

UNNET NEED FOR CARE

INDEPENDENT RESEARCH FUNDED BY NIHR SCHOOL FOR SOCIAL CARE RESEARCH







BACKGROUND, OBJECTIVES AND METHODOLOGY

Previous research has highlighted unmet need for social care among older people. In 2017 Age UK calculated that there are 1.2 million older people who don't receive the help they need with daily living activities and that this has been increasing over recent years. Since 2008 there have been substantial cuts to local authority budgets which has reduced the number of people receiving local authority funded social care, at a time when the population with these needs has increased. The majority of home care is provided by family or friends or is self-funded by older people and there are also pressures on these sources of support.

The Care Act 2014 has introduced a national eligibility framework for social care to be provided by local authorities and includes responsibility for prevention and support to carers even where the local authority is not responsible for meeting needs (based on means testing). 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.

In 2015, NIHR SSCR funded research to explore unmet needs among older adults who live in their own home. This project, carried out jointly by Ipsos MORI and NatCen in collaboration with Age UK and Independent Age, had four key objectives: Explore the nature of unmet need for social care,

2. Measure the prevalence of unmet need in England,

3. Identify factors which predict development of unmet need,

> Explore the links between unmet need for social care and well-being.

The research was conducted using secondary analysis of survey data from the English Longitudinal Study of Ageing (ELSA) and Health Survey for England (HSE) using data from 2011-13. It also involved 24 in-depth interviews among people with care needs during spring 2017.

THE NATURE OF 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 particular approach to defining unmet needs 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 difficulties and this cut across all groups regardless of wealth, age or other socio-demographic factors. Two main definitions were used for the analysis: one corresponding to the Care Act definition used by local authorities in which burden on the carer and impacts on

well-being were taken into consideration; and the other a wider definition in which lower levels of need were considered and adaptations and aids and all help from family and friends were considered as meeting needs.

The extent of unmet need was borne out by the in-depth interviews, which found that while participants did not often report unmet need with basic activities of daily living, where they did not have support, carrying out these activities could take a disproportionate amount of time and lead to pain and exhaustion. Where support was available 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 their needs. Thus, unmet needs

were often hidden; older people were not generally going hungry or cold or unsafe, but their needs were still unmet. Older people were much more likely to report on 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, and telephone befriending schemes, while valued, were not always enough to mitigate this lack of social interaction.

WHERE SUPPORT WAS AVAILABLE IT WAS OFTEN PRECARIOUS, EITHER ON A DAY TO DAY BASIS OR BECAUSE IT WAS NOT SUSTAINABLE IN THE LONG TERM BARRIERS TO ACCESSING CARE INCLUDED LACK OF PLANNING FOR FUTURE NEEDS, DIFFICULTY ACCESSING INFORMATION AND IDENTIFYING SUITABLE SUPPORT, CONCERNS ABOUT THE COST OF CARE

WHAT PREDICTS AND CONTRIBUTES TO UNMET NEED FOR SUPPORT

The secondary analysis showed that the only significant factors which predicted the development of 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. The findings from the in-depth 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). 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.

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.

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. This analysis showed that levels of wellbeing did not predict the development of care needs over a ten-year period and that levels of unmet need were not related to how well-being developed over a ten-year period. The way in which wellbeing changed over a ten-year period was determined more by ageing, financial situation and the extent of care needs and not by unmet needs.

During the in-depth interviews, unmet need for care was found to be associated with poor mental health and anxiety for some people. 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. Social isolation was an unmet need closely linked with poor well-being. 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 wellbeing. Mobility was also important. Those who could get out to run errands, meet others and go to places for pleasure experienced more positive well-being. Unmet need for care was not the only issue affecting wellbeing. 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. Furthermore, maintaining independence and managing alone brought benefits to wellbeing for some older people. These qualitative findings help explain the lack of relationship between unmet need and well-being in the quantitative analysis and help us understand the ways in which unmet need for care does take its toll on the well-being and quality of life of older people.

FRUSTRATION, BOREDOM AND LACK OF PURPOSE WERE WIDESPREAD, RESULTING FROM NOT BEING ABLE TO DO THE THINGS PARTICIPANTS USED TO DO AND THE DAILY STRUGGLE TO MEET THEIR BASIC NEEDS

CONCLUSIONS AND IMPLICATIONS

Unmet need for social care is widespread and affects all parts of society. Not all of this this unmet need is recognised by older people or picked up by surveys. However, managing to cope, but with impacts on exhaustion and pain, or by limiting expectations is an indication of unmet need. Furthermore, older people raised unmet need for social contact and mobility as being as important, if not more important as meeting basic needs of daily living. The links between unmet need and well-being were found to be related to the pressures involved in coping day to day, associated loss of wider interests and mobility, and lack of social contact.

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 relishing 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 reliant. However, our research has shown there are no quick

fixes in identifying particular factors which 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; 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. The responsibility for tackling unmet need for care lies not just with social care practitioners and providers but with wider services and society.



We are grateful for funding from the National Institute for Health Research (NIHR) School for Social Care Research (Grant: C088/T14-035/IMMB-P66). This project is independent research. The views expressed in here are those of the researchers involved and not necessarily those of the NHS, the NIHR or the Department of Health.

This work was carried out in accordance with the requirements of the international quality standard for Market Research, ISO 20252:2012.

FOR MORE INFORMATION

For the full reports, please go to: https://www.ipsos.com/ipsos-mori/en-uk/ unmet-social-care-needs-and-well-being

Margaret Blake margaret.blake@ipsos.com

Claire Lambert claire.lambert@ipsos.com

Zarina Siganporia zarina.siganporia@ipsos.com

Ipsos MORI 3 Thomas More Square London EIW IYW t: +44 (0)20 7347 3000 f: +44 (0)20 7347 3800

www.ipsos-mori.com www.twitter.com/lpsosMORI

ABOUT IPSOS PUBLIC AFFAIRS

Ipsos Public Affairs works closely with national governments, local public services and the notfor-profit sector. Its c.200 research staff focus on public service, policy and reputation issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methodological and communications expertise, helps ensure that our research makes a difference for decision makers and communities.









