

Assessment and support for South Asian carers

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RESEARCH FINDINGS FROM THE
SOCIAL POLICY RESEARCH UNIT

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THE UNIVERSITY *of* York

SEPTEMBER 2003
no.2003-03

This small study, funded by the Sir Halley Stewart Trust, was designed to test out the effectiveness with Asian carers and value of newly translated versions (Gujarati and Urdu) of instruments previously used mainly with white English carers: Carers' Assessment of Difficulties Index (CADI) and Carers' Assessment of Satisfaction Index (CASI). It also aimed to use these measures to gain an improved understanding of how Asian carers perceived the difficulties and satisfactions of caring. The key findings were:

The majority of the 26 carers interviewed found CADI/CASI to be intelligible and relevant. They did not identify any major areas not covered by original versions. First language versions were generally acceptable, although most chose also to refer to the English form. Most carers described the process of completing CADI/CASI as helpful in terms of improved understanding and affirmation of their caring role.

Carers identified the main sources of stress of caring as relating to taking a break, time for family and friends, and the degree of personal care they needed to provide.

Carers highlighted sources of satisfaction of caring that mainly related to their sense of family duty and religious faith, personal growth and development, the person cared for reaching their full potential, and being brought closer together by caring.

Carers valued and tended to prefer support from the familiar, for example Asian workers and support groups. Yet it was also important to be able to respect and rely on a worker who was supportive and available regardless of ethnicity.

Only three of the carers were certain they had received a formal assessment of their carer needs, although ten others were confident they had been subject to some form of wider care assessment. Most of this group of carers were aware that a right to assessment existed.

Six of these households had not received any formal care support beyond contact with social workers. The carers who had received help were positive about the support, with some saying they would have liked more help. A few complained about not receiving support even when their circumstances were known to services.

Background

Previous studies into outcomes of carer legislation suggest the need to improve support to minority ethnic carers. The instruments used in this study, CADI and CASI (Nolan, Grant and Keady, 1998), were designed for carers to identify and rate the extent to which statements about difficulties and satisfactions of caring applied to them. They were developed as a separate exercise from formal carers' assessment. They were seen as possibly useful in enabling carers to understand and share their perceptions of the impact of caring and facilitate an informed contribution to the formal assessment process. However, their applicability to minority ethnic carers was not known.

The Project

The main objectives were to assess the applicability of CADI and CASI to Asian carers and gain an improved understanding of their perceptions about their caring role. A secondary aim was to use the learning to assist local authorities to improve assessment and support for minority ethnic carers.

Findings

Carers' evaluation of the CADI and CASI

Most of these Asian carers reported that CADI and CASI were relevant and made sense. There were no obvious gaps from their perspective, in that they did not identify additional areas to be included. Most carers said it helped to have support, particularly first language support,

in ensuring they understood the meaning. Most chose to refer to more than one language version, and appreciated the opportunity for discussion and comparison with the English version. The Urdu version was judged to be acceptable and useable, whilst some helpful revisions were identified with the Gujarati version.

Carers gave a number of explanations for why they found CADI and CASI helpful:

- Helped their understanding of their situation and feelings and their caring role
- Recognised aspects of caring they had not thought of
- Recognised the importance of not denying aspects that were worrying
- Reaffirmed the appropriateness and reality of their feelings
- Reassurance about the quality of their caring
- Useful aid to think about difficulties
- Acknowledged aspects of caring that contributed to satisfaction
- Benefited from expressing and sharing their feelings
- Interesting exercise that 'rang bells' (reassured them of reality of their circumstances and that they were not alone)

Carers' perceptions of the stresses and satisfactions of caring

The major sources of stress identified through CADI by these carers related to the impact of the physical demands of caring and restrictions on social life. Carers were particularly concerned about not being able to take a break, give

enough time to family and friends, and the degree of personal care required by their dependant. As with other studies, satisfactions identified through CASI relating to benefits for the person cared for (e.g. seeing them happy and giving pleasure, keeping them clean and comfortable, and maintaining their dignity) were particularly important. With these Asian carers, high levels of satisfaction were also linked with religious faith and family duty.

The extent to which sources of stress and satisfaction can be inter-related was illustrated in the comments of the carers. They spoke of their anger at their situation at the same time as the happiness caring brought them. They spoke of their pride at making the best of difficult circumstances.

Carers' perceptions of care assessment and support in the community

Relations with professional workers

Contact with social workers was mainly through support groups and minority ethnic workers. Yet confidence in social workers was not exclusively related to ethnicity, but being able to respect and rely on a worker who was supportive and available. The concept of 'friendship' with professionals was important to some Asian carers.

Experience of assessment

Although the majority of carers assumed there had been some form of assessment, most could not clearly identify the event. There was a general awareness of the right to assessment as carers. A few confirmed they had consciously chosen not to exercise the right, not wishing to seek formal help unless

it became absolutely necessary. They spoke of feelings of disadvantage when dealing with officials and the benefits of support to help them to 'stand up for themselves.'

Help from social services

Most households were receiving or had received some form of care support in the community. Carers spoke positively of the support they received, although some said they would have liked more help. A few complained about not receiving support even when their circumstances were known. Carers' priorities for improvements were outreach support and befriending schemes, day respite and sitting support in the home.

Experience of health care

The main regular involvement with health care was with the general practitioner. Apart from routine child health contacts (mainly health visitors), there appeared to be little experience or awareness of nursing or other health care community support.

Carer support groups

For 21 of these 26 Asian carers, the minority ethnic carer support groups to which they belonged were important points of contact, with some carers maintaining their involvement despite serious practical difficulties. For some carers, their involvement was clearly a two-way commitment, with active participation giving purpose to life and a sense of achievement. They spoke of the benefits in terms of social interaction and mutual support, counteracting feelings of isolation, sharing common situations and difficulties, and a source of contact for more formal support and information.

Recommendations arising from the study

Use of CADI and CASI

- ▶ Self-assessment aids such as CADI and CASI could usefully be made available, with carers given the choice of completing them alone or with support. Provision of forms in English should be supplemented with the availability of first language versions and first language support from workers.
- ▶ As well as contributing to formal assessment, use of such forms may have benefit in its own right, as a tool for carers to examine their own thinking and feelings about the caring role, possibly in preparing them for formal assessment.

Response to carers' perceptions of stress and satisfactions

- ▶ Carers should be supported in acknowledging their satisfactions whilst still recognising the need for support.
- ▶ Along with the physical demands of caring, restrictions on social life and need for respite should be prime considerations in seeking to support Asian carers.
- ▶ The potential relationship of both stresses and satisfactions of caring of Asian carers with family duty and religious faith should be acknowledged.
- ▶ A useful pointer for working with Asian carers is that these carers perceived positive outcomes in terms of giving pleasure and happiness, maintaining dignity

and helping achieve full potential for the person cared for and personal growth, widening interests, testing self and strengthening family relationships for the carer.

Response to carers' perceptions of care assessment and support in the community

- ▶ There should be an out-reaching approach, for example through appropriate publicity and information in settings frequented by minority ethnic carers, and designated minority ethnic workers to undertake out-reaching.
- ▶ Community agencies should aim for an effective balance between matching workers with carers on an ethnic basis and an informed wider staff group so as to promote the general availability of services to minority ethnic carers.
- ▶ The need for adequate advocacy support for minority ethnic carers should be seen as essential to the carer's participation and of value for the organisation in contributing to effective assessment.

General recommendations

- ▶ Workshop discussions involving carers and workers reinforced the importance of care agencies and professionals being well informed and up to date with knowledge about the local community they served.
- ▶ Whilst cultural sensitivity is important, there should be an over-riding priority for heavily involved carers of whatever ethnicity to ensure their access

to formal carer's assessment and 'mainstream' support and services.

If careful monitoring of carer's assessments, service support outcomes and unmet needs with minority ethnic carers were in guidelines and part of inspection, then this study suggests that this would benefit the quality of understanding and support to carers.

These general recommendations are relevant to central government priorities, such as fair access, counteracting social exclusion and promoting partnerships with carers. The mainstreaming policy that aims to treat all people the same can contribute to greater equity and distribution of support. Yet this generalist approach carries with it the danger of over-looking minority needs and circumstances. Also care should be taken not to generalise what may be true of particular minority communities as a whole to every person or family.

Methods

Over five per cent of the research area populations were Asian with only one per cent being other non-white. Asian carers were recruited mainly through carer support groups and specialist workers. Twenty-eight Asian carers were interviewed, 26 of whom completed and returned the CADI/CASI forms. Although the sample of Asian carers was small and non-random, its composition reflects the national profile of Asian carers, which differs from the national

profile of White carers. Asian carers are more youthful than their counterparts, more likely to be caring for more than one dependant, to be looking after younger dependants as opposed to parents, and to be current and heavily involved carers.

Separate from the individual interviews, 17 of the carers took part in workshop discussions in local carer support groups. The interviews focused on their caring and demographic circumstances and the carer's evaluation of CADI and CASI. The workshops provided the opportunity for them to compare their evaluations of CADI and CASI and make general comments on assessment and support in the community. Translations of CADI and CASI were made available in Gujarati and Urdu as well as English, and the interviews and group discussions were supported by the availability of first language support workers.

General profile of the 26 Asian carer participants

- 15 were Indian and 10 Pakistani, with one Bangladeshi
- 24 were Muslim and 2 Hindu
- 22 were women and 4 men
- 4 were caring for their marriage partner; 16 were caring for their children (including some adults); 3 were caring for their parents and 3 for other relatives
- Collectively the 26 carers were caring for 31 disabled dependents: 5 were elderly, 15 were other adults and 11 were children aged less than 18 years

Reference: Nolan, M., Grant, G. and Keady, J. (1998) *Assessing the Needs of Family Carers*, Brighton: Pavilion Publishing.

Further information

This publication should be cited as: Hepworth, D. (2003) 'Assessment and support for South Asian carers', *Research Works*, 2003-03, Social Policy Research Unit, University of York: York.

Copies of the research report: Hepworth, D. (2002) 'Improving Assessment and Support for South Asian Carers' (SHST 1907 DH 10.02) are available from SPRU Publications Office (price £8.00). Copies of this Research Works in Urdu and Gujarati will also be available.

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