

**EXTRACARE:
MEETING THE NEEDS OF FIT OR FRAIL OLDER PEOPLE?**

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EXECUTIVE SUMMARY

'Extracare' has been described as innovative housing schemes that combine both independent living with high levels of care. The growth of extracare in recent years is due to an increasing ageing population; the market demand for retaining independence and choice; and the requirement for positive and suitable later life care arrangements, as an alternative to residential care. The assumptions behind these developments are that older people will be enabled to live for longer 'at home' whilst calling on a range of care and support services thereby potentially promoting their health, quality of life and well being and reducing social isolation. Extracare in this sense is portrayed for both fit and frail older people.

By identifying whose needs are met by extracare housing this project addresses some of the knowledge gaps regarding supported living environments. It looks at the integration and management of complex care in three settings by (i) examining the quality of life and experience of older people (ii) seeking views of managers and social workers as to whether complex integrated social and health care be delivered and (iii) exploring the cost effectiveness of extracare compared to residential and home care.

The study sample included 183 older people aged 60-98 years who completed a questionnaire survey: extracare housing ($n= 58$: South Wales $n=41$; North Wales $n=17$); residential care homes ($n= 66$: South Wales $n=36$; North Wales $n=30$) and people receiving care in the community ($n= 59$: South Wales $n=28$; North Wales $n=31$). Ninety-one participants also took part in in-depth interviews.

Key Findings

Overall, extracare provides for proportionally fewer frail older people than the other care environments. There are proportionally more physically frail older people in the community than in extracare, and a greater proportion of cognitively frail older people in residential care than in extracare. The care services provided within extracare facilities lack both breadth and depth. The limitations of the facilities are recognized by the residents, who realise that complex care needs (especially cognitive care needs) are not likely to be catered for within the facilities. For those in residential care, the majority felt that the environment was such that they would be able to stay as their needs increased, though not necessarily that they wanted to stay, and not necessarily that their increasingly complex needs would be dealt with satisfactorily.

Whilst the community care managers sought to keep people in their own homes using a mixture of professional interventions, the extracare managers sought to provide sufficient care for residents to engage in the community. Residential care managers focused on providing 24 hour care for the residents. The implication is that community care and residential care managers focus on providing the older person with care, whereas the extracare managers provide a purpose to the provision of care. This purpose is to enable older people to participate in the community.

When compared with residential and community care, extracare clearly has a variable capacity for meeting the needs of older people. Since those facilities labelled 'extracare' could take the form of a joint venture between Local Authority social services and a housing organisation acting as landlord, then extracare could clearly provide all of the services offered in the community. However, since none of the 'extracare' facilities had registered as domiciliary care providers the availability of the care '24' hours, as advertised in a majority of the organisations promotional material, is open to debate. Whereas residential care managers were quite clear about the categories of needs (nursing) that they were unwilling to admit such candour was not forthcoming from either community care or extracare managers. However, extracare managers were clearly unwilling to admit or continue to cater for people suffering with cognitive deterioration. Hence, the menu of services provided to older people in extracare facilities is structurally restricted from the outset. Consequently, older people applying to such a facility need to be well (and clearly) informed about the nature of the organisation, the type of care and support available (on-site or off-site) and what this entails, before making their decision.

We have noted that a few older people who are mildly to moderately cognitively impaired (i.e. not necessarily in need of nursing care, but possibly in need of other forms of support) are cared for in the community or in extracare. However, it appears, that on the whole, they are systematically excluded from these living environments through assessment and admissions processes that deem these settings as inappropriate for those 'who may pose a risk to themselves or others'.

The analysis of social networks indicated that extracare environments provide the conditions for increased social interaction and this is particularly effective for older widows. However, there were no differences in the levels of loneliness between the three living environments. The qualitative data serve to illustrate the point that although social interactions are increased in extracare environments the interactions do not necessarily lead to high quality and emotionally satisfying social relationships. Social resources appear to be fairly superficial in nature, and consist of encounters in the communal living areas in the facilities rather than in the private confines of the residents' flats.

The analysis revealed that, on the whole, the type of care environment is not predictive of quality of life (with two exceptions). Care environment predicted financial satisfaction and satisfaction with personal care services. Older people in residential care homes were least satisfied with control over financial matters, and extracare residents were least satisfied with access to personal care services. In the latter instance, it is clear that some extracare residents had not been informed adequately about the distinction between support services, personal care services and health services and the limitations of the facilities in providing in-house services.

Based on the evidence presented in this report we make the following recommendations to the Welsh Assembly Government:

1. A change in social ethos is required through public education – communities will need to accept the notion that there will be more older people with mild to moderate cognitive impairment living in the community. Communities need to prepare ways of meeting the challenge to provide for the welfare and safety of all of its members.
2. Deinstitutionalization of older people with mild to moderate cognitive impairment has resource implications (see discussion chapter). Evidence on the effectiveness of interventions should be used to prioritise which changes can be used to make the most positive impact on the lives of older people and their carers. A long term view needs to be taken by the Welsh Assembly Government to balance the initial costs and outlay, against the future costs of residential care and the impact on the quality of life and well-being of the older population in Wales.
3. Extracare should be defined clearly by the Welsh Assembly Government – there should be a gold standard so that it is clear to older people what they can demand/expect from these facilities either in the public or private sector. Furthermore, currently managers have the right to decline residents based on anticipated (imagined) future care needs and social grounds (whether or not they think a potential resident will be socially active in the community). A clear Welsh Assembly Government definition should indicate whether this is acceptable practice for (publicly funded) supported environments that are purported to provide for a mixed clientele.
4. During the process of making a decision to move, an explanation should be given to potential clients regarding what is available on-site and around the clock (clearly distinguishing between housing support services, personal care provision, and health care), who organises personal care and health care and how this differs (or not) from what they could expect to receive living in the community. Furthermore, the upper limits on care

provision (i.e. when a resident would be required to move out of the facility) should be clearly specified.

5. The Welsh Assembly Government should consider making changes in the Care Standards Act 2000 to allow a more flexible approach to the provision of complex care in extracare facilities. For example, there should be 24 hour provision for basic first aid, and other forms of emergency support that may be required by residents. The demarcation between housing support function and physical personal care makes little sense to those on the receiving end of services especially when they require immediate help (e.g. after a fall, or temporary assistance perhaps with accessing the dining room).
6. The unified assessment process needs to be re-examined and challenged especially with regard to the over-simplified outcome that older people with cognitive impairment 'pose a risk to themselves or others' and thus cannot live independently in the community. Examples of good practice should be provided to encourage care managers' use of innovative care packages to help people remain independent in the community or in extracare schemes (if they should wish to do so).
7. Although the development of a socially connected community within the facility may be an important facet for extracare home managers as they try to deliver the a range of facilities that promote participation, for those residents who have long-term friends in the community support to facilitate visits or other forms of communication between them may be more important. However, there are some examples of good practice that could be adapted from the extracare model to be used in residential care to provide meaningful social activities for residents in these facilities.
8. Increases in the volume of trained staff (and thus presumably funding for staffing) in residential care may have a positive impact on the sense of control that older people have over their lives.

INTRODUCTION

There is increasing policy emphasis on creating links across housing, health and social care. Subsequently, there is growing interest in innovative housing schemes that combine both independent living with high levels of care. Several related policies within Wales deal explicitly with the provision of supported living environments.

Designed for Life (WAG 2005) states that,

“Specialist housing where care services are available on site will become a much more widespread alternative to residential homes even for people with quite severe needs” (p.21).

The *NSF for Older People* (Welsh Assembly Government (WAG) 2006b) recognises that

“Home need not be the same house within which they have lived for years; other housing options such as sheltered housing, retirement villages or extracare housing can enable older people to retain their independence” (p.57).

The *Strategy for Older People in Wales* (WAG 2003) aims to

“Promote an adequate supply of special forms of housing which meet the varying and changing needs of older people and ensure they can remain independent as long as possible” (p.25)

Fulfilled Lives: Supportive Communities (WAG 2007) suggests that

“Extracare is a model of care that fits well in Wales. There are a range of facilities in extra care that promote participation and well-being” (p.57).

Better Homes for People in Wales - A National Housing Strategy (National Assembly for Wales (NAW) 2001) provides the framework and vision for housing in Wales and is actioned through complementary programmes, detailed in the *Strategy Action Plan*, and cascaded through *Local Housing Strategy Guidance*.

In order to go some way in meeting these aims, the Welsh Assembly has pledged £41 million for the provision of extracare housing. The *Guidelines for Developing Extra Care Housing in Wales* (WAG 2006a) state that extracare schemes should “take into consideration the likely impairments that residents will experience with increasing age and frailty” (p.11). However, research had not

clarified whether extracare accommodates the changing needs of both fit and frail older people. There is no evidence as to whether they successfully manage the delivery of complex integrated health and social care. Indeed, *Better Homes for People in Wales* suggests there may be a need to develop other forms of supported housing, specifically for frail older people (NAW 2001, p. 98).

While there have been quite a number of evaluations of different care environments, there have not been any evaluations that have compared the care provided by extracare with that provided in the community or by residential care providers. The objective of this report is to provide a partial response to the need for such a comparison by looking at the overall structure and function of each of these environments.

By identifying whose needs are met by extracare housing this project addresses some of the knowledge gaps regarding supported living environments. It looks at the integration and management of complex care in three settings by (i) examining the quality of life and experience of older people (ii) seeking views of managers and social workers as to whether complex integrated social and health care be delivered and (iii) exploring the cost effectiveness of extracare compared to residential and home care. The research contributes to our understanding of a 'person centred' approach in health and social care, one of the key policy objectives in the extracare development guidelines (WAG 2006a).

There is growing interest in innovative housing schemes that combine both independent living with high levels of care. Although there are a range of models (retirement communities, sheltered housing) and a variety of provision (size of dwelling, tenure of property, care package afforded to residents, availability of leisure facilities and amenities), collectively the concept is known as 'extracare'. Although there is currently no universal definition of extracare, there are common features in what is claimed to be offered by providers such as independent living, security, social interaction, and these echo many of the sentiments contained in the *Strategy for Older People in Wales* (WAG 2003).

The drivers to the emphasis and growth of extracare in Wales include:

- An increasingly ageing population
- Government policy objectives (see above)
- The market demand from older people and their carers for retaining independence and choice (Bexton 2006)

- The requirement for positive and suitable later life care arrangements, as an alternative to a care or nursing home
- The lack of alternative provision in mainstream housing. We know that although peoples' preferences are for provision of privacy and physical space, physical care, access to domestic services, security and control of life, there is little provision to meet their needs (Burholt & Windle 2007).

A review of recent literature (Croucher et al. 2006) concluded with a definition of extracare as “housing with care for later life”. This rather vague description means that there is considerable scope for interpretation within the extracare housing sector as to what this form of housing comprises. Potentially, the lack of clarity around the definition of extracare means that subjective interpretations could lead to self-styled substandard accommodation with inadequate facilities and poor care management. Tinker et al. (2007) have acknowledged the lack of uniform definition and support the case for further research to ensure that extracare consists of “good housing and good care, promoting well-being and good quality of life for all its residents” (p. 42).

Despite the lack of universal definition of extracare housing, the assumptions behind these developments are that older people will be enabled to live for longer in their own homes whilst calling on a range of care and support services (Riseborough & Fletcher 2003, Kerslake & Stilwell 2006) thereby potentially promoting their health and well being. Extracare in this sense is portrayed for both fit and frail older people (Bernard et al. 2004). There are further expectations around the potential of extracare in reducing social isolation and improving the quality of life (Croucher et al. 2006).

The research on extracare to date has been concentrated in England and does not combine a bio-medical and social care mixed method approach. Research shows that residents have high levels of satisfaction in such schemes, with independence and security being highly valued (Croucher et al. 2006). However, the evidence on cost effectiveness is scant and contradictory, and no comparisons have been made of housing with care, home care and residential care. Previous research has also failed to define and measure the degree of frailty amongst extracare residents. Assessing the degree of frailty is important, because it has been found to be independently predictive of disability, hospitalisation, institutionalisation and death (Bandeem-Roche et al. 2006). Cognitive decline also contributes to vulnerability and to the spectrum of frailty in older people and is associated with adverse outcomes.

This pilot project combines bio-medical and social care research using a mixed-method approach in an attempt to compare the profile of older people in extracare to those receiving home care and those in residential care. The aims of this project are to explore the following questions:

1. Does extracare accommodate the changing needs of both fit and frail older people, particularly those with cognitive impairments?
2. Can complex integrated health and social care be delivered in extracare? What are the views of managers and social workers?
3. What is the quality of life and experience of fit and frail older people in extracare schemes compared to those in residential and those receiving home care?
4. Is extracare cost effective compared to residential and home care matching residents of similar frailty?
5. What specific policy and practice implications are there for Wales?

METHOD

Sample selection

Two study populations were approached to address the research questions outlined in the introduction. These were (i) Residents / service users and (ii) Service providers / care managers / extracare managers.

A purposive sampling technique was adopted to identify three groups of older people: one group of older people in extracare (60), the second in residential care (60) and the third group of older people who were receiving social care services at home (60). The study population of older people was drawn from locations where extracare and residential schemes exist, spanning a rural site in North Wales (Conwy) and an urban location in South Wales (Cardiff). Residential care homes and extracare sheltered housing schemes in both Unitary Authorities were selected from the Elderly Accommodation Council (EAC) housing website (<http://www.housingcare.org/>).

Residents/service users

Using the contact information provided on the EAC website, managers of the facilities were contacted and personal visits arranged to explain the purpose of the study. When manager approval had been obtained, all residents were sent information packs and consent forms to return (by Freepost) to the University research team if they chose to participate in the project.

Older people receiving care in their own homes were recruited to the study through local council social services and their care services teams. Strategy co-ordinators and older persons care team managers were identified in each Unitary Authority and personal visits were arranged to explain the purpose of the study. Care team managers distributed the information packs and consent forms to service users via the care workers. Service users returned consent forms directly to the project team if they chose to participate in the project.

A stratified sample of 183 older people aged 60-98 years was recruited to the study and completed the questionnaire survey. The achieved sample comprised: extracare housing ($n= 58$: South Wales $n=41$; North Wales $n=17$); residential care homes ($n= 66$: South Wales $n=36$; North Wales $n=30$) and people receiving care in the community ($n= 59$: South Wales $n=28$; North Wales $n=31$).

Participants for the qualitative element of the study were randomly selected from those who had previously participated in the survey. The qualitative study had a target sample of 60 people across three care environments (20 each in extracare housing, residential care and receiving care in the community). It was intended that the sample would be divided equally between those living in North and South Wales. The achieved sample was greater than anticipated and comprised 91 participants: $n=30$ in extracare ($n=15$ North Wales: $n=15$ South Wales); $n=31$ in residential care ($n=15$ North Wales: $n=16$ South Wales), and $n=30$ receiving care in the community ($n=15$ North Wales: $n=15$ South Wales).

Service providers/ care managers/ extracare managers

A purposive sampling technique was adopted to identify care managers from whom to collect basic data about the facilities in the scheme and financial information. The managers of extracare facilities, residential homes and home care (identified in relation to the sampling strategy above) were provided with participant information sheets and consent forms that were completed and returned to project staff if they chose to participate. The achieved sample consisted of four extracare scheme managers (North Wales $n=2$; South Wales $n=2$), five residential care home managers (North Wales $n=3$; South Wales $n=2$) and five community care team managers (North Wales $n=3$; South Wales $n=2$).

Non-response

In North Wales two residential homes refused to participate. In South Wales one housing association refused to participate. This association was responsible for six care homes that were subsequently excluded from the study. In addition in South Wales, two BME/Religious residential care environments refused to participate. Of the three organisations that declined to participate, two cited 'privacy' of the residents of the reasons for non participation while the other noted that they did not want residents 'burdened' with taking part in a research project. In each instance, service users had not been approached because the managers of the respective facility or managing association had acted as gatekeepers. Basic contact information about residents had not been divulged to the research team, therefore we could not provide information to residents to allow them to make their own informed decisions about whether to participate. Therefore, there is no data available for individual non-response of services users as access was via gatekeepers.

Sample characteristics

Table 1 shows the demographic characteristics of the sample. The mean age of participants was 80.3 years. Overall, 27% of the sample were male and 73% female. A majority of participants were

widowed, however, marital status is significantly different across the three living environments (χ^2 20.11, d.f. 5, $p < .005$). The difference observed in marital status across the care environments can be accounted for by the following: fifty-six percent of all married participants lived in the in community, 62% of all divorced participants lived in residential care and 41% of all widowed participants lived in extracare sheltered housing.

There were significant differences in the mean score relating to the physical health of participants ($F(1/172)=16.5$, $p < .001$). In this respect, those with the worse mean physical health scores were located in the community, whilst those with the highest mean scores (best health) lived in residential care. There were no significant differences in participants' mean scores between residential care, extracare and the community for mental health or levels of depression of the participants.

Table 1 displays some psychological characteristics of the sample. These relate to resilience (including self esteem, control and competence) and loneliness (including emotional and social loneliness). Overall, there are no differences in levels of loneliness, self-esteem or competence between the living environments. However, there are differences in resilience per se ($F(2/180)=3.37$ $p < .05$) and in the resilience sub-scale interpersonal control ($F(2/180)=4.42$, $p < .05$), with those in residential care experiencing the lowest mean levels of both characteristics.

Interviews

The main research tools were:

- Individual interviews with older people using a structured questionnaire
- Individual semi-structured in-depth interviews with older people
- Individual semi-structured in-depth interviews with managers in extracare, residential care and the community

Interviews with older people using a structured questionnaire

Interviewers were recruited and trained by the research team. Training included standardisation of interview techniques (through an in-depth understanding of the interview schedule and assessed practice sessions), management of data, confidentiality, consent and safety. Training was provided for the physical frailty tests (see below), and a consultant geriatrician provided training in the use of the Mini Mental State Examination.

Face-to-face interviews were conducted with participants in their own homes (in private rooms in residential care home settings), and completion of the questionnaire and physical tests took approximately 60 minutes.

Table 1. Sample characteristics

	Residential (n=66) %	Extracare (n=58) %	Community (n=59) %	Total (n=183)
Gender:				
Male	23	29	29	27
Female	77	71	71	73
Marital Status: **				
Single	17	12	16	15
Married	9	12	30	17
Divorced	25	7	11	15
Widowed	49	68	44	53
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age	82.3 (8.4)	79.2 (9.8)	79.0 (9.3)	80.3 (9.2)
SF36: Physical Component Score***	47.9 (9.2)	41.4 (7.9)	39.7 (7.2)	43.1 (8.9)
SF36: Mental Component Score	53.1 (8.9)	51.0 (8.4)	52.4 (9.9)	52.2 (9.1)
Geriatric Depression Scale	8.6 (10.1)	6.8 (6.5)	8.1 (7.9)	7.9 (8.3)
Resilience *	104.3 (17.9)	109.5 (16.6)	112.1 (16.3)	108.5 (17.2)
Resilience sub-scales:				
Self-esteem	43.3(8.4)	44.5(9.3)	46.1 (8.7)	44.6 (8.8)
Interpersonal control*	26.8 (6.9)	29.2 (4.5)	29.5 (4.4)	28.4 (5.6)
Competence	34.2 (6.1)	35.8 (5.4)	36.7 (6.1)	35.5 (5.9)
Loneliness	3.6 (1.0)	3.7 (0.9)	4.0 (1.0)	3.7 (1.0)
Loneliness sub-scales:				
Emotional loneliness	1.8 (0.7)	1.9 (0.5)	2.0 (0.6)	1.9 (0.6)
Social loneliness	1.8 (0.8)	1.8 (0.9)	2.0 (0.9)	1.9 (0.9)

* p<.05 **p<.005 ***p<.001

Semi-structured in-depth interviews with older people and with managers

Each interviewer underwent a full day course on in-depth interview technique specifically using the semi-structured protocols. Emphasis was placed on engaging with the participant and allowing the participant (either the care manager or older person) to tell their story and share their experiences. Each of the interviewers practiced interviewing using the schedule.

Face-to-face interviews were conducted with older participants in their own homes or in staff designated private rooms. Where possible, the interviews were conducted alone to ensure that all opinions expressed by the participant were their own. Each interview lasted approximately one hour.

Data on Costs of Care Provision

Our intention was to employ both micro-costing and gross costing approaches, involving the scrutiny of relevant financial documents. The intention was to derive cost differentials between the care settings and compare with other estimates evident from within the UK literature. To this end we anticipated that detailed interviews with care managers and key staff involved in the extracare scheme and social services departments were determine the various service inputs relating to service provision - staff involvement, materials, equipment and buildings utilised – and these would be translated into costs using published unit cost data (Curtis 2009).

Three weeks prior to the care managers' interviews, each manager was sent a letter requesting costing information on FTE staffing, equipment and maintenance costs. Managers were advised that accounts could be submitted and that the research team would extract relevant information whilst ensuring no sensitive or identifying data were used. During the managers' interviews (if no information had been supplied), the manager was asked again to provide the requested information or to send to the research team at their earliest convenience.

Very few managers ($n=14$) submitted costing information (extracare $n=4$; residential care $n=5$; and community care $n=5$) despite receiving several reminders and offers of assistance to collate the information. Full costing information was received from one extracare scheme and one residential care home. Partial costing information was received from two extracare schemes, one residential care home, and two care team managers. The key reasons for not returning data included the perceived time commitment and the release of potentially commercially sensitive data despite assurances of confidentiality and anonymity.

To supplement the sparse data, additional information was sought from public records stored at Companies' House. However, only one residential home was individually listed, the others had returns amalgamated with other businesses under a holding company so these data were not used. Due to the lack of substantive data, minimal cost analysis was conducted.

Measures

Each older participant completed a questionnaire consisting of nine sections including two physical tests. The questionnaire comprised measures that had previously been tested for validity and reliability including; Health related quality of life (SF36: Ware et al. 2000); Nutrition (Mini Nutritional Assessment: Guigaz et al. 1996); Cognition (Mini Mental State Examination (MMSE): Folstein et al. 1975); Activities of daily living (Older Americans and Resources (OARS) Activities of Daily Living Scale: Fillenbaum 1988); Depression/Mood (Geriatric Depression Scale (GDS): Yesavage et al. 1983); Self reported physical health (GDS: Yesavage et al. 1983); Psychological Resilience (Windle et al. 2008); Lubben Social Networks Scale (LSNS-18: Lubben & Girona 2003); Loneliness (De Jong Gierveld & Kamphuis 1985) and Satisfaction With Life Scale (SWLS: Diener et al. 1985). The questionnaire included two physical measures: timed get up and go test (Podsiadlo & Richardson 1991); and grip strength test (Fess & Moran 1981). These tests were strategically placed within the questionnaire to break the interview into three parts of similar length thus reducing the demands on participants. Questionnaires were pre-tested (piloted) to ensure that structure and content of the schedule was not difficult or ambiguous, and to estimate interview duration.

For each of the scales below (with the exception of the SF-36) missing values were imputed using the EM (expectation-maximization) method. This method consists of iteration of an E step (conditional expectation of the 'missing' data given the observed data in the set, and estimates of parameters) and an M step (computed maximum likelihood estimates of the parameters) (Little & Rubin 1987, Schafer 1997, McLachlan & Krishnan 1997).

The *SF-36* is a 36-item scale that measures eight domains of health status: physical functioning; physical role limitations; bodily pain; general health perceptions; energy/vitality; social functioning; emotional role limitations and mental health. A scoring algorithm was used to convert the raw scores into eight dimensions listed above (standardized using a z-score transformation) using British normative data for appropriate age groups (ONS omnibus survey of Britain (1992): Bowling et al. 1992). The transformed scores were aggregated into two scores (physical component score (PCS) and mental component score (MCS)) using weights (factor score coefficients) (Ware et al. 2000). Aggregate scores were standardised using a linear T-score transformation to have a mean of 50 and a standard deviation of 10. Scores on each scale (PCS and MCS) ranging from zero (worst possible health) to 100 (best possible health). It has been reported that the domains have internal consistency (Cronbach's $\alpha > 0.7$) and the measure has test-retest reliability after a two week interval (91-97% for each domain at 95% confidence interval) (Brazier et al. 1992). Missing values were recoded

with person-specific mean substitution (where 50% or items are available – or for odd numbers of items 50% +1 item) as recommended in the SF36 handbook (Ware et al. 2000 s.6:4).

The *Mini-Mental State Examination* (MMSE) is a brief 30-item questionnaire test to screen for cognitive impairment. The questionnaire includes questions covering six dimensions: orientation, registration, attention and calculation, recall, language and copying. Scores greater than or equal to 25 points (out of 30) indicate that the person is not cognitively impaired. Lower scores indicate severe (≤ 9), moderate (10-20) or mild (21-24) cognitive impairment (Folstein et al. 1975). Test-retest validity at eight weeks has been reported as 0.84 (Conner et al. 1989) and at one week ranging from 0.90-0.97 ($p < .001$) (Pangman et al. 2000). Internal consistency is reported as acceptable (Cronbach's $\alpha > 0.8$) (Pangman et al. 2000).

The *Geriatric Depression Scale* short form (GDS15) is derived from the GDS30 (Yesavage et al. 1983) and can be used to assess depressive symptoms in older people. In previous studies the GDS15 has demonstrated a high level of internal consistency (Cronbach's $\alpha = 0.80$) and construct validity (D'ath et al. 1994). Further to this Wancata et al. (2006) have reported sensitivity values of 0.805 with specificity values of 0.750.

The *Lubben Social Network Scale* (LSNS-18) measures perceived social support from friends and family. The scale consists of an equally weighted sum of 18 items used to measure size, closeness and frequency of contacts with friend and relatives within the participants' social network. The scale ranges from 0 to 90, with lower scores indicating fewer social resources. The LSNS-18 consists of three sub-scales (with ranges from 0 – 30) that distinguish between relatives, neighbours (defined as local friends) and friends (not in the local community) (Lubben & Girona 2003). The LSNS-18 has reported internal reliability for the total scale (Cronbach's $\alpha = 0.82$), and high internal consistency for each of the subscales: (Family: $\alpha = 0.82$; friends: $\alpha = 0.87$; and neighbours: $\alpha = 0.80$) (Lubben & Girona 2003). In this current study internal reliability of the 18 items was strong (Cronbach's $\alpha = .85$). The scale appears to have construct validity, because low scores have been correlated with mortality, hospitalization and depression (Lubben & Girona 2004).

The *de Jong Gierveld Loneliness Scale* is a 6-item measure that captures participants' degrees of emotional and social loneliness (De Jong Gierveld & Kamphuis 1985). Confirmatory factor analyses has confirmed the specification of these two latent factors (De Jong Gierveld & Tilburg 2006). Congruent validity and the relationship with determinants (partner status, health) are optimal (De Jong Gierveld & Tilburg 2006). Typically, scale reliability is reported as 0.80 to 0.90 (Cronbach's α) (König-Zahn et al. 1994).

The *Satisfaction with Life Scale* (SWLS) is a five-item scale that measures life satisfaction. Scores range from 5-35 with lower scores representing a lower level of life satisfaction. The scale has been reported as reliable (two month test-retest correlation coefficient of 0.82) and internally consistent (Cronbach's $\alpha = 0.87$) (Diener et al. 1985). In this present study, internal reliability was also strong (Cronbach's $\alpha = .81$). The measure has construct validity and has been shown to correlate with numerous measures of subjective well-being and life satisfaction (Diener et al. 1985, Pavot et al. 1991). In the analysis of quality of life domains, a personal mean score (over the five items) is used in place of the overall score, in order to maintain parity with the other measures used in the analysis. In this analysis only, mean scores can range from 1 – 7 with higher scores representing greater levels of satisfaction.

The *Timed Get Up and Go Test* is a standardised procedure requiring participants to start from a seated position on a chair¹. Participants are required to stand, walk three metres, turn round, walk back and sit back down. The time is recorded from the point the participant's back leaves the rest of the chair until the point they are seated again with their back against the chair. Up to two trial attempts are permitted, followed by three recorded test attempts (with a one minute break between each to prevent fatigue). Each trial is recorded, and the mean average performance time for each participant is used in the analysis. The time score has reported reliability (inter-rater and intra-rater); and construct validity (correlation with the Berg Balance Scale ($r=-0.81$), gait speed ($r=-0.61$) and Barthel Index of ADL ($r=-0.78$)) (Podsiadlo & Richardson 1991).

Grip Strength is measured using a Saehan SH5001 hydraulic dynamometer. Participants are required to sit on the chair provided (or remain seated in their own chair if they were unable to transfer to the chair provided) with their forearm at 90 degrees to their torso. Participants are instructed to grip the dynamometer in their strongest/writing hand and grip as hard as they can manage for five seconds (Fess & Moran 1981). Up to two trial attempts are permitted, followed by three recorded test attempts (with a one minute break between each to prevent fatigue). Each trial is recorded, and the mean average performance time for each participant is used in the analysis.

Resilience was measured using a scale developed by Windle et al. (2008). The scale comprises of three sub-scales: self-esteem (adapted from Rosenberg (1965) Self Esteem Scale) using eight items that are answered on a five-point scale ranging from strongly agree (1) to strongly disagree (5);

¹ Interviewers each took the same model folding chair to the interviews. These were 46cm high (base to seat) and did not have arm rests.

interpersonal control (adapted from Spheres of Control Scales, Paulus & Christie 1981) consisting of five questions rated on a seven-point scale from strongly agree (1) to strongly disagree (5); and personal competence (adapted from the Resilience Scale, Wagnild & Young 1993) comprising six items answered on a seven-point scale from strongly disagree (1) to strongly agree (7). Internal consistency for scale has been reported as high (Cronbach's $\alpha = 0.83$). In this study internal consistency of each of the sub-scales was acceptable (self-esteem Cronbach's $\alpha = .82$; interpersonal control Cronbach's $\alpha = .71$; competence Cronbach's $\alpha = .78$). A score representing resilience is derived from summing sub-scale scores.

Frailty was operationalised using an adapted version of Freid et al.'s (2001) measure of frailty phenotypes that includes measures of unintentional weight loss, weakness, poor endurance (exhaustion), slowness and low activity. Participants were coded as frail (score of 1) on each dimension according to the criteria listed below, and the frailty score was calculated by summing the values for each of the domains, with higher scores representing greater levels of frailty. Participants are deemed positive for the frailty phenotype if they score equal to or more than three (i.e. at least three criteria are present). Those with one or two criteria present are classified as intermediate or pre-frail. Where we use a binary indicator of frailty, this compares those with three or more criteria present (frail) to all others.

- Unintentional weight loss was measured using a single item enquiring whether the participant had unintentionally lost three or more kilograms of weight in the prior year (Fried et al. 2001).
- Weakness was measured as lowest 20% (for valid scores only, thus excluding those who were unable to complete the test) for grip strength adjusted for gender (in this study scores < 4.4 for women and < 13.4 for men) (Fried et al. 2001). Those who could not do the test were also classified as frail in this domain.
- Poor endurance (exhaustion) was defined as those who scored in the lowest quintile for the vitality domain of the SF36 (in this study < 25).
- Slowness was quantified as the slowest 20% (excluding those who did not do the test) in the timed get up and go test (in this study < 31.33 seconds). Those who could not do the test were also classified as frail in this domain.
- Low activity was measured using a single item that asked participants to specify the level of physical activity in the prior month. Those classified as frail in this domain responded either as 'hardly any' or as 'mostly sitting, sometimes a short walk around the home and light household activities such as heating up food' (Bartali et al. 2006).

Participants were considered to be cognitively frail if they scored less than 25 on the MMSE. Using a combination of the frailty measures, participants were also classified as not frail, physically frail only, cognitively frail only, or both physically and cognitively frail.

Quality of life: We originally intended to use the Quality of Life in Later Life (QuiLL) assessment (Evans et al. 2005) to compare the quality of life of residents between the three settings. However, the measure has not been tested for use in supported living environments and it was felt that certain questions (e.g. how frequently (if at all) do you find it difficult to meet the cost of household bills) would not be appropriate for participants in residential care. Additionally, items subsumed within QuiLL would replicate subject areas that were covered by other instruments (e.g. loneliness, health).

Despite an extensive search of the literature, we found no validated Life Satisfaction questionnaires specific to the residential setting that would gather evidence on specific aspects that were of particular interest to us. Instead, in this report we have chosen to use a personal measure of life satisfaction (SWLS above) (see e.g. Andrews & Withey 1976, Larson 1978, Andrews 1986), together with other measures of satisfaction. We have chosen these because we feel they would provide us with an indication of quality of life in different domains not already covered elsewhere in the report.² For this reason we included eleven questions on levels of satisfaction concerning (i) access to social and community groups (Gabriel & Bowling 2004, Burholt & Windle 2007), (ii) access to transport, (iii) access to personal services (Burholt & Windle 2007), (iv) access to health services (Burholt & Windle 2007), (v) support from friends, (vi) support from family, (vii) amount of company, (viii) ability to perform everyday activities (Gabriel & Bowling 2004), (ix) conditions of place of living (Gabriel & Bowling 2004), (x) control over financial matters (Burholt & Windle 2007) and (xi) level of security (Burholt & Windle 2007). These were rated on a Likert-type scale ranging from very dissatisfied (1) to very satisfied (5).

Frequencies revealed that $\geq 6\%$ of cases had missing values on five of the items, one of which was 'How satisfied are you with your access to transport?' Here, 20 responses (11%) were missing. During quality monitoring early on in the study it was found that some interviewers had presumed the question to be not applicable and had not asked the question to the participants (e.g. if the participant was housebound). Therefore all missing values were recoded as the midpoint 'neither satisfied nor dissatisfied'. For all other items missing values were imputed using the EM algorithm (see note above).

² For those covered elsewhere see: loneliness (Evans et al. 2005), health (Bowling 2001, Gabriel & Bowling 2004), resilience (Baltes and Baltes 1990), social resources (Evans et al. 2005).

Principle axis factoring with direct oblique rotation was employed to examine whether some of these aspects represented smaller dimensions and/or whether some of these were distinct and stand-alone measures. Models were tested for 2 – 4 components, and the best resolution comprised three components with an Eigen value of greater than 1 (see Table 2), and the model overall accounted for 55.6% of variance.

Table 2. Factor structure of satisfaction, variance explained and internal reliability of factors

Item	Factor		
	1 Social Satisfaction	2 Environmental Satisfaction	3 Satisfaction with Access to Personal Services
Support from friends	.78		
Amount of company	.66		
Access community groups	.65		
Support from family	.62		
Financial control †	.45	.44	
Living conditions		.71	
Access to transport		.64	
Security at residence		.54	
Ability to perform everyday activities		.48	
Access to health services		.43	
Access to personal services			.61
% Variance explained	35.41	10.75	9.48
Internal reliability (Cronbach's α)	0.76	0.67	n.a.

* Only factor loadings ≥ 0.4 are included in the table for ease of interpretation.

† Treated as a single item in future analysis – internal reliability scores exclude this variable.

- **Social satisfaction:** comprised 'support from friends', 'amount of company', 'access to community groups and support from family', and these items loaded from .62 - .78. The fifth item, 'financial control', loaded weakly at .45. Internal reliability was strong (Cronbach's $\alpha = .76$) and the alpha value remained unchanged if 'financial control' were omitted from the factor. Thus, 'financial control' was excluded from the measure. The personal mean of the four remaining variables is used as a new variable 'social satisfaction' in which higher mean scores

represent greater levels of satisfaction. This measure captures the levels of satisfaction with contact with friends and family, as well as the ability to access and engage in social activities.

- Environmental satisfaction: comprised ‘living conditions’ and ‘levels of security at place of residence’, ‘access to transport’ and to ‘health services’, as well as the ‘ability to participate in everyday activities’. A sixth item, ‘financial control’, loaded weakly (.44). The personal mean of the five variables is used as a new variable ‘environmental satisfaction’ in which higher mean scores represent greater levels of satisfaction. This measure captures environmental living conditions, lack of barriers to obtaining services and the person-environment interaction. Internal reliability for the five items is fairly good (Cronbach’s $\alpha = .67$).
- Satisfaction with financial control is used as a single item in analyses. Scores can range from 1 – 5 with higher scores representing greater levels of satisfaction.
- Satisfaction with access to personal services: is used as a single item in analyses. Scores can range from 1 – 5 with higher scores representing greater levels of satisfaction.

Analysis

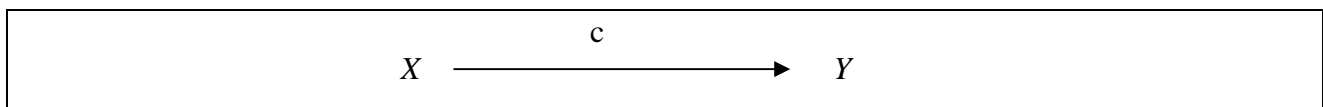
Throughout this report analysis of variance (ANOVA) of means is used to compare scalar data between care environments (e.g. level of physical frailty between extracare housing, residential care and community). Pearson chi square tests (χ^2) are used to compare the distribution of categorical data between care environments. Significance is assumed at the 5% level (i.e. $p < .05$).

In order to explore and to compare the structure and function of the care environments, we draw on qualitative data to look at the general scope and purpose of extracare, residential care, and community care, and at how these three types of care providers recruit users. By looking both at the general orientation of these three care environments, and at their recruitment practices, we can gain a clear understanding of how each environment is socially located, as well as where they gain their financing and at who is included and excluded from being offered care. The purpose is not to compare the quality of care offered in these environments (although comments on what is on offer may become relevant at certain points), but to clarify the orientation of the providers, to gain an insight into their objectives in delivering care and their recruitment practices. This will allow us to discern the nature of the kinds of needs these environments are organised to cater for. These comparisons furnish us with an idea of the social locations of these three types of care environment in the context of care provision for older people. Furthermore, we employ thematic content analysis of qualitative data to triangulate with the quantitative data analysis on frailty (perceptions of limitation of care in each environment), quality of life and satisfaction in various domains, and social interaction and friendship formation in extracare. The gender (indicated by F (female) and M

(male)) and age of the participants are indicated in brackets after verbatim quotes included in the text.

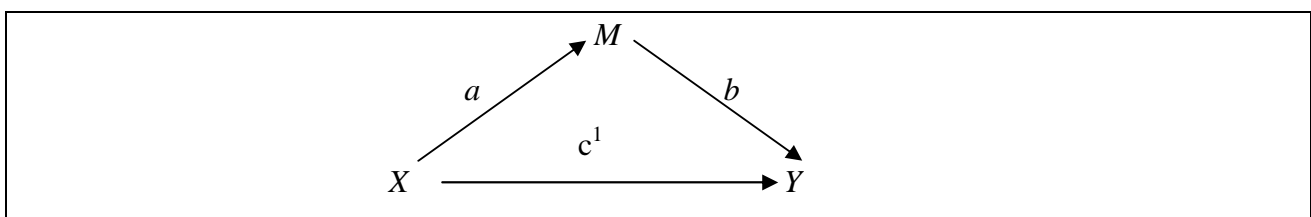
We use two types of quantitative analysis to empirically examine the quality of life and life experiences of older people in the three settings: mediation analysis and linear regression. Mediation analysis is used to examine the impact of care environment on the social resources of older widows (see Chapter 5 for an explanation the selection of widows for this analysis). Mediation models assume that variable *x* (the initial variable) affects variable *y* (the outcome variable). This is an unmediated model and is shown in Figure 1. The pathway between the two variables ‘*c*’ is called the ‘total effect’.

Figure 1. Unmediated model



In a mediation model it is hypothesised that the mediating variable (*M*) has an intervening effect on pathway *c* (see figure 2). In order to test the mediation model certain assumptions must be met: in separate regression models variable *X* must predict *Y*, and *M*. Furthermore, variable *M* must predict *Y*. If perfect mediation occurs, then *X* no longer effects *Y* after *M* has been controlled in a regression model. However, partial mediation occurs when the relationship between *X* and *Y* is reduced in size (but is different from zero) (*c*¹).

Figure 2. Mediation model



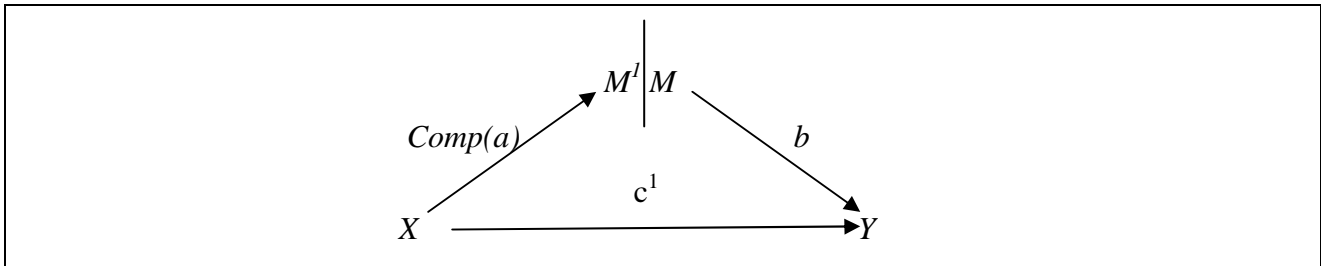
The equations for the model are:

$$\begin{aligned}
 Y &= cX + E1 \\
 M &= aX + E2 \\
 Y &= bM + c^1X + E3
 \end{aligned}$$

In the mediation model tested in this report, the relationship between *X* (widowhood) and *M* (care environment) are established using binary logistic regression and the relationship between *X* (widowhood) and *Y* (social resources) and *M* (care environment) and *Y* (social resources) are established using multiple regression. This requires a transformation of the co-efficients for the path (a) between *X* and *M* to ensure comparability of coefficients in the equation. This is achieved by

multiplying the coefficient of path a by the standard deviation of X and then dividing by the standard deviation of M . Thus, in this analysis the mediation model is specified in figure 3 and the equation for $comp(a) = a * SD(X)/SD(M)$. In this analysis, we use the Sobel test to ascertain the significance of the change in c (i.e. of mediation).

Figure 3. Mediation model where 'M' is a dichotomous variable



Meeting these steps does not establish conclusively that mediation has occurred, because there may be other models that may also fit the data. Therefore, we adopted a triangulation strategy and examine qualitative data to see if there was experiential evidence of changes in social resources after a move to extracare for widows. Thematic content analysis of the in-depth interviews of older widows living in extracare environments ($n=20$) explored the themes in relation to the dynamics of social networks both prior to and after the move to the facilities.

Linear regression was used to examine the predictors of quality of life in five domains. The dependent variables are (1) personal satisfaction (SWLS), (2) social, satisfaction (3) environmental satisfaction (4) financial satisfaction and (5) satisfaction with access to personal services. We established whether the care environment and/or social networks and/or resilience predict quality of life. To this end, 'care environment' was transformed into three dichotomous variables (i.e. residential care/not residential care, extracare/not extracare, community care/not community care). A total of ten multiple regression models were run. For each of the five outcome variables, two regression models were tested. In each regression, gender, age and general health (PCS of the SF36) were entered in block one (i.e. were controlled for), and the care environment and either the social network measure or the resilience measure in block two.

FRAILITY AND COMPLEX CARE: THE FUNCTION OF THREE CARE ENVIRONMENTS

Introduction

Frailty is a concept that is contested, yet frequently adopted in the medical model of ageing. It is often used as a proxy for the severity of 'ageing' in an individual, and is linked to, but distinct from, chronic diseases (comorbidity) and disability (Slaets 2006). Some believe that frailty has a biological basis and is a distinct clinical syndrome (Lang et al. 2009). However, elsewhere frailty has been defined as "a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes" (Gobbens et al. 2009, p. 1). This suggests that a person can be classified on a continuum between non frail and frail (Gobbens et al. 2009).

Grenier (2007) has argued that the classification of a person as frail is a dividing practice: frailty is used in the allocation of care with those deemed 'frail' eligible for welfare services, whilst those who are not defined as frail are barred from services. In the bio-medical discourse concerned with the 'treatment' of frailty or the allocation of health and social care services to 'the frail' there has been a focus on how to operationalise the concept. No single conceptual and operational definition of frailty exists, thus the prevalence figures for frailty among older people are variable: 33% to 88%, depending on definition that is used (Van Iersel & Rikkert 2006). One of the most commonly used biomedical operationalisations of frailty takes into account unintentional weight loss, weakness, poor endurance, slowness and low activity (Fried et al. 2001). More recently Gobbens et al. (2009) suggested that any measurement or assessment of frailty should also taken into account cognition, sensory functions, mood, coping, social relations and social support.

In this report we recognise that that the concept of 'frailty' is useful in determining whether each care environment (community, extracare housing, residential care) provide for older people with a range of physical and functional deficits. However, by using a measure of frailty in our analysis we are not condoning resource allocation based on a combination of physical and functional characteristics of an individual. We conclude this chapter with a discussion of the functional capacity of each care environment to provide for complex care needs. Furthermore, in Chapter 4 we discuss the structure of each of the three care environments and illustrate how the use of the

concept of ‘frailty’ in care management/care allocation excludes some older people from public spaces.

Results

Table 3 shows the proportion of participants identified as frail on each of the frailty indicators. Results of Pearson chi-square tests show that there are significant differences in levels of physical or functional deficits between the three environments for speed, endurance, activity, physical frailty and cognitive frailty. A significantly greater proportion of participants in the community (than those living in either residential care or in the community) are identified as impaired with regard to speed (χ^2 9.44, d.f. 2, $p < .01$), vitality (χ^2 15.52, d.f. 2, $p < .001$), strength (χ^2 6.23, d.f. 2, $p < .05$), and overall physical frailty (χ^2 19.43, d.f. 2, $p < .001$). Fewer of those people living in extracare facilities (than those living in either residential care or the community) are considered frail with regard to levels of activity (χ^2 8.44, d.f. 2, $p < .05$). A significantly greater proportion of older people living in residential care are cognitively frail compared to the other two environments (χ^2 40.2, d.f. 2, $p < .001$).

Table 3. Proportion of participants identified as frail on each indicator and measure of physical and cognitive frailty

	Residential Care %	Extracare housing %	Community care %	All %
Weight loss	6	5	9	7
Speed**	60	48	76	61
Strength*	27	26	46	32
Endurance***	9	12	35	18
Activity*	83	64	83	77
Physical Frailty***	22	24	56	33
Cognitive frailty***	86	46	28	55

* $p < .05$ ** $p < .005$ *** $p < .001$

Table 4 displays the mean scores for both frailty scores for each of the three living environment. Results of ANOVA tests show that there are significant difference between care environments in the levels of physical frailty ($F(2/174) = 9.00, p < 0.001$) and cognitive impairment ($F(2/170) = 31.5, p < 0.001$). The data show that the least physically frail older people are being cared for within extracare schemes ($M=1.6$ SD 1.3), closely followed by residential care ($M=1.8$ SD 0.9), with those who are most physically frail receiving care in the community ($M=2.4$ SD 1.1). In the case of

cognitive frailty, those with the highest level impairment were supported in residential care environments ($M=19.0$ SD 5.8) with extracare ($M =24.5$ SD 4.1) and community care ($M=25.6$ SD 4.2) supporting the least cognitively frail elders. The mean scores for MMSE indicate that older people in residential care have mild to moderate cognitive impairment (10-20: moderate; 21-24: mild), whilst the average scores for those older people living in the other environments suggest that they are cognitively intact.

Table 4. Mean scores for MMSE and physical frailty scores in each environment

	Residential Care Mean (SD)	Extracare housing Mean (SD)	Community care Mean (SD)	All Mean (SD)
MMSE***	19.0 (5.8)	24.5 (4.1)	25.6 (4.2)	22.8 (5.6)
Physical frailty***	1.8 (0.9)	1.6 (1.3)	2.4 (1.1)	1.9 (1.2)

*** $p<.001$

Table 5 shows the distribution of the residents classified as not frail, physically frail only, cognitively frail, or both physically and cognitively frail. There are significant differences between the care environments, with residential care more likely to contain residents who are cognitively frail only compared to either of the other two environments, while those receiving care in the community are more likely to be physically frail than residents in the other two environment. Strikingly, extracare housing is more likely than the other environments to house residents who are not frail (Pearson $\chi^2 = 40.2$, d.f. 2, $p<.001$).

Table 5. Proportion in each care environment according to type of frailty

	Residential Care ($n=60$) %	Extracare Housing ($n=56$) %	Care in the Community ($n=49$) %	All ($n=165$) %
Not Frail	13	41	39	30
Physically frail only	2	13	33	15
Cognitively frail only	65	36	8	38
Physically and cognitively frail	20	11	20	17

The capacity to provide complex care to frail elders

In order to assess the level of care given by care providers, we have taken up Rankin and Regan’s observation that, from a users point of view, “complex needs frequently have both breadth and depth: there is a range of needs as well as a high level of need” (2004, pp. 7-8) Our objective was to identify whether the interviewees made use of a range of services, and to some degree the depth of services they accessed. Therefore we adopted Rankin and Regan’s (2004) observation and used it to construct a grid that we then used to map degrees of complexity. This grid, and the associated data, are presented in Figure 4:

Figure 4. Degree of complexity of services used in each of the care environments

		High Depth			
	Community Care	15	Community Care	1	
	Extracare	4	Extracare	1	
	Residential Care	15	Residential Care	0	
Low Breadth					High Breadth
	Community Care	9	Community Care	5	
	Extracare	18	Extracare	4	
	Residential Care	5	Residential Care	5	
		Low Depth			

A low breadth of services use is indicated by the use of one type of care or support service, that is, the use of personal care services, or a single health care service. High breadth is equated to the use of two or more such services. Low depth is indicated by a limited use of this service. For instance, an older person who is called upon once a day by one personal carer, and provided with some help cleaning, showering etc. A high depth is indicated by more extensive use of a service – for instance, a personal care service is composed of two or more calls and involves a number of care tasks.

As we can see, only two of those interviewed in the qualitative phase of the study reported receiving a number of different types of care, and a high degree of depth of this care (high breadth-high depth). The only community care user who uses both a high breadth and depth of services was a participant who had dementia and was cared for at home by his wife. This participant regularly went into hospital to receive some physiotherapy, received regular visits from the Community

Psychiatric Nurse, and received some personal care services. The extracare user who is similarly classified has a carer who works “a four to eight shift yes” (F, 61), and since this participant is wheelchair bound, has severe osteoporosis, arthritis and heart problems she also make frequent visits to the local GP.

In all, fourteen interviewees reported making use of two or more types of services, but to a limited extent (high breadth-low depth). But what is more interesting is how residents of residential care and community care facilities made similar use of services (high depth-low breadth), while more than one half (18 of 30) of the extracare residents interviewed made a limited use of one type of service (low breadth-low depth). Indeed, eleven extracare users reported not using any services that were additional to those offered as part of the tenancy agreement, while four receive some help washing or in the bath, and one participant only receives some help from the district nurse. This kind of limited use (low-depth) of care resources contrasts with the use made by community or residential care users (high-depth), both of whom receive considerably more help with a range of tasks, for example with washing or getting out of bed.

When participants were asked about how they anticipated managing their future care needs the limitations of each care environment (in terms of breadth and depth of service provision) were recognized by the participants. Below the qualitative data from in-depth interviews are used to highlight the perceptions of these limitations that are held by participants in each of the environments. Special attention is given the perceptions of care and support provision for people with different levels or types (physical or cognitive) of frailty.

Perceptions of the limits of Community Care

The community care interviewees were, largely, adamant that they planned to remain in their own home. Nineteen of those interviewed confirmed that this was their plan, with only five reporting that they expected to move, and three admitting that their future domiciliary arrangements depended on how their care needs developed. However, when asked for their view on the amount of care that was available in the system, only twelve interviewees expressed their confidence that the system was capable of providing them with any care needs they may have in the future. This is important considering that in this study the most physically frail older people are cared for in the community. A number of participants noted that financing their own future personal care may be problematic. Some felt that their pension may not stretch to pay for their needs as they grow older (F, 78), while others were willing to pay for any increases in their care needs:

“Oh yes I mean if I needed anymore I could pay for it couldn't I, you know. I could say ‘Could you please provide well what somebody to do my washing or something.’ You know I could ask for something else couldn't I?” (F, 80)

Three interviewees reported that they were dissatisfied with the amount of care available. One felt a rearrangement of her allotted care work did not deliver the promised benefits, one interviewee felt unable to ask for more care as she could not pay for it (“if I say I want more care then I'm just told that I've got to pay for it. I don't go into it because I just know I can't afford it” (F, 67)) and the daughter of one interviewee indicated dissatisfaction with the way the system deals with her mother's support needs:

“And they do like to send you round in circles. And then I was told if I wanted a cushion I'd have to buy it myself because they didn't provide them because mum was living in so-called rented private accommodation. She wasn't in council rented accommodation; she wasn't in a nursing home. Because my sisters now own the house mum sort of escapes, she just sort of, you know.” (daughter of F, 88)

Nevertheless, these dissatisfactions did not indicate unease with the amount of care that was available in the system, but rather a perception that the system had some contradictory features. There were, however, six interviewees who demonstrated awareness that there was a certain quantum of care available in the community care system, and this care may have limits. For three of these, the pressures on the system were impenetrable (“Some things are going to change and I don't know what it is because we don't know normally” (F, 63); “Well I don't know, it depends what they're going to allow them to do you see we don't know what's going on. The girls themselves don't even know what's going on, they're talking a lot about, like they're closing the [local hospital] aren't they?” (F, 89)) and had an enormous effect on their life since such change led to them have “all different carers coming in from different areas, like I don't know who's who anymore” (F, 72).

Perceptions of the limits of extracare provision

When asked about how they anticipated managing their future care needs, ten interviewees said they expected to stay in the extracare facility, five expected to move, and eight said the decision about whether or not to move would depend on how their care needs unfolded. Those who planned to stay provided a number of reasons for this position. Firstly, the structure of the facility met their needs (“just supposing you had to use a wheelchair, all the doors are wide, the corridors are wide so

you could use a wheelchair” (F, 84)), secondly two interviewees pointed to the ways in which they were tied into the facility as tenants (F, 85) or owner occupiers:

“We can’t afford to move we bought them and if you move then the company that run it get 3% of the price. And I mean we’d never sell them because they haven’t sold even the... You know there’s about two thirds sold so we wouldn’t have any chance of selling them.” (F, 78)

Some interviewees reported they wished to remain because “I like the place” (F, 88), “It’s just that there’s some good people in here” (F, 62) or “Because I’m happy here. I’ve been more happy here than I’ve been anywhere” (F, 88).

A further eight interviewees took a more conditional attitude to this question. While they wished to remain in the extracare facility, they nonetheless anticipated moving to another care provider. These interviewees were aware of the limits of their capacities to manage their own care themselves (“if my wife died before me I wouldn’t, I’m sure I wouldn’t be able to live here on my own” (M, 88) “See arthritis is worrying me more than anything now because I’ve got it everywhere; in my hips and everything. But as long as I can get out and walk a bit, it’s not so bad, but when you can’t breathe it’s difficult, you know” (M, 67)), or their vulnerability to changes in their partners’ capacities (“Only if my wife’s or my medical condition deteriorated a lot” (M, 70)). In addition, four interviewees mentioned the onset of dementia as a condition for moving people to another facility:

“Well I watch what happens to other people and if you become incapable of coping then what has happened to people here is obviously it’s not a place where people with Alzheimer’s disease could stay. And what has happened, they have gone into a nursing home.” (F, 88)

“We did have one lady and didn’t realise how, I don’t think they realised how ill she was and she started wandering and so straight away they had to take her to a nursing home.” (F, 88)

One interviewee responded to this question by talking about the possibility of dying in the facility. This interviewee linked a future increase in their care needs with palliative care, and considered the connection between their tenancy and the likelihood they would die in hospital. As we can see, this interviewee felt the facility could support increased care needs, but this support needed to be balanced with the wishes of the older person’s family:

“I think they will but that would be, they cater for people who have had strokes, they have them back from hospital because this is their home, you’ve got to keep paying the rent even though you are in hospital and they die here even, but they try not to if they can help it. Usually if somebody is that ill they go into hospital and eventually they will end their lives in hospital. But that doesn’t mean to say you will be pushed out if I was dying here [the manager] would see to it that I was kept here then. It would be up to your relatives or your next of kin or yourself to – well if you were dying you wouldn’t care where you are would you? I shouldn’t think so anyway.” (F, 82)

As noted above, eight residents of extracare felt in the future they could remain in the facility depending on how their needs developed and five thought that they would need to move. It follows that these interviewees were aware of the scope of the care available in this type of facility. Indeed, all of those who were asked about the boundaries of care or the maximum level of care that were provided by the facility pointed to these limitations. Nine participants felt that the maximum level of care provided by the facility was rather restricted. The majority of these interviewees pointed to limits resulting in the lack of a license to provide personal care or any form of medical care:

“The other day, and other people - I fell over, at lunchtime I caught my shoe on the carpet and fell over and they can't - they won't touch you, they're not allowed to touch you. What they held - they held a chair so that - but it was some of the other residents, I mean they've all got something wrong with them, helping me up. They won't.” (F, 84)

“Well she was in hospital one day. She come out on a Friday, I went up to see them I didn’t really want to talk reacting and I asked them, she needs her tablets all over the weekend and they just wouldn’t do it. They said “We don’t know nothing about it” so I had to come over again and give her her tablets. But they should have someone here in case someone does come out on a weekend.” (F, 76)

Respondent: Well there are only the carers but they're not even allowed to put drops in your eyes.

Interviewer: Okay why's that?

Respondent: Well I don't know, they're not trained to do it, I don't know why. I've been asked when we had a little lady across the road there; the district nurse couldn't come for a time so Helen asked me to do it twice a day. So why I can do it and the carers cant' do it, it doesn't make sense to me. Why don't they send them on a course, train them up to do the basic things

that anybody could, as long as you don't touch the eye. But there's nothing like that, you've got to send for the doctor. With me if I get really bad, I've got what they call an emergency pack.” (M, 67)

Others felt “we should be checked on more often” (F, 61) as a protection against falling and that the facility needed more staff given “the amount of people that are here now that need more help” (F, age unknown). Thus, the users’ perspective on the maximum level of care provided by extracare was that these facilities were limited by their lack of registration (under the Care Standards Act 2000) for the on-site provision of personal (or health) care and the absence of staff who could provide basic personal or health-related care and support.

A number of interviewees mentioned a general lack of sufficient staff members to cater for the care needs of those in the facility:

“But no I think they could cope, but I don’t know what they’d do if more staff left, more staff that have been really faithful and hard working, because they keep saying to the management you know ‘When can we have more staff?’ ‘Oh we’re working within the right limits’ you see, it is no and they’re taking the advantage and they would have them work their normal hours should we say from two till nine or from seven in the morning till two in the afternoon, then they say ‘Oh so and so can’t come in, will you do another shift,’ you see? And you feel that you are letting the patient down if you don’t and they’ve got you in the corner.” (F, 75)

Eight of those interviewed described the maximum level of care in terms of the actual personal care work provided. These interviewees emphasised the services the facility did provide and how they expected that these services would be sufficient for their needs:

Respondent: The maximum level of care as far as I could see and we’ve got some that are severely disabled, we’ve got some people who never, ever come out of their apartments. Is, you can have somebody to wake you in the morning, get you washed, get you dressed, make your meal, bring you down for any of the activities that are going on. They will bring you down to lunch. If you’re able to come down for lunch, then if not, they’ll bring your lunch up to you. They’ll help you go to the toilet, basically everything. (Laughter)

Interviewer: Okay brilliant. And do you think you’ll receive all the care you’ll ever need here?

Respondent: Oh yes.” (F, 61)

“Interviewer: At what stage do you think, what level of ill health would somebody not be able to manage here...?

Respondent: I think with a person who couldn't walk properly, like we have one young woman and every day somebody has to help her get to her flat or to come out of it or things like that. I feel so sorry for her because even when she's in the restaurant it takes her ages to get up. So a person like that is not capable of, even with a wheeler, of going and being to be able to open their front door, are you with me. But they look at that yes.” (F, 85)

“They will tell you that it's not a nursing home as such but I prefer to be here than in hospital or nursing home because as much as they can do it, they will do for you. You couldn't expect them to, there's not enough staff to be in and out, in and out. When I was poorly I pulled the cord and they were here, I had wonderful attention and other people say the same. You can't expect them to just drop everything and run. For instance there are two ladies here with MS and they need two people with a hoist. Well if there are only two girls on and they are with one of those well you couldn't expect them to drop everything and come to you because they would say ‘As soon as we can we will be there.’ And they are.” (F, 88)

For these interviewees, the extracare facility provided a great deal of care and was highly valued. They were aware there that were limits to the care that was provided, so that, for example, people who were ‘bedridden’ and had “got to the place where you got to be in bed, it's not the facilities here for it” (F, 98) nor for people suffering from cognitive deterioration. As one participant said, “Oh when you can't do anything for yourself and you can't wash yourself and you can't see, and deaf and... isn't it you know? When you lose your faculties that's it isn't it?” (F, 85). Nevertheless, these participants had a strong sense that the facility could provide a great deal of care until such complex needs such as cognitive impairment arose.

Perceptions of the limits of Residential Care provision

Twenty two of the residential care users responded to question about whether they felt the residential care environment would meet their future care needs. Of these, fifteen participants expected to be able to stay in the residential care facility. These older people rationalised this view in a variety of ways including they were doomed to remain (“I am – I'm frightened and worried and there's no way out of it I'm here for life and...” (F, 87)), or were happy or wished to remain (“Yes. Well I hope not [will not have to move]. I hope I'll be here till I die.” (F, 95)), or the geographic location of the care environment meant they were close to some members of their family and so

wanted to remain. One interviewee wanted to move home after spending a month in the residential care facility, and three people said they expected to move, two to a nursing home and one planned to return home after a short stay in the residential care facility.

The proportion of the participants who indicated they would remain in the residential care facility indicates a perception that the facility could accommodate complex and palliative care needs. When asked about the maximum level of care that the residential care facility could provide, only seven people said they felt the facility could meet an increase in their care needs. But while seven people felt the facility could provide the care they needed, one of these raised a concern about the amount of staff time available:

“As far as I know I will. The only thing, in my opinion as I always say the staff ... I don't think there is enough staff work here.” (M, 77)

This concern was shared by two others who also felt the care environment lacked a sufficient amount of staff time for the demands of the users:

Interviewer: And is that something that's been the entire time that you've been receiving care or is it just since you've moved here or was it the same where you were?

Respondent: No it was much different. It was much more relaxed and friendly over there. The staff I think had more time over there, they don't have the time here.

Interviewer: Is it the same staff?

Respondent: It is the same staff but they haven't got the time because everybody's allotted a certain person, so many minutes.

Interviewer: Right.

Respondent: It's not their fault I'm not slating their staff but...

Interviewer: Sure, no. So you feel that you have less – there's less time available to you?

Respondent: This isn't the place for me I'm so lonely.” (F, 87)

“And I don't like it when I have to do it in my trousers, nobody does. But that's about the only thing, you know, you ask to go to the toilet “Can you hang on a bit?” A bit is about three parts of an hour and I'll ask them, they said “Well you know we've got to do this, we've got to do that.” I said “In my opinion why don't you employ some more staff?” It's as simple as that.” (M, 77)

On the other hand, eight people felt the care environment provided a sufficient level of care to meet their needs.

Summary

Overall, extracare environments provide for the least frail older people (least physically frail, and least cognitively frail). Older people in the community are most physically frail, and those in residential care are most cognitively frail. The care services provided within extracare facilities lack both breadth and depth. The limitations of the facilities are recognized by the residents, who realise that complex care needs (especially cognitive care needs) are not likely to be catered for within the facilities. For those in residential care, the majority felt that the environment was such that they would be able to stay as their needs increased, though not necessarily that they wanted to stay, and not necessarily that their increasingly complex needs would be dealt with satisfactorily.

DELIVERING COMPLEX CARE: THE STRUCTURE OF THREE CARE ENVIRONMENTS

Introduction

The experiences of the residents in each of the three care environments with regard to the limitation of the care provision (see Chapter 3) were structured by the realities of government policies and the management of the care homes. The community care providers were constrained by government policy and the centralisation of management discretion using the tool of the Unified Assessment. There were two types of structure behind extracare facilities. They were constructed as forms of housing with care, either where an organisation operated the facility as a landlord and the statutory sector managed the provision of care, or where both the tenancy and care arrangements were managed by the organisations who nonetheless liaised with local social and healthcare services. These two structures provided two different types of experiences. In the former, care management in extracare was organised by social services and as such, was constrained by government statute. In the latter case, care management was transferred to the individual, and the extracare facility struggled to meet its obligations as a provider of sheltered accommodation. Finally, residential care managers were in a strong position to manage care themselves and had little interest in liaising with social services departments. In the following chapter we unpack these observations, and draw out some of the implications for the provision of care for older people.

Community care

Community care provision is governed by the *NHS and Community Care Act (1990)* and by the centralised organisation of the role of community care assessors. Following from this, every older person in Wales “is entitled to an [unified] assessment and they’re allowed the information as to the process, what to expect and the care that they receive” (Manager NW9). This means that each older person has “the right then to be assessed and have the care that is deemed responsible” (Manager NW9), that is, a right to have an assessment carried out, and a right to receive the care judged necessary as a result of that assessment. Social services are obliged to provide an assessment and the care deemed necessary only as a result of this assessment – which can be made only for those older people who provide their consent.

Overall, community care was organised in such a way as to maximise the delivery of care to older people in their own homes:

“... Our direction of travel is about enabling and about maintaining people independent in their own homes as much as we can. Obviously we also have the Occupational Therapy Service which I don’t manage but we work very closely with them. We’ve organised [area] into four localities. So we have locality teams and in each of those locality teams we have social workers, we have occupational therapists and we link very closely with our in-house home care. Also we have product providers that we link very closely with. So if there are any aids, adaptations needing to be done with the social worker and the OT would work close together. And in two localities they are co-located with health. So they have district nurses also, actually located with them, which has proved to be really beneficial. So that’s what we’re going to be looking at long term. That each locality will be co-located. So it means that there is a lot of joint working with health, district nurses, social workers, working together which is really good.” (Manager NW8)

What this means is that users enter into a system that is designed to maintain “people independent in their own home” (Manager NW8). But the way to achieve this remained up for discussion:

“The ‘through many eyes concept’, have you heard about ‘through many eyes’? Using another WAG bit of legislation, well it’s not legislation it was consulted on and it may become Section 7 mandatory or not, it’s still in the in-tray. It’s about joined up working and many people supporting people in the community either through personal care for chiropody services, OT support services, befriending services and so on. The theory is the more people who look after someone who’s lonely and old, in their own place the better other than one person visiting once every three months.” (Manager SW7)

There are obvious strengths and weaknesses to this approach. Within the general structure of this approach stands an older person who forms a relationship with each of the various teams and their representatives, within their own home. However, the older person is linking with various health and social care teams to varying degrees over time, and based on a variety of rationales.

The assessment

From the point of view of the community care managers, assessment refers to a process defined under the *NHS and Community Care Act* (1990) that defines both the process of assessing, and the definitions of care need. According to this Act, each local authority has a duty to carry out a needs assessment for anybody who “may be in need” of “of community care services” (Section 47). In addition, the *NHS and Community Care Act* (1990) provides an authorised person with the power to

inspect any premises “in which community care services are or are proposed to be provided by a local authority” (1990, Section 48). The Unified Assessment process in Wales was introduced under the premise that:

“A common understanding of needs and risk assessment, and the ability to identify and assess the impact of those factors, which promote independence for individuals, is essential.” (WAG 2002, pp. 6-7)

Accordingly, the Unified Assessment is a process that is supposed “to identify, describe and evaluate people's needs, circumstances, risks to independence and other aspects of daily life” (WAG 2002, p. 15). It does this by identifying four levels that define a person's eligibility for care – critical, substantial, moderate or low (WAG 2002). However, the initial assessment (prior to the Unified Assessment) can be carried out by a call centre worker who decides whether there is a care need that ought to be examined:

“Manager: [...] So they will contact our customer care team who will ask the seven key questions of unified assessment.

Interviewer: Right.

Manager: To establish base line. Sometimes they can redirect them, what their actual problem is, transport or something. Nothing related to us at all. Or water coming through the ceiling – get all sorts of telephone calls. So we will re-direct them to the right person. But if their needs are care, then they will be referred through to the locality teams and then they will be allocated a social worker or an occupational therapist who will then go out and do an assessment. So we use the unified assessment documentation and in that we have the eligibility criteria, so related to their access to care. And if they come out as substantial and critical of them, we will look at what care we can provide.” (Manager NW8)

For the care managers interviewed, the assessment *process* was of little concern. The more interesting aspect had to do with the outcome of the assessment. Where the older person is assessed as having low or moderate needs, then the care manager must make a decision about the care needs of the client. It was at this point that the care manager would have to produce an assessment of care needs, and a decision about whether these needs “call for the provision” of care services (NHS and Community Care Act 1990). The care managers interviewed discussed how they would:

“[...] look at care homes as a last resort. We are very much for keeping people in the community. So it’s like a menu of services, but we try to, if at all possible, keep people in their own homes. There are urgent situations where we may have to admit somebody, you know, if the carer has suddenly had to go into hospital or whatever. But that would only be on a temporary basis. There are situations where people’s needs are so high that they cannot be managed in the community – so in those situations. But it would be a longer journey, if you like, a pathway.” (Manager NW8).

For the community care manager the main issue appears to be to ascertain whether they can offer the older person the services they require to remain in the community. Failing that, the community care manager would look at the most appropriate placement for the older person at the time of the assessment, whether they should go to hospital for a time, or whether they should be placed in some form of sheltered accommodation (with residential care considered as a ‘last resort’).

Residential care

Managers perceived that the function of residential care facilities were to look after some of the older residents individual needs, whilst providing a supportive function:

“What we should be doing in residential care really is serving their meals to them so they don’t have to worry about that, doing their washing for them so they don’t have to worry about that. But the rest of the time should be their own. It should really be like a private hotel where you would go and pay for those services. The trouble is more and more it’s not getting like that.” (Manager NW6)

Whilst residential care may be structured to relieve residents of the burden of dealing with their personal care needs, this raises the issue of what residents are expected to use their time to achieve. This type of facility was supposed to provide users with ‘time’ that ‘should be their own’ (Manager NW6). This particular manager elaborates on the social construction of the residential care home to locate it within a system that aims to keep older people at home:

“Because people are staying at home longer because they’re being pushed to stay at home longer, no bad thing. Then all of a sudden they can’t do it anymore, we’re now getting them in after they are 90 and their mobility has virtually gone. They haven’t eaten properly, they haven’t drunk property so consequently you’ve got a problem then with getting food into

them, getting the liquids into them. It then stops becoming a residential home.” (Manager NW6)

This positioning of residential care of an active provider of care for older people rather than a passive provider of support was shared by all of the residential care managers. Thus, residential care was not about servicing the needs of a fit and mobile older population to enable them to live an active life, but was about:

“just enabling them to fulfil what independence they’ve got left and to give them the support they may need whether it be physical, emotional, mentally everything.” (Manager NW5)

In order to support the ‘remnants’ of the older person’s independence, residential care was presented as ‘total care’ or ‘24 hour’ care.

“Manager: Right, where would I start? Residential care is where people come to stay, hopefully they decide to come to stay when the option of staying at home is not an option anymore. They need actual physical care.

Interviewer: So would you say that this was different from say extracare, where they...?

Respondent: Yes, it’s where a package can’t be obtained for 24 hours a day. Where people get that they couldn’t be left at home in a safe environment for the time in between carers coming in.

Interviewer: So you would provide more?

Respondent: We provide the 24 hours don’t we. The full 24 hours. There’s somebody there all the time.” (Manager NW4)

The overall orientation of residential care was, therefore, either to service the personal care needs of older users to enable them to have time of their own, or to deal with support needs associated with severe deterioration to enable users “to fulfil what independence they’ve got left” (Manager NW5). But these managers did not detail what the users were expected to do with this time, or their remaining independence.

Residential care was constructed for older people with advanced care needs, but still remained separate from nursing home care provision, keeping personal care needs distinct from health care needs. Thus, for instance, one residential facility was built to deal with the needs of older people from “all four categories. Which is general nursing, general residential, residential mental health

and nursing mental health” (Manager SW4) and designed with housing units that were separate care facilities. Each unit was staffed with carers appropriate to the care needs of the residents and the units were constructed and decorated to be physically identical:

“What it is... I mean, in this home if somebody comes in and they’re on general residential, should they deteriorate or their needs become more progressed then obviously they haven’t got to move out of the home. They can just move to another house so their needs can be cared for. Rather than them moving on to another home. So it’s better for them; it’s not so traumatic. And if you look, every house is exactly the same – decorated the same. So it’s not traumatic when they do have to move. And because we do have rotation of staff as well, it’s not like they’re having to get used to new staff. They more or less know the staff as well. So it makes it all easier for them.” (Manager SW4)

Here again, the facility was designed to cater for complex care needs around the clock. A second residential care manager talked of using an approach that was designed to deal with the needs of people suffering from cognitive deterioration. The objective of this ‘person centred approach’ was to deal with the individual in terms of the person they had been in the past, rather than the person with an impaired cognitive capability:

“Person centred approach is really literally getting to know the resident before they were ill rather than us looking at a person that’s unwell. We try and find out everything about their past, what their personality was like, what type of work they used to do, what they like, what they dislike, colours whatever, everything literally about them in that way. We are looking at that personality rather than looking at someone who now they've got memory loss so that's what we try to bring back in to their life is the normality from before rather than... Because they are forgetful we need to stimulate the brain all the time to keep it going active.” (Manager SW5)

Thus residential care providers worked to manage residents’ physical or cognitive deterioration. They do this either by changing the physical environment in order to reduce the trauma associated with relocating for increasing care needs, or by deploying a psychological toolkit to reduce the trauma associated with cognitive deterioration.

Admissions

The process of admitting an older person to a residential scheme was quite similar to that used in extracare (see below). Care managers would visit the applicant prior to admitting them, and carry out an initial assessment. If the applicant was to be funded by the state, then the residential scheme would discuss with community care managers about the level of care they judged appropriate:

“Yes. I mean, normally if somebody is – before they come in they’ve already been assessed by the social worker and whatever. So they tell us which category of care they think they need. And then we would go out and say ‘Yes’ or ‘No’ as to whether we agree with it or not.”
(Manager SW4)

Echoing this procedure was a second scheme. However, the extracare manager added that once they had agreed with the community care manager on the care needs of the older person, the extracare manager would conduct an additional battery of assessments:

“*Manager1*: Then when they come in then we've got an intense assessment procedure here. I mean we've got, the books that we've got the good care planning books, we do physical assessment, we do the mental assessment, we do the dietary assessment, we do the...

Manager2: ... mobility assessment we have the mental health we have nutrition risk assessment. What else do we have... harmony assistance” (Manager SW5)

During this process, the residential care manager in conversation with the community care manager seeks to identify the care needs of the older person, and to make a determination. Conversely, private applications involved a simpler process:

“If a client is privately funded, again I have to decide then you know what category of care they come into. And again, it’s a price isn’t it? So you know I tell them what our rates are and go and assess them and it just depends as to how much care they require.” (Manager NW4)

Hence a private application did not involve community care managers and the unified assessment process, but merely the residential care manager making their own assessment and quoting the individual or their family a rate for the appropriate care package.

Two residential care managers discussed their unwillingness to admit older people with a certain range of care needs:

“But you do get those that sit right in the middle, you know they’re not high dependency but they’re not basic residential. And because they’re sat in the middle and you’re just getting basic residential funding for them - when they’re actually needing more than Mrs X who’s getting up in the morning, getting herself washed and dressed, bringing herself down for breakfast and even asking the cleaners for a duster so she can pot around her room. And yet this lady needs a little bit of help going to the loo or you know she can’t walk so she has to come down in a wheelchair but you’re still getting the same money. But because she doesn’t need hoisting and everything doing for her by us, we can’t get the higher rate either.”
(Manager NW5)

As this interviewee points out, the difference in categories amounts to around £100 per week and felt there needed to be a ‘middle band’. On the other hand, two residential facility managers expressed an unwillingness to accept an application from an older person who was borderline ‘very dependent elderly’ (VDE) or potentially in need of nursing care:

“Manager: I don’t really try to accept anybody who is borderline between VDE and nursing, because that means that in a couple of months when their condition isn’t really getting better.

Interviewer: So they would have to move?

Manager: So they would have to move.” (Manager NW4)

This particular manager linked a structural unwillingness on the part of community care managers to label an older person as VDE because this would require the community care manager to refer the assessment to a panel, which had significant paperwork implications. This was despite the fact that “When they actually get them to panel and look at the holistic person, they decide ‘Well actually no.’ So often there’s a very thin line between ‘very dependent elderly’ and nursing” (Manager ID4).

Finally, a number of the residential care managers explained that they would not admit an older person who required nursing care:

“... if I felt that somebody was needing constantly monitoring by a registered nurse, I’d say that no they weren’t suitable for here. So that would start off.” (Manager NW4)

But not only were those who were assessed by the residential care managers as requiring the services of a registered nurse deemed unsuitable, but also people who could reasonably be expected to require constant nursing care in the near future were equally likely to be rejected:

“Manager: By myself, so I have to go out and meet them and chat with them and see what their expectations are and whether I can fulfil them or not. Also thinking ahead because you go out and meet somebody you’ll like “Yes, yes I can do that now but I don’t think I’ll be able to in six months time.” Which means they’re going to have to move on again.

Interviewer: Do you mean if they get...yes if they get worse.

Manager: If they get worse. And you can usually tell from their case notes and their history if they’re going to get worse or not. So the last thing you want to do is get somebody moving in and you’re like “Yes, yes everything’s settled.” And then in three months you’re saying “Right now you’re settled go and look for somewhere else because we can’t look after you anymore.” Which is unfair.” (Manager NW5)

Overall, then, residential care would admit users either through the statutory sector, or through private referrals. But these facilities were unwilling to admit certain categories of older people. Those whose needs were more severe than basic personal care, but less severe than those who needed constant monitoring or constant nursing care, or those who were anticipated to require a move to a nursing home in the near future were all deemed unsuitable candidates for admission.

Extracare

Generally speaking, extracare sheltered housing offered a combination of accommodation, support workers and on- or off-site care co-ordination that:

“... enables older people to stay more independent because there is access to care on site in emergency situations along with well trained care staff that can deliver pre-agreed care plans of care and support. It allows older people to come into contact with other people on a social side where not necessarily, quite often necessarily when they've been in the community that's been a big void for a lot of people.” (Manager NW3)

In effect, extracare was a form of accommodation in which care was provided as part of the tenancy agreement, and where the form of care provided was either limited to ‘emergency situations’ or extended to ‘pre-arranged care plans’ that were provided from the local authority or agencies

outside of the facility. Moreover, as the above interviewee alludes to, the provision of housing with care was seen as enabling older users to develop their social networks.

Extracare facilities seemed to focus on providing care as a scaffold for a more socially active older population. This meant that, on the one hand, extracare managers were interested in the care provision that provided the scaffold, and this in turn resulted in a sense of independence and social engagement. Indeed, a willingness to engage with the community was a condition of entry:

“It’s one of the eligibility criteria is that it is compulsory that you have the meal in the restaurant. And we do try to encourage it, because again it increases their social activity and also their health. You know nutrition side of it. And I have to say pretty much yes. If people don’t tend to use it it’s because they’re going out. They’ve got hospital appointments. We don’t have any tenant here who doesn’t ever use it.” (Manager NW2)

Given this assumed willingness to engage in the community, it is hardly surprising that many residents are quite socially active (see also Chapter 5):

“But there are a lot of independent tenants who have a full and active life outside the scheme and you know they feed in as well as taking stuff out and that gets - that's a very positive sense that you pick up of people. You know it's only because they've been able to come into this environment that they have reconnected with links outside in the community, because you know whether it's their health has improved or their confidence has improved, you know they're networking with friends and family back in the community.” (Manager NW3)

It is this link between the social engagement and care to facilitate interaction, that is the foundation of extracare. It is central to ensuring that the facilities promotes a more socially active and engaged population of older people. Nevertheless, this ethos is not for everyone and one extracare manager spoke of the people who are unwilling to engage:

“[...] It is open but it's hard to like evaluate it I suppose, it is hard to do that. But people as well in the community out there, because it is now a community, not everybody wants to live here, there are some people, very few people who don’t want to live here. And some people can be quite awkward and make it difficult for other people. But the majority; the vast majority of people really like to be here and they've made friendships amongst themselves.” (Manager SW2)

For such people, extracare can be “a little bit too, perhaps claustrophobic”, such people “feel watched and they feel I'm [facility manager] the dictator, you know and that's sad” (Manager SW2). For this interviewee the very aspects of extracare that some people liked made others feel ‘claustrophobic’:

“They want to have a bungalow or a separate dwelling and not to be... for people to see their every move because that can happen here. You can have curtain twitchers and things, you know some people don't mind that, they see it as very supportive really” (Manager SW2)

What is also interesting is how this ethos generated tasks for managers who found they had a role in bolstering a sense of community and solidarity:

“But just sort of the motivation sometimes you need to help with. And they get very frustrated because we have perhaps the most critical client group and for example we've got a shop here today, a card company has come in, and they're quite modern cards. Now rather than just look and walk away they'll, you know, ‘These are rubbish, they haven't got a verse in, what have you got them here for?’ And the tenants’ committee will find that very difficult because they've really tried to find a whole variety of things that will suit everybody. So you know that will have repercussions and they will struggle with that and it does affect their mood.” (Manager SW3)

In this case, the tenants’ committee found their work undermined by other extracare residents. Subsequently, the manager had to rebuild the committee’s sense of confidence and purpose that was required in carrying out their community work.

In order to allow this kind of social activity and engagement to flourish, extracare facilities are supposed to provide a suitable care sub-structure. However, the precise way in which care was managed in these facilities was structured by the relationships between the social services and the organisations involved in the management and operation of the facilities. Two of the managers interviewed worked in facilities that were operated as joint ventures between a county council and a housing association, where the care workers were employees of the county council, and were managed by a care managers located on the extracare site. The care arrangements within one facility were based on the local authority contracting out care provision to a voluntary sector registered care provider. The fourth manager worked in a facility that was discussing the possibility of becoming a

domiciliary care provider (under the Care Standards Act 2000). This facility relied on social services to carry out needs assessments and arrange the care package (either from the local authority or other contracted providers) for residents.

Ultimately, the interviews that were carried out with managers in four different extracare facilities illuminate the different ways of mixing housing with care. While one 'housed' a care manager from the local authority to manage the care, the others relied on either subcontracted care provision or provision direct from social services. The one facility that wished to provide on-site personal care to residents required registration as a domiciliary care provider. Subsequently, the request to apply for registration as domiciliary care provider was declined by the Board of Directors. If the request had been granted, in order to for the facility to remain as an extracare facility (rather than a residential care facility) it would have to ensure that the tenants/residents retained a choice over who provided their personal care (i.e. they could obtain care from in-house or external domiciliary care providers) (CSIW 2003).

The variations in the delivery of care and support between those facilities were clearly reflected in the views of users. Nine extracare users pointed out that the care delivered in their extracare environment was limited by the lack of a registered status (i.e. they were neither residential care homes nor domiciliary care providers). This has presumably been a topic of particular interest for five of the participants who were residents in the facility that was negotiating domiciliary care registration. This had resulted in confusion over what care was provided and what services or care the tenants were paying for:

“All of a sudden, it was extracare, I forget what they named it³, but they've now got up 'retirement apartments'. But we've got a query coming on and I haven't got a letter here, and it says it's 'care facilities'. But not the extra because the extra everyone has to pay more for. The staff have to be trained. And at present with the fact that we're not getting any interest on our money that's - you pay every month and there's money put by. And the situation as it is we can't afford the extracare for everybody. Because when you're filled up and its normal times perhaps it's different. But at present we feel we can't afford to pay for people that need extra care. They'll have to pay for themselves until such time as we can really afford it. Because staff have to go for training - that means to say you know...” (F, 81)

³ This provider called the extracare provision – very sheltered housing.

The resident above clearly believed that some aspect of care provision had changed (which it had not). There was clearly a problem with public relations and clarity over the proposed changes, because the perception that something had changed with regard to the level of personal care available was echoed by another interviewee. She described feeling “conned” at having moved into the scheme having “bought it as very sheltered housing. It’s now advertised as sheltered housing” (F, 78).

In this (and the other extracare facilities), there was clear demarcation between personal care and support services. The Care Standards Act (2000) requires personal care to be delivered either within a residential care home (registered to provide that care), or by a domiciliary care provider that can be external to the extracare environment or within it (although in the latter instance the resident must also be given the choice to obtain personal care from elsewhere). Thus,

“The Care Standards Act states, in s.121(9) that “an establishment is not a care home for the purpose of this Act unless the care which it provides includes **assistance with bodily functions where such assistance is required**”. It should be noted that the Act does not require such assistance to be available all the time, only when “required” (CSIW 2003).

Furthermore, a guide to the meaning of ‘bodily functions’ has been derived from case law (Cockburn v Chief Adjudication Officer (CSIW 2003)).

“the House of Lords held that under the social security legislation the term refers to the ordinary action of any organ or set of organs of the *body*. This will include assistance with carrying out such actions as movement, eating, drinking, urinating and defecating, seeing and hearing. As movement is a bodily function (the relevant organ being the limbs), activities such as physical assistance with getting in and out of a bath and dressing will also be included in the definition.” (CSIW 2003)

Despite the continuity in (external) domiciliary care provision in the extracare facility referred to above, residents described the lack of personal care available within the facility. They described succinctly the difference between personal care services and the support services (not concerned with ‘bodily functions’) provided by the extracare scheme:

“Well you get care in that they will look after you but they...they’re not allowed to grab hold of you and try and get you up themselves because they may not be doing the right thing for a

start. But I meant to say of the five we've got, only two are trained sufficiently to be able to get hold of somebody.” (M, 70)

“But I had to go and have lessons and get a diploma for first aid. They don't have anything like that, nothing. And if you have a fall they'll not pick you up, they'll ring for the ambulance. Even if I just fall there and you need someone to pick you up, hold your hand, they don't do it.” (F, 75)

It seems from the residents' accounts that the way the regulations were applied about personal care relating to 'bodily function' operated in different ways across extracare sites. Whilst in some instances the residents complained about the restricted amount of personal care that was available to the users (i.e. personal care was available from off-site domiciliary care providers), in other instances there was evidence of flexibility. Thus, for instance, ten people reported receiving a bath as part of their extracare residential service⁴, but two others did not receive such help (“In the past we've had people have got stuck in the bath and that, but if they can't be got out they have to get the ambulance people to come and get them out” (F, 84)). Another participant explained, that residents were able to cope with the lack of help to take a bath because they were “able just about to do that [shower themselves]” (F, age unknown).

A majority of the extracare facilities in this study were reliant on personal care service provision from local authority or other external domiciliary care agencies. As far as we are aware, none of the facilities was registered to provide domiciliary care services to their clients. However, prior to moving to extracare facilities, residents are often assured of 24-hour flexible care. Examples of the literature promoting extracare in Wales state⁵:

“Support to maintain independence including 24 hour care should you need it”

“Once you have met the eligibility criteria and allocations policy for the scheme, the on-site 24 hour care team will arrange a package of care and support, tailored to meet your individual social and physical needs”

⁴ This either suggests that support staff are flexible and provide 'assistance with bodily functions' that is contrary to statutory regulations, or perhaps represents the participants' confusion over the sources and differences between residential support services and personal care.

⁵ Although these quotes are from brochures advertising extracare facilities in Wales, they are not necessarily from extracare homes in the study. However, references to specific extracare facilities have not been included to retain the anonymity of the organisations from which the promotional material has been obtained.

“A number of flexible on-site services to meet various and changing needs”

“You will have the security of flexible personal home care according to your needs with an emphasis on independence”

It seems that some older people are not adequately forewarned that the ‘arrangement’ of on-site care does not mean that the care is provided from the facility, nor is it available around the clock. Some promotional material does mention limits on the care provision, for example:

“It must be stressed that extracare is not intended to be a substitute for a residential care setting. Whilst high levels of support and care can be provided, it may be possible that if your care needs became so great that you needed 24 hour residential or nursing care then other alternative options would be discussed with you and your family/ carers, such as care in the care home rooms at the scheme”

“*Home for life* – a Scheme aims to provide a home for life with care and a range of supporting facilities which are all easily accessible. However, a home for life may not always be possible, for example if someone becomes a risk to themselves or others, but it is the aim.”

However, a majority of the publicity brochures for extracare sheltered housing schemes in Wales do not explicitly mention that older people will have to move to a different type of care if their level of physical or cognitive impairment exceeds the levels that the facility is prepared to cater for. Contrary to our findings, some of the advertisements create the illusion that the facility would support an older person with both the breadth and depth of assistance that they may require in the future:

“Assistance, care and support will be on hand 24 hours a day for when you need it. When you don't need it you will have the space, privacy and dignity to live your own life fully independently. **The choice will always be yours.**” (emphasis in original)

Extracare facilities spend a lot of effort in the demarcation of housing support and personal care. However, this does not appear to impact positively on the well-being on residents. Namely, the boundary between the kinds of tasks that an individual could receive help with and the tasks they wish to receive help with, very much depends several factors. These are the provision of in-house

personal care and abilities of the staff, the flexibility of housing support staff, rigidity of the Care Standards legislation, and the willingness and capacity of the residents to manage themselves.

Assessment and admission processes

The question of assessment and admission to extracare facilities raised a number of conflicting interests. On the one hand, care managers were engaged in the process of assessing potential residents. However, the assessment of extracare managers may conflict with the assessment made by community care managers. That there may be a conflict is of less interest than the implications of this conflict.

Of the five extracare scheme managers interviewed, only one received applications both from community care providers and through private referrals. Some of the private referrals were routed through a contact centre that assesses potential residents in terms of the level of care and support they require, and their willingness to “embrace the ethos of the scheme” and to “take full use of the services within the scheme” (M3). For other care managers, the admission process was structured around the local authority care managers’ use of the unified assessment. There was no standard assessment process across the facilities. One facility carried out its own care assessment before the community care assessment was carried out, while another extracare manager carried out an assessment after the unified assessment. In a third facility, the initial assessment was carried out by the scheme manager working in tandem with the community care manager. The final and fourth extracare manager described how a decision on admission was made by a panel that comprised the extracare, community care and housing association representatives, but which drew on a community care unified assessment. In general, the purpose of carrying out the unified assessment is (i) to ascertain whether the applicant qualifies as ‘critical’ or ‘substantial need’, and (ii) to determine the level of care required by the older person, whereas the extracare facilities’ own assessment may involve making the decision on the (a) older person’s care needs, (b) their willingness to engage with the scheme, and (c) to establish what the older person wants from the scheme. Thus, those facilities that were more independent of the local authority would apply their own criteria to admissions. In contrast, those that were operated as joint ventures between community care and an extracare landlord depended on the community care manager’s unified assessment. On top of this, there was a certain pressure arising from waiting lists:

“We've got a list and we look at that list and we allocate the places accordingly then, whoever has the most need. We'll look at the care plans, the social worker has gone out, done the assessment, sent the assessment back to the panel. And on there between what they're saying

they need and a care manager, she'll work out then looking at it, how many hours are needed for everything. And that's reviewed on a regular basis then." (Manager SW2)

In effect, those extracare facilities that are part owned and managed by social services, or are sub-contracted to social services, admit users based on the same pressures borne by social services - the outcomes of the unified assessment, waiting lists, and outcomes of the ongoing case reviews.

Summary

Whilst the community care managers sought to keep people in their own homes using a mixture of professional interventions, the extracare managers sought to provide sufficient care for residents to engage in the community. Residential care managers focused on providing 24 hour care for the residents. The implication is that community care and residential care managers focus on providing the older person with care, whereas the extracare managers provide a purpose to the provision of care. This purpose is to enable older people to participate in the community.

While community care was focused on re-enabling people to live in their own homes after a crisis or stay in hospital, extracare was focused on promoting a sense of community among older people, while residential care merely looked after the needs of older people and allowed them to have time or some quantum of independence. In a sense, residential care providers could take up some of the approaches found in extracare in order to help older people find a purpose or activity for their time.

While extracare providers had clearly invested energy in promoting a communal spirit, residential care providers had invested energy in managing and reducing the trauma associated with eventual decline. On the other hand, community care providers were focused on enabling people to live in their own homes, but did not provide a justification for care provision to enable ageing in place, other than this is what (they assumed) people want.

When compared with residential and community care, extracare clearly has a variable capacity for meeting the needs of older people. Since those facilities labelled 'extracare' could take the form of a joint venture between Local Authority social services and a housing organisation acting as landlord, then extracare could clearly provide all of the services offered in the community. However, since none of the 'extracare' facilities had registered as domiciliary care providers the availability of the care '24' hours, as advertised in a majority of the organisations promotional material, is open to debate. Whereas residential care managers were quite clear about the categories of needs (nursing) that they were unwilling to admit such candour was not forthcoming from either community care or

extracare managers. However, extracare managers were clearly unwilling to admit or continue to cater for people suffering with cognitive deterioration. Hence, the menu of services provided to older people in extracare facilities is structurally restricted from the outset. Consequently, older people applying to such a facility need to be well (and clearly) informed about the nature of the organisation, the type of care and support available (on-site or off-site) and what this entails, before making their decision.

SOCIAL NETWORKS

Introduction

Extracare has the potential to reduce social isolation and improve quality of life by increasing opportunities for social interaction (Croucher et al. 2006). This may be particularly important for older people if they experience shrinkage of their social network.

The majority of older people living alone are widowed (Peeters et al. 2001, De Jong Gierveld et al. 2001) and it has been suggested that living alone will become more pronounced in the future (De Jong Gierveld et al. 2001). Rising divorce rates are also likely to increase the numbers living alone.

Although children are often an important source of help in later life (Wittenberg et al. 1998), research has shown that relationships with friends may be more important for well-being in old age than relationships with family members (Larson et al. 1986, Crohan & Antonucci 1989, Dykstra 1990, Pinqart & Sörensen 2000). In the UK, friends tend to be of similar age in the early years of retirement, but loss through disability and death accelerates with age and replacement friends are on average 15 years younger (Jerrome & Wenger 1999). Friends are important for self-esteem in old age and help combat against loneliness (Holmén et al. 1992, Jerrome & Wenger 1999), but the loss of friends with advancing age is inevitable (Jerrome & Wenger 1999, McCamish-Svensson et al. 1999b).

Friendships and social interaction may become particularly salient after the loss of a spouse. A majority of studies examining widowhood in later life focus on the emotional and psychological aspects of loss (e.g. Costello and Kendrick 2000, Winter et al. 2000, Hagedoorn et al. 2006). Older widows considered social activity and effective way to combat psychological distress associated with the loss of a spouse (Utz et al. 2002). However, certain structural disadvantages (such as economic disadvantage) can impact on an older persons ability to participate fully (Gordon et al. 2000), and thus may impact on the capacity to cope adequately with their loss. As noted above, other research suggests that increased physical impairment of older people and their peers, coupled with death and the attrition of members from social networks, leads to decreases in social interaction (Hill et al 2007). Subsequently, when older people lack the capacity or resource to form new contacts their level of social resources decrease (McCamish-Svensson et al. 1999a). We may therefore assume that the promise of increased social interaction offered by extracare sheltered housing may be particularly appealing to older widows who have experienced decline in their social networks in the community.

In a review of the literature, Croucher et al. (2006) found that several studies reported the development of new and larger social networks following the move to congregate living facilities in the USA (Potts 1997, Sherwood et al. 1997, Stoller 1998, Erickson et al. 2000). However other research suggests that the social environment has a differential impact on the social resources of discrete groups of older people. For example, in Australia Kupke (2000) found that couples were more likely to remain independent of social networks within congregate facilities and maintain their own social independence. In the USA Perkinson and Rockermann (1996) found that more intimate relationships were maintained with people outside of the facilities rather than developed within the facility. We do not know if these findings are applicable in the UK, where the norms governing social interaction and formation of friendships may differ. Given that extracare sheltered housing complexes are a relatively new development in the UK, there is not a body of evidence that explores these phenomena. The aim of this chapter is to examine the relationships between social resources, marital status and living environment, to see whether supported living environments do provide increased social interaction for older people.

Results

Using the LSNS 18 sub-scales we found that there are significant differences in the mean level of family, friend and neighbour resources between the three care environments (see Table 6). The level of family ($F(2/182)=7.13, p<.01$) and friend ($F(2/182)=7.21, p<.001$) resources were significantly lower in residential care than in the other two environments. The levels of neighbours (defined as local friends) was significantly higher in extracare sheltered housing than in the other two environments ($F(2/182)= 15.5, p<.005$). We can draw a tentative conclusion from these data that extracare increases local contacts, but does not have an impact on the level quantity or frequency of interaction with family and distant friends (because the levels are the same as in the community). However, further examination of the data is required to support this supposition.

Figure 5 shows that the overall mean scores for social resources are highest in extracare ($M=43.4$ SD 14.2), slightly lower for those living in the community ($M=38.3$ SD 14.1) and lowest for those in residential care ($M=32.6$ SD 16.5). An ANOVA with social networks as the dependent variable reveals that the care environment has a significant effect on social networks ($F(2,182)=7.94, p<.001$). Post hoc test showed that those living in residential care have significantly poorer social networks than those living in extracare ($p<.001$). However, we know from the literature that social resources are also related to factors other than the residential setting. Using parametric and non-

parametric tests we looked for associations between social resources and age, gender, mental and physical health and marital status.

Table 6. Mean scores for LSNS18 subscales: family, friends and neighbours as social resources by care environment

	Residential Care	Extracare	Community	All
Social Resources	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>
Family**	13.4 (6.9)	16.9 (6.7)	16.7 (7.1)	15.5 (7.1)
Friends***	6.8 (7.2)	12.2. (8.6)	11.7 (7.4)	10.1 (8.1)
Neighbours*	11.5 (6.5)	14.4 (5.9)	10.0 (6.7)	11.9 (6.6)

* p<.05 **p<.005 ***p<.001

We found that age, gender, mental and physical health were not significantly associated with social resources, however, marital status was ($F(3/178)=3.76$, $p<.05$). Mean social resource scores show that those that had never married and those that were divorced or separated had the lowest social resources scores. Those that were married and those that were widowed had higher, and very similar levels of social resources. The high level of social resources for widowed care recipients is counterintuitive and contrary to the evidence generally reported for community population samples.

Splitting the file by marital status and comparing social resources between care environments using ANOVA we saw that the differences in mean social resource scores in the different care environments were not significantly different for those people who have never married, nor for those that were currently married or living with a partner (Table 7). However, there were significant differences in mean social resource scores for those that were widowed and those that were divorced. In both instances, those living in extracare facilities had greater levels of social resources than those living elsewhere.

The regression models (as specified in analysis section on mediation) indicated that widowhood was associated with living in extracare, and that widowhood was associated with social resources (Figure 6). The final multiple regression model shows that extracare was a predictor of social resources, and significantly changed the effect of widowhood on social resources (Sobel test = $p<.05$).

Figure 5. Social resources in three living environments

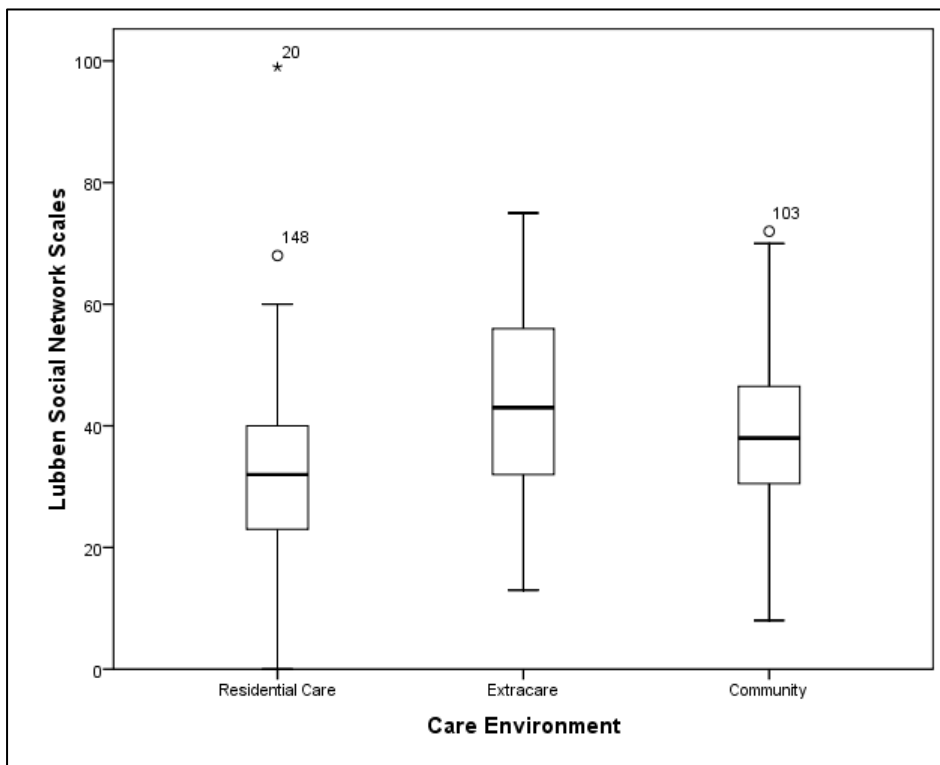
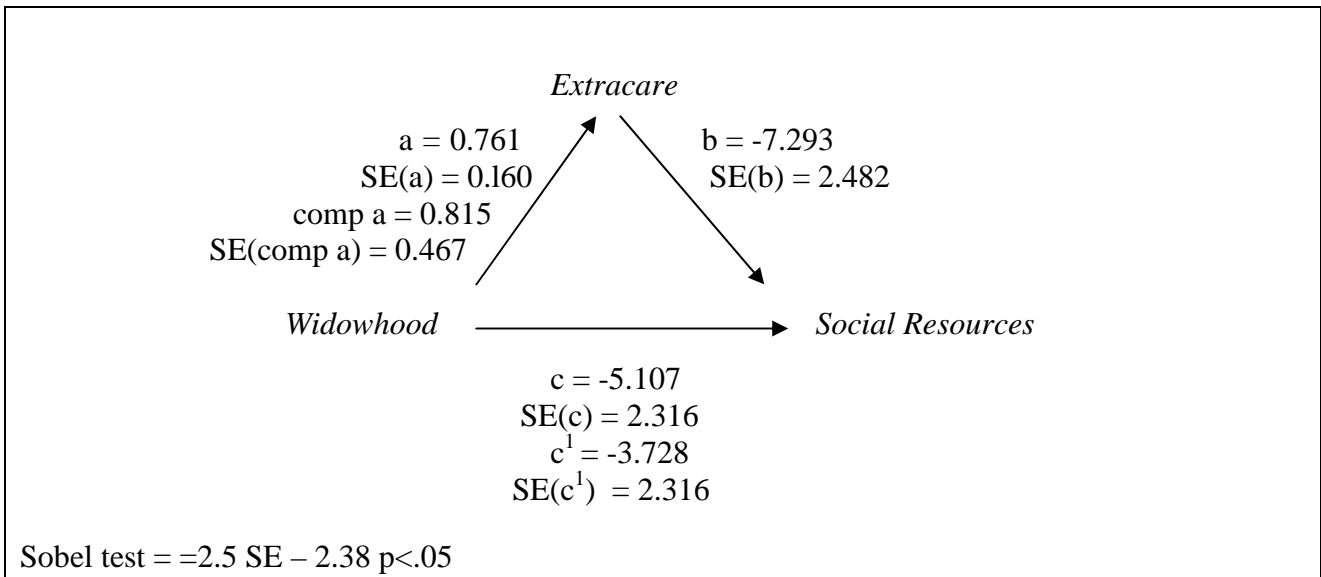


Table 7. Mean scores for LSNS18 for those who were never married, married, divorced/separated and widowed by care environment

	Residential Care	Extracare	Community	ANOVA test
Social Resources	<i>Mean (SD)</i>	<i>Mean (SD)</i>	<i>Mean (SD)</i>	
Score for:				
Never Married	29.3 (26.0)	32.0 (13.4)	33.6 (12.6)	(F(2/26)=0.12, p>.05)
Married	37.5 (13.7)	41.1 (17.0)	42.1 (12.6)	(F(2/29)=0.25, p>.05)
Divorced/separated	27.2 (14.8)	47.5 (9.9)	37.2 (7.8)	(F(2/25)=4.35, p<.05)
Widowed	35.9 (13.4)	46.0 (13.6)	37.0 (16.3)	(F(2/95)=5.37, p<.01)

* p<.05 **p<.005 ***p<.001

Figure 6. Mediation model for the effect of extracare sheltered housing on the social resources of older widows



Turning now to qualitative findings, thematic content analysis of the in-depth interviews of older widows living in extracare environments ($n=20$) explored the themes in relation to the dynamics of social networks both prior to and after the move to the facilities. Although two participants mentioned the death of their spouse during their interviews, they did not state that the move to extracare was related to a desire for more social contact after the bereavement. However, older widows did frequently talk about the shrinkage or attrition of their social networks before moving to extracare and related this either to the death of friends ($n=5$) or reduced mobility of themselves ($n=3$), friends ($n=3$) or family members ($n=4$). For example,

“I used to rely on my sisters a lot. I've got two sisters, three sisters, let me think, three sisters I've got. But I used to rely on them more so than actual friends, because my friends have died. At this age you lose friends don't you?” (F, 82)

“We still have friends that I have left, we still write to each other. Unfortunately they can't drive any longer so they're held up you know. Probably see them once or twice a year. Those are what I call friends.” (F, 83)

Although some widows talked about social network attrition, four others had previously been family oriented and prior to moving had made few friends in the community whilst others may have described themselves as ‘loners’ before relocation ($n=3$). For example,

“I never went out much, but of course I had two children you see and there was nine years between them, so when I got old enough to, when the first one was old enough that we could have gone out, my husband and I, well we couldn’t go because you can’t go out and leave your children.” (F, 98)

“Interviewer: Are you happy with the level of social interaction that you have?

Respondent: Yes it's enough for me any rate, yes. Maybe some are not, they like company all the time, which I don't. I like a bit of company, I like going down to lunch. It's an hour and a half, hour, hour and a half down there which we have a chat at the table; that to me is alright. But I'm not one for sitting around in groups gossiping then shall I say, you know what I mean, because they do.” (F, 83)

One of the most important themes that emerged from the data was in relation to the emotional aspect of the new social relationships formed in extracare environments. Although the widowed participants talked about an increase in social contact, there was a distinction made between friendships and ‘acquaintances’. The language used by some people to make this distinction was quite explicit, for example:

“Well I suppose they’ve [*my social network has*] grown, they probably have grown. It’s a...the word to explain it. But it’s through association I suppose with that, particularly with the meetings and that, you know. You’re in close contact with most people like.” (M, 88)

Although the distinction between acquaintances and friends was explicit in some interviews, in others the language used was implicit. In this second quote, one can distinguish the difference in meaning between friendships and friendly. ‘Friendly’ seems to imply a sense of cohesion but limited access to personal space, whereas visiting each other’s home is a normative expectation within intimate friendships.

“Oh we’re all friendly. I mean we’re all friendly, I mean well we’re all like a big happy family really, but we don’t run in and out of each other flats a lot.” (F, 98)

Even when one other participant refers to the residents of a particular extracare facility as a ‘family’, the language used suggests that it is the frequency of social contact within the environment compared to infrequent contact with relatives, rather than the quality or depth of the relationships that has made an impact on her life.

“It’s just like a little village, more like a family. For instance when we go down to lunch, it’s “Hello” “Hello, how are you today?” that sort of thing [*from the carers*]. And if anyone is in hospital we send cards and we are always asking how they are because really speaking we sometimes see more of the people here than we do of distant relatives.” (F, 88)

Although some people did refer to meaningful friendships that had been made within extracare, these references were infrequent. This helps explain why we find that although extracare mediates the effect of widowhood on social resources, it has no impact on the levels of loneliness. As indicated in Table 1 there were no significant differences in the levels of loneliness of participants in each of the three settings. The last two quotes, illustrate that on the whole, when friendships were referred to these were in reference to relationships that were maintained with others living outside of the facility:

“Last Christmas I had about 120 Christmas cards. Of course having said that that’s church and Mothers Union and Women’s Institute that I used to go to as well... and I’ve got a lot of old friends I’ve kept up over the years.” (F, 88)

“That special couple next door, living next door to one another for 50 years, you know, so, no they come out to see me and bring stuff out of the garden for me, that sort of thing you know. They are close; close friends they were.” (F, 83)

Summary

The analysis of social networks indicated that extracare environments provide the conditions for increased social interaction and this is particularly effective for older widows. However, in the earlier description of the sample characteristics, it was noted that there were no difference in the levels of loneliness between the three living environments. The qualitative data serve to illustrate the point that although social interactions are increased in extracare environments the interactions do not necessarily lead to high quality and emotionally satisfying social relationships. Social resources appear to be fairly superficial in nature, and consist of encounters in the communal living areas in the facilities rather than in the private confines of the residents’ flats.

6 QUALITY OF LIFE

Introduction

Quality of life (QOL) is a multi-faceted concept that reflects the impact of macro to micro level influences on the well-being of an older person. Thus, any measurement of QOL needs to take into account a whole range of issues or subject areas that may impact on an older person's life. Although QOL is multidimensional, there is often a tendency for researchers to assume that QOL refers to health related quality of life indicators (e.g. Garratt et al. 2002, Haywood et al. 2005). This is not the position that is adopted in this chapter. Quality of life is entirely subjective, and is personal to the individual concerned. Furthermore, the objective situation (e.g. good quality housing) does not necessarily directly correlate with quality of life (e.g. high satisfaction with housing) (see e.g. Streib & Schneider 1971, Campbell et al. 1976, Herzog & Rogers 1981, Palmore et al. 1984, Stoller & Stoller 2003).

Despite the vision that extracare housing improves the quality of life of residents, we have found no empirical evidence comparing this aspect of older people's lives across different living environments (for an attempt to measure QOL for older people living in extracare sheltered housing see the Evolve project - <http://www.pssru.ac.uk/pdf/p072.pdf>). Consequently, we do not know whether extracare environments have a positive, negative or neutral impact on the quality of life of residents. Regardless of the lack of empirical evidence, the rhetoric used to describe extracare facilities frequently asserts that the facilities either do, or will have a positive impact on the quality of life of residents. For example, on-line advertisements for Wales' extracare facilities frequently refer to 'improvements in quality of life' for residents such as the following:

“The schemes emphasize ***⁶ commitment to enhancing the quality of life for frail older people and preserving their independence.”

“*** aims to deliver a whole lifestyle for older people, with an emphasis on quality of life and positive opportunity.”

Despite the assurance that QOL will be enhanced, or at the very least be central to the mission of the supported living environment, very little is known about the quality of life of older people in extracare compared with other settings. This chapter sets out to address this gap in our knowledge by examining five domains of satisfaction or quality of life. These are: (1) personal satisfaction

⁶ *** are substituted for the name of the extracare facility.

(SWLS), (2) social satisfaction, (3) environmental satisfaction (4) satisfaction with control of finances and (5) satisfaction with access to personal services. The goal was to establish whether there are any significant differences in expressed levels of satisfaction between care settings.

Results

A summary of mean scores for each of the five domains of satisfaction of quality of life are reported in Table 8. The care setting care environment had no significant direct impact upon personal, social, environmental satisfaction, or satisfaction with access to personal services. However, care setting did have a significant impact on satisfaction with financial control ($F(2/179)=8.3, p<.001$), 1. Those in residential care ($M=4.20, SD=1.09$) reported significantly lower financial satisfaction than extracare residents ($M=4.74, SD=.52; p=.001$) or community dwellers ($M=4.64, SD=.55; p<.01$).

Table 8. Mean scores for satisfaction in domains of personal, social, environmental, financial and access to personal services by care setting

Satisfaction	Residential		Extracare		Community	
	<i>n</i>	M (SD)	<i>n</i>	M (SD)	<i>n</i>	M (SD)
Personal	65	5.0 (1.4)	58	5.1 (1.1)	58	4.8 (1.6)
Social	66	4.0 (0.8)	58	4.2 (0.8)	59	4.0 (1.0)
Environmental	65	3.9 (0.7)	58	4.0 (0.7)	59	3.9 (0.7)
Financial Control***	64	4.2 (1.1)	58	4.7 (0.5)	58	4.6 (0.6)
Access to Personal Services	64	4.3 (0.9)	53	3.9 (1.0)	56	4.3 (0.9)

*** $p<.001$

Personal satisfaction

In the first regression model where personal satisfaction was the outcome variable and social resources the predictor variable, both blocks of the model were significant (Block 1: $F(3,160)=4.20, p<.01$; Block 2: $F(6,160)=7.83, p<.001$). However, the variables in the model only accounted for approximately 3% of variance. Nonetheless, as shown in Table 9 (showing the second model with both blocks of variables), the findings demonstrated that physical health (PCS) and social resources (LSNS) were a significant predictor of personal satisfaction. Care environment did not have an impact on personal satisfaction.

Table 9. Regression models for personal satisfaction controlling for gender, age and physical health for models including (i) social networks and care environment and (ii) resilience and care environment.

Variables	B	95% CI (Lower bound, upper bound)	Sig.
Social networks:			
Gender	0.11	(-0.48, 0.51)	
Age	-0.11	(-0.04, 0.01)	
Physical health	0.03	(0.00, 0.06)	
Social resources	0.02	(0.00, 0.03)	*
Residential care	-0.10	(-0.68, 0.49)	*
Extracare	0.06	(-0.48, 0.59)	
(Constant)	3.84	(1.70, 5.98)	**
Resilience:			
Gender	0.08	(-0.36, 0.52)	
Age	-0.01	(-0.04, 0.01)	
Physical health	0.02	(-0.00, 0.04)	
Resilience	0.04	(0.03, 0.05)	***
Residential care	0.16	(-.037, 0.69)	
Extracare	0.28	(-0.20, 0.75)	
(Constant)	0.73	(-1.47, 2.93)	

* $p < .05$ ** $p < .01$ *** $p < .001$

In the second model with personal satisfaction as the outcome variable, resilience was tested for its predictive value. In this model, only block two had a significant impact on the fit of the model ($F(6,160)=8.14$, $p < .001$), and accounted for 21% of variance. Only resilience was a predictor of personal satisfaction. Care environment did not have a significant impact on personal satisfaction which suggests that for this particular sample this type of satisfaction is predicted by individual characteristics rather than an environmental setting.

Social satisfaction

In the regressions models where social satisfaction was the dependent variable and social resources and care environment were included as independent variable, only block two had a significant impact on the fit of the model to the data ($F(6,160)=9.07$, $p < .001$) and accounted for 23% of

variance. In contrast to the regression models for personal satisfaction, general health was not a predictor of social satisfaction. However, social networks did predict social satisfaction (Table 10). Care environment did not predict social satisfaction.

Table 10. Regression models for social satisfaction controlling for gender, age and physical health for models including (i) social networks and care environment and (ii) resilience and care environment.

Variables	B	95% CI (Lower bound, upper bound)	Sig.
Social networks:			
Gender	-0.05	(-0.32, 0.21)	
Age	-0.01	(-0.02, 0.01)	
Physical health	0.01	(-0.00, 0.03)	
Social resources	0.03	(0.02, 0.04)	***
Residential care	0.07	(-0.25, 0.38)	
Extracare	0.06	(-0.23, 0.35)	
(Constant)	3.21	(2.06, 4.37)	
Resilience:			
Gender	0.10	(-0.18, 0.38)	
Age	-0.01	(-0.03, 0.00)	
Physical health	0.01	(-0.01, 0.02)	
Resilience	0.02	(0.01, 0.02)	***
Residential care	0.06	(-0.28, 0.40)	
Extracare	0.28	(-0.02, 0.59)	
(Constant)	2.58	(1.17, 3.98)	***

* $p < .05$ ** $p < .01$ *** $p < .001$

When the resilience measures were tested for their predictive value, block two had a significant impact on the model ($F(6,160)=4.76$, $p < .001$), and accounted for 12% of variance. However, only one significant predictor emerged: resilience. Care environment was not a significant predictor of social satisfaction.

Environmental satisfaction

When environmental satisfaction was the dependent variable and social resources the possible predictors, both blocks entered in the first model had a significant impact (Block 1: $F(3, 160)=4.20$,

$p < .01$; Block 2: $F(6/160) = 3.05$, $p < .01$) and accounted for 6% and 7% of variance respectively. In block 1, age and health predicted environmental satisfaction, and indicated that those who were younger and in better health had higher levels of environmental satisfaction. In block two (in addition to age and health), gender (being female), and greater levels of social resources predicted higher environmental satisfaction. As described in Chapter 5 during their qualitative interviews some older people noted the attrition of their social networks because of the (i) death of friends or (ii) poor mobility that impacted on the ability to visit. It seems therefore, that as the relationships between older people and their distant friends become less frequent, that the accessibility and security of the local environment (all aspects of environmental satisfaction) become more important in maintaining local social connections.

Table 11. Regression models for environmental satisfaction controlling for gender, age and physical health for models including (i) social networks and care environment and (ii) resilience and care environment.

Variables	B	95% CI (Lower bound, upper bound)	Sig.
Social networks:			
Gender	-0.24	(-0.47, -0.01)	*
Age	-0.01	(-0.02, -0.00)	*
Physical health	0.02	(0.01, 0.03)	**
Social resources	0.01	(0.00, 0.01)	*
Residential care	-0.01	(-0.28, 0.26)	
Extracare	0.04	(-0.21, 0.28)	
(Constant)	4.30	(3.31, 5.30)	***
Resilience:			
Gender	-0.21	(-0.42, -0.00)	*
Age	-0.01	(-0.02, -0.00)	*
Physical health	0.01	(0.00, 0.03)	*
Resilience	0.02	(0.01, 0.02)	***
Residential care	0.09	(-0.16, 0.35)	
Extracare	0.13	(-0.10, 0.36)	
(Constant)	3.03	(1.98, 4.07)	***

* $p < .05$ ** $p < .01$ *** $p < .001$

When the resilience measures were entered as possible predictor variables in regression models, both blocks were significant (Block 1: $F(3,160)=4.20$, $p<.01$; Block 2: $F(6,160)=7.83$, $p<.001$), where block 2 accounted for 20% of variance. Although gender was not significant in block 1, it gained significance with the addition of resilience and care environments in block 2. Thus, in block 2, gender, age, health and resilience predicted environmental satisfaction: greater levels of resilience, being female, younger and in better health served to predict environmental satisfaction (Table 11). However, care environment did not predict environmental satisfaction.

Financial satisfaction

With financial satisfaction as the dependent variable and social resources and care environment the possible predictors, only block 2 had a significant impact on the model ($F(6/160)=3.73$, $p<.01$) and accounted for 9% of variance. Table 12 indicates that social resources and being in residential care (that is, not in extracare or in the community) predicted the degree of financial satisfaction. Greater social resources are related to higher levels of financial satisfaction, whereas residential care participants reported significantly lower financial satisfaction than those living in the community or extracare sheltered housing.

When the resilience measure and care environment were entered as possible predictor variables, block two was significant, ($F(6,160)=3.47$, $p<.01$), accounting for 9% of variance. In line with the previous model (including social resources and care environment), the care environment remained a significant predictor of financial satisfaction (Table 12). Furthermore, resilience predicted financial satisfaction. In other words, we may assume that financial satisfaction is predicted by social (resources), environmental (i.e. care environment) and individual (resilience) characteristics: those with fewer social resources, lower levels of resilience and those in residential care are more likely to experience lower life satisfaction in this domain.

Table 12. Regression models for financial satisfaction controlling for gender, age and physical health for models including (i) social networks and care environment and (ii) resilience and care environment.

Variables	B	95% CI (Lower bound, upper bound)	Sig.
Social networks:			
Gender	0.13	(-0.13, 0.40)	
Age	0.00	(-0.01, 0.01)	
Physical health	0.01	(-0.01, 0.03)	
Social resources	0.01	(0.00, 0.02)	*
Residential care	-0.38	(-0.70, -0.07)	*
Extracare	0.02	(-0.27, 0.30)	
(Constant)	3.54	(2.40, 4.69)	***
Resilience:			
Gender	0.19	(-0.07, 0.45)	
Age	0.00	(-0.01, 0.01)	
Physical health	0.01	(-0.01, 0.02)	
Resilience	0.01	(0.00, 0.01)	*
Residential care	-0.37	(-0.69, -0.05)	*
Extracare	0.11	(-0.18, 0.39)	
(Constant)	3.15	(1.84, 4.47)	***

* $p < .05$ ** $p < .01$ *** $p < .001$

Satisfaction with access to personal services

When satisfaction with access to personal services was the dependent variable and social resources and care environment the possible predictors in the regression model, only the second block had a significant impact ($F(6, 151)=2.35, p<.05$) and accounted for 5% of variance. Only living in an extracare environment was a predictor of lower satisfaction with access to services. This indicates that the access to personal services provided to extracare residents is not optimal.

Table 13. Regression models for satisfaction with access to personal services controlling for gender, age and physical health for models including (i) social networks and care environment and (ii) resilience and care environment.

Variables	B	95% CI (Lower bound, upper bound)	Sig.
Social networks:			
Gender	0.14	(-.020, 0.48)	
Age	-0.00	(-0.02, 0.02)	
Physical health	-0.02	(-0.04, 0.00)	
Social resources	0.01	(0.00, 0.02)	
Residential care	0.24	(-0.16, 0.64)	
Extracare	-0.38	(-0.74, -0.01)	*
(Constant)	4.62	(3.13, 6.11)	***
Resilience:			
Gender	0.20	(-0.14, 0.54)	
Age	-0.00	(-0.02, 0.02)	
Physical health	-0.02	(-0.04, 0.00)	
Resilience	0.00	(-0.01, 0.01)	
Residential care	0.20	(-0.21, 0.60)	
Extracare	-0.30	(-0.67, 0.06)	
(Constant)	4.88	(3.16, 6.59)	***

* $p < .05$ ** $p < .01$ *** $p < .001$

Nether of the blocks in the regression models for personal characteristics with the resilience measure and care environment made a significant difference to the model, with the predictor variables only accounting for 3% of variance. However, poor physical health predicted greater satisfaction with access to personal services.

These quantitative data were triangulated with thematic content analysis of the qualitative data from in-depth interviews. Participants were asked if they were happy with the amount of care available to them in their care environment. Alongside quantitative findings, this allows us to establish a greater understanding of the dissatisfaction expressed in extracare facilities.

Twenty-one community care users said they were happy with the amount of care available to them in their care environment, with only four people reporting that they were dissatisfied and one

declining to answer the question about their level of satisfaction. Those voicing their dissatisfaction were displeased with the services they received (“I suppose they could do more, but they don’t have the time you see. They don’t clean the way you want to do it. They don’t do the things the way you want them. That’s me, you know. I’m not that fussy, but you like a nice place” (F, 78)) or are displeased by having to wait for the carers to arrive (“because they do so much running around to so many different people and it takes them a long time to come in to see me” (F, 81)) or waiting for the council to install promised alterations (F, 82).

The participants that were residing in extracare facilities were similarly asked whether they were satisfied with the level of care that was available to them in the care facility. Sixteen interviewees said they were satisfied with the level of care that was available to them. These responses were not of an enthusiastic sort, for example “I mean I can’t put my finger on anything which is missing” (M, 88) or, as demonstrated in the following quotation, rather balanced but positive:

“Yes, yes I would say it’s adequate because these young ladies are just hygienists or looking after your cleanliness and your everyday wants and things like that. So on the whole I think it’s adequate really. I know that I have forgotten to take my insulin a couple of times at night so now it’s on the form “Please remind Mrs [X] to do her insulin.” Because I said “In the morning everything is rotation.” So therefore I follow that. You know this morning I’ve taken my tablets and I’ve taken... Because I’ve got these blister packs with my tablets in and I take them all day at different times. So all that’s mapped out for me.” (F, 78)

In effect, these interviewees accept the limitations of the extracare facility. Even if the available care insufficient (“[care] isn’t enough for me in my circumstances but I suppose it’s... those are the rules” (F, age unknown) they are content to comply with these rules (see Chapter 4 for a description of the legislation prescribing personal care/support care). Indeed, one person observed how those who required more care were “in touch with the social services. Now I think they [social services] send people out to help them but they pay for it. I mean the individual pays for it” (F, 88). Therefore, the rules that applied in the extracare facility were formulated around an identification and negotiation of care needs between the individual and social services. None of the in-depth interviews mentioned domiciliary care provision from the extracare facility itself.

Three interviewees felt they did not need care at the time of the interview, and so the question did not apply to them. Two interviewees talked about the limited amount of health care that was

available which suggests that they had not been sufficiently informed about the type of care that was available within the facility:

“I think the majority of people thought there would be more actual medical care than there is. See so there’s a play on words really. I don’t know really, you have sheltered accommodation, you have very sheltered accommodation, well what does that mean? You know it’s a play on words isn’t it?” (M, 70)

This view was echoed by another interviewee who shared the view that the level of care available was acceptable only because she did not require more care at present “But I don’t know if I’d be so satisfied if I was ill and had to pay out all this money” (F, 78). Whereas those who were satisfied with the available care were either receiving an amount of care that was adequate to their needs, or were content to accept their role in procuring and financing their own care, some participants were unhappy with the future burdens that would be placed on them to secure their own care and had assumed (or been lead to believe) that this would be available within the extracare facility.

Summary

The analysis revealed that, on the whole, the type of care environment is not predictive of quality of life (with two exceptions). Care environment predicted financial satisfaction and satisfaction with personal care services. Older people in residential care homes were least satisfied with control over financial matters, and extracare residents were least satisfied with access to personal care services. In the latter instance, it is clear that some extracare residents had not been informed adequately about the distinction between support services, personal care services and health services and the limitations of the facilities in providing in-house services.

COST-EFFECTIVENESS

As noted in the methods section financial documents were received from four of the participating organisations (3 extracare and 1 residential), email responses with some relevant information from two organisations (1 extracare and 1 residential), extracts from interview transcripts from two other organisations (1 extracare and 1 residential) and the results from a customer satisfaction survey, with no financial information, provided by the home care services.

The email responses provided some useful details but far from complete information regarding costs of service provision and, given that they were from a single organisation in each sector, it is not appropriate to present any of the responses or draw any conclusions from these sources. The extracts from the interview transcripts were of interest but lacking in precision and detail – and as there was only one from extracare and one from the residential sector, it was not possible to use these either.

Of the financial documents provided, one was the complete financial statements and accounts from the housing association, which made it impossible to separate specific service components relating to extracare and other services provided. The same problem applied to the documents supplied relating to residential care and therefore it was not possible to extract relevant data to ascertain costs of provision.

Of the two extracare settings that provided relevant information, there was a conflict in one between the accounts presented and the accompanying email information in relation to cost per person/week. This left one set of accounts for analysis. From the information it was possible to estimate cost per resident week, which was slightly less than that estimated by the English evaluation (Bäumker et al, 2008). However, given that this was the only data source deemed to be of use, it was felt that this was not necessarily representative of the sector as a whole, or that we should report such findings. Therefore, it has not been possible to ascertain the costs for extracare within the study, nor make any reasonable comparison with costs from other care settings.

DISCUSSION

A number of different housing and care models that provide access to health and social care services exist in the UK. Models that involve the relocation of older people to supported environments, include, residential care, sheltered housing and extracare sheltered housing. These three types of facilities have been developed over time in response to calls for reforms in the provision of care environments. However, the notion that older people have to relocate to receive social or health care in an institutional setting has traditionally been viewed as a less positive outcome than receiving care within the older person's own home.

Currently, only 3.2% of the population aged 75-84 and 15.6% of the population aged 85+ years in Wales live in residential care (Banks et al. 2006). The effects of relocation into residential care have been the subject of study since at least 1945 and an abundance of the literature about residential care has focused on the negative aspects of institutionalisation (e.g. Goffman 1961, Townsend 1962). Peter Townsend's study of residential care, entitled *The Last Refuge* was published in 1962 and the key research question was 'Are long-stay institutions for old people necessary in our society, and if so, what form should they take?' This question has enduring importance today.

Studies have revealed how loss of control over the environment, decreases in decision making and loss of privacy can lead to a fall in self esteem. Townsend coined the phrase 'structured dependency' to put forward the thesis that the dependency of older people in the twentieth century was socially manufactured (Townsend 1981). He related this dependency to social structures such as the imposition, and acceptance, of earlier retirement; the legitimization of low income through pensions; the denial of rights to self-determination in institutions; and the construction of community services for recipients assumed to be predominantly passive. He said of residential care "The majority of residents in Homes are placed in a category of enforced dependence. The routine of residential Homes, made necessary by small staffs and economical administration, and committed to an ideology of 'care and attention' rather than the encouragement of self-help and self-management, seems to deprive many residents of the opportunity if not the incentive to occupy themselves and even of the means of communication" (Townsend 1981, p. 20).

Fifty-four years after Townsend's study, in 2002 a study in North Wales asked older people living in the community which aspects of a supported living environment would be important to them. Eighty-six percent of respondents reported that privacy and physical space were very important and

87 % rated control of life as very important. However, fewer than one-tenth (9%) of the sample thought that residential care would meet their requirements for privacy or control over life (Burholt & Windle 2007). This present study also shows that participants in residential care had the lowest levels of interpersonal control, and lowest levels of satisfaction with control over financial matters, suggesting that there are elements of residential care that do not meet residents' expectations for control.

Furthermore, this study has demonstrated that residential care caters for the most cognitively frail older people in society (i.e. of those that do not require nursing care). Thus we could conclude that two generations on from Townsend's study, the setting caters predominantly for those people that are excluded from other public spaces. We have noted that a few older people who are mildly to moderately cognitively impaired (i.e. not necessarily in need of nursing care, but possibly in need of other forms of support) are cared for in the community or in extracare. However, it appears, that on the whole, they are systematically excluded from these living environments through assessment and admissions processes that deem these settings as inappropriate for those 'who may pose a risk to themselves or others'.

Sheltered housing was developed in a backlash against the lack of dignity and privacy associated with residential care. This followed the publication of Peter Townsend's book *The Last Refuge*, which was outspoken in its criticism of residential care homes for older people. Townsend saw sheltered housing as a positive alternative to residential care, an environment that older people would choose to move to (rather than being moved there by others) where they could lead dignified lives whilst obtaining the support they required. In the 1970s the sheltered housing policy agenda was given another boost. It became apparent that in addition to residential care being undesirable, it was also very expensive and was being used by people who did not need the care provided within it (Thompson & West 1984). Therefore, the government encouraged local authorities and housing associations to develop sheltered housing.

Essentially sheltered housing is grouped accommodation providing residents not only with their own homes (with their own front doors) but also with some communal facilities, such as a laundry, or a common room. Groups of accommodation may be small, less than twenty units, or large with over 100 units. The houses or apartments are usually equipped with an alarm system that may be linked to a warden who can respond to emergencies and call out appropriate services if required. Currently only 5% of people aged 65 and over in the UK live in sheltered housing (Burholt & Windle 2007). Since the development of sheltered housing facilities, important issues have arisen

that impact on the desirability of these types of supported living environments: these include location, size and stigma (Burholt & Windle 2007).

In 2002 when we examined the importance of physical care in a supported living environment, we found that eighty-two percent of participants rated this domain as high in importance. Overall, over half of the total sample (51%) thought that sheltered housing would meet their needs for physical care. People who preferred this housing option felt that having a warden ‘on call’ or knowing that someone was nearby was very important. They felt that in sheltered housing they would be able to access services but retain their independence (Burholt & Windle 2007). This suggests that many older people do not understand the limitations of this type of facility: namely, that sheltered housing is unable to house and care for very frail older people. The inability to discern between different living environments is not surprising given that there has been a consistent failure within policy to define the objectives of residential care or sheltered housing (Burholt & Windle 2007). Despite the lack of clarity about provision of care in the existing residential environments, the next innovation in supported living, extracare, focused on this.

As noted in the introduction to the report, extracare sheltered housing (also referred to as very sheltered housing) broadly differs from models of sheltered housing in three main ways: the provision of a meal or meals; the provision of additional health and social support services; and a barrier-free environment. When compared with residential care, extracare sheltered housing is supposed to offer a larger living space, extra disposable income for tenants, a vibrant community and flexible packages of care. The interest in this type of housing in Wales is reflected by the ongoing commitments made by the Welsh Assembly Government through a pledge of £41 million for the provision of extra care housing. The Guidelines for Developing Extracare Housing in Wales state “The design of an extra care scheme should take into consideration the likely impairments that residents will experience with increasing age and frailty” and list visual impairment, hearing impairment, mobility impairment and cognitive impairment as factors that should be taken into consideration (WAG 2006a, p. 11).

Having examined the provision of long-term care and supported living environments in the UK, in 1999 the Royal Commission on Long Term Care (RCLTC) noted “on this analysis, the current system is failing” (RCLTC 1999, s.4.46). Over one decade later, unfortunately, the same could be said regarding the provision of care to ‘fit and frail’ older people in extracare sheltered housing in Wales. As extracare facilities are new to Wales, it could be argued that the populations who have elected (recently) to move to these environments are likely to be younger and healthier than

populations ageing in place. However, our analysis of assessment and admissions process suggest that whilst there are elements within these procedures that allow care managers to accommodate physically frail older people in the community, they also heighten care managers' perception of 'risk' with regard to cognitively frail elders, ultimately rendering those with cognitive impairment reliant on residential care. Although extracare is meant to provide flexible, 24-hour care, the evidence suggests that it is only able to support the most fit older people (i.e. cognitively fitter than those living in residential care, and physically fitter than those receiving care in the community). Furthermore, it could be argued that the advertisements for extracare employ subtle trickery in the use of language that does not distinguish explicitly between 'support' and 'care' (not adequately defining either). Landlords are using 'smoke and mirrors' to convince potential tenants/owners of the benefits of such environments. These benefits are not apparent to many of the inhabitants once they are in residence, as shown by their lack of satisfaction regarding access to personal care services.

On a more positive note, our research did show that extracare facilities can reduce social isolation of widows by increasing the opportunity for social interaction. However, the facilities do not have an impact on loneliness. In essence, friendships develop over time, and as noted in the USA (Perkinson & Rockermann 1996) those who talk about friends refer to those people with whom relationships have been developed outside of the facilities. As the demographic data showed in Chapter 2, levels of loneliness are similar across all three living environments, suggesting that although social resources are increased in extracare facilities, this has little impact on this emotional aspect of friendships in older people lives.

There are of course some implications that could be drawn from the evidence on the (lack of) development of meaningful friendships in extracare sheltered housing. We have shown that many facilities concentrate on the provision of social activities for residents. Although the development of a socially connected community within the facility may be an important for care home managers as they try to deliver a range of activities that promote participation, for those residents who have long-term friends in the community, the provision of transport or other types support to facilitate visits or communication may be more important.

In 1990, the *NHS and Community Care Act* (1990) became the most significant piece of legislation concerning the personal care and welfare of older people (Phillips et al. 2006). In 1993, the reforms outlined in the Act sought to change the mechanisms of funding residential care so that there were not 'perverse incentives' to institutionalise older people (DoH 1989). Community care budgets were

transferred to local authorities who were then responsible for funding care management either in institutional residential care home settings or in the older person's home in the community (Peace 2003). The purpose of community care was to "enable people affected by ageing or disability to live as independently as possible" (DoH 1990). The white paper 'Caring for People' had previously set the objective to "encourage the targeting of home based services on those people whose need for them is greatest" (DoH 1989). Thus, crucial to the delivery of home base care was 'care management' and in this respect, care managers decide on 'package of care' or care home placements which based around principles of both eligibility (functional) and financial criteria (Challis & Henwood 1994).

Our results showed that the participants who were living in the community were more physically frail than older people in the other two supported living environments. This suggests that community care teams are achieving their self-defined objectives of 'maintaining the independence of some older people in their own homes' (see p. 40) through the delivery packages of care to case loads of physically frail older people. Overall, there were more married participants living in the community than in the other environments suggesting that many of the community dwellers utilised a combination of both formal and informal care. However, our findings show that there are very few cognitively frail older people supported in the community. We should add a proviso here and provide information on our sample limitations. As noted in Chapter 2, the community sample was obtained through community care managers and teams, it is not a random probability sample drawn from the population of older care recipients in Wales. It may be that the community social workers acted as gatekeepers and restricted potential access to the study for those with cognitive impairment. Perhaps managers or care-workers assumed that older people with cognitive impairment would not wish to participate in the study, and failed to pass on details of the study to these potential participants. It is also possible that older people with cognitive impairment decided not to participate in the study after being provided with participant information forms (however, as this did not apply to those living in residential care this seems a less plausible explanation).

Assuming that our results concerning the difference in levels of cognitive frailty are robust (and the sample is unbiased), we could speculate that community care managers and extracare managers are excluding older people with cognitive impairment from the option to be cared for in the community/extracare. Essentially this practice excludes older people with mild to moderate cognitive impairment from public spaces (i.e. in the community or extracare) and this has serious implications for the future provision of long term care for older people in Wales. Furthermore, it suggests that little has changed since research conducted in Wales in 1993 which concluded that

care management was underdeveloped and that there was little evidence of skill sharing and support in the management of older people with dementia at home (Burholt et al. 1997).

The population of the UK is ageing. Over the last 25 years the percentage of the population aged 65 and over increased from 15% in 1983 to 16 per cent in 2008, an increase of 1.5 million people in this age group. This trend is projected to continue and by 2033, 23 per cent of the population will be aged 65 and over (ONS 2009). The prevalence of dementia is around 5% in the population age 65 years of more. However, it is present in approximately 30% of the population aged over 90 years (Hofman et al. 1991). The fastest population increase has been in the number of people aged 85 and over. Since 1983 when there were just over 600,000 people aged 85+ in the UK, the numbers have more than doubled reaching 1.3 million in 2008. By 2033 the number of people aged 85 and over is projected to more than double again to reach 3.2 million, and to account for 5% of the total population (ONS 2009). This demographic transition and the impact on the age structure of the population, with an exponential increase in numbers of people with dementia living in Wales, requires a national paradigm shift away from the medical or custodial models of care that are currently adopted for those with cognitive impairment.

The importance of this issue – the need to rethink how and where older people with cognitive impairment are cared for - cannot be stressed enough. One can draw a parallel between the sort of realignment of social responsibility that is required and the radical shift in the accommodation and care provision that has occurred for people with intellectual disabilities over the last 30 years. As Felce (2005) has noted the reform meant that “adults with intellectual disabilities living independently of their families, [moved] from predominantly large, remote institutions to community-based housing” (p. 10). Although this change in provision of services was prompted by poor standards of care in existing institutional services, we could similarly argue that older people with cognitive impairment should not be removed from the public sphere into institutions but should be accommodated in society based on the “principle of inclusion, and an emphasis on community integration” (Felce 2005, p. 10).

Evidence suggests that with appropriate support, older people with mild to cognitive impairment can live a fulfilling life within the community (and in this instance one can extrapolate that this would also apply to extracare environments) (O’Malley & Croucher 2005). However, the shift away from institutionalisation of people with mild to moderate cognitive impairment will have resources implications. The sort of interventions that may be required to support community/extracare living may include way finding techniques adopted on the local level (in individuals home) as well as

more widely in urban and rural planning (Passini et al. 1998, Passini 1999, 2000, Mitchell et al. 2004), staff or carer training (Brodaty et al. 2003, Gitlin et al. 2003), cognitive stimulation therapy (Spector et al. 2003, Orrell et al. 2005, Knapp et al. 2006), occupational therapy (Graff & Melick 2000, Melick & Graff 2000, Graff et al. 2003, 2006a, 2006b, Steultjens et al. 2004), and/or assistive technology (Monahan & Wall 2007, Orpwood et al. 2007, Rowe et al. 2008, Veldkamp et al. 2008).

Although we can predict that changing the structure and function of care services to extend the options for cognitively frail older people beyond residential care provision, we have not been able to examine the cost-effectiveness of current extracare environments. The lack of evidence about the potential, the costs and benefits and, consequently, the cost-effectiveness of extracare housing was also highlighted in one of the reports emanating from the evaluation of extracare in England (Bäumker et al. 2008). Their research arrived at a tentative conclusion that costs associated with living in extracare housing were higher than when people received services in their previous homes. An average cost per person per week of £380 arose before the transition to extracare housing, compared with £470 after moving to extracare facilities, with an average cost per resident of £360 to the public sector. Informal care costs fell, with estimated costs to the carer of £80 per week before the person they cared for moved to extracare compared with £25 per week after the move. The researchers estimated that, from a societal perspective, the total costs per resident per week would be £430 before the move and £490 after the move. However, these additional costs were associated with improved social care outcomes and improvements in quality of life, neither of which seem to be outcomes that are replicated in Wales.

The findings from the English evaluation suggested that the additional costs associated with extracare were offset by the important benefits for residents and their informal carers. In order for a cost-effectiveness study to be conducted, the costs and outcomes for people moving into extracare would need to be compared with those for people receiving alternative services, which is what was intended in this study. Ideally, information would need to be collected at the point of assessment, when the decision is made about the most appropriate service for the individual. This was not possible within the confines of this study but is required before a definitive judgement can be made regarding the relative cost-effectiveness of extracare.

This study (as with all social and health research) allowed participants the choice to participate or decline to take part in the research. We initially thought that managers were unwilling to divulge financial information about the services and, given their right to decline to participate, we did not press the matter after three requests for information. However, having highlighted the demarcation

between personal care provision, housing support provision and health care services – each of which could be sourced from different agencies – it is perhaps not surprising that managers (usually responsible for a single aspect of care or housing support) were unable to provide the information required for cost-benefit analysis.

This pilot study has relied on a comparison of data between three care environments. We have assumed that this is a valid comparison because we have used minimum age (60 years) and receipt of a care package as the common inclusion criteria for all participants. This method has provided us with some extremely useful information about the level of frailty of participants in each care environment, their quality of life and social resources. Furthermore, we have been able to explore the delivery of complex care packages in each environment through interviews with older people and managers. However, we need to bear in mind that the residents in extracare and residential care settings may have had somewhat different lifestyles or characteristics than those people who remain supported in the community, and it may be these characteristics that played a part in their move to a supported living environment. In order to truly identify the impact of extracare housing on older people's lives a research study adopting a before and after design is required. This could measure the impact of extracare housing (or residential care) in the lives of older people. We intend to use the findings presented in this report to form the basis of a further application for funding (perhaps to ESRC) to explore this in a more extensive study.

CONCLUSIONS

In this chapter we revisit the research questions posed at the outset of this study and provide a round-up of the results. Furthermore we make some recommendations for the Welsh Assembly Government based on these findings.

- Does extracare accommodate the changing needs of both fit and frail older people, particularly those with cognitive impairments?

Our findings suggest that extracare does not accommodate the changing needs of both fit and frail older people. Furthermore, it is clear that older people with cognitive impairment are frequently excluded from these environments. There seems to be a misconception that all people with cognitive impairment require ‘nursing’ care or health interventions. This is not the case, and older people with early stages of mild to moderate cognitive impairment (which need not result in decline for many years) can be supported in the community, or in extracare facilities. We argue that it is morally and ethically unacceptable to exclude mildly cognitively impaired people from community living on the basis that they constitute a risk to others or themselves, especially when this risk comprises ‘annoying neighbours’ and/or ‘wandering’ either of which can be managed with additional resources and a compassionate social ethos.

Recommendations:

1. A change in social ethos is required through public education – communities will need to accept the notion that there will be more older people with mild to moderate cognitive impairment living in the community. Communities need to prepare ways of meeting the challenge to provide for the welfare and safety of all of its members.
2. Deinstitutionalization of older people with mild to moderate cognitive impairment has resource implications (see discussion chapter). Evidence on the effectiveness of interventions should be used to prioritise which changes can be used to make the most positive impact on the lives of older people and their carers. A long term view needs to be taken by the Welsh Assembly Government to balance the initial costs and outlay, against the future costs of residential care and the impact on the quality of life and well-being of the older population in Wales.

- Can complex integrated health and social care be delivered in extracare? What are the views of managers and social workers?

Our findings suggest that complex health and social packages are not being delivered in extracare. On the whole, the care that was provided was low breadth-low depth, that is few services provided (one or two) on a limited basis (not frequently). We also found that those living in extracare environments were least satisfied with the access to personal care services. Limited access to (off-site) personal care, and demarcation in the types of support provided by housing support services, personal services and health services have an impact on the expressed satisfaction with care. On the whole, older people seem to be less concerned about who provides the care, than the notion that it is there when they need it. The interpretation of the differences between housing support services and personal service results in situations where older people are not provided help at the point of need, for example to access public areas of the communal living facility (e.g. help is not provided to push a wheelchair to the dining room), or assistance after a fall, unless this is offered by fellow residents. This situation is exacerbated by the language that is used to describe extracare facilities that could be considered disingenuous and in a majority of advertisements it cleverly disguises any limitation in care provision from within the facilities. Under these conditions it seems very unlikely that extracare will be able to provide adequately for both fit and frail older people.

Recommendations:

3. Extracare should be defined clearly by the Welsh Assembly Government – there should be a gold standard so that it is clear to older people what they can demand/expect from these facilities either in the public or private sector. Furthermore, currently managers have the right to decline residents based on anticipated (imagined) future care needs and social grounds (whether or not they think a potential resident will be socially active in the community). A clear Welsh Assembly Government definition should indicate whether this is acceptable practice for (publicly funded) supported environments that are purported to provide for a mixed clientele.
4. During the process of making a decision to move, an explanation should be given to potential clients regarding what is available on-site and around the clock (clearly distinguishing between housing support services, personal care provision, and health care), who organises personal care and health care and how this differs (or not) from what they could expect to receive living in the community. Furthermore, the upper limits on care provision (i.e. when a resident would be required to move out of the facility) should be clearly specified.

5. The Welsh Assembly Government should consider making changes in the Care Standards Act 2000 to allow a more flexible approach to the provision of complex care in extracare facilities. For example, there should be 24 hour provision for basic first aid, and other forms of emergency support that may be required by residents. The demarcation between housing support function and physical personal care makes little sense to those on the receiving end of services especially when they require immediate help (e.g. after a fall, or temporary assistance perhaps with accessing the dining room).
 6. The unified assessment process needs to be re-examined and challenged especially with regard to the over-simplified outcome that older people with cognitive impairment 'pose a risk to themselves or others' and thus cannot live independently in the community. Examples of good practice should be provided to encourage care managers' use of innovative care packages to help people remain independent in the community or in extracare schemes (if they should wish to do so).
- What is the quality of life and experience of fit and frail older people in extracare schemes compared to residential and home care?

We examined three distinct areas to understand the experiences of older people in each of the living environments: quality of life, resilience and social interaction. Our analysis indicated that the quality of life for extracare residents is no better than the quality of life for older people living in the community or in residential care. In fact, when one considers one particular domain (access to personal care services) we found that quality of life of residents in extracare was worse than those living elsewhere.

We found (as in previous studies), that older people living in residential care had lower levels of interpersonal control, and lower satisfaction with control over financial matters. However, rather than 'overcare' being an issue that leads to deleterious outcomes (see e.g. Ransen 1978), it seems that the lack of control may be down to the insufficient staff resources in residential facilities. Where people could retain some aspects of independence and dignity (for example being helped to get to the toilet), understaffing led residents to feel unsupported and unable to control certain elements of their lives.

We found that social interaction was higher for those living in extracare facility. Although the analysis presented here demonstrates that extracare facilities can reduce social isolation of widows by increasing the opportunity for social interaction, the facilities do not have an impact on

loneliness. In essence, friendships develop over time, and those who talked about friends referred to those people with whom relationships have been developed outside of the facilities.

Recommendations:

7. Although the development of a socially connected community within the facility may be an important facet for extracare home managers as they try to deliver the a range of facilities that promote participation, for those residents who have long-term friends in the community support to facilitate visits or other forms of communication between them may be more important. However, there are some examples of good practice that could be adapted from the extracare model to be used in residential care to provide meaningful social activities for residents in these facilities.
 8. Increases in the volume of trained staff (and thus presumably funding for staffing) in residential care may have a positive impact on the sense of control that older people have over their lives.
- Is extracare cost effective compared to residential and home care matching residents of similar frailty?

Unfortunately we were unable to answer this question. It is suggested that for a cost-effectiveness study to be conducted, the information would have to be acquired from a range of sources for each facility, which would vary according to the support/care arrangements that were arranged locally. This was beyond the scope of the present research because the research resources that we had funded were sufficient for one interview with one manager only in each facility. This may have been increased up to four-fold were we to pursue interviews and data collection from all care/housing/support providers.

In our concluding statement we would like to offer some food for thought. If we were asked to summarise our findings for the benefit of an older person considering a move to extracare, they would read something like this:

“Extracare will provide you with a low-level of care if you need it. You will usually obtain this in the same way that you would in the community (though a unified assessment and a care package delivered by the local authority or approved provider). Don’t expect personal care to be available on-site 24 hours a day. Don’t expect the care package to be flexible enough to support you if you get early signs of dementia or other memory problems. In

these instances you are likely to be either denied entry to extracare, or if you are already resident in a facility, you may be asked to move on.

The bottom line is that extracare facilities will provide you with a ‘social club,’ so if you like your privacy or solitude they may not be suitable for you. The facilities promote social participation and help you meet other residents (and often offer outings), but this will not necessarily lead to the formation of new friendships or reduce loneliness. Extracare housing will provide you with more control over your life than you may get if you are in a residential care setting, but it is unlikely to improve your quality of life. In fact it may have a negative impact on your satisfaction with access to services.”

This description bears little resemblance to the policy rhetoric of the Welsh Assembly Government or the descriptions of extracare provision distributed by the providers of extracare. The vision for housing in Wales addresses the varying and changing needs of older people ensuring independence for as long as possible. For extracare sheltered housing to provide the substance behind this vision, there is an urgent need for the Welsh Assembly Government to put in place measures to guide or regulate the delivery of this type of provision.

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