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MORALE AND QUALITY OF LIFE AMONG FRAIL OLDER USERS OF COMMUNITY CARE: KEY ISSUES FOR SUCCESS OF COMMUNITY CARE

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ABSTRACT

Many Social Services Departments have successfully developed services which meet older people's physical survival needs so that they can continue living in their own homes despite serious disabilities. An emerging priority is to support the morale and quality of life of the same individuals.

Assisted by SPRU, a team of Social Services managers conducted a programme of interviews, designed to obtain the views of very old, frail home care clients about their services and their lives in general. Interviewees' most common discontents concerned difficulties in travelling outside their homes, insufficient social contact, and loss of sources of interest and stimulation in everyday life. Factors included reduced mobility owing to ill-health and loss of valued pastimes like knitting or reading through eyesight problems or arthritis. A few interviewees expressed very low morale and this seemed to substantially reduce their ratings of satisfaction with the help they received.

Some interviewees communicated high morale in spite of major physical disabilities. Possible reasons included good social support from family, neighbours, and home care and sheltered housing staff, and help which compensated for physical disability, like car excursions provided by relatives, or electric wheelchairs. There seemed unused opportunities to help other interviewees through similar assistance: sometimes interviewers themselves arranged interventions which brought evident improvements.

While it is well established that disability and isolation are linked to depression in older

people, it is rare that services systematically address these problems. Some practical strategies for this purpose are proposed as a result of this survey. These merit testing.

Key words:

older people - home care - service user satisfaction - morale - depression - quality of life

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Introduction

Recent years have seen growing interest in service users' views as a source for guidance for service development. This paper reports findings about quality of life from a programme of in-depth interviews with older users of community care, which had been designed to supply guidance for improving local services. One reason for wider interest is that interview methods were tailored to reach very frail older people, who are an increasing proportion of the Home Care clientele owing to national changes in service targeting (Godfrey 1999) but hard to reach through conventional user consultation methods (Barnes & Bennett 1998). Preliminary consultations conveyed that home interviews would be the best method to reach frail older people and that the latter would prefer senior managers of their own community care services as interviewers (Patmore *et al* 2000). It proved possible to engage in such interviews a random sample of older service users, which represented the high proportion of very old people on local Home Care lists. Thus this interview programme offers insight into the experiences of this important group of service users.

Method

In a joint project between the Social Policy Research Unit (SPRU) and a Metropolitan District Social Services Department, two Area Office case lists for older community clients were studied: Area 'A' and Area 'B'. Each Office served a population of approximately 90,000. Stratified random samples of names were drawn from a Social Services computerised database to represent particular groups of service users, like people receiving more than 10 hours Home Care weekly, people who received Home Care alongside substantial help from a relative, and people who received low intensity service like weekly shopping deliveries. These names were screened for people unsuitable for interview. Home Care Organisers identified people who were currently very ill, away from home, recently bereaved, or anxious or depressed to the point that an interview would be distressing, and people with whom communication would be very difficult owing to dementia or severe speech or hearing problems. Screening procedures are further described elsewhere (Patmore 2001a, Patmore 2001b).

A semi-structured interview schedule was designed to collect feedback about older people's lives as a whole, as well as about existing services, to help inspire service development. One section examined how satisfactory an interviewee found 12 aspects of daily living, listed in Figure 1. For each item interviewers recorded an interviewee's opinion on a rating scale, plus reasons for this opinion and any sources of help - be it from Social Services, family, friends or neighbours. These domains were derived from extensive preliminary consultations (Qureshi *et al* 1998). A second component was questions concerning specific services received, see Figure 2. Many interviewees used day centres as well as Home Care and some had experienced short

residential breaks. A final component comprised some questions for completion by the interviewer after the interview, requiring them to evaluate what they had just heard.

Thirty people were interviewed, as described in Table 1. At each Area Office the interviewers included a Home Manager, a Principal Care Manager and a Service Development Manager. In one Area the Area Manager, who had overall responsibility, also participated.

Analysis was conducted by SPRU, using the notes made by interviewers. Responses were collated for each question. Additionally a holistic appraisal was made concerning each interviewee's situation. Separate sub-reports were produced for each catchment. These were then compared for common and contrasting themes and a final report was produced for Social Services.

The complete interview schedule, guidance notes, screening documents and analysis procedures are presented in Patmore (2001b). Information on methodology and use of managers as interviewers can also be found in Patmore (2000) and Patmore (2001a).

Findings

Quality of life

Findings which concern specific local services are presented elsewhere (Patmore 2001a). It is broader findings about perceived quality of life, which may have wider relevance, which are reported here.

Among the aspects of daily living listed in Figure 1, it was 'Getting out of the house', 'Social life', and 'Sources of interest in everyday life' which elicited most dissatisfaction. Problems in getting out of one's home were the greatest source of dissatisfaction. In Area 'A' ratings were especially negative - only two out of 13 interviewees rated their situation as satisfactory. Interviewees mentioned barriers to mobility like arthritis, recent amputation, fear of incontinence, depression and lack of money for taxis.

However certain interviewees illustrated how particular resources, if available, could redress mobility problems. Some interviewees enjoyed drives in the country provided by relatives. Others were taken on such excursions by workers from a small Social Services relief service for family carers, which interpreted its role flexibly and creatively. One interviewee and his wife had greatly benefited from an electric wheelchair recently obtained privately, whereas a similar couple had been waiting in frustration for nearly a year for the same item via public channels. An interviewee, who was in her nineties and suffered serious arthritis, could nevertheless enjoy regular outings for meals thanks to a neighbour who took her by taxi.

Another interviewee greatly valued his walks and had devised his own exercise programme to maintain his mobility. For some interviewees their ability to somehow still manage outings from home seemed linked to good morale.

While most interviewees strongly aspired to get of their homes, there were some contrasting individuals who appeared completely content never to leave home. While some of the latter seemed solitary and inactive, others led active, sociable, even busy lives, receiving frequent visitors.

In both catchments, the second most pronounced source of dissatisfaction was interviewees' present amount of social life. Interviewees from Area 'A' again used strong expressions of dissatisfaction much more often and more of them seemed isolated. Among the 17 interviewees from Area 'B', there was no-one who did not at least once a week see someone with whom they had a relationship, additional to paid helpers like Home Care. But among the 13 Area 'A' interviewees there were four people without such social connections. Unsurprisingly, a common source of unhappiness was interviewees' steady loss of friends and relatives through ageing and death. Another source was that some interviewees' children spent less time with them than the interviewee desired. Some of the most isolated interviewees indicated the sort of extra social contact they desired. They did not seek day centres. Rather, they wanted more contact with particular Home Care staff, whom they already liked and trusted.

Nevertheless, around half the interviewees rated their social life as satisfactory. Common reasons were happy married relationships, visits from relatives, friends and neighbours, and friendly, enjoyable relationships with Home Care. Nearly half the interviewees regularly attended day centres and generally valued the company there. Half lived in sheltered housing which sometimes contributed valued relationships with friendly, trusted housing wardens. For some interviewees there was a single individual - sometimes a relative, sometimes a neighbour - who visited very often and made a crucial contribution in terms of both social contact and practical help.

Lack of sources of interest in everyday life was the third focus for dissatisfaction. For Area 'A' interviewees, this was only slightly less problematic than mobility and social life, which obviously can influence this rating. Other influences were that eyesight problems or arthritis were steadily depriving many interviewees of valued hobbies like knitting, needlework, reading or writing. Some interviewees felt confined to watching television for such reasons. For some interviewees, decline in vision had made excursions from their home especially important, since this was a rare activity which they could still enjoy. One partially-sighted interviewee felt upset on days when her arthritis prevented her being taken on outings because there was little else for her to do.

There seemed a case for assessing service users for resources which could improve their quality of life at home. Despite widespread eyesight and mobility difficulties, only a couple of interviewees mentioned large print or tape-recorded books or the mobile library. One interviewer arranged repair for the malfunctioning television of a very disabled interviewee

for whom TV was the main pastime. Another intervention by an interviewer had major consequences. An interviewee, who was very depressed through progressive arthritis, gained greatly from rehousing in a well-adapted ground floor flat, which maximised her abilities.

Thus mobility, social life and general sources of interest were interviewees' main unresolved problems. These areas are rarely the focus for systematic Social Services help, other than through what day centres can provide. Nevertheless they are very important, not least because of an established connection between depression among older people and disabling health problems, bereavement and isolation - as discussed shortly. Ideas for helpful interventions could be suggested by the ways some interviewees' difficulties were being ameliorated, as described earlier.

Differences in morale - and the apparent importance of morale

A recurrent theme in interviewers' notes was respect and admiration for how some very frail or disabled interviewees seemed to have transcended many troubles, like severe arthritis, loss of sight, death of loved ones, amputations or major mobility problems. In spite of such difficulties, certain interviewees could be cheerful, friendly, even entertaining towards interviewers and expressed much appreciation of help from Social Services. They affirmed strongly how, despite their health problems, they enjoyed life and valued being helped to stay in their own homes. They tended to play down any shortcomings of their Home Care services. While they made occasional firm criticisms, their general attitude seemed to be attentiveness to good things in their lives and their services, consideration for staff needs, and a feeling that they were well cared for.

In contrast were a few interviewees, who seemed distressed about many aspects of their lives and inclined to dwell on the shortcomings of their services. Generally these were isolated people, who both lacked supportive informal networks and showed difficulty in forming the friendly relationships with Home Care staff, which seemed to come easily for other interviewees. Conspicuous was their frequent use of negative ratings and strongly negative ratings about their life-situations and their services. In contrast, other interviewees were restrained and selective in their use of the stronger negative ratings on the rating scales, even when expressing explicit criticisms. The strongest negative rating, 'Very Unsatisfactory', was used only 12 times in total during the many sets of ratings of outcomes and life situations in Section Three. But ten of these 12 ratings came from the same three individuals among the 30 interviewees.

A question was evident whether such contrasting attitudes might affect the actual service which interviewees received. If Home Care staff respond to high morale clients with the same sentiments as interviewers, it is easy to see how very thoughtful care arrangements, like such interviewees described, might evolve in a virtuous circle interaction between staff aspiration to provide good care and the appreciation and consideration shown by these clients. Conversely, an interviewer, who had much experience of providing Home Care, commented that staff might find certain troubled interviewees so stressful or discouraging that they would minimise contact. Olsson & Ingvad (2001) have described the development of good and bad relationships between Home Care staff and clients in terms of such virtuous circle and vicious circle interactions.

There seemed a sense in which older people might construct their experience of services themselves, according to their level of morale. Some individuals clearly dwelled on good aspects of the care they received, while others focussed on its shortcomings. Possibly, as mentioned, this might also affect actual service. It seemed that, if older people were distressed or depressed, they did not obtain full benefit from the same provision which drew appreciation, even sometimes applause, from other interviewees.

Differences between catchments

Unexpectedly pronounced differences emerged between the two catchments. During the interview, interviewees formally rated the satisfactoriness of various aspects of their lives, particular services, and their services overall. Generally, less favourable ratings were given by Area 'A' interviewees both for their services and for life-situations independent from services. While eight interviewees among the 17 from Area 'B' never rated any aspect of their lives or their services as 'Unsatisfactory', there was only one similarly contented person among the 13 interviewees from Area 'A'. As Table 2 shows, a markedly smaller proportion of Area 'A' interviewees used the most positive ratings for help from Social Services. The same applied to ratings specific to Home Care services. While conspicuously troubled, critical and isolated individuals were almost all from Area 'A', there was also a less satisfied tone among many other Area 'A' interviewees. A factor may be that Area 'B' interviewees enjoyed greater social and practical support from relatives and friends as a result of longstanding family and neighbourhood social networks in Area 'B', for which this community had some reputation. Social Services was helping a clearly larger proportion of interviewees with house cleaning,

laundry, shopping and pension-collection in Area 'A' than in Area 'B'. In Area 'A', when an interviewee was not receiving help with such a task from Social Services, often they were doing it for themselves. In Area 'B', in contrast, it was being done for them by relatives, friends or neighbours. Interestingly, a study by Wenger & Tucker (2002) compared the networks of older clients of two social work teams, which served two contrasting communities. The team whose clients had distinctly fewer relatives living locally also experienced greater burden on staff.

DISCUSSION

Observations from this study concur with other research findings. Concerning morale and satisfaction**,** Woodruff and Applebaum (1996) concluded from in-depth case studies of older Home Care users: "Those consumers who had positive outlooks on life seemed to carry this attitude over into evaluations of their services, whereas those consumers with negative outlooks could find little or nothing good about the services they received." Vetter *et al* (1988) found that older people with questionnaire scores which suggested anxiety and depression gave much lower satisfaction ratings about all aspects of their lives than did other older people. Grundy and Bowling (1999) noted very negative ratings on all aspects of life from some interviewees who experienced illness or disability, were isolated and very lonely, and had questionnaire scores which suggested psychiatric problems. Chesterman *et al* (2001) found older Social Services clients who were lonely or generally dissatisfied with life were less likely to be satisfied with Social Services.

Depression and anxiety should be anticipated among Home Care clients on account of their

physical health problems. There is widespread evidence that physical ill-health is a common trigger for depression in older people (Denihan *et al* 2000). People are now living more years in poor health or with a limiting longstanding illness (National Statistics 2000). Increasingly the Home Care service is becoming dedicated to people with major health problems, including people who would otherwise be in residential care (Godfrey 1999). Banerjee & Macdonald (1996) found that a quarter of a sample of older Home Care clients were depressed. Significantly 84% of these were not receiving appropriate treatment for depression, even though effective treatments exist (Banerjee *et al* 1996).

In terms of factors causing depression among older people, Prince *et al* (1998) and Copeland *et al* (1999) emphasise those physical health problems which lead to loss of accustomed roles or functions - like loss of mobility. Vetter *et al* (1986) found a strong association between severity of disability and both anxiety and depression among older people. Lack of supportive relationships can increase the risk of an older person becoming depressed in response to adversities like disabling illness or bereavement (Murphy 1982, Prince *et al* 1998 and Copeland *et al* 1999). Wenger (1992) noted how older people's morale benefited if they knew a person with whom they could talk intimately "about the joys, sorrows and problems of life". Some researchers believe that lack of supportive relationships can also delay recovery from depression (Prince *et al* 1998).

Differences between communities concerning life-satisfaction or emotional well-being among their older residents have been repeatedly identified. Bowling *et al* (1997) observed marked contrasts between older people's satisfaction with life in a deprived part of London

and in a prosperous Essex community. Vetter *et al* (1986) compared older people in a Welsh inner-city general practice and a Welsh rural practice. 23% suffered depression or anxiety in the former compared to 11% in the latter. Chesterman *et al* (2001) found markedly lower satisfaction both with life in general and with Social Services help among older Social Services clients in four out of ten places studied. One factor may be large local differences in how much older people receive emotional and practical support from longstanding social networks. Wenger (1992) found highest levels of general satisfaction among older people who had many family members, friends and long-standing neighbours living nearby. Communities can differ markedly in the frequency of such networks (Wenger & Tucker 2002).

Thus Home Care client lists may be acquiring large proportions of older people who are either at risk of depression or already depressed, owing to the health problems which nowadays are often a condition for obtaining Home Care. Depression is a particular risk for people with serious health problems who also lack social supports. In certain communities isolated, dissatisfied or depressed older people may be much more common than in others. What can be done?

Improving referral for medical treatment for depression should bring valuable gains, as recommended by Prince *et al* (1998) and Grundy and Bowling (1999). Widespread failure to treat depression in older people has been found repeatedly (Livingston *et al* 1990, Copeland *et al* 1999, Denihan *et al* 2000). Home Care staff could be trained to screen for depression at assessment and review (Banerjee & Macdonald 1996). Both Prince *et al* (1998) and Grundy

and Bowling (1999) argue for design improvements to housing, transport and community facilities to enable mobility and social activity for frail older people. Prince *et al* also suggest medical and social interventions on an individual level to address problems in daily living which result from disabling illnesses. Additionally, they recommend social support as a preventive measure for older people facing disabling illnesses and as part of treatment for people who have already become depressed.

The report from the SPRU / Social Services interview programme proposed social interventions on the latter, individual level. Two broad responses were recommended. Firstly, when older Home Care clients were known to suffer disabling illnesses, they should be offered a co-ordinated programme to reduce impact of disability, according to each service user's aspirations. Assistance might include, for instance, referral to Occupational Therapists for rehabilitative help, links to workers who could provide periodic excursions by car, or introduction to resources like the mobile library. The interview programme highlighted two types of help commonly sought by people who appeared candidates for intervention. Many sought periodic excursions by car, something also noted as common by Bowling *et al* (1997). Also in demand was help with household tasks related to pride in one's home - like dusting ornaments or washing curtains - which an interviewee's disabilities now prevented them doing but which Home Care was not allowed to undertake. Often interviewees seemed ready to pay, if someone else would organise service. Clark *et al* (1998) noted how many older women's morale is affected by the appearance of their home.

A second recommendation was that when older Home Care clients, who were known to be

isolated, encountered major adversities like disabling health problems or bereavement, they should have opportunity for a long-term supportive relationship with a worker who could visit them at home. Who might provide such help? In many Authorities there are no ready answers. Often Care Managers have little contact with older community clients after a care package has been set up. Home Care is often centred round fulfilling practical tasks and not organised so as to promote such relationships (though many Home Care staff give excellent social support on an unofficial basis). Social support is sometimes officially seen as the remit of day centres, a problem for housebound people, or as the province of voluntary sector befrienders, who are often a very scarce resource (Salvage 1998). But a case exists for developing social support functions of two groups of front-line workers - Home Care staff and the wardens of Sheltered Housing. Both are well-placed in that they routinely visit frail older people in their own homes, long-term, and can develop relationships through their ordinary duties. Indeed, the SPRU / Social Services interview programme noted how some isolated and troubled interviewees sought more contact with particular Home Care staff with whom they already felt rapport. Likewise some interviewees in Sheltered Housing greatly enjoyed daily visits from well-liked wardens, who sometimes also organised social events and excursions. There were other housing wardens, though, whom interviewees portrayed as ill-attuned to such roles. It seemed that housing wardens could be excellently placed for social care roles but that there were no policies to use them systematically to help isolated residents.

To develop selected Home Care staff for social support and keyworker roles would fit Sinclair's (2000) model, whereby a better resourced, more professional Home Care service utilises its vantage point in its clients' everyday lives to respond to miscellaneous emerging needs through referrals or direct assistance. However, it certainly does not fit a current trend

whereby Home Care pay and conditions seem driven downwards by Local Authorities which seek to minimise costs, so that it is hard to recruit appropriate workers for the complex service needed by today's very frail clientele (Brindle 2001). Concerning Sheltered Housing, a movement already exists to expand wardens' roles in directions like those proposed here on a similar argument that they are an under-utilised resource for Social Services (ERoSH). However, while many older Home Care clients do live in Sheltered Housing - for instance half of our interview sample - many do not. For the latter, Home Care services need to find ways of giving social support systematically to selected clients. There also needs to be training and support for all Home Care staff in recognising depression and responding appropriately.

Conclusions

Many Social Services Departments have successfully developed services which can meet older people's physical survival needs so that they can remain in their own homes despite severe disabilities. A new priority may be the morale and quality of life of the same individuals. One clear message from this interview programme was that Home Care clients with serious, disabling health problems truly can enjoy good quality of life, given appropriate social and practical help. Another message was that more could be done to support morale, improve quality of life and reduce impact of disability. This was suggested by interventions which the interviewers, themselves all Social Services managers, undertook on their own initiative when they saw opportunities. It was suggested too by noticing factors which seemed to support some interviewees' morale. Of course the suggested intervention programmes need to be evaluated in practice, since the area is complex (e.g. Cattan & White 1998, Andersson 1998) and outcomes must be demonstrated, not presumed. However there are strong reasons

why effort is warranted to develop and test such intervention programmes. Yet another message was that low morale and quality of life will reduce older people's ratings of satisfaction with whatever help Social Services does give them - and that this may be pronounced in certain communities. The latter also emerges from the study by Chesterman *et al* (2001) of satisfaction surveys, like those which *Modernising Social Services* (Department of Health 1998) has made mandatory. Conducted in 10 Local Authorities, this study found that low general life satisfaction and problems like loneliness, arthritis, feeling cold, and depression, reduced older people's ratings of satisfaction with Social Services help like Home Care, day centres, home delivered meals or Care Management. Improving morale and quality of life for infirm, isolated older people may sound a formidable challenge for older people's services. But, like it or not, services will have to respond to the concerns of the whole person if low satisfaction ratings are to be addressed, because there are some conditions under which older people simply cannot feel well cared for.

[ENDS]

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Figure 1: *12 aspects of daily living investigated in each interview*

- Meals / refreshment
- Shopping
- Laundry
- House cleaning
- Household repairs / decoration / gardening
- Access to help in emergency
- Feeling safe from crime and nuisance
- Managing with money, bill, pensions, benefits and legal matters
- Personal care
- Getting out of the house
- Social life
- Sources of interest in everyday life

Figure 2: *Items of enquiry about services received*

- Home Care
- Day centres
- Other significant social care services
- Care following any recent hospital discharges
- Views of any family carer present
- Any additional help sought from Social Services, other Council Services or Health Service
- Rating of satisfactoriness of help received from Social Services

Table 1: *Facts about interviews*

Number of interviewees	30
Number of women	21
Age range	66-95 years
Mean age	83 years
Range of Home Care hours per week	15 minutes - 33 hours
Mean Home Care hours	8 hours 48 minutes
Living alone	24 people
In sheltered housing	15 people
Range of lengths of interview	25 minutes - 1 hour 50 minutes
Mean length of interview	1 hour 7 minutes
Number of interviewers	11 managers

Table 2: *'How far would you say that your present situation, considering your needs and the sort of help you get to meet them, is satisfactory in terms of what you think Social Services should be doing for you?'*

Interviewees' replies	Area 'A'	Area 'B'
'Fully satisfactory'	2	10
'Very satisfactory'	2	4
'Moderately satisfactory'	8	-
'Hard-to-say'	1	-
'Moderately unsatisfactory'	-	-
'Very unsatisfactory'	-	-
No reply	-	3
Total	13	17