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‘In our Blood’: Respite Services, Family Care & Asian Communities in Leicester

Summary Report

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Summary Report

Introduction

This Summary Report outlines the findings of a research study of the use of respite care services by Asian carers and elders in the city of Leicester. The study explores attitudes towards respite care within the context of Asian family relationships more generally. An extended version of the analysis briefly presented here is to be found in the Full Report, which comprises nine chapters totalling 125K words. The full report can be downloaded at <http://www.le.ac.uk/sociology/respitecare/>. Text versions of the full report can also be obtained from the authors.

The Nature of Respite Care

Respite care encompasses a wide range of formal social and health care services, provided in order to support and sustain carers in maintaining their informal caring responsibilities. Respite care services are often said to fall into three broad types: short-term residential stays, day care, and services in the home. However, the defining characteristic of respite care lies not in the kind of services provided but the reasons for which they are offered. Respite services are intended to:

- provide carers with temporary breaks from the pressures of caring responsibilities;
- address the needs of carers whilst facilitating the continuation of care relationships;
- refresh and reinvigorate carers without disrupting their caring roles.

Respite care, thus, supports carers but, by so doing, benefits elders too.

Research Funding

The research project was commissioned by Ethnic Elders and supported by funding from Leicestershire Social Services and Leicestershire Health Authority.

Research Methodology

The study was conducted between 1999 and 2001. Hindu, Muslim, Sikh and white Christian carers and elders were interviewed in three contrasting areas of Leicester – Belgrave, Highfields and Evington. These locations were chosen for their contrasting ethnic and socio-economic characteristics. A team of experienced interviewers with relevant language skills called at houses in selected streets. In the first phase, interviews lasting approximately twenty minutes were conducted with households containing 143 Asian elders. In the second phase, in-depth interviews, lasting approximately one hour, were conducted with 61 elders and 36 carers. For the purpose of the research, elders were defined as people aged 60 years and above. In addition, a total of 45 in-depth interviews were conducted with service providers and planners, drawn from voluntary sector associations, social services, primary and tertiary health care professionals, private sector providers and other agencies.

Interviews with carers and elders included questions on: the history and extent of elders' care needs, patterns of family relationships, networks of family support, the process of becoming a carer/elder, use & perceptions of a range of formal care services, the meaning & experience of being a carer/elder, perceptions of the current state of family care for elders in Asian communities, and details of carer/elder's socio-economic background. Interviews with service providers and planners focused on: application procedures and assessment processes for respite care, take-up by members of Asian communities, the cultural sensitivity of respite services, attitudes of Asian families to respite care, design and strategy of services, suggestions for improvements to respite care, and the professional background of respondents.

Growth of Asian Elders

Older members of Asian communities are rapidly increasing in numbers and as a proportion of the total Asian population, both nationally and in Leicester. As those who migrated to the UK in the 1960s and 1970s grow older, many of their children and other family members have become carers. The Full Report reviews previous research indicating that a relatively high proportion of Asian elders suffer from distinctive patterns of ill health, material deprivation and emotional distress, many of which are associated with their experiences of migration. Although in some respects their circumstances are similar to those of older people in general, Asian elders also face particular difficulties and problems.

Needs of Elders & Carers for Respite Care Services

Our research interviews suggest that a substantial proportion of Asian carers and elders are in need of support by formal care providers and would benefit from respite care services. This is indicated by the range and intensity of the care needs of a sizable minority of the elders interviewed in all the Asian communities studied, as well as by the levels of stress and pressure endured by a significant number of their carers.

Use of Respite Care by Asian Carers & Elders

Our research also suggests that many Asian carers and elders do not make use of respite care in proportion to their needs. Many of those eligible do not apply. As a result, there is a 'respite iceberg' in Asian communities: that is, a large and unfulfilled need for respite care hidden beneath the surface of on-going family support for elders. This situation may, in part, be masked by the relatively large numbers of Asian elders in Leicester who attend day care centres and luncheon clubs. It should not be assumed that substantial use of these services is indicative that all the needs of all Asian carers and elders have been met. Our research suggests that many would benefit from additional respite interventions.

Fears of Decline in Family Care

To understand the place of respite care services within Asian communities it is necessary to examine the dynamics of family and community life. A majority of the Asian elders and carers who participated in the study strongly suggested that there had been a decline in the quality and quantity of family care in their communities. There was, for example, a widespread fear and belief that many Asian families were consigning older people to permanent residential accommodation rather than looking after them within the household. It was also suggested – particularly by elders but also by carers – that respect for older people and commitment to the moral duties of family care were on the wane. Many middle-aged carers said that they did not expect that their children would look after them in the way that they were caring for their own parents. It should be added here that carers and elders interviewed almost invariably insisted that these problems did not apply to their own family circumstances but that decline in family care was characteristic of their community more widely.

Evidence of the Persistence of Family Care

The findings of our study, however, do not paint as gloomy a picture as some of the perceptions of the carers and elders interviewed. Our interviews certainly indicated that changes in family relationships were underway and that traditional patterns of care were adapting to new circumstances. Furthermore, some carers and elders were grappling with very difficult circumstances. Nevertheless, our findings did not suggest the wholesale disappearance of family care or the widespread abandonment of elders.

Asian Elders Surrounded by Family Members

Our findings suggest that family relationships remained strong within Asian communities in the three areas of Leicester where the study was conducted – including Hindu, Muslim and Sikh communities. This was indicated by the proportion of Asian elders interviewed who lived in large joint households with other relatives, the numbers of elders who had relatives resident in the same street, and the numbers of elders with relatives resident in the wider city. Furthermore, a high proportion of Asian elders in our survey had resident or non-resident carers. Only a small percentage of those identified in our interviews lived alone.

Family Relationships & Networks of Care

In many cases, a network of care for elders had been established within Asian families, involving a range of members of the kin group in a variety of roles. These patterns compared favourably with those for white elders in the same areas, who were more likely to be socially isolated and without carers.

Eligibility for Carer Roles with Asian Families

The culturally preferred option in all the Asian communities studied was for the eldest son and his wife to take on the primary responsibility for looking after aged parents, preferably in the context of a joint household. However, in practice, this arrangement was not always possible. In the households we studied, other relatives sometimes took on the role – including younger sons and their wives, unmarried daughters, and married daughters – when circumstances appeared to leave no other option.

Changing Family Dynamics & the Need for Respite Care

Notwithstanding these findings, there is also evidence in our report that those providing family care within Asian households often encountered major problems or difficulties. High levels of family care were in place but often entailed great personal costs for individual carers. Even when extended kinship ties were present and relatives were in close proximity, the main burden of caring could fall on the shoulders of just one carer. It should not be assumed, therefore, that active family networks obviated the need for respite care.

Moreover, our interviews suggest that networks of family care, and established patterns of family caring, can be disrupted by a number of factors. These include:

- conflicts and tensions in family relationships;
- increasing employment of married women;
- occupational and career mobility of carers;
- residential mobility of households, including relocation from inner city areas to outer suburbs.

A sense of family honour may generate reluctance to highlight the effects of these trends on the distribution of caring tasks.

The Role of Daughter-in-Law

Changes in the lives of daughters-in-law were seen by respondents across the board as having major implications for the availability of traditional carers and/or traditional forms of caring. In some communities, an increasing number of daughters-in-law were said to be inclined to establish independent rather than joint households. Those in employment were said to be less available to take up carer roles than in the past. These changes did not necessarily indicate an unwillingness to offer family care but might have implications for the location, timing and form of care. Where networks of care and/or traditional family patterns were undermined, caring responsibilities might be unevenly distributed among family members. In these circumstances, there could be a particular need for carers to avail themselves of respite care.

Attitudes Towards Respite Care

Carers and elders were uncomfortable with, even in some cases suspicious of, some aspects of respite care. These attitudes reflected their fears about the break-up of traditional Asian family values and their experiences of changes in patterns of family life.

A high proportion of elders and carers did not make a clear distinction between some types of respite care – particularly short-term residential breaks – and long term institutional residence. For these respondents, respite care could appear to be tantamount to abandoning elders in residential homes. Moreover, they feared that other family and community members would also perceive respite care in these terms. As already noted, there was considerable anxiety among respondents about the consignment of elders to residential accommodation. Any apparent movement in this direction by carers was likely to encounter strong family and community disapproval, since it was regarded as an affront to the moral and ethical basis on which many carers offered care.

Respite care provided in the home was seen as less problematic by elders and carers but could run also into problems of cultural and personal acceptability. Strangers entering the home could, albeit unwittingly, represent an affront to the symbolic meanings and moral values of everyday domestic routines. Elders and carers suggested that was more likely to be the case where service providers were not members of the same Asian communities as clients.

Day care centres (and similar services) were the most acceptable form of respite among our respondents, since they did not entail overnight stays and did not encroach on the cultural space of the home. Even here, however, there could be resistance by elders and carers if use was perceived as in some way a criticism of the quality of care provided by the family.

When, during interviews, the principles of respite care were briefly outlined to respondents, many carers and elders could see the benefits in principle. Elders were more apprehensive and hostile than carers but they, too, expressed a degree of support in principle for the idea of respite. However, in practice few were willing to consider it as an option in their own circumstances. Frequently carers recognised potential benefits but did not want to embark on a course of action that would deeply upset elders.

The Cultural Meaning of Ageing

Our research suggested that the emotional disposition of many elders interviewed could, in part, be understood in terms of the distinctive culture of ageing that had been predominant in the societies in which they spent their early formative years. This involved a high degree of interdependence between family members and exchange of personal care across the generations. Most elders interviewed had been carers themselves when young, usually in the Indian Sub-Continent or East Africa. They regarded it as both morally appropriate and the natural course of events that they, in turn, would receive support in old age. This was not merely an instrumental arrangement but carried moral, ethical and cultural significance – it was an aspect of their ethnic identity. As one respondent remarked: 'It is our tradition to look after elders – it is in our blood'. The perceived decline of family life and elder care could, therefore, generate disorientation and distress among elders, representing a threat to their sense of identity.

Institutional Barriers to the Use of Respite Care

Even when elders and carers were prepared to make use of respite care, they encountered a variety of institutional obstacles in accessing services. The extent and nature of these varied between different types of respite care – details are contained in the Full Report.

The most important barriers perceived by respondents included:

- lack of information available in a relevant or user friendly form;
- language problems and limited translation facilities;
- absence of transport;
- confusing or opaque assessment processes;
- confusing presence of several channels for obtaining respite care, utilising differing assessment criteria and generating outcomes perceived as inconsistent by clients;
- perceived absence of culturally-appropriate services.

Less frequently mentioned were:

- stereotypes of Asian family life held by white professionals;
- financial barriers;
- racism.

Availability of Culturally Appropriate Services

It was overwhelmingly agreed by carers and elders interviewed that it was essential for acceptable respite care services to be attuned to the religious practices, dietary rules, cultural values, language use, and everyday customs of elders. The importance of addressing the specific needs of a range of different Asian communities was emphasised. This, it was frequently suggested, required the employment of staff from the communities concerned. Where culturally appropriate services were provided, bringing together people of similar cultures and communities, use could be extensive and very much appreciated. Day care centres and luncheon clubs were widely mentioned in this context. Fear of an absence of culturally appropriate service could be a major disincentive. Limited availability of culturally sensitive short-term residential respite services geographically close to the communities was mentioned in this context, particularly by service providers interviewed.

Changing Relations between Service Providers & Carers

During the course of our research, important changes in the character of relationships between service providers and lay carers were in train. These entailed a re-evaluation by professionals of the role and contribution of family carers. Providers and planners of formal social and health care services increasingly regarded lay carers as co-workers or co-clients, with needs and interests in their own right independently of those of their dependents. These developments were embedded in procedural changes, policy shifts and legislative innovations at national and local levels. In the context of these changes, respite care was increasingly perceived by care providers in a new light; that is, as a preventative rather than a crisis measure. This general approach heightened awareness of the specific needs and cultural traditions of carers in particular Asian communities.

Respite Care Focused on the Needs of Asian Carers & Elders

In some important respects, the needs of Asian carers and elders in Leicester had received enhanced attention from service planners and providers in the years immediately prior to our research. In particular, there had been major successes in the provision of dedicated day care services for Asian elders, greatly increasing the uptake of this form of respite care. This had been achieved through service agreements between social services and voluntary sector organisations. A number of interviewees argued that many voluntary sector organisations were close to the communities and were able to provide culturally sensitive services to Asian clients.

Nevertheless, at the time of our research, supply side problems in the delivery of some aspects of respite care to Asian carers and elders continued to attract comment from our respondents among service providers and planners. Some referred to difficulties in providing culturally sensitive respite care services within the home. Others drew attention to the low number of places available in statutory-provided and culturally-appropriate short break residential accommodation. It was also noted that, unlike much day care, elders could find themselves in institutions where there few other clients from their particular community. Some Asian elders were said to have been placed in community hospitals in the county where staff had little experience of the cultural issues involved. 'Colour blind' models of service provision were said still to be found in some sectors, especially health care, and indeed were apparent in some of our interviews.

Future Developments

Our brief did not include the provision of detailed recommendations. However, our findings do suggest that there is scope for a partnership to advance respite care services between social services, health authority, voluntary sector and community organisations. Community organisations could take a leading role in facilitating out reach contacts with Asian elders, carers and community members. Positive evaluation of the principles of respite care by carers and elders, revealed in our interviews, could provide a starting point for advocates seeking to change community misconceptions, challenge residual stigma attached to respite care and encourage individual applications. Community and voluntary sector organisations could also play a pivotal role in opening channels in which carers and elders informed professional service providers and planners of the difficulties and uncertainties they face in utilising respite care. This could provide an opportunity to tackle the institutional barriers impeding the access of Asian carers and elders to respite care, identified in this study.

Conclusions

Much of the policy and academic debate about family care of Asian elders and use of formal services has taken one of two positions. In the past, it was often argued that Asian families successfully look after their own members and, therefore, little professional support was needed. In recent years, contrary to this complacent view, a number of

continued overleaf.

commentators have suggested that the effects of poverty, migration and cultural change mean that stereotypes of close Asian family life are misleading and that Asian families are in crisis. Our findings suggest a third position. Interviews with elders and carers indicate that, in general, Asian family relationships in Leicester remain strong but face changing circumstances and are evolving new forms. A high proportion of elders continue to be looked after by family carers but in circumstances that are often very difficult. Potentially, respite care has a major part to play in sustaining caring relationships but, overall, use of respite care in Asian communities does not match need and eligibility. Service planners and providers have revised their conception of the role of respite care in ways that are likely to enhance sensitivity to the specific needs of Asian clients. Nevertheless, increased take-up requires the elimination of institutional barriers to access as well as changes in community attitudes. Success has already been achieved with day care but further progress calls for a partnership between providers and communities.

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