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Home Alone or Not? A Mixed Methods Study of Different Perceptions of Social Isolation between Care Managers and Older Housebound Adults

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Abstract

Purpose: This paper aims to discuss whether the level of social isolation and loneliness as assessed by care managers corresponds to the level of social isolation and loneliness as perceived by the older persons whose care needs are being assessed.

Design/methodology/approach: This mixed methods study followed up the assessment of 40 older people by 20 care managers with a focus on the accuracy of the care manager's assessment on the level of social isolation experienced by the service user. In order for this to be achieved structured interviews were conducted with both the older person and the care manager assessing their needs, with a specific focus on the assessment of loneliness and social isolation. Following these initial interviews two focus groups were then undertaken with the care manager to discuss the findings and unpack the assessment process.

Findings: The key issues were that the true level of social isolation and loneliness was under assessed by the care manager completing the assessment. That the care manager's assessment was predominantly focused on the physical well-being of the older person and heavily influenced by the assessment paperwork.

Originality/value: This provides lessons for professionals about the lack of effectiveness of their assessment of social isolation and loneliness in older people, and the potential impact this has on the older person's quality of life.

Keywords: Older people, Social isolation, Care management.

Introduction

The assessment of older people and their needs has been examined in some depth by Richards, Challis and Powell, et al. with these different studies considering that the process of assessment frames the narrative of the service user leading to problems in the care manager's ability to accurately assess the care needs of older people [1-3]. This problem has been examined in particular by Weiner et al. who identified that the construction of the service user by the assessment process normally focuses on the physical aspects of the individual and strips away the human element of the person [4].

The impact of social isolation with regard to older people has been studied in some depth in the post-war era, with the initial research of Sheldon, Halmos and more recently by Davidson and Rossall all identifying social isolation and specifically loneliness as a problem in later old age [5-7]. However social isolation and loneliness are two concepts that tend to be used interchangeably in the literature focused around the care of older people. This case study has taken the view that they are two distinctly different phenomena, and has

used the definition of social isolation as set out by Wenger and colleagues as being [8]:

“The objective state of having minimal contact with other people, whilst seeing loneliness as: the subjective state of negative feelings associated with perceived social isolation, a lower level of contact than that desired or the absence of a specific desired companion”. (P; 333).

Hadley and Webb and Bury and Holme have established that living alone does not have a direct correlation with experiencing loneliness [9,10]. These studies demonstrated that living by oneself per se was not necessarily an indicator of being socially isolated; that it was a lack of relationships outside of the family that was a better indicator of social isolation. The participants in this case study only had relationships outside of the family with their home care workers. Therefore their level of social isolation differentiates them from the wider body of society termed as older people. The level of loneliness was also much more prevalent in this case study than that found in the Bangor Longitudinal Study of Aging which studied the general older population [11]. This BLSA study considered loneliness to be present if the following

indicators were found:

- Feels lonely much of the time
- Does not see enough of friends or relatives
- Does not meet enough people

The BLSA longitudinal study of 543 older people was conducted over a period of 20 years with the final data set being gathered for the last time in 1999. This final data set involved the study of the remaining group of older people (n=63). This final group, were then subdivided into those living in institutional care and those living independently within the community. Those living in the community (n=47), equate to a similar sample size to the sample group in this case study (n=40). However the reported levels of social isolation in this case study and the BLSA study were markedly different. The BLSA cohort only reported feeling moderately lonely (29%) or very lonely (9%) compared to 40% of the sample in this case study who considered them self to be very lonely. However when the level of social isolation is considered for the sample group in the BLSA case study with the BLSA measure of social isolation (spending 9 hours or more without social interaction), only 34% were moderately isolated with a further 6% considering themselves to be very isolated. In this case study 73% of the participants was considered to be very socially isolated and met the same conditions for isolation as the BLSA study inasmuch as they were:

- Living alone
- Is alone and isolated for more than nine hours a day
- Never left the house

This shows that there is a significant group of highly isolated older people within England who are living in the community. The participants in this case study are probably some of the most socially excluded and isolated within English society. This differentiates them as a group from the wider English population of older people, on which research has more usually been conducted. This is important to note as a number of large studies in both the United States and Europe have indicated that the level of loneliness in older people is not significantly different from the level of loneliness in other age groups within society [12,13].

Perceptions of Social Isolation and Loneliness Samples

The care manager sample group was made up of twenty staff (n=20) who had between 2 and 20 years fieldwork experience and were employed by a partnership local government and health services to assess the needs of adults. The professional group were drawn from nursing, social work and Occupational therapy. The sample of older people consisted of forty (n= 40) participants. All participants were over the age of 65 and were assessed as having care needs that were critical and substantial [14]. No service users were accepted onto the study if they were considered to lack mental capacity as defined in the Mental Capacity Act, 2005 [15]. The participants in the sample had a mean age of 77 and were divided 58per cent female and 42 per cent male. This would be expected within the United Kingdom as women tend to live longer than men.

Levels of Social Support

The first set of structured questions was focused around the level of social contact the participants had outside of their formal paid carers. These questions are outlined in table 1 below.

Structured questions /Participants	Themed area
Do you have family and friends that you visit or that visit you?	Family-based and informal care and support
How often do you see your family?	Level of contact
When your family visits, how long do they stay for?	Level of contact
How far away does your family live from you?	Family-based and informal care and support
Structured Questions/Care Managers	Themed area
Do the service users have friends and family they either receive visits or visit?	Family-based and informal care and support
How often do they see their family or friends?	Level of contact
How far away does the service users family live from them?	Level of contact

Table 1: Structured questions /Participants/ Care Managers and themed area.

The first question asked was: “Do you have family and friends that you visit or visit you?”. We can see that Table 2 below shows that the majority of participants did have some form of contact with family or friends, with 67.5% (n=27) stating yes and 32.5% (n=13) stating no.

Do you have family and friends that you visit or visit you?	Number of Participants Responding	Percentage of Respondents
Yes	27	67.5
No	13	32.5
Total	40	100.0

Table 2: Family or other informal social contacts.

The care managers were also asked a similar question, “how many of the services users have friends or family that visit them”?

How many of the services users have friends or family that visit them?	Number of service users	Percentage of Respondents
Have family/friends that visit or they visit	35	95 %
No	5	5 %
Total	40	100 %

Table 3: Family or other informal social contacts (social workers response).

The responses of the 20 care managers indicated that they believed the vast majority of their service user had some form of contact with friends and family, and therefore had inappropriately assessed the level of social contact the service users actually received. The next question then moved on to examine the level of support the

older person received and was divided into six categories which are outlined in figure 1. These responses are shown in Figure 1 below.

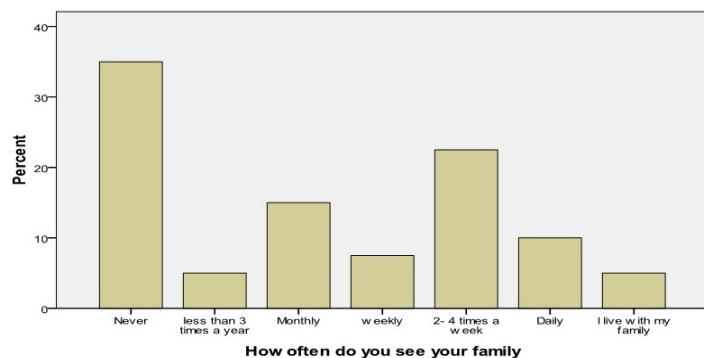


Figure 1: How often do you see your family.

The care managers and participants were asked how often they either received or in the case of the care managers perceived the participant to have contact other than the paid care staff.

Support level	Care managers assessed level of contact	Service users perceived level of contact	Difference in two measurements
High Multiple visits per day	12%	8%	4%
Good has daily contact	8%	9%	1%
Moderate has contact on multiple occasions (more than 3) throughout the week	12%	2%	10%
Medium has contact with family and friends at least twice per week	38%	4%	34%
Low has very limited contact with friends and family	9%	35%	26%
Very low has little or no contact with friends or family	29%	45%	16%

Table 4: Assessment Levels of social support.

These questions showed the large discrepancies between the care managers perceived level of social contact and the actual level of social contact received by the participants. The most striking differences are shown in the last three categories which include the participants with the most pronounced level of social isolation. The largest of these discrepancies appears in the middle band where the participants receive at least two visits a week, and where the care manager's perception of the length of these visits differed greatly from the reality. The care managers were asked how long they thought the visits in the lower three bands lasted. The care managers on average believed that the twice weekly and single

weekly visits lasted between 4 – 7 hours. The service users were then asked “When your family visits how long do they stay?”. This as is shown in table 5, showed a further discrepancy in the perceived length of the family visits by the care managers and the actual length of the visit received. Only seven of the 40 service users received visits of the length of time as assessed by the care managers. Therefore the care managers overestimated the level and length of contact by a considerable difference.

When your family visits how long do they stay?	Number of Participants Responding	Percentage of Respondents
Never visit	14	35.0
Less than 1 hour	7	17.5
No more than 2 hours	9	22.5
Up to 4 hours	7	17.5
5 hours or more	2	5.0
Overnight stay or weekend visit	1	2.5
Total	40	100.0

Table 5: When your family visits how long do they stay.

The final structured question was focused on establishing how near to the service user their family lived and whether care managers were aware of the proximity or lack of proximity of the service user to their family. This final question showed the greatest congruence between the groups. It became apparent that the distance of the family from the service user was one of the standard questions within the care planning process. However it will become apparent in the focus group that this information had a profound impact upon the care manager's perception of the level of social contact with the family.

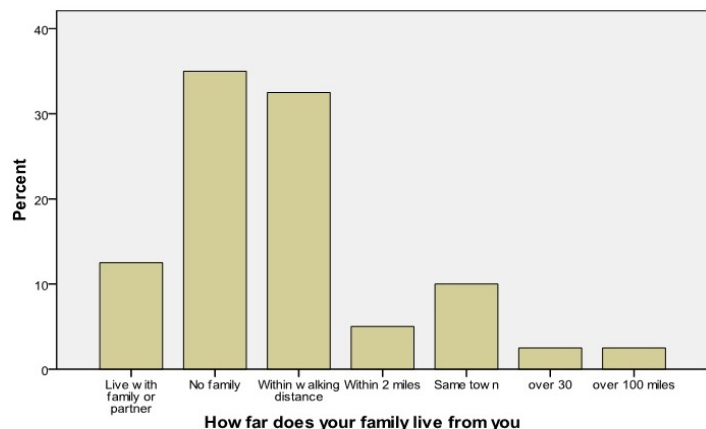


Figure 2: How far does your family live from you.

Focus Groups Findings and Discussion

The care managers were divided into two manageable focus groups of ten participants. Prior to the focus groups being undertaken the care managers were supplied with the findings of the original structured questions. The two groups of care managers were then asked to comment on why they believed there was such a wide variance in their assessment of social isolation when considered against the service users' comments.

The first question put to the group was: “Having read the findings, why do you believe that your perception and the older person’s perception of social isolation are so different?” These are some of the responses:

“The forms are very much focused around ensuring that the physical activities of daily living are met, you know getting dressed, washing and having a meal. Once you have met those the forms don’t really lend themselves to looking at how lonely you are”. (Care managers, 1)

“The assessment forms do have a section of mental health and psychological well-being, but really we tend to focus on whether they have depression and with that I mean treatable diagnosed depression, I suppose given the persons stage in life I assume that there psychological well-being won’t be that good.” (Care managers, 5)

“Well to be fair to us I feel that a lot of times the service user (older person) over plays the role of the family and we make assumptions that they are getting more support than they are. I focus on what tasks the family do, so that they can be excluded from the funded package. I rarely meet the family as a lot are at work in the day when the assessments are completed as we only work 9 to 5.” (Care managers, 11).

The general theme strongly expressed in both focus groups was that the assessment process was framed by an adherence to the assessment form which was a document jointly agreed between the local governments social services with the local health service. This form on examination was based on Roper, Logan and Tierney’s nursing assessment of the activities of daily living, with a few additions to deal with finances and housing modification issues [16]. It also became apparent in conversations with the care managers that in the vast majority of assessments limited or no interaction occurred with the older person’s families and when this did occur it was focused on the financial assessment of the older person’s ability to pay.

The focus group was then asked. “What if any impacts will these findings have on your practice?” Some of the responses to this question were quite interesting given the all respondents in the group believed they used a person centred holistic approach in their practice.

“Well it is clear that the form doesn’t work and that managers need to change it.” (Care manager, 7)

“I’m not sure what you mean by this question it feels like you are trying to blame the care manager for the families lack of interest in the older person, so I am not sure it is something we can or should change.” (Care manager, 2)

“It is the fault of the form; if the form changed then we might do it differently.”

This question led to a heated debate in both focus groups. The overarching theme when analyzed was that care managers externalized the assessment process to the form, and did not demonstrate that they felt they had any agency or responsibility for not assessing the level of social isolation themselves. The responsibility was either the fault of the form, the families or of the way that management that had designed the process. This led to the final question. “Who is responsible for the assessment of social isolation and possible loneliness in this group of older people?”

“One of the categories on the form is psychological well-being, so that could include loneliness, however I think it needs to be a doctor, as loneliness and depression are linked.” (Care manager, 6)

“I think I assume because most of the older peoples family live within 2 miles of them or at least in the same town that they will be visiting regularly.” (Care manager, 20)

Yes I think it is the medical staff, so that if they are lonely and depressed they can get the correct treatment.” (Care manager, 19)

In both of the focus groups the managers linked isolation and loneliness to depression. Loneliness was not perceived as a social need but a health need constantly linked to a mental illness, and therefore outside the remit of the assessment. This externalization of the individuals’ social interaction was either put onto the responsibility of the family or the medics. As the form did not explicitly mention the need to assess loneliness or social isolation the care managers did not perceive it to be within their remit. However they did see the need for other non-health related activities that involved referrals to other organizations as within their remit these included referrals to church groups or Age concern (voluntary organization), but these were seen as extras and not an essential part of the assessment, which they believed was on the meeting of the daily living needs for the individual to remain in the home.

The care managers were therefore focused on the need to meet the activities of daily living and for the necessity for the care managers to box these needs into clearly defined categories which in turn enabled them to be priced into 15 minute time slots to allow for the financial costs to be calculated. The fact that they perceived the families to have more involvement in the older persons life than they actually did allowed them to not concern themselves with the problems of social isolation and to hewn their focus on the older person’s physical needs.

Conclusion

This case study has indicated that the assessment of social isolation and in some cases loneliness with housebound older people by their care managers tends to overestimate the positive impact of having families nearby has on the older persons self-perceived social isolation and potential loneliness. Additionally that the care managers in this case study did not perceive a difference between social isolation and loneliness which previous research has established is not the same thing. It has also shown that the

assessment process involved in this particular case study does not provide enough depth to the older person's level of social isolation which allows for the separation between social isolation and loneliness and for an adequate assessment on the impact of this on the individual. These finding dovetail with the research of Cattán, et al. and more recently Bernard that assessment and subsequent provision of services in England and Wales do not take into account the complexities and inter relationship causes of loneliness, and that the input of family support tends to be overestimated as loneliness and social isolation are not necessarily linked [17-19]. Most concerning for the practice of care managers is that their assessments appear too driven by an assessment document rather than the care manager conducting their own holistic assessment.

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