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Self-talk versus needs-talk:

An exploration of the priorities of housebound older people

John Baldock and Jan Hadlow

John Baldock teaches and conducts research in the School of Social Policy, Sociology and Social Research at the University of Kent at Canterbury. He has recently completed, with Jan Hadlow, a study of how older people maintain self-esteem after becoming housebound as a result of illness or disability. He has published widely on the social care of older people and is particularly interested in comparisons of different national systems of social care.

Jan Hadlow is Research Associate within the School of Social Policy, Sociology and Social Research at the University of Kent at Canterbury and a qualified social worker. She is currently involved in a comparative European Union study of how households combine employment and family care responsibilities.

ABSTRACT

This article argues that the material and social circumstances of older people living with disabilities mean that their priorities and subjective evaluations of quality of life are likely to be categorically different from those used by service provider organisations. Based on a qualitative study of a purposive sample of older people, who are over 75 and have recently become housebound as a result of disability, the paper describes two modes of understanding: 'Self-talk' and 'Needs-talk'. It is suggested that these two modes are to an extent irreconcilable and limit the degree to which care assessments and care-management can satisfy users.

KEY WORDS

older people

disability

quality of life

care assessments

INTRODUCTION: THE LIMITS TO TARGETING

Much of the reform of community care for older people over the last decade has been designed to ensure that those with greater needs are the more likely to receive services,

and that the services they get are those most likely to benefit them. This is a logical and laudable aim and grew out of a substantial research literature that had shown that those in greatest need were often being missed, imposing unacceptable burdens on them and their informal carers. At the same time others with lesser needs were receiving services

(Audit Commission, 1986; Martin *et al*, 1989; Davies *et al*, 1990). Of course reductions in spending on health and social care had an influence on the rationing of services, however there is also growing evidence that the community care reforms introduced in Britain since 1994 have resulted in better targeting of services (Bauld *et al*, 2000; Pickard *et al*, 2001). The principal methods have been the greater use of need assessments and care management techniques. However, within this pattern of improvement some older people still go without help. The findings of the General Household Survey, which demonstrate better targeting overall, also show that at any one time small but significant numbers of needy older people are going without the services to which they are probably entitled. The General Household Survey 1998–1999 found that of those aged 75 and over in the survey (1374), 51% live on their own and that of these 19% or 136 people are unable to go out of their homes and walk down the road without assistance (authors' analysis of GHS data set). At this point the numbers become too few to draw more than suggestive conclusions, but it is notable that many of these 136 housebound people living on their own do not receive services; 82 are without a home help; 93 without a private helper; 104 had not been seen by a district nurse in the last month and 113 had not used a day centre. It is likely that many were receiving all or most of their help from a key informal carer. It is also likely that there is a lot of turnover amongst this group as they either move to new accommodation or more complete care arrangements are made. Nonetheless, hidden in the small number picked up by the GHS (the 136 would represent just under 40,000 people in the UK today) are those needy older people who struggle on by themselves, 'coping' without the services for which they are likely to be eligible. There is some evidence that this is particularly likely in the early stages of dependency when older people are likely either not to recognise what they need and are entitled to, or when they are first assessed and then refuse help (Baldock & Ungerson, 1994; Audit Commission, 1998; MacDonald, 1999).

Here we report tentative findings from a small qualitative survey of people over 75 and living on their own that may shed some light on why the assessment processes and care

management do not always work as well as intended. Part of the problem may lie in the very use of language, and the constructs behind it that are used to carry out assessments and arrange help. In a study carried out as part of the ESRC's Growing Older Programme we observed that the categories that older people used to describe their lives differed substantially from those that would be needed to conduct effective assessments. There is a gap in meaning and language between service users and service providers and we characterise this as a difference between 'Self-talk' and 'Needs-talk'. The patterns found are summarised in **Table 1**. After a brief account of the research and its methods we explain the findings in more detail.

Table 1: Categories most used by the sample to describe their lives

Self-talk		
Selfhood	Feelings	Relationships
What sort of person am I?	Pain	Family plus and minus
Now and in the past	Loneliness	Friends plus and minus
Assertions of status and importance to others	Weepyness	Bereavement
Illness and coping emotionally		Helpers who are friends
		Others who do not help
Needs-talk		
Resources	Abilities	Disabilities
Income	Limitations in self-care	
	Intervals between needs	
Savings	Risks	
Availability of informal help		

In **Table 1** the categories under 'Self-talk' are those that were generated by the analysis of the interviews with older people. Those listed under 'Needs-talk' are the categories that needs assessors and care managers will necessarily have to use, if not directly with the service user, then in reaching judgements about provision. However, these are not categories we have extracted directly from interviews with service providers. Rather they are broad categories derived from the

assessment criteria used by local authorities. Our study did not include interviews with providers.

THE RESEARCH AND ITS METHODS

The main objective of the research was to discover how older people managed their identities and maintained their self-esteem when they were restricted to their homes by physical disability. We therefore sought a sample of older people whose health had changed recently, making them likely to need regular help but where they had not already established links with service providers. We chose to study people aged 75 and over, living on their own and who had recently become unable to go out without assistance. The literature and our own previous work suggested that a key turning point in old age comes when illness or disability makes one housebound; that is unable to go out without the help of others. This shift to dependence is particularly acute if one is living alone. Many of the things one takes for granted – shopping, driving or using public transport, visiting friends, helping others, going to the doctor – become more complicated and dependent on the help of others. Much of the autonomy that defines the self is compromised and identity and relationships with others have to be re-negotiated.

The sample and the interviews

Finding the sample was easier than we had anticipated. By talking to staff and members at day centres and to local carers groups we found it remarkably easy to identify people who had recently (in the last three months or so) become newly housebound through ill health and who probably needed help. This was clearly a stage in old age that was recognisable and which resonated with both staff and older people. We accumulated a sample of 38 (29 women and 9 men) and interviewed them twice, 6 months apart, in their own homes between November 1999 and November 2000. The questionnaire was relatively open-ended. Interviews were

recorded and transcribed in part. They included validated measures such as the Bartel index and the General Health Questionnaire. In addition the interviews used two scales developed by Peter Coleman and colleagues (1993) in their work on the Southampton Ageing Project, a study which began with 339 people over 65 in 1977 and which followed them well into old age. The first scale seeks to understand the sources of people's self-esteem and to measure broadly how strong it is (self-esteem scale); the second assesses continuities and discontinuities in people's sense of self (the life course interview). The interviews obtained from our sample were analysed using the classic methods of grounded theory building (Strauss & Corbin, 1990) to construct concepts and themes that fit the sample's experiences, and by using the Coleman scales to identify what was distinctive about the sample and the individuals within it.

RESULTS

The effects of disability and living alone on sources of self-esteem

At the beginning of the Southampton series of interviews in 1977/8, the most commonly mentioned positive source of self-esteem was 'health' followed by 'family', 'others', 'interests' and 'inner self'. As the sample grew older so the positive sources changed order: in 1990/1 they were: 'interests', 'health', 'family', 'others' and 'inner self'. In our sample, selected because they were on their own and recently housebound, the order of positive sources was dominated by 'inner self' followed by 'family', 'interests' and 'others' (Coleman, 1984). Also in our sample the order of sources of self-esteem was almost the reverse of those found in the larger, random sample, survey. Explanations couched in terms of inner emotional and intellectual resources were the dominant source of high self-esteem, followed by support from a family member. **Table 2** shows the results using the same methods to assess the sources of self-esteem in the two samples when they were the same age, an average of 82 for both samples. The Southampton sample was of a cross-section of people of that age, both well and fit, living

alone and with others. In comparison our sample, 'The GO sample' showed how the experience of disability and living on one's own appeared to re-order the criteria by which one judged quality of life. Where good health and contact with others were less available, other more inwardly focused criteria were used. Only 'family' remained similarly important for both samples. These patterns were given more substance when we analysed the main categories of experience which people use to describe their lives and their needs.

Table 2: Sources of self-esteem

GO sample	Southampton sample
Inner self	Health
Family	Family
Interests	Others
Others	Interests
Health	Inner Self

Some older people downplay or even fail to mention help and services they are getting

The two interviews, six months apart, were non-directive. However, they sought to cover the ground that would be necessary for a care assessment. Where key information was not given spontaneously it was probed for more directly towards the end of the interview. At the first interview, 15 of our sample had been assessed by a care manager, 10 were receiving home help or home care services arranged by social services and 20 had privately arranged home help or home care services. However, these arrangements were often not revealed to us until, towards the end of the interviews, we asked very directly. Initially we asked what difficulties people faced and how they coped. Not one respondent revealed having been assessed by a care manager until we asked about this directly. This pattern appeared to be related to ways in which people perceived their abilities and problems. Particular medical conditions were mostly described early on though in some cases very serious medical problems seemed to be suppressed. However, people were much less likely to state explicitly the everyday things that their medical conditions meant they could not do. Illness

was mentioned primarily in terms of pain and not in terms of capacity to cope. By selecting a housebound sample we had necessarily chosen people who often could not bathe, dress, shop, cook, get things out of cupboards and pick things off the floor. All had routine long interval needs and most had short interval needs but neither these disabilities nor how they were got round dominated the respondents' accounts of how they felt and coped. They talked rather of feelings, the self and relationships and much less of practicalities (Table 1).

The need for a particular service was never stated in the direct way that an assessment interview might seek. Rather, when asked how they felt about services that were available, the older people's answers were mediated by their conceptions of self:

'I can't apply for help. That would be admitting failure.' (F02.2)

'I wanted to help my self... not sit and watch someone else do it.'
(MO6.1 after ending home help)

'Social services are for people who don't mind sitting on their bottoms and letting others do it.' (F14.2)

'I don't want help (from social workers etc)... I want to be independent.'
(MO7.1)

These are examples where the self is portrayed as a strength that makes service use unnecessary. The more depressed in our sample would equally speak in terms of 'self' but of an inadequate or damaged self. This too would be offered as a reason why services would not help.

'No I don't want them. They wouldn't help. It's because I've lost my confidence you see.' (F01.1)

Use of services was also likely to be interpreted in terms of the absence of family or other support networks. These are sustaining sources of self-esteem and use of services was linked to their failure.

'Their family puts them there because they don't want to look after them.' (F04.2)

'[Nursing homes are for] those whose family want to get shot of them.' (F17.2)

'I'm not dependent on that sort of help at the moment... I'll bear it in mind for the future if I'm unable to sustain friendships. Friends are who you rely on, give support to one another. That is the big aspect of old age, you have got to have friends you can rely on.' (M01.1)

Services put in place and apparently working could, nonetheless, fail the test of subjective acceptability. They were either ignored as much as possible in the older person's presentation of self, or, less often, denigrated explicitly and even eventually rejected and cancelled. However, although the outcome here was different to acceptance, users' accounts of both acceptance and rejection were given in forms that linked the services to how people thought about themselves.

USER VERSUS PROVIDER PERSPECTIVES

We selected people for our sample because they had recently become more disabled in some way and because they were likely to need help and services. While we deliberately sought not to ask provider-led questions, we cannot but admit our initial surprise and puzzlement at how often people failed to emphasise the substantial practical limitations they faced and the sources of help they used to get round them. We realise in retrospect that we did expect them to talk the language of needs and services. Instead they spoke more often of feelings, family and friends. It is only when one starts to appreciate the whole quality of life of an older and housebound person that one can understand why the assistance of care managers and the visits (where they happen), of home helps, community nurses and personal carers are not given the prominence that might be predicted.

The external-provider view of dependent older people's lives is one that highlights change, urgency and pattern. The older person's view, in contrast, is one of continuity, delay and no apparent pattern. There is a very sharp dichotomy between the long, slow days of a frail older person and the fast, active, time-pressured existence of a care worker. One analogy from a very different setting might be the contrast between the experience of many airport users, of endless sitting around and waiting with very little understanding of why it is so and when it might change, compared with the perspectives of airport workers that so many television documentaries have brought to us: days of vigorous activity, tight timetables and crisis management. Just as the delayed passenger will remember the sitting around with little other stimulus than their own thoughts, how they felt rather than what they did, so the people in our sample complained about their frustration with the constraints of their new disabilities and the tedium and loneliness it often brought. In this world, the visits of home helps or the much more occasional ministrations of GPs, nurses and social workers were, although welcome, relatively unimportant in the overall experience of things. Feelings, ill-health and pain, and both the good and bad of family and friends – these are much more significant features of life than the input of service providers. To switch to another crude analogy, professionals and other service providers are often viewed rather as a diner sees a waiter in an overcrowded restaurant; difficult to contact and influence, often distracted, slow and forgetful, and producing a rather unsatisfactory product when they eventually do deliver the meal. The waiter's perspective is surely different – of ceaseless activity and continuous interaction with customers.

These are findings consistent with other studies of the home care management process. For example following Charlotte MacDonald's (1999) qualitative study of 79 older people in Scotland she reports:

'Evidence of the home care service playing a monitoring role was patchy: people talked about the organiser occasionally phoning...'

'Although assistance had been provided on occasions, there were very few examples of continuing contact or of the individual feeling able to reactivate the relationship with the same worker if another need arose. Characteristic of many accounts was a sense of the social worker as elusive and someone who was never in one place or one job for very long.'

Our respondents spoke in similar terms:

'I had a visit from the worker at the council but nothing happened.' (F05.1)

'I was offered home aids. I used to have a home help but lost this when the home help service was changed.' (F10.1)

'I was told when I was in hospital last week that someone would come and see I'm all right. I am thankfully, [as she hadn't yet been visited].' (F19.2)

SELF-TALK VERSUS NEEDS-TALK

Despite the fact that later in the interviews, when the facts and issues about which we wanted evidence had not been mentioned, we were more directive, our ability to influence what our respondents would talk about was quite limited. They had had many hours to consider their priorities and (with some distinct exceptions) once trust was established, they took firm control of the content of the interviews. A 'report-back' to the respondent was read to them at the second interview. This was initially intended as a mechanism to check facts, but in practice it became a vehicle through which the respondents would remind us of and re-iterate their original agendas. The analysis of the language of the interviews generated concepts, categories and linkages between them which were quite distinct from those likely to be necessary to an assessment agenda.

The vigour and length of the Self-talk in the interviews was a reflection of the identity work that the respondents had been doing, and not merely of solitary living. Indeed, only a

minority told us they were lonely. This was to an extent a self-selected group who were happy and even keen to be on their own most of the time. However, because they were housebound, and sometimes in a house that was not the one in which they had spent most of their lives, they were to a degree without the signs, the people and the accoutrements that defined their identities and status. This was pronounced in the cases of the men, but often of the women too, most of whom had been in employment as well as caring for families. The desire to assert the self and the unseen that defined it and its status (children and family particularly, but also the past in general) was strong. Illness featured largely only when it was directly related to present pain. During the interviews the respondents would check that we were willing to hear of all these issues. They sometimes remarked with surprise that we were prepared to listen. When we reported the same categories back at the beginning of the second interviews, that we had listened was remarked upon by most people and two even wept with surprise. We conclude that one of the reasons they did not report to us the assessment interviews many had, was because they were not remembered as occasions upon which they were listened to.

We have checked our interviews to confirm that the categories and the linkages between them which typify Self-talk were widely and frequently used. If our sample is broadly representative of older people living in the community with these levels of need, then we would expect that effective needs assessment interviews are particularly difficult to carry out. Interviewers will necessarily have to interrupt, cut short and change the direction of the discussion if they are to complete assessments reasonably quickly.

Equally, these findings and our experience of the interviews make us suspicious of research that uses a substantial proportion of pre-coded questions with older people in these situations. Our attempts to pursue particular lines of questioning were frequently ignored or diverted to the respondents' agendas. It is possible that once the respondents decided they would not be allowed to determine the content of an interview they would acquiesce to implied or suggested answers.

CONCLUSION

Studies of the user perspective are most commonly used to suggest ways in which services providers might change and improve their services to match better the users' needs and allow them greater participation. Our conclusions are to an extent of this kind, but with qualifications. The qualitative gulf between the realities that users and providers inhabit is so profound that it may always be to an extent unbridgeable. The gap between the waiter and the diner or between the terminal user and the airport staff will always limit understanding.

Assessments of care needs have to integrate quite different realms of meaning: evidence about the subjective realm of wellbeing, how happy or sad people are and evidence about forms of help people receive and their effectiveness in supporting them in the community. There is no reason in logic, nor based on the actual cases observed in this study, why both these dimensions should be satisfactory or positive at the same time. They are linked but not the same. In other words it is quite possible for a person to be enjoying subjective wellbeing, but for their care circumstances to be 'inadequate' in terms of social and professional norms of welfare and risk. Similarly, there were cases in our sample where the support package would have passed the 'objective' tests of adequacy while subjective wellbeing was clearly poor or getting worse. The differences between 'Self-talk' and 'Needs-talk' reflect real differences between users and providers and their conceptions of an acceptable quality of life.

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Address for correspondence:

John Baldock
School of Social Policy, Sociology and Social Research
Darwin College
University of Kent
Canterbury
Kent CT2 7NT
Email: jcb4@ukc.ac.uk

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