Rural-urban differences in the effects on mental well-being of caring for

people with stroke or dementia

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Rural and urban differences in the effects of care-giving are not well documented. This paper reports data on 122 carers for people with stroke or dementia living in rural and urban settings in Wales. Carers completed a postal questionnaire, including the SF-12v2 Health Survey. Definitions of rural and urban were based on the Urban/Rural Indicator from the Office of National Statistics (ONS) All Fields Postcode Directory 2004. Carers' mean Mental Component Summary (MCS) score (adjusted for age and sex) was one standard deviation below the population mean (-12.03). Male carers living in urban areas reported better mental health than male carers in rural areas ($p<0.05$), and female carers in both settings ($p<0.05$). A full model and a parsimonious model were developed, using MCS scores as outcome variables. In the full model sitting service provision in rural and urban locations was linked to better carer mental health, while support from friends and family was linked to better mental health for urban carers only. Our findings indicate the existence of both gender and location differences in carer experiences.

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Introduction

Differences in physical health and psychological well-being between individuals who have caring responsibilities and those who do not are well documented (see, for example, Hirst, 2005). A number of studies have reported carers to have significantly poorer mental and emotional health, and to a lesser extent poorer physical health. From their meta-analysis of 84 papers, Pinquart and Sörensen (2003) concluded that carers have significantly higher levels of depression and stress, and lower levels of subjective well-being, self efficacy and physical health than those without caring responsibilities. They also reported differences between carers according to the medical condition of the care recipient and the relationship of the carer to care recipient. The greatest impact on these variables appeared to be: where the care recipient was a person with dementia rather than physically frail or disabled; where the carer was the spouse of the care recipient as opposed to being an adult child looking after a parent; for female carers compared with male carers; and for older carers. Although beyond the scope of their analysis, they acknowledged that Socio Economic Status and duration of care could also be important factors in carer health.

Although dementia was highlighted as the condition most associated with negative carer impact, comparative studies suggest that caring for a person who has had a stroke is associated with similar levels of depression (Wright *et al*., 1999) and stress (Thommessen *et al*., 2002). The cognitive impairment and changes in personality often associated with stroke appear to lead to similar difficulties for these two groups

of carers. Dementia is, of course, often associated with stroke, developing in around 20% of cases (Ivan *et al.,* 2004).

Gender differences in caregiving experiences are well documented. Yee and Schulz (2000) published a review of empirical research concerning gender differences in caregiving. They reviewed 30 research reports published between 1985 and 1998 and concluded that female spousal carers reported higher levels of depressive symptoms than male spousal carers. They also reported that women's scores (spouses and adult daughters looking after a parent) were very close to or above the cut off point for being at risk of clinical depression. Conversely, almost all the scores for male carers fell below that cut off point. As well as depression, higher levels of stress, anxiety and paranoia were reported among female carers, and lower levels of life satisfaction.

Gender differences in reporting behaviours and coping strategies have been identified. Lutzky and Knight (1994) suggest that male carers may experience as much distress as female carers, but are less likely to express and report it. They also suggest that female carers are more likely to use avoidance coping strategies, which appear to be ineffective in relation to managing the challenges associated with chronic conditions such as dementia, and increase the risk of depression and distress. Gender differences in rates of depression and distress in the general population are well-documented, of course.

It has often been suggested that male carers receive more support than female carers and historically, in England, that has been the case (Charlesworth *et al*., 1984). Yee and Schulz investigated this issue and reported that the majority of studies in their

review did find that male carers received more support from family and friends than female carers. However, the evidence for service provision was inconclusive.

Despite the wealth of published literature concerning dementia, papers comparing the experiences of carers living in rural and urban areas are scarce. Rural and urban differences were not explored, for example, in Pinquart and Sorenson's (2003) extensive meta-analytic review and Markowitz *et al*. (2003) did not investigate rural and urban issues or indicate whether their sample population was predominantly rural or urban. Wenger *et al*. (2002) make some comparison of a particular rural are (North Wales) and a particular urban area (Liverpool), but did not formally assess mood or well-being. They highlighted the perceived importance of neighbours (even though contact might be infrequent), and noted relatively low levels of service provision; among these, day care was highly valued. Furthermore, the terms 'rural' and 'urban' are rarely defined, making it difficult to compare findings across different studies. Godden and Richards (2003) acknowledged this comparison problem, and also commented that a single definition of rurality may be unachievable.

Defining 'rural' and 'urban' is far from straightforward and prone to contradictions. Whilst defining an inner-city high rise housing development as urban and a remote highland croft as rural presents no problem, much of the UK is neither. The contrast in population density between inner city housing and remote sparsely populated communities leads to an impression that rural and urban areas can be defined using population density alone. However, affluent suburbs with low density housing may be less densely populated than a village consisting mainly of old farm workers' cottages, indicating the need to take into consideration the nature of the wider

geographical area. The presence of services and amenities also cannot be taken as a sole indicator; rural areas are typically associated with a restricted range of services such as Post Offices, banks and shops, but so are affluent suburbs.

In the UK, the Office of National Statistics (ONS) has devised a system which classifies rural and urban into 8 different area types (ONS Geography, 2004). England and Wales is divided into 175,434 Output Areas which were introduced by the Office of National Statistics in 2001. Wherever possible these areas do not combine urban and rural postcodes and have a minimum size of 40 households but a recommended size of 125 households. Output areas are described as urban if the majority of the population live in a settlement of a population of 10,000 or more. This can be further subdivided into 'urban – sparse' and 'urban – less sparse'. The remaining areas range from 'town and fringe' through to 'hamlet and isolated dwelling'. These rurality codes are linked to postcodes which allows for reasonably consistent use of the terms 'rural' and 'urban' within the UK as any postcode can be linked to one of the eight rurality codes. However, the problems of comparing rural and urban across Europe and other countries such as the US remains.

Despite the lack of precise definition there is much in the general literature to suggest that rural carers will face more difficulties than their urban counterparts. In a policy briefing, Carers UK (2003) outlined the additional problems involved in supporting carers in rural communities; lack of services, isolation, lack of privacy and financial hardship. A number of policy initiatives have been put in place to address these problems. Under the terms of the Carers and Disabled Children's Act (DoH, 2000) the nature of services to be provided are not specified, rather, a local authority may

provide *"….any services which, in their view, will support the carer in their caring role."* This allows for an innovative approach in extending the traditional range of services offered, with the emphasis on the needs and circumstances of the individual carer. For example, if driving lessons would be of most help to a carer living in a rural area they can be provided. The Carers (Equal Opportunities) Act 2004 went on to state that consideration must be taken of whether the carer … *"is undertaking, or wishes to undertake, education, training or any leisure activity."* In England the Rural White Paper published by the Department for Environment Food and Rural Affairs (DEFRA, 2000) gave, for the first time, a Rural Service Standard explaining what rural service users could expect, and also stressed the need for innovative thinking.

Indeed, historically rural areas have spent less on social care. Craig and Manthorpe (2000) explored the changes occurring after the local government re-organisation of the late 1990's. They observed that because the rural authorities had spent less on social care services, it made it difficult for them to cope with the costs associated with re-organisation. They also observed that while at a local level there may be a range of initiatives being piloted, poor dissemination meant that the outcomes do not become widely known.

Problems associated with rurality are not confined to the UK, in the US McCutchen (2004) reported urban carers to have significantly more access to respite care, home health aide care and day care than their rural counterparts. Perhaps surprisingly given their increased access to support, more urban carers identified social isolation as a problem than rural carers.

The aim of the current study is to apply an operational definition of rurality to a UK care-giver sample, focusing on those caring for a person with dementia or for a person who has had a stroke. From the available literature it is predicted that female carers will fare worse than male carers and spousal carers worse than adult children looking after a parent. We aim to identify whether there are differences between rural and urban carers in psychological distress. We anticipate that rural carers will receive less services and support than their urban counterparts, and so may be more likely to experience higher levels of distress.

Method

This paper reports data from the first phase of a longitudinal study, being conducted over 5 years, considering the effects of the Carers Strategy in Wales and presents data from the first of three postal surveys of carers in Wales. Although Wales has historically been associated with lower levels of health than England, recent figures published by the ONS (2006b) indicate that life expectancy is only slightly lower. Males in Wales can expect to live for 76.3 years (England 76.9 years) and females 80.7 (England 81.2).

*Participants*

Ethical approval for the study has been given by the Multi-Centre Research Ethics Committee for Wales (MREC). Although a number of health and social care agencies maintain lists of carers they are in contact with, it was not appropriate or possible for the research team to be given direct access to the databases. Instead, a number of agencies across Wales agreed to forward the questionnaire to carers on our behalf.

The initial sample was identified by the following agencies, who distributed the confidential postal questionnaire:

- NHS consultants (*n*=29);

- General Practitioners (*n*=13);

- Local Authorities(*n*=16);

- Voluntary organisations (*n*=29).

*Procedure*

Each carer received a pack containing:

- A letter inviting them to take part in the study;

- A leaflet explaining the purpose of the study;

- A copy of the questionnaire in English and in Welsh;

- A Freepost envelope for returning the completed questionnaire to the research team.

The information leaflet explained that as it was a longitudinal study it would be helpful if carers supplied their names and addresses, to enable follow up questionnaires to be sent. It was stressed that this information would be kept separately from the questionnaire.

*Measures*

The survey form comprised fixed-choice and open-ended questions, relating to carer experiences, support needs and services received. It began with questions requesting demographic and employment information about the carer and information regarding the severity and medical condition of the care recipient. Questions were also asked regarding the frequency of services received (home care, day care, respite care, sitting service, district nurse, occupational therapist, and other), and help received from

family, friends and neighbours.  An open ended question asked if carers had any needs that were not being met at the time of completing the survey.  The final question enabled carers to state the areas of their life most affected by their caring role.  Space was provided for carers to identify up to five areas and to identify areas positively affected as well as negatively.  Examples were given but carers generated their own list.

The survey also included the SF12v2 Health Survey which is a standardised measure of health and wellbeing, has been validated in the US and translated and widely used in 28 countries.  It is a reliable and easy to use means of assessing physical and mental health, and has previously been used in carer research (Markowitz *et al*., 2003).  The SF12v2 is a short (12 question) questionnaire module derived from the widely used SF36 (Ware et al., 2002).  Both are generic measures rather than being aimed at particular age groups or disease types.  The overall score is broken down into two components; the Physical Component Summary score (PCS) and the Mental Component Summary score (MCS), measuring physical and mental well-being respectively.  Five of the questions measure physical health and five measure mental health.  The remaining two questions encompass both.  The questions cover the impact of physical and emotional issues on the respondent's daily life over the previous 4 weeks.  Normed scores, by gender and age group, have been published for the general population.  As our primary interest was carers' mental health the MCS scores were used in the analyses.  For the total population the range of normed scores is 8.14 to 73.24 (mean 49.37, SD 9.75) with higher scores indicating better mental health.

Mental and physical health does not remain constant across the lifespan. For example, physical health declines with age, while mental health is typically not as good for a person in their early twenties as someone in their thirties. To allow for these developmental patterns carers' Mental Component Summary (MCS) scores on the SF12v2 were adjusted for age and gender by subtracting the published normed score from the raw score (Ware *et al.*, 2002). These adjusted scores have been used throughout.

Analysis

For our analyses evaluating carers' experience in caring for a person experiencing an acquired cognitive impairment we have included individuals caring for a person with either a stroke or a dementia, in view of the evidence previously cited of the similar impact of the conditions and their overlap. It was not possible to differentiate sub-types of dementia.

In order to obtain the rural or urban categorisation we took the postcode data from the questionnaire and used the All Fields Postcode Directory (ONS Geography, 2004) to assign it to one of four categories: Urban; Town and Fringe; Village; Hamlet and Isolated Dwelling. Conventionally a minimum sample size of 20 level 1 units (carers) to each level 2 unit (geographical category) is sought for multilevel analysis, resulting in a total minimum required sample of 80. However, when a multilevel model was developed (using the multilevel modelling software package *MLwiN*) based on these four categories there were insufficient respondents in certain categories (for example, home care, day care and respite care) for the model to run. The problem in this instance not being the total number of carers, but the number of carers receiving some services. For the final analysis these four categories were reduced to 2: rural and

urban. Reducing the categories in this way gave rise to the problem of how to assign Town and Fringe as 'Town' would be more likely to be urban and 'Fringe' rural. One of the questionnaire questions asked carers whether they lived in a rural or urban area as it was anticipated that some participants would prefer not to give their precise location details. Their responses were therefore used for this category only. The categories Village and Hamlet and Isolated Dwelling were assigned to the new category of rural and the Urban category remained urban. The multilevel model became a single level model with location (rural or urban) as a fixed effect explanatory variable.

Results

A total of 387 postal questionnaires were received (1512 distributed, response rate 25.6%) from carers aged 19 to 88 years living across Wales. One hundred and twenty two were carers for people with dementia or stroke, and are the focus of the analyses. Although the questionnaires were made available in English and Welsh only 4 Welsh questionnaires were received. The statistics package SPSSv12 was used for the descriptives and *MLwiN* for the multilevel modelling. The results are presented in three sections:

    i)  Carer Mental Component Summary (MCS) scores on the SF12v2;

    ii)  Support carers receive and their unmet need;

    iii)  An exploration of the link between services received and carer MCS

       scores.

*Carer scores on the SF12v2*

Most carers answered all questions on the SF12v2, resulting in only a small amount of missing data. QualityMetric publish a computer program which is able to estimate a

small amount of missing data and by using this the scores of only one carer were lost to analysis.

Table 1:  Carer MCS Scores by rurality and gender

Table 1 indicates that MCS scores of men living in urban locations are significantly higher than rural male MCS scores, indicating better mental and emotional health.  On the other hand female carers have similar scores, irrespective of location.  As shown in Table 2, where carer and care recipient were co-resident, rural adult child carers MCS scores were significantly lower than those of their urban counterparts.

Table 2:  Carer MCS scores and relationship of care recipient

We explored a number of factors likely to account for the apparent better mental health of urban males, including support received and unmet need.  Table 3 provides details of support received.

Table 3:  Services received and support from family and friends[1]

Urban male carers are more likely to receive day care and sitting service provision than rural male carers (Table 3).  Rural female carers receive more respite care than urban female carers, but less sitting service provision.  The penultimate row, total service provision, indicates that the volume of service provision is similar across

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[1] Day care is a non residential facility attended by the care recipient on a regular basis, perhaps for a whole or half day, or just for 2-3 hours.  Respite care is a residential facility involving at least one overnight stay and frequently for longer periods of time.  Sitting service is a service whereby someone comes into the home to care for the care recipient, thereby giving the carer some time away from their caring responsibilities.

locations.  The final row suggests that more rural carers receive help from family and friends than urban carers, with no gender difference.

Carers were asked to consider those aspects of their life most affected by the caring role.  Table 4 indicates there are adverse effects relating to social exclusion, family life and inter-personal relationships.  Urban male carers report a higher average number of social concerns than any other carer group.

Table 4:  Social exclusion, family life and inter-personal relationships

*Multi-variate analysis of factors influencing carer scores on the SF12v2*

As described above, single level models with MCS scores as the outcome variable and location included as an explanatory variable were developed.  As severity of the condition of the care recipient was a major source of individual variation in the care-giving situation the correlation between severity and carer MCS score was calculated.  Although significant the correlation was not high (Pearson's r = -0.205, *p*=0.027), carer mental and emotional health worsened as the severity of the care recipient's condition increased.

Table 5 indicates a significant interaction, in both models, between location and gender in their influence on MCS scores.  Unmet need makes a significant independent contribution to MCS scores, as does severity when included in the full model.  The addition of caring for a spouse compared to caring for a parent is not significant.

Table 5:  Factors influencing carer MCS scores

The full model indicates that unmet need, the interaction between location and gender, and severity of the condition of the care recipient have a significant influence on carer MCS scores.  These were therefore included in the parsimonious model.  Home care, day care, respite care and sitting service were also included as candidates in case of correlation between sitting and the other services.  The variables were entered into the equation in a stepwise manner to investigate which variable resulted in the largest reduction in -2*log-likelihood at each step.  In step one the interaction between location and gender resulted in the greatest reduction of 8.888 which when compared with the chi-square distribution gives a significance level of 0.012.  Russell and Gregson (1981) detail a procedure for adjusting the significance level to obtain a significance range that takes into account the relationship between these variables. The significance range can be expressed as $p$ to $1-(1-p)^n$ where n is the number of variables.  For the interaction this gives an upper value of $1-(1-0.012)^7 = 1-0.919 = 0.081$.  The significance range is therefore 0.012 to 0.081.  At step two the addition of unmet need resulted in the largest reduction of 5.841, giving a significance level of 0.016.  The significance range is therefore 0.016 to $1-(1-0.016)^6$ or 0.016 to 0.092.  At step 3 severity resulted in the largest reduction but at 3.264 was not significant.

Discussion

Carers Mental Component Summary (MCS) scores on the SF12v2 (see Table 1) were significantly lower than the general population.  This finding is not surprising as there is a wealth of published work highlighting the emotional and mental health problems experienced by carers.

The carers for our sample were selected through voluntary organisations and a small number of medical and local authority staff; we had very limited control over which carers received the questionnaire. This recruitment method meant that all carers had already been in touch with voluntary organisations or services, possibly as a result of experiencing difficulties related to their caring role. It is possible therefore that carers in our sample were more likely to be suffering problems as a result of their caring role than the general carer population. However, the findings from our study are in accord with findings from the Welsh Health Survey 2003/04 (ONS, 2006a) which reported that a higher percentage of female carers were treated for mental illness as opposed to non-carers. For males there was no difference between carers and non-carers.

One aspect of caring not explored by Pinquart and Sörensen (2003) in their meta-analysis was location; whether living in a rural or urban area has a bearing on carer experiences. Table 1 shows a significant difference between rural and urban carer's MCS scores with rural carers scoring significantly lower than urban carers. The breakdown by gender and location indicates that it is male carers whose scores are causing this significant difference. Female carers do not differ greatly between rural and urban locations, whereas male carers do, and significantly so.

An obvious explanation for the rural and urban differences found would be differences in the level of help received, and there is evidence in the literature to suggest that will be the case. The Carers UK 2003 policy briefing suggests that rural carers will face more difficulties than their urban counterparts; namely, lack of services, lack of privacy, isolation and financial hardship. Furthermore, as noted by Craig and Manthorpe (2000) authorities in rural areas have traditionally spent less on

social care, which may be expected to have an effect on service provision. This suggestion that rural carers will receive fewer services is only partially substantiated by our findings. Table 3 indicates that rural carers did receive less day care and sitting service provision, but they also received *higher* levels of respite care. The figure for total service provision (home care, day care, respite care, sitting service, district nurse and occupational therapist), although a fairly crude index, is very similar across location and gender. Urban male carers do receive slightly more services than their rural counterparts, but the differences are very slight. What the figures demonstrate is how low the level of overall provision is; less than two services weekly. The key factor may well be the extent to which the service provided meets the most pressing needs for that individual carer.

Whilst there is some evidence in the literature (Yee & Schulz, 2000; Charlesworth *et al*., 1984) that male carers receive more help than female carers we did not find that to be the case. The situation is more complex in our sample, with male carers receiving more home care than female carers, but female carers receiving more respite care. Day care provision for urban carers is roughly similar for males and females, but female rural carers receive more day care than male rural carers.

What is of particular interest here is how levels of support affect carers' mental and emotional health as measured by MCS scores on the SF12v2. To explore this issue levels of support were entered into the models as explanatory variables, along with rurality and gender. Perhaps surprisingly the implication is that service provision and the existence of social support from family and friends do little, if anything, to improve carers' mental and emotional health. Only sitting service provision (in both

rural and urban locations), and social support (in urban areas only) were linked with higher MCS scores, but neither significantly so. The implication is that a few hours sitting service on a regular basis is of more benefit than a longer, but less frequent break. It is interesting to note that levels of sitting service provision were lower in rural areas than urban. The difficulties of providing a regular home based service are most likely the reason for the lower levels of service, but our research suggests that the benefits of such a service are greater than the benefits of longer 'respite' care that most likely takes place away from the home.

Although fewer urban carers receive support from friends and family, when they do it has a positive effect on their mental health. In the full model social support for urban carers was almost significantly linked with higher MCS scores.

Perhaps unsurprisingly a significant link between unmet need and MCS scores was found. Those carers who stated that they had unmet needs scored significantly lower than those who did not. No interaction between location and unmet need was found.

The final row of Table 5 shows the effect of adding spouse v parent as care recipient into the model and the effect did not approach significance. Given the findings reported in some of the research literature (see, for example, Pinquart & Sörensen, 2003) that spousal carers fare worse this is somewhat surprising. However, this lack of significant difference is **after** the other explanatory variables (including rurality) have been taken into consideration. Table 2 shows that whilst urban spousal carers have lower MCS scores than adults caring for a parent, for rural carers the opposite is

the case.  This is a good example of a situation where failing to take rurality into consideration may lead to a false assumption being made.

In the final section of the questionnaire carers were asked to list aspects of their lives most affected by their caring role.  Although examples were given carers were able to generate their own list of the factors most affecting them.  A breakdown of the responses to that question is given in Table 4.  As can be seen, more urban carers listed aspects of social life than rural carers.  Carers could list up to 5 areas of concern, and again urban carers listed slightly more social aspects.  This is in broad agreement with McCutchen (2004) who reported more urban carers to identify social isolation as a factor than rural carers.  The paradox then is why urban male carers report more social concerns, but have better mental health scores.  One possible explanation for this apparent contradiction is that although they have concerns regarding those aspects their mental and emotional health is not affected.  This is in agreement with Lutsky and Knight (1994); males do experience stress, but it has less global effect, and is less likely to lead to depression.  However, it is still unclear why rural male carers should score so differently on the SF12 from urban male carers.

Conclusion

The findings from this study indicate the presence of differences in carer experiences that are attributable to living in a rural or urban location.  In particular we found that differences previously assumed to hold true for all carers were only true for the urban carers in our sample.  This highlights the importance of considering rurality alongside gender and other carer characteristics in future research.

Our findings have important implications for researchers and service providers. Researchers must ensure that issues relating to location are addressed in their studies, otherwise there is a danger that findings which are only attributable to a proportion of carers will be generalised as applying to all. The nature of the interaction between help provided and tangible benefits to carers is complex and not clearly understood at present. Further research is needed to better understand the processes involved. Service providers should be aware of the different needs of rural and urban, male and female carers and also be aware that simply providing a service will not automatically be of benefit to the carer.

Following a review of the literature a number of predictions regarding the findings of this study were made, among them that female carers would fare worse than male carers and that spousal carers would fare worse than adults looking after a parent. Both of those predictions were only found to be true for the urban carers in our study. No difference was found between the MCS scores of the male and female rural carers, and rural spousal carers actually fared slightly better than adults looking after a parent. Whilst rural carers did report overall worse mental health, this could not simply be attributed to them receiving fewer services than their urban counterparts. The total volume of service provision was similar for urban and rural areas, but importantly we found rural areas to receive less regular sitting service provision and of all the services provided, sitting service provision was the only one to be linked with higher MCS scores.

A limitation of this study is the sample size. Although the questionnaire was completed by 122 carers for people with stroke or dementia there were too few respondents in certain categories for analysis. For example, due to the low overall provision of services such as home care, the breakdown of provision by location and gender resulted in too few respondents for meaningful analysis. However, this data does clearly indicate the importance of taking into account the effects of rurality, and we have shown the feasibility of using an agreed operational definition, at least for the UK context.

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Table 1: Carer MCS Scores by rurality and gender:

| | Rural (n=66) | | | | Urban (n=56) | | | |
| | Male (n=21) | | Female (n=45) | | Male (n=19) | | Female (n=37) | |
| | Mean | SD | Mean | SD | Mean | SD | Mean | SD |
|---|---|---|---|---|---|---|---|---|
| MCS scores (n=122) | -16.31* | 11.28 | -12.94 | 11.95 | -5.13* | 11.57 | -12.06 | 10.03 |

*significant difference ($p$=0.004; independent samples $t$ test)

Table 2:  Carer MCS scores and relationship of care recipient:

| | Rural | | Urban | |
| --- | --- | --- | --- | --- |
| | Live with care recipient (Mean, SD, n) | Do not live with care recipient (Mean, SD, n) | Live with care recipient (Mean, SD, n) | Do not live with care recipient (Mean, SD, n) |
| Spouse (n=64) | -13.63; 11.37 (27) | | -10.55; 10.39 (37) | |
| Parent (n=39) | -18.40; 8.03** (17) | -12.38; 12.96 (11) | -8.04; 11.86** (8) | -3.51; 17.85 (3) |

**Significant difference ($p$=0.017; independent samples $t$ test).

Table 3:  Services received and help from family and friends:

| | | Rural | | Urban | |
|---|---|---|---|---|---|
| | | Male (n=21) | Female (n=45) | Male (n=19) | Female (n=37) |
| Home care | Daily or Weekly | 10 (48%) | 15 (33%) | 9 (47%) | 14 (38%) |
| Day care | Daily or Weekly | 4 (19%) | 13 (29%) | 7 (37%) | 13 (35%) |
| Respite care | Occasionally | 4 (19%) | 20 (44%) | 4 (21%) | 12 (32%) |
| Sitting service | Weekly or monthly | 6 (29%) | 9 (20%) | 7 (37%) | 14 (38%) |
| Total service provision* | | 5.63 | 4.81 | 5.68 | 5.17 |
| Receive help from friends and family | | 14 (67%) | 32 (71%) | 10 (53%) | 22 (59%) |

* Services included were: home care, day care, respite care, sitting service, district nurse and

occupational therapist.  If a carer received all services on a daily basis they would score 24, if they

received no services their score would be 0.

Table 4:  Social exclusion, family life and inter-personal relationships

|  | Rural | | | Urban | | |
|---|---|---|---|---|---|---|
|  | Male ($n$=21) | Female ($n$=45) | All ($n$=66) | Male ($n$=19) | Female ($n$=37) | All ($n$=56) |
| Family Life | 2 | 17 | 19 | 5 | 10 | 15 |
| Visiting Friends | 3 | 12 | 15 | 10 | 17 | 27 |
| Social Life | 8 | 16 | 24 | 11 | 8 | 19 |
| Church Activities | 0 | 6 | 6 | 0 | 6 | 6 |
| Lack of friends/isolation | 1 | 2 | 3 | 1 | 0 | 1 |
| **Total number of social concerns listed** | **14** | **53** | **67** | **27** | **41** | **68** |
| Total number of carers highlighting social concerns | 11 (52%) | 28 (62%) | 39 (59%) | 14 (74%) | 24 (65%) | 38 (68%) |
| Mean per carer | 1.27 | 1.89 | 1.72 | 2.08 | 1.78 | 1.89 |

Table 5:  Factors influencing carer MCS scores

| | Full Model<br>n=113<br>Mean (standard error) | Parsimonious Model<br>n=113<br>Mean (standard error) |
|---|---|---|
| Intercept | -6.744 (3.267) | -9.963 (2.069) |
| Location | -5.762 (4.041) | 0.168 (2.598) |
| Gender | -4.102 (3.241) | -3.373 (3.173) |
| Interaction between<br>Location and Gender | **10.367 (4.593)** [a] | **9.862 (4.576)** [e] |
| Home care | -1.281 (2.367) | |
| Day care | -0.282 (2.439) | |
| Respite care | -2.487 (2.401) | |
| Sitting service | **4.511 (2.627)** [b] | |
| Social support | -3.655 (3.277) | |
| Interaction between<br>social support and<br>location | **8.007 (4.546)** [c] | |
| Unmet need | **-5.046 (2.214)** [d] | **-5.174 (2.147)** [f] |
| Severity | **-1.468 (0.711)*** | |
| Spouse v parent care<br>recipient (*n*=96) | 0.179 (2.301) | |

Significance levels for the full model were calculated using the Wald test.

[a]$p$=0.024;  [b]$p$=0.086; [c]$p$=0.078; [d]$p$=0.022  *$p$=0.038.

Parsimonious model [e] significance range between 0.012 and 0.081; [f] between 0.016 and 0.092.  (See text for more details).