all on some days. When enquiries were made, Mr Palmer was told that priority of nursing care was being given to senior citizens living alone.

With no further help promised and with deteriorating health due to carrying his mother up and down the stairs, Mr Palmer sought the help of his sister in Jamaica.

The family then decided that his mother should return to Jamaica to be looked after by her daughter and the extended family there.

Although Mr Palmer was able to solve his caring problem, he feels very angry about the way the system offered help to him. He found it "strange for social services to be willing to pay over £200 a week to a residential home for services which a senior citizen does not want, yet refuses to pay half that amount for a more suitable service in their home."

He wanted to see "social services finance those services which carers and their elderly relatives find beneficial to them, instead of dictating what services should be available".

2 VIETNAMESE/ CHINESE CARER

Help has been promised but none given

Ching is a 19-year-old woman who arrived with her grandparents in Britain eight years ago as a refugee from Vietnam. Both her parents are dead and her only surviving relatives are her grandparents.

Three years ago her grandmother became ill and suffered a stroke, from which she made a remarkable recovery. However, two years later she suffered another stroke which left her paralysed and bedridden. All care for the grandmother is now provided by Ching and her grandfather. There is no help from social services despite repeated requests. Ching experienced great difficulties in caring and maintaining full-time employment and consequently had to give up her job.

Her GP visits only when called in an emergency and the community nurse visited once after grandmother was discharged home from hospital. Both GP and social services have been repeatedly approached for help. However, although both have promised help, none has been given.

Ching is finding it increasingly difficult to cope as her grandfather is also frail. Her most difficult task is to wash and dress her grandmother and encourage her to take small amounts of soft food.

Ideally, she would like her grandmother to be admitted to a residential home as she feels that her relative would receive better care and attention there. At present Ching feels that no one cares about her problems as all of the promises of help come to nothing.

3 ASIAN CARER

This proud lady and her son sit in the cold

Mrs Patel is an 80-year-old woman living alone in Southwark. Her son is medically retired from work and travels daily from North to South East London to care for his mother.

Although Mrs Patel is not bedridden, she does suffer from rheumatoid arthritis, deafness and is generally slow in moving around. However, she enjoys going out and visits a council day centre twice weekly.

Her son cleans her bedsit, shops, cooks, and generally takes care of all her correspondence. However, the financial help she receives is inadequate to meet the costs of maintaining her small bedsit. Both Mrs Patel and her son often sit in a cold room with their coats on to save on heating bills. This proud lady is afraid to have bills she cannot pay so tries to live on income support totalling £48.80 a week, plus rent and rates rebates. Extra money had been sought, but none granted. So she and her son continue to sit in the cold.

CHAPTER SEVEN

Discussion of research findings

The number of carers interviewed in each community was small. No claim is made that these were representative samples. The purpose of this discussion is to discern, in the lives and experiences of these carers, patterns which might help us to understand better how we can support minority ethnic carers in Southwark and elsewhere.

1 Afro-Caribbean carers: alone and under stress

Carers in the Afro-Caribbean community, from this evidence, are of similar ages compared to carers in the general population. (1) Like others,they are usually the wife, daughter or husband of the elderly person they look after. This similarity includes the proportion of men as carers; however, more men seem to be receiving care. (2) This fits with predictions of the growth minority ethnic elders (3)
The carers generally had to provide many forms of care for their elderly relatives, looking after most personal, practical and domestic tasks, and being responsible much of the time. Several had to provide care at night. Many carers had responsibility for children and also reported some illnesses. These patterns we know from the wider population of carers. (4)

What is striking is how many carers worked. Having a job as well as providing care could place enormous pressure on carers. Respite care was needed by many of them. Many also reported the financial difficulties associated with caring. Several had to juggle work and caring, for example, in relation to patterns of shift work. Some had to work fewer hours. Others also had to sacrifice career prospects (5).

The experiences of the carers did not bear out any ideas of a markedly different pattern of family help compared with the community at large. The Afro-Caribbean carers had a strong wish to care for their elderly relatives, and if they were the eldest child, it was expected that it would be their role. When carers had other family members living locally, they received

visits and could get short-term cover from their relatives. But still most caring was done by one person - as it is everywhere. Help received from other family members was incidental or occasional, or at best, called on for lack of any alternative; several carers received none. Assumptions that Afro-Caribbeans are more ready to care, or likely to receive more help, should be modified on the evidence of this study (6).

Services were not providing a high degree of support to this group. Some services are well publicised; almost all knew of home help, community nurses. Meals on Wheels, chiropody, day care, holidays, and luncheon clubs. But, except for day centres, few services are used. Many of the carers interviewed were very sceptical of social services, and hostile to the researcher if they thought she represented them. Some had tried and failed to get services directly. The perception of the services as under pressure, cut back, or restricted by policy, may have contributed to this scepticism.

The various therapies, continence help, aids, and, significantly, respite care, are much less well known and much less used than the other services. The research shows that although carers and their elderly relatives could benefit from these services, they need to be modified to meet particular needs. For example, carers wanted a break but not residential respite care; someone to give them time off at home by taking the elderly relativ out.

Respite care in this context is relief from caring at regular intervals. More home help hours would give carers in order time to relax from the mental and physical stress of caring. Other examples could include a care attendant scheme when another person assumes the caring role in the home for a part of the day, week or month. Respite care could also mean someone encouraging the elderly relative to visit and socialise with other people.

The limited knowledge and low take up suggests that access to services and information is inadequate. Social services did not seem successful in providing direct access; some carers felt they had been misinformed or had experienced rejection by social services when trying to gain access. Many assumed you could not get help if you were working. Carers had a poor knowledge of health services, but nevertheless valued the relationship with the GP and his/her help in obtaining what services they had.

From the experiences of the carers, few, if any, efforts were being made to coordinate services provided for them. It is clear is that carers were willing to use their own community organisations, and lunch clubs. Moreover, churches provided a high degree of support including worship, visits by ministers and church members. Day centres serving the whole community were also used.

Several of the respondents were found through day centres and said they were satisfied with them. However, Afro-Caribbean elders were often in a minority among white users and some said they *felt* in a minority; but preferences for types of day

care were not asked for in this survey.

Although services have the potential to be an important source of support, many carers raised basic questions about accommodation and finance when articulating their own needs. Most financially supported their relatives.

2 Asian carers: Isolated, ill-informed, under stress, and in fear

The results of the interviews in this study are notable because they disclosed needs of a group of carers who were not well known. They were mainly women caring for their husbands whose illnesses were severe. Their only relatives were their immediate family, mostly young children. There were not many long-term carers (over five years). A majority of women also had the added responsibility of financially supporting their families.

This is not the typical received picture of carers, nor is it the only one in the Asian community. It emerges because the carers were mainly members of the Bengali community found through workers in one particular housing estate, not through community organisations. However, it also reminds us that although the debate on caring is often focused on the very elderly, the younger elderly - including those under 65 - may be in need of care and support (7).

Like the Vietnamese/Chinese carers in this report, and many carers generally, these women had a full time caring role within the household - none had a job. The people they cared for could move around with help, but needed a great deal of attention, and required constant attention.

This group had an alarmingly high degree of isolation. There was very little family help except from their own children. Many had no other family members nearby.

Their awareness of services was very low : even day care, home helps and community nurses (well recognised by the Afro-Caribbean carers) were known to only a few Asian carers. Only one carer received home help and only one was visited by a community nurse. None received respite care. There is no Asian run day centre in Southwark so Asians attending other day centres are often very isolated.

Isolation for this group was made worse because their community organisations were not in a position to offer them practical support. Their greatest reliance was on their local community worker. Not surprisingly, their own health was suffering - and more were ready to say so.

Communication was a constant problem for these carers. In dealing with professionals such as GPs, community nurses, home helps and coping with paperwork, their difficulties are compounded by a language barrier which no

one seems to be willing to remove. There seem to be no interpreters at doctors' surgeries, housing offices or other places of similar importance. English classes are often recommended but there seems to be little or no short-term help while they are trying to learn.

Many carers use their young children as interpreters but this is embarassing for parents and inhibits them expressing what they need. They also wanted more information about the nature of their relative's illness. As one carer stated when her husband was sent home from hospital after having a stroke, "I am expected to look after my husband at home, but no one has told me what to do in order to help him to recover".

However, many carers reported problems of more immediacy and magnitude than just lack of communication and poor services. For them, their day to day problems concerned poor heating, bad housing, the reality of racial attacks and lack of money. These need to be tackled on a wider front than just the caring issue. But as far as community care goes, for this group the issue is not how to obtain better services, but how to obtain even the basic services.

There is clearly a case for more work to get a rounded picture of the needs of all the diverse parts of the Asian community in Southwark. This is a big task. But there are a number of encouraging precedents to build on, such as the valuable work of community workers and welfare rights services and the trust and communication which Asian organisations have established in their own community. However, workers who can communicate with the community are often under great stress because of the demands on them.

3 Vietnamese carers: a community isolated and at risk

The carers in this sample were mainly married women and men, often with children at home. However, there was also a group of younger single women, including at least one teenager - a 'young carer'. A number of male carers were represented in this sample, looking after their wives and parents. Only one carer was working. These carers had often been caring for under five years. The elderly relatives were rather older in this group than in the others. Some were grandparents of the carer.

These are full-time carers, as in the other communities, carrying out the complete range of tasks including personal care, taking out, domestic duties and constant supervision. Caring was central to their lives, even when the elderly relative could be left alone for a short time or could move about unaided.

The Vietnamese/Chinese carers received more family help and support than the other groups and received daily visits and short term relief. This does not mean they are a self-sufficient group with no need of services. When services give few welcoming messages to people recently arrived in this country, it is natural for them to turn to their own communities for support. But the plight of the carers without any family is potentially grave. Since they receive no services, they continue to care with hardly any help.

All the carers had a very low awareness of services : none received home help or community nursing, and they had no knowledge of other services with which the Afro-Caribbean and Asians had more contact, like the CAB or chiropody. As a result, services from within their own community were very important. Their community workers are effectively trying to bridge the gap between those who do not speak English and the range of public services.

The carers saw health as a priority area, and visited GPs as well as often using herbal remedies. But communication with GPs was still a major problem for them.

Day-to-day caring was a restriction on the lives of many Vietnamese/Chinese carers : they mentioned travel difficulties and impact on their ability to work. Some lacked the basics of money and warmth.

The lack of support from services meant that some caring situations may be seriously neglected : especially where there are very young carers, and where they have no other family and have to struggle on unaided. These carers needed urgent action to improve practical help and day to day coping, information on disabling conditions, and take up of benefits.

4 Similarities and differences in the three communities

These summaries have concentrated on the general circumstances of the carers and the services they do or - more often - do not receive. The experience of receiving little or no support from services and pressures in their day-to-day lives are common to all carers.

There is no real reason why the situations of the communities should be the same: indeed the different degree of difficulty in finding carers - when paradoxically the smallest group with least contact with services were easiest to find - reflects the different stage of development of each community and its organisations. The Afro-Caribbean carers used services more, were more likely to be owner occupiers, and less likely to be in receipt of housing benefit. Over half of them worked; hardly any of the carers in the other communities did. Diabetes was a particular health problem for their

elderly relatives.

Being able to speak and read English obviously helped this group find out about services and enabled them to get access to them. It did not mean they were satisfied or that their needs were met. Two carers felt the services were inappropriate to their cultural or religious background.

Knowledge and use of services were much lower in the Asian and Vietnamese and Chinese groups. About half the small sample of Asian carers could speak English compared to less than a quarter of the Vietnamese/Chinese. Asian carers included far more spouse carers than the other two communities, and so were looking after fewer very elderly (aged 75 plus) relatives. The Vietnamese/Chinese carers were looking after older relatives and had a wider range of ages of carers. Their relatives were very unlikely to be receiving attendance allowance. Unlike the Afro-Caribbean carers, the Asian and Vietnamese/Chinese elderly were not regular attenders at day centres or religious groups.

Racism affected the daily lives of some people interviewed, particularly Asian carers living on one estate where threats and violence were commonplace. But few complained about discrimination from community care services. Asked about the the suitability of services for their religious and cultural needs, almost all the carers could not answer.

Superficially, these findings might seem to suggest that racism does not exist among service providers and that they are sensitive to ethnic needs.

But evidence here and elsewhere (8) (9) of low take-up by minority ethnic communities suggests otherwise. In addition, the success of locally-based community resources, such as churches and community workers, contrasts with the performance of statutory and voluntary services which are little known, poorly used, and held in low esteem. Plainly, they have failed to adapt to meet the needs of people in these communities who say they want and need their services. The failure points to the conclusion that racism, conscious or unconscious, has played a part.

5 Common issues

Carers in each of the minority communities had special needs which were not being met, but there were common issues to all three. These were:

- lack of information on health, diet and illnesses

- inadequate accommodation - overcrowded flats and maisonettes, lack of repair to council housing and unsuitable accommodation for elderly relatives

- inadequate access to services such as home helps, aids and adaptations, alarm schemes, respite care, and holidays for the

elderly

- inadequate finances to provide a substantial level of care

Signs that families are no longer caring for their elderly relatives are now emerging among the Afro-Caribbean and Asian communities. More elderly relatives are beginning to live on their own in Southwark and this trend is expected to continue. In order to meet the needs of minority ethnic elderly in 2001, policies must be developed and be implemented now.

6 Locating carers

Finding carers was a major difficulty in the Afro-Caribbean and Asian communities. In both cases, religious and community organisations were contacted by letter and post and sometimes visited to explain the project. Individuals with standing in the Asian community were contacted. Interpreters were used in contacts with Asian carers and organisations. Appeals to the general public were also used: the local paper in Southwark carried an article and press releases and a poster in four languages were issued.

A street canvass was used in Peckham Rye, a major shopping centre, where Afro-Caribbean women were asked by the researcher if they were looking after a relative.

None of these efforts proved easy ways of finding carers. It was only by visiting several organisations and much follow up work (including several visits to people who were not carers within the definition of the project) that carers willing to be interviewed were found. Day centres were a route to finding Afro-Caribbean carers, and a community worker who worked on an estate with a large number of Asian families was another important contact.

It seems likely that Afro-Caribbean community organisations saw their main purpose as looking after elderly people, in particular those who lived alone. Therefore they did not know the carers personally, or in many cases there was no carer. The same priority may have applied to a number of Asian organisations, although one in particular went out of its way to contribute to the project. In both cases a lack of understanding or a mistrust of the project's purpose may have been important factors.

The support of the workers at the Vietnamese/Chinese community centres was essential to the success of contacting Vietnamese/Chinese carers. They arranged translation of the questionnaires so that some carers could fill them in themselves and also found interpreters for meetings.

Attempts were also made to locate carers through letters and visits to social services and GPs, and also through requests to the district nursing service. In general these produced no results. Indeed, some services wrote back requesting information from the project worker.

References

(1) *Informal Carers*, HMSO shows that of all carers caring more than 20 hours per week, 31 per cent are under 45 (table 4.4); whereas eight out of 13 were under 50 in the present study. The range of ages is similar, even though this sample is younger.

(2) Sixty one per cent of carers in this sample were female, compared to 64 per cent of all carers (table 4.4 above). But 38 per cent of the people receiving care in this sample of carers of elders are men, compared to 30 per cent in the OPCS survey, which applies to all carers of people of all ages.

(3) See for example Steve Fenton, Health, Work and Growing Old: the Afro-Caribbean Experience, *New Community*, Vol 14, No. 3, Spring 1988, pages 426-443.

(4) *Informal Carers* HMSO shows that 54 per cent of carers had a dependent child under 16 (table 2.18) and 44 per cent had a long standing illness (table 4.6) - both figures for those caring more than 20 hours per week.

(5) Forty three per cent of carers who devote 20 hours per week to caring also work full or part time *Informal Carers* (table 4.5) HMSO.

(6) This assumption is implied, for example, in *Caring for People*, para 2.9 : 'minority communities may have different concepts of community care'.

(7) A study in Newham Health Authority concludes that 'the Asian population is ageing earlier than the rest of the population and is therefore in need of services, support and surveillance at a younger age. The Asian population between the ages of 65 and 74 are effectively in need of the kind and level of service provision currently anticipated for people over the age of 75 (in the rest of the population)'. It further recommends investigating the medical and social status of 'younger Asians' in the 55-65 age group. Catherine Itzin,'Asian Elderly in Newham', *Elderly People in the Community: screening, support and services* , Newham Health Authority, 1986.

(8) See for example, Alison Norman, *Triple Jeopardy*, (1985), page 98.

(9) Put Race on the Agenda, Frances Badger et al, *Health Service Journal*, December 8, 1988, page 1426.

CHAPTER EIGHT

Support for carers: conclusions and recommendations

CONCLUSIONS

The research findings show that in Afro-Caribbean, Asian and Vietnamese/Chinese communities individual carers are taking the main responsibility for the care of their elderly relatives, are looking after them for long hours, and are undertaking all the personal and household tasks. They are doing this at some considerable cost to themselves. This is a consistent pattern across the three communities surveyed. Although the sample numbers are small, if there were any notions that caring was not happening in minority communities, or that extended families within them made caring easier, this report provides strong evidence to the contrary. Minority ethnic carers are caring in the same way as white carers.

However, their circumstances are among the worst, especially in inner city areas like the one covered in this survey. The carers interviewed reported as their major worries the lack of basic necessities for caring: unsuitable accommodation, lack of warmth, insufficient money. Some of the carers lived in fear due to racial harassment.

Health, social services and voluntary agencies have an important part to play in supporting carers. Yet the report shows that the services are seldom received or provided, either through lack of knowledge or through an assumption that help is not needed. The language barrier adds to the isolation and hinders support being sought or received by carers.

Services that do exist (and, in a few cases, were reaching carers) are not adequately meeting their needs. All carers needed more practical help in the home to enable them to provide the best possible care. Respite services were needed to give them get a break from continuous care. Home help or home care services and community nursing, which might have been expected to be of most relevance, were not widely used or offered. More specialised services supporting elderly people in the community, and the services of voluntary organisations, were very little known: occupational therapy, physiotherapy, dial-a-ride, alarms, etc. Particular mention should be made of continence services: in all

communities, our small sample suggests that continence is a particular problem for a significant minority of elderly people - but one where help was lacking.

The problems for service providers included lack of knowledge of services among potential users, the way services were organised, policies about allocation, over-subscription, and the appropriateness of services to the needs of users. Lack of continuity by these services also made them seem less relevant to carers whose role tended to extend over several years. None of the services had succeeded in giving welcoming messages to carers in minority ethnic communities.

Service providers need to review their approach. There is no evidence that they understand the needs of carers in minority ethnic communities. They may have had assumptions that there were more informal networks of support; or that because carers were not coming forward and asking for services, they had no needs. They may have felt that minority ethnic community organisations were meeting all the needs of their communities.

All these notions now need to be rejected. So does the idea that improvements necessarily will involve huge amounts of new money. Most of the recommendations in the following pages involve better procedures and new management initiatives. They require organisations to look more carefully at how their services can reach minority ethnic communities, and may involve some shift to redress past imbalances, or new monies to seed new developments.

Finally, the report shows that there are many encouraging examples to draw on in building better support. Minority ethnic community organisations have done the most work in identifying and providing support to carers: through community centres, day centres, luncheon clubs, religous bodies and their networks. For many people in their communities, individual community workers have been effective advocates, linking carers with services, providing support and building relationships. But there are limits to what they and their organisations can do when their resources are so stretched. The report shows how much more needs to be done.

RECOMMENDATIONS

1 Minority ethnic community organisations

Minority ethnic community organisations have great potential and should continue to play their part in supporting carers.

Minority ethnic organisations have great potential to help and communicate with carers in the communities they serve, overcoming mistrust of traditionally run services

and providing language help. Through their networks, they have access to carers. This report provides strong evidence of all these functions. But support to carers still has a relatively low priority among these organisations, and is limited by lack of resources. In order to fulfil their potential, community organisations should :

- learn to recognise carers and understand their needs. The carers' perspective is not yet common in these organisations, which may focus on elderly people themselves, or else embrace the concerns of a wide spectrum of the community without a specific focus on carers. They should set up appropriate channels to hear carers' views
- become familiar with relevant reports and legislation (for example, the Griffiths Report on community care, the NHS and Community Care Bill, The Disabled Persons Act) so that they can respond to carers' issues
- support their workers in passing on information about benefits, services, and national and local policies which affect carers
- find appropriate ways to share information, discuss policies and coordinate their work with statutory and voluntary organisations concerned with carers
- run services such as day centres, visiting and meals services. This can be a direct way to organise provision when none exists, and can ensure that cultural and religious needs are met. However, the long-term management responsibility and resources must be carefully planned and agreed with funders: running such services can severely restrict some groups

2 Health services

Health services should develop a positive strategy to reach out to minority ethnic carers.

The language barrier is a severe obstacle for many carers in minority ethnic communities. But it is not just a question of language - and many members of these communities are making a determined effort to learn English. There are problems amongst Afro-Caribbean carers whose only language is English. Health services must improve not just in terms of language and information, but also in the nature and location of their services. Health services should :

- promote and explain their services more to minority ethnic communities, so people understand what is available. This can be done face to face as well as through printed information
- take services to community centres where carers are in familiar surroundings and community workers can provide assistance and, if necessary, translation or advocacy set up specific clinics for elderly people and

their carers

- provide health education relevant to the needs of carers and elderly people. This can be undertaken by a variety of means, including meetings about particular issues and by greater use of health visitors.

GPs should:

- ensure that they employ staff who can communicate with the communities they serve when their surgeries are within areas housing large numbers of people who do not speak English
- improve their understanding of carers' needs, give information and make the appropriate referrals.

3 Social services

Social services should increase the level of support given to carers in minority ethnic communities.

Social services are not meeting the needs of these communities and must begin to make changes so that they do. The employment of minority ethnic community workers in each area is a welcome start but one worker per area, per community is not adequate. Limitations on finance and community care legislation present great challenges to social services. Fortunately, there are a number of things which can be improved at relatively little cost:

- long waiting lists for services should be reduced
- more people from minority ethnic communities should be employed at all levels so that carers can make use of services
- services should be reviewed and adapted to meet the needs of different communities through, for example, help at day centres, interpreting help, female staff to care for women, appropriate food in residential homes, centres and for Meals on Wheels, staff familiar with religious or cultural customs including diets and festivals.
- access to services should be improved: services should be explained, application forms written in clear, simple language (translated where appropriate), and questions should not be asked which do not relate to the request for services
- they should take the lead in coordinating services (case management) to overcome the fragmentation which makes carers' lives more difficult
- community based projects should be set up in conjunction with minority ethnic organisations. These should be given adequate

funds, a realistic timetable, and their effectiveness assessed

4 Information

Information about services should be improved for minority ethnic carers.

Many carers do not know about services which may be able to help. This is especially true when a high proportion of carers do not speak English.

Voluntary organisations and more specialised health and social services are very little known.

Information must be local and it should be in the language and style which will communicate most effectively.

This may not always be printed material: both audio and video cassettes have been used effectively elsewhere. It is recommended that:

- health, social services and voluntary organisations should produce translated and printed information
- voluntary organisations should undertake outreach work to explain their services to black and minority ethnic organisations
- the Department of Social Security and advice organisations should give priority to encouraging take up of benefits
- a telephone information helpline should be considered, with staff able to give up-to-date assistance in the main languages used in minority ethnic communities in Southwark.

5 Consultation

Services should be planned in consultation with minority ethnic carers and their organisations.

Health, social services and voluntary organisations should do a better job of finding out the needs of black elders and their carers. The subject is hardly on the agenda at the moment. There is no regular system of consulting black organisations or involving individual carers in decisions about the people they look after. It is recommended that:

- community organisations should tell statutory and voluntary bodies what they can offer to the consultation process, and the most suitable ways of getting their views, given their limited resources
- national voluntary organisations should encourage their local branches to consult minority ethnic communities, to explain the services they offer, to elicit views, and where appropriate, to mount projects for carers
- statutory organisations should find ways of consulting minority ethnic groups on a

regular basis, and devote sufficient resources to this.

6 Respite care

Respite care options should be improved and increased.

Urgent improvements are required to respite care services, including short-stay residential care, holidays, and care assistance in the person's own home. These will involve new managerial responsibilities and, possibly, new services and new resources. Most of the carers interviewed in this report received little or no respite. Some struggled with the bare minimum. Respite care was not viewed as part of a package of support tailored to meet the needs of the carer and the elderly person.It is recommended that:

- there should be a coordinated review of all the respite services available to carers in Southwark, with the number of places specified. A coherent strategy should be drawn up, including day care and family placement, as well as the services listed above
- respite services should be available throughout the week and carers should have as much direct access as possible to the organisation providing them
- substitute carers working in respite services should be able to meet the needs of carers and elderly people through communication in a common language and understanding of cultural needs
- respite care services should be able to meet carers' religious and cultural preferences (for example, women caring for women), and be able to meet dietary needs
- a night sitting service should be available.

7 Researchers

Organisations need to plan carefully when researching the needs of minority ethnic carers.

During the project in Southwark, the researcher and advisory committee became aware of problems that other similar initiatives could encounter.

The points we make about these are made as a way of sharing our experiences and are not intended as any criticism of those involved in the project. We would certainly encourage others to mount projects to find out the needs of minority ethnic carers in their own areas. Circumstances of minority ethnic communities vary enormously in different parts of the country, and a project such as ours can be an important first step in understanding their needs. But it might not be appropriate to follow in detail the Southwark methodology. And, as always, the most important test of a project is the action that follows it. The following

- recommendations are made to researchers. Plenty of time should be allowed to explain the purpose of the project to those community organisations most affected. This should be done before the research starts. Some people may be sceptical since many minority ethnic communities have been asked to cooperate in research when they feel what is needed is money spent to meet their needs now. It is particularly important to explain the focus on carers as this may not be shared by community organisations if they have developed primarily to meet the needs of elderly people.

- The project needs sustained backing and firmly committed resources. If management or funding problems arise during the course of the project, the worker may well be drawn into sorting them out thus disrupting the main work. The managers of the project must accept this responsibility. An advisory group with representatives from the health, social services and voluntary organisations, and from the management structure of the agency carrying out the project can act as an essential support and guide for the project worker.

- Organisations must take a realistic view of what is possible in the allocated time. For example, it might not be possible for one worker to be able to carry out research and provide and distribute information. In this project it had been envisaged that the worker would set up community networks to help meet the needs of carers. This idea was subsequently dropped because it proved unrealistic. It had also been intended to produce information for carers. In fact it did not prove possible because of the time taken to find carers. The resources earmarked for producing information were very limited in any case: design and translation of information material need realistic amounts of money allocated to them

- Whenever possible, a local project should address the needs of carers in all the minority communities with substantial representation in the area. It was only with great reluctance that the Cypriot and other numerically smaller minority ethnic communities were omitted from this research: there simply was not sufficient time for one worker in one year. However, it is hoped that the recommendations of this report will be a valuable basis for discussion for those communities in Southwark not included

- Perhaps the most important lesson for other authorities is to beware of making easy assumptions about locating minority ethnic carers. It is not possible to find them just by tapping into the network of minority ethnic communities and their organisations. Much preparation and painstaking work are needed. Also, in many cases, statutory agencies are simply not in touch with minority ethnic carers: traditional voluntary organisations may be even less so.

APPENDIX ONE

Steering committee

James Alexander (from January '89)	Standing Conference of Ethnic Minority Senior Citizens (SCEMSC)
Martin Bould	Carers Unit - King's Fund Centre
Martha Brown	Black Elderly Group Southwark
Julie Burman (until December '88)	Carers National Association - London Region
Marilyn Collyer	Age Concern - Greater London
Sam Daniel (until December '88)	Standing Conference of Ethnic Minority Senior Citizens
Ms Escritt (until October '88)	Camberwell Health Authority - Nursing Services
Dr Ann Hodgson	Help The Aged
Zafar Iqbal	Southwark Muslim Women's Association
K H Le	Vietnamese Refugee Elderly Group
Lineve Moore	Southwark Social Services
Virginia Morley (until December '88)	Camberwell Health Authority - Kings College School of Medicine
Anjana Nathwani	Standing Conference of Ethnic Minority Senior Citizens
Grace Smomo-Mboto	Age Concern England
Ann Smith (until January '99)	Carers National Association Southwark
Joannah Weightman	Age Concern England

Researcher:

Joy Ann McCalman	Standing Conference of Ethnic Minority Senior Citizens (SCEMSC)

APPENDIX TWO

Programme of work

MAY - JUNE 1988

- Induction to SCEMSC
- Establish aims of the organisation
- Establish aims of the project
- Establish links with steering committee, social services, voluntary and statutory organisations and primary health care teams in Southwark
- Progress report

JULY - AUG 1988

- Plan of questionnaire
- Draft questionnaire
- Establish criteria for interviewees
- Establish number of people to be interviewed in each group
- Run pilot scheme
- Finalise questionnaire
- Progress report

SEPT - OCT 1988

- Interview Afro-Caribbean carers
- Write up results
- Progress report

NOV - DEC 1988

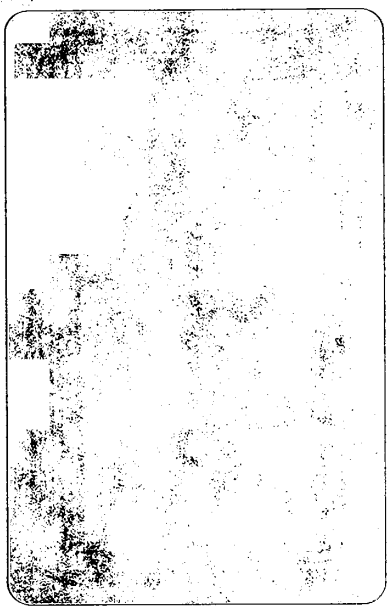
- Interview Asian carers
- Write up results
- Progress report

JAN - FEB 1989

- Interview Vietnamese/Chinese carers
- Write up results
- Progress report

MAR - APR 1989

- Write up report
- Disseminate Information on results of research
- Progress report



Many minority ethnic communities have a reputation for close family ties and mutual help. Consequently, it might be thought that carers in these communities need less support from voluntary or statutory agencies.

To discover the realities of life for these "forgotten people", Joy Ann McCalman spent 12 months researching the problems and needs among carers in Afro-Caribbean, Asian and Vietnamese/Chinese communities in the London Borough of Southwark Her findings show clearly that carers in minority ethnic communities need at least as much help as other carers, but get very little.

The Forgotten People has recommendations for the National Health Service, general practitioners, social services, voluntary agencies and minority ethnic community organisations. As these organisations prepare for their new roles in providing more comprehensive community care services in the 1990s, Joy Ann McCalman's book is a timely reminder of a too neglected group of carers.

About the author

Joy Ann McCalman has been working in the voluntary sector with the Afro-Caribbean community since 1983. A qualified nurse, she works full-time for the North Kensington Family Centre and became involved with the research project through her voluntary work with the Standing Conference of Ethnic Minority Senior Citizens. She is a carer and in the final year of a social sciences degree course.

Copies of this book can be obtained from Dept. D/KFP, Bailey Distribution Ltd, Warner House, Folkestone, Kent, CT19 6PH. Cheques payable to Bailey Distribution Ltd. Price £4.45 plus 50p postage.

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