Predicting future unmet social care needs and examining links with well-being

Unmet need is widespread among those assessed as having some care needs

Unmet need can be hidden

Those particularly at risk of unmet needs are those who are younger and healthier before needs develop, those living alone and those who have lost a partner

Unmet need affects those with and without support from families, those who are self-funders and those supported by local authority funded care. All of these groups need support in meeting their needs

Social isolation and loneliness were found to be important areas of unmet need

There were no clear links between unmet need and well-being
BACKGROUND

Since 2008 there have been substantial cuts to local authority budgets, reducing the number of people receiving local authority funded social care, at a time when the population with these needs has increased. Self-funded care and care provided by family or friends – the most common forms of home care – have also faced increased pressures.

The Care Act 2014 has introduced a national eligibility framework for local authority-provided social care and includes responsibility for prevention and support to carers even where the local authority is not responsible (based on means testing) for meeting needs. The framework includes consideration of difficulties with tasks of daily living and wider outcomes such as developing and maintaining relationships and their impact on well-being.

This study aimed to explore the nature and prevalence of unmet need for social care among older people living at home, the factors predicting the development of unmet need and the complex links between unmet need and well-being.

Methods


The research was conducted by NatCen (secondary analysis) and Ipsos MORI (overall project co-ordination and in-depth interviews) in close collaboration with Independent Age and Age UK.

FINDINGS

THE NATURE AND PREVALENCE OF UNMET NEED FOR SOCIAL CARE

This study confirmed previous research that unmet need for social care is widespread. The focus of the project was on whether or not needs are met among people who have difficulty with daily living or mobility, not on whether people have care needs or not.

The measures of difficulty with daily living used included activities of daily living (ADLs) such as dressing and undressing, bathing and showering, and eating, as well as instrumental activities of daily living (IADLs) such as shopping for food and taking medication.

The measures of mobility included getting around indoors and climbing stairs. The particular definition of unmet needs used affects the precise figure, but whichever definition was used, data from ELSA and HSE showed over half of older people with care needs had unmet need for support with at least some of their care needs and this cut across all groups regardless of wealth, age or other socio-demographic factors.

Two main definitions were used for the analysis. The first definition is designed to reflect the approach taken by local authorities in carrying out needs assessments based on the requirements of the Care Act. Within this definition burden on the carer and impacts on the older person’s well-being were taken into consideration in deciding whether needs were eligible and whether they were met.

The second definition is a wider definition in which lower levels of need were considered (difficulties with at least one ADL or two or more ADLs or mobility) and in which adaptations and aids and all help from family and friends were considered as meeting needs.

The in-depth interviews found that while participants did not generally describe themselves as having unmet need for help with basic activities of daily living, where they did not have support from any source, carrying out these activities could take a disproportionate amount of time and lead to pain and exhaustion, which is an indicator of unmet need.

Where support was available, particularly unpaid help from family or friends, it was often precarious, either on a day-to-day basis or because it was not sustainable in the long term, for example because of a reliance on a partner to meet care needs. Thus, unmet needs were often hidden; older people were not generally going hungry or cold or unsafe, but their needs were still not being reliably met.

Furthermore, older people’s needs changed over time and this meant that the support they received was not always matched to their current level of need.

Older people were much more likely in the interviews to report unmet need for social contact, being unable to participate in hobbies and interests and being unable to get out of the house. These were regarded as more important issues by older people. In particular, loneliness and isolation impacted hugely on the lives of those who experienced them.

WHAT PREDICTS AND CONTRIBUTES TO UNMET NEED FOR SUPPORT

The analysis of ELSA and HSE data also showed that the only significant factors which predicted
the development of unmet care needs over a ten-year period were being younger and healthier at the start, living alone or being widowed and having difficulties with personal care rather than more general activities of daily living. There are a number of possible explanations for greater unmet need among those who were younger and healthier initially, including delays in getting the support needed and a greater reluctance among those who do not yet feel old enough to seek help.

The findings from the interviews uncovered in more detail the ways in which care needs went unmet. Barriers to accessing care included lack of planning for future needs, difficulty accessing information and identifying suitable support, concerns about the cost of care including the need to save money for when it was really needed, concerns about being a burden on family members and the state and a lack of confidence in accessing services or using the aids and adaptations which were available.

Alongside this was a strong sense of resilience and independence among older people. Value was placed on managing by themselves as it contributed to a sense of purpose and maintained their independence and their sense of identity (not being old enough for certain kinds of support). This means that for some older people lack of support with activities they find difficult is not necessarily a sign of an unmet need even though for another person the same lack of support would indicate unmet need.

Older people were also concerned that by accessing support too soon they could become dependent on it. Where people had support from co-resident carers, flexible support could be provided which impacted less on independence, and care could be provided without asking for it, including with activities which might not even be recognised as a care need.

However, those living with partners were vulnerable to the loss of their partner or a situation developing in which their needs increased or the ability of their partner to support them was diminished and older people had not generally made plans for dealing with this eventuality.

**UNMET NEED AND WELL-BEING**

The focus in this research was on positive well-being and quality of life. The secondary analysis used CASP-15 which is a quality of life measure specifically developed for older people covering Control, Autonomy, Self-realisation and Pleasure. This showed that levels of well-being did not predict the development of care needs over a ten-year period and nor were levels of unmet need related to how well-being developed over a ten-year period. The way in which well-being changed over a ten-year period was determined more by ageing, financial situation and the extent of care needs and not by unmet needs.

In contrast to the findings from the data analysis, during the in-depth interviews, unmet need for care was found to be associated with poor mental health and anxiety for some people.

The difference in findings may relate to that fact that the data analysis looks at the overall picture, whereas the interviews can uncover the diverse experience of individuals. The interviews also allowed older people to describe their well-being in their own terms, whereas the data analysis was reliant on standard measures of well-being.

During the interviews, a small number of participants described their situation in terms of wishing to die as the only way out. However, far more widespread was a sense of frustration, boredom and lack of purpose resulting from not being able to do the things they used to do and the daily struggle to meet their basic needs, even among people whose mental health was good.

Even where people had unmet care needs or their support was precarious, maintaining or taking up new hobbies and interests, having friends and links in their community, being supported
by a partner, making a contribution to their community or family and accessing helplines or community centres were important in mitigating the negative impacts on well-being.

Mobility was also important. Those who could get out to run errands, meet others and go places for pleasure experienced more positive well-being. This suggests that personalisation is a good approach as it allows people to decide how their needs would best be met.

Unmet need for care was not the only issue affecting well-being. Other things going on in people’s lives such as relationships, bereavement, long-term mental health problems, and worries about their families’ problems also impacted on well-being and therefore may have affected the relationship between well-being and unmet need in the data analysis, where these other situations were not all captured.

Furthermore, maintaining independence and managing alone brought benefits to well-being for some older people. These qualitative findings help explain the lack of relationship between unmet need and well-being in the survey data analysis and help us understand the ways in which unmet need for care takes its toll on the well-being and quality of life of older people.

In the context of some of the differences between the data analysis and in-depth interview findings, it should be noted that the ELSA dataset has some limitations for this particular analysis, including the relatively small sample size for people with care needs and the fact that it captures data every two years and so cannot explore the multiple changes and transitions in care needs and support which occur during the two year gaps in data collection.

Unmet need for social care amongst older people is widespread and affects all parts of society. Not all of this unmet need is recognised by older people or picked up by surveys as they may feel they are managing to cope. However, the Care Act 2014 does recognise situations in which carrying out activities of daily living is possible but requires very significant effort (involving exhaustion or pain) as indicating eligible need for support. Furthermore, older people raised unmet need for social contact and mobility as being important, if not more important than meeting basic needs of daily living.

Although at an overall level the survey data found no links between unmet need and well-being, interviews with older people showed that pressures involved in coping day-to-day, associated loss of wider interests and mobility, and lack of social contact do represent ways in which unmet need for care and well-being are linked.

Alongside this, older people showed resilience and independence in meeting their needs and the challenges they faced. This was associated with positive well-being, even in the face of unmet need for support with particular tasks.

The challenge for social care practice is how to balance the need to support people with tasks of daily living, so that people are not left struggling with the basics of life at the cost of wider interests and relationships, while at the same time recognising the value that older people place on their independence, managing by themselves and the contributions they can still make.

The in-depth interviews showed that people in similar situations in terms of the support available to them and their level of need could experience them in very different ways, with one reliking their independence and the other feeling they were merely coping and existing, or that they lacked the confidence to use the adaptations they had.

The importance placed on prevention in social care policy aligns with views expressed by older people about the importance of managing while they can and not becoming dependent. However, our survey data analysis has shown there are no quick fixes in identifying particular factors that make it more likely that people will develop unmet needs in the future and which could be associated with prevention.

It has highlighted that certain groups are more vulnerable and social care practice should be aware of this in planning services and (re-)assessing needs; for example, those who may feel too young to access support and those living alone or who have been widowed.

Support for older people in meeting their care needs came from beyond social care services or the help that their family could provide. This included accessible and affordable or free public transport, being supported in maintaining hobbies or interests or the contacts from them even if they could not participate fully, having control over their housing and the ability to keep it warm and add adaptations when they needed them.

Access to benefits such as Attendance Allowance also helped people to pay for care and support arranged themselves and signposting to these and assistance with applying were valuable. These wider services and social policies should be considered alongside formal social services when identifying needs and how they can be met.
Dr Margaret Blake, from Ipsos MORI, gets to the heart of the matter when she posits that individuals may have more of a responsibility to plan for their older age and future care needs.

Their research, together with the National Centre for Social Research, confirms what a number of other studies have also shown: unmet needs are widespread. They are often hidden. And to be real about the challenges ahead of us, with mounting pressures on services, we need to do what we can now to minimise the risk that future generations of older people go on to experience difficulties. These include problems with daily living, getting out-and-about, and critically, social isolation and loneliness.

The study was led by Dr Margaret Blake at Ipsos MORI. The research team included Allison Dunatchik and Rossella Icardi from the National Centre for Social Research and Claire Lambert and Zarina Siganporia from Ipsos MORI.

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