



Ipsos MORI

UNMET NEED FOR CARE

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EXECUTIVE SUMMARY



1. Executive Summary

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, the National Institute for Health Research School for Social Care Research (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 Social Research in collaboration with Age UK and Independent Age, had four key objectives:

- Explore the nature of unmet need for social care,
- Measure the prevalence of unmet need in England,
- 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.

Key findings

The nature of and prevalence of unmet need for social care

This study confirmed previous research that unmet needs 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.

What predicts and contributes to unmet need for support

The secondary analysis also 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.

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 subjective quality of life measure specifically developed for older people. This analysis showed that levels of well-being 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 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.

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. 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 to places for pleasure experienced more positive well-being. 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. 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 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.

Conclusion and implications

Unmet need for social care is widespread and affects all parts of society. Not all of 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.

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INTRODUCTION



2. Introduction

2.1 Background and Objectives

Ipsos MORI, in collaboration with NatCen, Age UK and Independent Age, have received a grant from the National Institute for Health Research School for Social Care Research (NIHR SSCR) to conduct a research project exploring care and support needs among older adults who need help or have difficulties with day-to-day tasks. The overall aim of the project was to explore the nature of unmet need for social care, the prevalence of unmet need for care, what predicts the development of unmet needs for care and the links between unmet need for care and well-being. The research involved secondary analysis of survey data and in-depth qualitative interviews to explore these overall issues.

The secondary analysis of survey data has been reported on fully in a previous report¹. The key findings of the secondary analysis are outlined in section 2.2 of this report and the implications for the qualitative phase have been drawn out. The main part of this report focuses on the qualitative element of the research project. In the conclusions, we draw together the joint conclusions of the quantitative and qualitative elements and how they relate to each other.

The focus of the qualitative phase of the project was on the following issues:

- how people develop care and support needs;
- whether these needs are met, and if not why not;
- how these needs are met through care and support services, support from family and friends and adaptations and aids;
- the impacts of living alone or with other people on how care needs are met and the links with social isolation;
- the extent of planning for care needs; and
- how having unmet care and support needs affect people's well-being and other aspects of their lives.

These findings will help local authorities, policy makers and providers of care and support in:

- preventing future unmet need through policies and practices which promote those activities and resources, which contribute to lower levels of unmet needs; and
- understanding hidden unmet needs, where needs are not being met, or are being met but only at financial or social cost to the families of those with care needs.

¹ Dunatchik, A., Icardi, R., Roberts, C., Blake, M. (2016) Predicting unmet social care needs and links with well-being: findings from the secondary analysis NatCen and Ipsos MORI. Prepared for the NIHR School for Social Care Research. <https://www.ipsos.com/ipsos-mori/en-uk/unmet-social-care-needs-and-well-being>

The report of the secondary analysis includes a more extensive chapter on the key literature and policy context (chapter 2)². Here we briefly outline the context in which this research was carried out. In England, the Care Act 2014 came into force during 2015 and introduced a national eligibility framework for social care to be provided by local authorities (where someone meets the means testing criteria). This is based on an adult being able to achieve outcomes such as maintaining personal hygiene, maintaining nutrition and developing and maintaining relationships without it causing significant pain, distress or anxiety and without it taking significantly longer than expected. It also included a focus on prevention of care needs and consideration for the impact of care needs on well-being. This has been introduced in a context of declining local authority budgets for services, including social care, with declines in the number of older people receiving care from local authorities in the period since 2008³. The LGA has predicted future shortfalls in the budgets if local authorities are to meet their responsibilities under the Care Act⁴ and ADASS research as also highlighted the funding shortfalls⁵. An ageing population, the introduction of the living wage and cuts in central funding have all contributed to this situation. Although cuts to local authority funding and proposals to change the means testing thresholds and include housing wealth in calculating who should be eligible for home care have generated widespread debate nationally, most home care support is provided by unpaid carers or is self-funded by older people⁶.

Previous research by Age UK has highlighted unmet need for care among older people with 31% of people aged 65 and over who have difficulties in carrying out essential activities of daily life not receiving any help from formal sources or from family or friends (Age UK, 2014)⁷ and research by Independent Age has uncovered similar issues⁸. 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, a substantial increase on previous years⁹.

2.2 Key findings from the Quantitative Secondary Analysis

A full report of the secondary analysis of English Longitudinal Study of Ageing (ELSA) and the Health Survey for England (HSE) data carried out as the first part of this research project is available together with an associated technical report¹⁰. The report also includes fuller information on the policy context and background to the research than has been included here. In this section we outline the key findings of the secondary analysis and highlight their relevance to the qualitative element of the research.

² Dunatchik, A., Icardi, R., Roberts, C., Blake, M. (2016) Predicting unmet social care needs and links with well-being: findings from the secondary analysis NatCen and Ipsos MORI. Prepared for the NIHR School for Social Care Research. <https://www.ipsos.com/ipsos-mori/en-uk/unmet-social-care-needs-and-well-being>

³ HSCIC, Adult Social Care Statistics team (2014) Community Care Statistics on Social Services Activity in England for 2013-14

⁴ Local Government Association (2014) Future funding outlook 2014: Funding Outlook for councils to 2019/20.

⁵ ADASS Budget Survey 2016: <https://www.adass.org.uk/media/5379/adass-budget-survey-report-2016.pdf>

⁶ Health Survey for England, 2014 Report. Health and Social Care Information Centre.

⁷ Age UK (2014) 'Care in Crisis'.

⁸ Lloyd, J. and Ross, A. (2014) 'The Bigger Picture: Understanding disability and care in England's older population'. The Strategic Society Centre and Independent Age.

⁹ Age UK (2017) 'The Health and Care of Older people in England'.

¹⁰ Dunatchik, A., Icardi, R., Roberts, C., Blake, M. (2016) Predicting unmet social care needs and links with well-being: findings from the secondary analysis NatCen and Ipsos MORI. Prepared for the NIHR School for Social Care Research: TECHNICAL REPORT <http://natcen.ac.uk/our-research/research/predicting-unmet-social-care-needs-links-with-wellbeing/> and <https://www.ipsos.com/ipsos-mori/en-uk/unmet-social-care-needs-and-wellbeing>

The survey data used included information about difficulties Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) and mobility¹¹ alongside information about the nature of care received to help with these difficulties as well as aids and adaptations available. The first finding of the secondary analysis was that the way in which need for care and ways of meeting those needs are defined affect the level of unmet need. Even with a relatively constrained set of survey data, multiple assumptions had to be made in defining and analysing unmet need. These included what level of difficulty with ADLs, IADLs and mobility should be considered to indicate a social care need, whether adaptations and aids could be considered to meet needs, whether unpaid care from family and friends can be considered as meeting needs or whether, in some circumstances, intensive care from family indicates an unmet need for help. After much analysis two definitions were decided on for the analysis. The first approximates as closely as possible to the definition local authorities use under the Care Act 2014 in assessing whether someone has eligible needs for care and support, including consideration of the impacts of care needs on well-being. The second takes a wider definition of need, but allows greater flexibility in how those needs are met. The table below shows the two definitions and their prevalence in HSE 2011-2013 data¹².

<i>Local authority (Care Act) definition</i>	<p>Individual has LA qualifying level of need: 3+ ADLs or 2 ADLs and poor well-being (base)</p> <p>AND</p> <ul style="list-style-type: none"> • they either receive no care, OR • the care they receive does not meet all their need types, OR • they only receive unpaid care for at least one need type AND • the level of unpaid care is deemed intensive for at least one of the carers (providing care for 20 hours or more per week) 	73% of HSE participants with a qualifying level of need under the Care Act definition had unmet need
<i>Wider definition</i>	<p>Individual has at least one ADL, or 2 or more IADL or mobility difficulties (excluding difficulties with stairs) (base)</p> <p>AND</p> <p>does not receive care or have an adaptation for each of their ADL difficulties or at least all but one of their non-ADL difficulties.</p>	58% of HSE participants with eligible needs under the wider definition had unmet need

The implication of this for the qualitative phase was that in-depth narrative interviews offer the opportunity for a more nuanced approach to understand care needs and unmet needs. Unlike the secondary data analysis approach, we could explore how people defined their own need for care and whether they felt the support they received met their needs. We were also able to explore unmet needs, such as loneliness and social isolation, which are not included in the unmet need approach in HSE and ELSA¹³.

As well as exploring differing definitions of unmet need for care and measuring prevalence, the aim of the secondary analysis was to explore what predicts unmet need for care. This was focussed on what predicts needs being unmet, not what predicts needs developing at all. Analysis also explored the links between unmet need and well-being, including the extent to which well-being predicts unmet need and how unmet need impacts on trajectories of well-being as people age. These analyses used the longitudinal nature of ELSA data to understand impacts over a ten-year period.

¹¹ Activities of daily living (ADL) refer to basic functional abilities (personal care and mobility in the home), while Instrumental activities of daily living (IADLs) refer to activities involving a higher level of mental and physical functioning, which may deteriorate earlier than ADLs.

¹² The Local Authority Care Act definition uses HSE 2011-13 data and the wider definition uses HSE 2013 data.

¹³ Although those surveys collect data on social contacts and isolation it is outside the framework of the unmet need for care measures.

The key findings were that very few of the factors explored predicted the development of unmet need¹⁴ ten years later. The only statistically significant factors were being younger and healthier, living alone and being widowed over the ten-year period. After controlling for other factors, gender, wealth, socio-economic status, well-being, cognitive ability and other lifestyle factors were not found to be predictive of unmet need. Unmet need was found among people from all socio-economic groups including those who would be eligible for local authority financial support with care and those who would need to self-fund. This raised a series of questions, which we have sought to answer in the qualitative analysis.

These include:

- whether unmet need is a temporary state as needs develop (explaining why those who were younger and healthier at the start were less likely to have their needs met);
- whether people move in and out of a state of unmet need as their needs develop and change or as the support available changes;
- whether unmet need results from financial difficulties with accessing support; and
- what steps people have taken to find ways of meeting their needs for care and support including whether they have been in touch with the local authority.

The secondary analysis of the links between unmet need and well-being¹⁵ showed that unmet need does not have a clear impact on the trajectory of well-being over time. Among this older population, well-being declined with age and those who were more financially secure had better well-being. However, whether or not their care needs were met did not significantly affect how well-being changed over time. The report of the secondary analysis explains these findings in more detail, including the caveats related to the limitations of the available data¹⁶. The questions raised by these findings, which have been explored in the qualitative research, include:

- whether in some circumstances having care needs met can have a detrimental impact on well-being because of impacts on autonomy and self-realisation; and
- whether there are other aspects of older people's lives which have a much greater impact on well-being than whether they receive help with the difficulties they face with activities of daily living.

The qualitative research described in this report can stand alone but it also allows us to gain further understanding of the findings of the quantitative analysis, as well as suggesting alternative perspectives in exploring unmet need for care among older people.

2.3 Methodology

Qualitative approach

A qualitative approach was adopted in the second stage of the project in order to provide in-depth insight into the experiences of unmet need of those taking part. This involved conducting 24 individual in-depth interviews with people

¹⁴ Using the wider definition of unmet need

¹⁵ Using the CASP-15 measure of quality of life in older people which covers the domains of control/autonomy, pleasure and self-realisation.

¹⁶ Dunatchik, A., Icardi, R., Roberts, C., Blake, M. (2016) Predicting unmet social care needs and links with well-being: findings from the secondary analysis NatCen and Ipsos MORI. Prepared for the NIHR School for Social Care Research.

with different types and levels of care and support needs. This included people who find getting around or doing day-to-day tasks such as looking after themselves or their home difficult, but manage to cope on their own.

Fieldwork took place between February 2017 and May 2017 in London, Essex, Hertfordshire, Surrey, Kent, Lancashire and Greater Manchester. These areas were chosen to provide a mix of urban and rural areas, geographically spread across the country and including more and less affluent areas. When carrying out the interviews, a researcher from Ipsos MORI met participants in their homes on a day and time that suited them, or in two cases at a day centre they were attending. Six participants invited a friend, family member, or carer to accompany them throughout the interview.

It is important to note that qualitative research is used to explore people's views and experiences, rather than to estimate or quantify how many people hold those views. Such research is intended to be illustrative rather than statistically representative of a wider population. When interpreting the findings from this research, it should be remembered that the results are based on a small number of people who have discussed the relevant issues in-depth; the views stated here are not facts, rather they are the participants' perceptions and the truth as they see it.

This project received a favourable ethical opinion from the West London and GTAC Research Ethics Committee on 25th November 2016.

Sample and recruitment

Participants were recruited using a step-by-step approach, with the help of Age UK and Independent Age. Help with recruitment was also offered by a private provider of adult social care (one participant came through this route) and a volunteer organisation providing support to older people (no one was recruited through this route). They each circulated invitation letters, information sheets and expression of interest forms to potential participants by post, email or in person. People who wanted to take part were able to express interest by contacting Ipsos MORI by post (a freepost envelope was provided), email or telephone. Where preferred, volunteers or staff from the support organisations assisted people in completing the expression of interest form and returning them. An Ipsos MORI recruiter then contacted potential participants to ask them a few questions to confirm their eligibility and collect a few demographic details. Where a participant was eligible and willing to take part, a date and time convenient for the participant was arranged.

To be eligible for the research, participants needed to meet the following criteria:

- Be aged 60 years old or over;
- Have difficulties doing two or more Instrumental Activities of Daily Living (IADL) by themselves and/or have difficulties doing at least one Activity of Daily Living (ADL) by themselves.

The rationale for recruiting participants on the basis of IADLs and ADLs was to keep consistent with the approach adopted for the secondary data analysis. The minimum eligibility criteria on difficulties were set up to ensure that participants had care needs, and varying levels thereof. Having needs in relation to ADLs indicates more personal care needs so having difficulties with only one of these activities was needed. For IADLs difficulties with at least two activities were needed to be eligible to avoid recruiting people who just needed help with shopping or gardening. Further characteristics were monitored during recruitment including:

- Whether any care or support was received;
- The source of care and support including formal services, family and friends and adaptations;

- How long they had care needs;
- Whether the local authority contributed to costs of care and support;
- Level of assets;
- Whether they lived alone; and
- Age.

Since the spread of people who contacted the research team covered all the quota groups and it was important to interview 24 participants, no one was screened out because a quota group was full. The quotas were adjusted during fieldwork and were used for monitoring.

Information on eligibility was first collected at the expression of interest stage, and then further clarified by the recruitment teams upon review of the forms sent in. Where it was found that somebody lacked the capacity to provide informed consent for taking part in an interview (under the Mental Capacity Act), they were not included in the research.

Before each interview took place, the interviewer went through the information sheet with the participant, and invited them to sign a consent form. As a thank you for taking part, participants were offered £25 in cash. They were also handed out a thank you letter with the contact details of relevant organisations that they might have found useful, at the end of each interview.

Conducting the interviews:

The interviews were conducted by the Ipsos MORI research team, and lasted between 1 to 2 hours each using a topic guide. Researchers made clear to participants when seeking consent that they could have a break or stop the interview at any time without having to give a reason. Researchers proactively offered breaks when they felt this was necessary, especially when the participant showed signs of distress. A number of actions were taken to minimise the risk of distress, and to handle it if it occurred, which included:

- clearly indicating the objectives of the research and the topics to be discussed on the recruitment materials, so that participants could decide if they wanted to take part and prepare themselves mentally;
- making it clear to participants that they could have a break or stop at any time, without having to give a reason;
- when distress occurred, staying with the participant until they felt better; and
- at the end of the interview, handing out a thank you letter with contact details of organisations that participants could call for help and advice regarding care needs, or for emotional support.

In addition, the recruitment approach (with participants contacting Ipsos MORI to express an interest) was thought to be non-coercive and ensured participants had time to think about their participation without feeling pressured to take part.

Profile of participants:

The table that follows shows participants' demographic profile.

Demographic	Group	Number of participants
Gender	Male	7
	Female	17
Age	60-69	7
	70-79	5
	80-89	10
	90-99	1
	Unknown	1
Does local authority contribute towards care?	Yes, in part or full	7
	No	16
	Don't know	1
Capital Assets	Less than £15k	5
	£15k-£25k	2
	£25k and over	1
	Don't know/prefer not to say	16
Live with others, or alone?	Alone	20
	With others (e.g. husband, wife)	4

The majority of the participants lived in their own home or in rented accommodation, but three lived in warden-controlled housing, and one lived in a care home.

The majority of the interviews took place with the participant alone, however in three interviews participants had their partner with them, and in another three participants had invited a friend, family member or carer. Two interviews with women of Indian origin were conducted with the help of a translator.

Stakeholders' input

We are extremely grateful to Age UK, Independent Age, Research in Practice for Adults (RiPfA) for their input into the project at various stages, such as:

- agreeing the objectives and the recruitment approach;
- designing the recruitment materials and the topic guide;
- analysing, interpreting and contextualising the findings;
- commenting on the report; and
- disseminating the findings.

This built on input and advice provided throughout the research project as whole by a variety of charities, provider organisations, government bodies and academics and researchers. Age UK runs a Sounding Board to obtain views on

issues facing older people and reactions to planned Age UK policies and developments. A panel of older people from all walks of life, some of whom are carers, some who are service users and some who are social care practitioners are on this panel. At a meeting of the Sounding Board in February 2016, details of this project were presented and a discussion held about some key issues facing the project. We are grateful for the input of all those involved in guiding and advising on this project.

Analysis (NVivo)

With participants' consent, interviews were recorded using an encrypted digital recorder. The recordings were then transcribed, and subsequently uploaded into NVivo, a qualitative-data analysis computer software package. This software enabled the qualitative data to be analysed using a coding approach.

The coding approach consisted of the following:

- Establishing key themes emerging out of the data throughout the fieldwork stage; and
- Creating thematic codes to which the data could then be assigned.

This systematic way of exploring the data and themes in detail enabled a rigorous and comprehensive approach to the data analysis. This was an iterative process whereby codes were constantly refined and adjusted as the data was analysed. To facilitate more in-depth analysis and understanding of the data, key themes were analysed according to different classifications of the participants.

2.4 Acknowledgements

Ipsos MORI would like to thank Andrew Kaye, Sue Arthur and Ciaran Osborne at Independent Age, Marcus Green and Sujata Ray (Age UK) for their input throughout the project. We are also very grateful to the 24 participants who gave us their time to speak to us and agreed to share important aspects of their lives with us. Throughout the project as a whole, we have worked closely with NatCen Social Research. The project was developed with previous colleagues at NatCen including Sally McManus and Jenny Chanfreau, whose input was key to the development of the project. NatCen led on the secondary analysis (Allison Dunatchik, Rossella Icardi and Caireen Roberts) and Ipsos MORI have led on the qualitative phase. The input of Age UK and Independent Age and the private provider organisation were crucial for the recruitment of the sample for this project and without this the qualitative research would not have been possible.

2.5 Disclaimer

We are grateful for funding from the National Institute for Health Research School for Social Care Research (NIHR SSCR; 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.

03

SETTING THE SCENE: PARTICIPANTS' CARE NEEDS AND SUPPORT RECEIVED



3. Setting the scene: participants' care needs and support received

This chapter describes participants' care needs and support received, to contextualise the findings. The 24 participants interviewed formed a diverse group, whose care and support needs ranged from low to high. Some of them received a great deal of support and others did not have much support at all.

3.1 Identifying types of needs

Information on care and support needs were identified during the Expression of Interest and recruitment stages, using simple questions related to Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). It is important to note that the researchers who conducted the fieldwork were not trained social workers, and the interviews did not involve an assessment of people's care needs. Instead the information on type of needs was based on the questions below, which were included in the Expression of Interest form and were designed to be easy and simple for people to answer. They aimed to identify people who had difficulties doing IADLs and ADLs by themselves, and were preceded with the following instruction: 'When answering these questions, please think about any difficulties you have, even if you manage to do the activities yourself.'

- Because of a health or memory problem, do you have difficulty doing any of the following activities: shopping for groceries, doing work around the house or garden, managing money (such as paying bills and keeping track of expenses)?
- Because of a health or memory problem, do you have difficulty doing any of the following activities: taking medications, dressing and undressing, putting on shoes and socks, getting around indoors, having a bath or shower including getting in and out, washing face and hands, eating or cutting up food, getting in and out of bed, using the toilet?

During the interviews, the information provided at the recruitment stage was sense checked. Acknowledging that some people may be unwilling to admit that they need help, information was elicited gradually through show cards, whereby people could indicate whether they needed help with any of the activities listed on the show cards, and if so, how many of them. As asking about support needs is intrusive, participants were not asked to disclose which IADL(s) and ADL(s) they required help with, although participants were generally willing to do this. In total, **21 out of 24 participants had difficulties with both IADLs & ADLs, and three participants struggled with IADLs or mobility only** (interview numbers 6, 16 and 20)¹⁷.

3.2 Support received

Participants were asked during the recruitment if they received any support, aids and adaptations for any of the difficulties they experienced, and if so, whether it was towards all or some of the difficulties they faced. During the interview, their needs and the extent to which they were met were explored in more depth. Although the vast majority of people received support towards at least some of the difficulties they faced, the support was not always enough or did not always meet

¹⁷ In this section we have used reference numbers to identify different participants in the research. These same numbers are used when identifying quotes so that readers who wish to can link the background context with the findings reported.

their needs, even among people who received support towards all their difficulties. Participants can be considered as falling into the groups below, however it should be noted that judgements are involved in these classifications and it depends on the way in which participants described their difficulties and the support they received for them.

- Five participants received support for all of their difficulties (interview numbers 2, 8, 11, 13, 23 and 24);
- The majority of participants received support for most but not all of their difficulties or received help with all their difficulties but the help was not quite sufficient or appropriate (interview numbers 1, 3, 4, 5, 6, 9, 10, 14, 16, 18, 20, 21 and 22);
- Six participants had support with their basic needs (e.g. they were clean, had enough to eat and lived in suitable accommodation) but did not receive support with a wide range of other difficulties (interview numbers 2, 7, 12, 15 and 19);
- One participant did not receive any support for any of their difficulties, though they managed to meet their basic needs themselves (interview number 17).

The **types of support** participants received greatly varied, including:

- Gardening, housework and handyman work;
- Bathing and showering;
- Putting on shoes and socks;
- Help dealing with finances, checking and paying bills;
- Getting to places (especially for heavy shopping), and going to medical appointments;
- Help in crises;
- Keeping them company;
- Help with caring responsibilities; and
- Help dealing with paperwork, and help accessing information and support.

The **sources of support** also varied, with some participants receiving multiple sources of support:

- three participants received support from a co-resident partner (interview numbers 9, 10 and 20);
- 17 received support from family living elsewhere- this could be in addition to partners, friends, volunteers, and formal care (interview numbers 1, 2, 4, 5, 6, 7, 8, 11, 12, 13, 15, 16, 20, 21, 22, 23 and 24);
- four participants received support from friends (interview numbers 3, 12, 18 and 19);
- 11 participants received adaptions and aids (interview numbers 2, 3, 4, 9, 11, 22, 23, 24, 21, 19 and 18);

- six participants received support from volunteers and charitable organisations (interview numbers 1, 2, 10, 14, 18 and 19);
- four participants received personal care and support from someone who got paid for it, such as a care worker (interview numbers 10, 19, 21 and 24);
- 17 participants received help with cleaning, gardening, shopping or cooking from someone who got paid (interview numbers 2, 3, 4, 5, 6, 7, 9, 11, 13, 14, 18, 19, 20, 21, 22, 23 and 24).

3.3 Onset and development of care needs

The onset and development of care and support needs differed between individuals.

- Ten people started to develop difficulties within the last year (interview numbers 6, 4, 11, 15, 16, 20, 12, 17, 19 and 21).
- 14 people started to develop difficulties over a year ago (interview numbers 1, 2, 3, 5, 7, 8, 9, 10, 13, 14, 18, 22, 23 and 24) but in several of these cases their needs had become worse in the last year.

There were several different patterns of experience and factors which contributed to people developing care needs, which often overlapped:

- **An incident a long time ago** (e.g. a car accident – interview number 13), **a condition from childhood** (e.g. epilepsy or – interview number 19) **or a chronic long-term condition such as rheumatism and MS** (e.g. interview number 12 and 18) which got progressively worse since, leading to the gradual development of needs over many years;
- **A more recent sudden incident** which resulted in care needs (e.g. breaking femur, surgery going wrong, side effects of drugs) (interview numbers 2, 3, 4, 20 and 24) which sometimes came on top of previous manageable conditions (interview number 18). Some of these needs may have reduced as the situation improved, but substantial needs could still remain (e.g. interview numbers 3, 20, 21 and 24);
- **A gradual development of needs associated with age** - at varying stages, and sometimes with an acceleration in recent months (some of which could be explained and some which were just because of old age). The main impact of this type of change was on mobility, and this made people more dependent on aids such as zimmer frames (interview numbers 6, 7, 8, 11, 16 and 23);
- **A long period of ill-health with health crises, followed by improvements, followed by further crises** (could be combined with the sudden incident category) and a feeling that even if things were fine now they could change next week (interview numbers 2, 5, 9, 14, 15 and 17);
- **A recent bereavement, usually the loss of a spouse or close family member who provided support** (interview numbers 22 and 24);
- **Learning disabilities** (interview number 21) or **mental health issues such as anxiety and depression** (interview numbers 1 and 10), which was sometimes associated with a sudden bereavement. Combined with ill health in old age, this made care and support needs more complicated.

3.4 Local authority contribution towards care costs or adaptations

Information from the recruitment screener gained an insight into whether participants received any local authority contribution towards care costs. Few participants thought they were in receipt of local authority support, whether this was fully-funded or partly-funded (interview numbers 10, 19 and 21). It is however important to bear in mind that from our experience, people whose local authority makes a contribution towards their care cost are not always aware of this - instead they assume that what they pay actually covers the full costs of their support. During the interviews it emerged that further participants had received local authority support with adaptations which they were still using even though they were not in regular receipt of local authority care (interview numbers 2, 4 and 11).

Whilst the majority of participants did not receive any local authority support, it was not possible to determine whether anyone who was not receiving local authority support *should* have been receiving this. This was partly due to the patchy information gleaned about savings in both the recruitment stages and throughout the interviews (participants did not know or preferred not to answer questions about their savings), and additionally because a proper care assessment was not conducted. Furthermore, it was not one of the research objectives, and so the discussion guide did not focus on this issue.

04

THE
HIDDEN
NATURE
OF UNMET
NEEDS



4. The hidden nature of unmet needs

Summary

A widely shared mindset led many participants to deny or minimise their unmet needs, which made it difficult to uncover the extent of unmet needs for care and support. Still, many examples were found of participants struggling significantly in their day-to-day life, lowering their expectations and re-prioritising their needs. Many more were receiving support from sources of support that were unstable or unsustainable, leaving them vulnerable to crisis. Overall, most participants appeared to have their basic needs for personal care met, especially needs related to Activities of Daily Living¹⁸ (ADL): they did not go hungry, they could wash/get washed, were dressed, had a roof over their head, and were reasonably safe – though in many cases getting these needs met was hugely challenging: it took a lot of time and effort, left some participants (and family carers) exhausted and sometimes put them at risk of fall or injury (which are all factors which would indicate a qualifying level of care need under the Care Act 2014). More unmet needs were found in relation to Instrumental Activities of Daily Living¹⁹ (IADL) and social interactions. Overall, the extent of participants' unmet needs fluctuated over time, as their circumstances changed: when their care needs increased, or their sources of support collapsed, it usually took them time to adjust and get their needs met, or to reach a level of unmet needs they could cope with.

4.1 Reluctance to admit to having unmet needs

Reluctance to admit that one has unmet needs for care and support was common among participants. Previous research has shown that among older people receiving care from a family member, care recipients were less likely to report unmet need than their carer was, partly through the needs not being fully acknowledged by the care recipient²⁰.

In this research some participants took pride in being independent, and emphasised what they were still able to do instead.

"I try not to use too many resources when I can manage it myself. I'd rather just be independent."

(Int. 10; female, age group 60 - 69; living in own home with partner; suffers from depression and anxiety)

¹⁸ ADLs are activities relating to personal care and mobility inside the home that are basic to daily living. They include activities related to personal hygiene, dressing, eating, maintaining continence and getting around indoors.

¹⁹ IADLs are activities which, while not fundamental to functioning, are important aspects of living independently. They include basic communication skills, transportation, shopping for groceries and clothing, housework, meal preparation, managing medications, managing personal finances.

²⁰ Brimblecombe, N., Pickard, L., King, D., Knapp, M. (2016) 'Perceptions of unmet need for community social care services in England. A comparison of working carers and the people they care for. Vol 25: 2: pp 435-446 Health and Social Care in the Community.'

Others showed a lot of acceptance about their situation, and normalised it: they felt that the difficulties they faced were inevitable, that they were to be expected when one is getting old, and they preferred to look at the positive side. They did not recognise their unmet needs as such.

"It is just acceptance. Whatever is there is good."

(Int. 23; Female, age group 90+; living alone in supported living accommodation; interview conducted with a translator)

"I take things as they come. There's no point worrying, that's my way of looking at life. So I try to be as positive as possible."

(Int. 6; male, age group 80-89; lives with wife in own home; carer for his wife who has dementia)

Participants also frequently compared their situation to others around them, which led them to a sense of others faring worse, and a need to feel grateful, fortunate and appreciative for what they had. Several expressed how 'lucky' they were.

"I always think that there're so many people out there who are in worse situation than us, so. One has to be grateful for what it is."

(Int. 6; male, age group 80-89; lives with wife in own home; carer for his wife who has dementia)

"There's a lot of people suffering out there, types of anxiety, depression. It's horrendous. People go through horrendous stuff, far worse than me, far worse, with no support."

(Int. 10; female, age group 60 - 69; living in own home with partner)

Overall, these attitudes led some participants to deny or minimise their needs for care and support, and/or to normalise challenging situations, such as:

- living on microwave food only, due to not being able to shop or cook;
- sleeping on a chair downstairs for two weeks, due to being unable to climb the stairs, temporarily;
- attending the day centre to counter social isolation but not having anyone to talk to while being there and feeling even more lonely than when at home;
- carrying out day-to-day activities leaving people exhausted, with no spare time or energy to engage in any other activities or hobbies. For example, some explained how they now went to bed earlier than they used to, fell asleep in front of the TV, and did not have the energy to do anything in the afternoon.

Acceptance and stoicism were common, and while in some cases it was caused by people not wanting to make a fuss, cause trouble or be a burden to their family, in other cases it was also driven by the perception that there was no point creating troubles because nothing could be done about it and no help would be made available anyway.

"There's nothing that can be done. I can't bang my head against a brick wall because I know that there's no help, that this is, this is the road to hell, really. Road to nowhere."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

4.2 What types of needs go unmet?

Needs in relation to ADLs

Across the 24 participants, a few cases of unmet needs in relation to ADLs were identified. It is important to bear in mind that the three researchers who conducted the fieldwork are not social workers and that the interviews did not involve an assessment of people care needs. The examples reported below should therefore be considered as indicative of the situations typically experienced by target audience. With the exception of the last example (who received financial support from his council), the participants affected were not in receipt of local authority funded care, and the information collected during the recruitment and the interviews indicate that they would probably not be eligible for it. These were:

- lack of equipment/adaptations leading to a bad fall/injury inside the home (2 cases);
- a participant postponing her visit to the GP due to lack of transport;
- a participant showering less often than they used to and wanted to, because they need someone present in the home while having a shower in case of fall;
- a participant in need of a grab rail to get in and out the shower/bath following a fall. While on the waiting list the participant could not use his bath/shower and for the last three months he had resorted to strip washing.

In many more cases, while needs in relation to ADLs appeared to be met, meeting these needs was in itself a challenge for the participant or their unpaid carer. It took them a lot of time and energy, leaving them exhausted and unable to engage in any other activities. Some participants described how getting up, washed, dressed, preparing and having breakfast took them most of the morning, and how they needed to rest in the afternoon. Performing these activities sometimes generated pain or put people at risk of fall or injury because they did not have the support, equipment or adaptation they needed. Because of the difficulties these participants experienced with ADLs, they could be described as having unmet needs for ADLs – reflecting the approach taken in the secondary data analysis²¹.

"Up until recently, very recently, it was so much effort. If I had to do something in the morning, I couldn't do anything in the afternoon. Or if I was doing something in the afternoon, I couldn't do anything in the morning. I was so slow and everything took time. Everything was so much of an effort. I had to push, push, push, push. And sometimes I used to sit down here and cry and think, 'why am I bothering?'"

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner who recently died)

"When I've had my lunch I just have to go and lie down all afternoon. I have no strength, and they call it fatigue but to me it's a weakness. If I don't lie down, I fall down."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

²¹ The secondary data analysis defined unmet needs in relation to ADLs as having difficulties with an activity and not getting any help towards it.

The situation for those living with a partner who was able to care for them could be different, as they did not have to struggle with day-to-day living to such an extent and their basic needs could just be met:

"Susan looks after me like a Dutch uncle, and my meal's on the table and I just eat."

(Int. 20; male, age group 80 – 89; living with partner in own home)

Needs in relation to IADLs

Participants varied in their level of unmet needs in relation to IADLs. Some found that they managed IADLs well (with or without support), and therefore did not think they had any unmet needs. Other participants mentioned that they needed help, or more help, with activities such as tidying up and cleaning their home, gardening, shopping and DIY activities. Insufficient support meant that they had to lower their expectations or their standards, and to prioritise their needs, focusing on ADLs first and postponing IADLs until they could find help, or until they were absolutely necessary.

"It's getting harder to cleaning up and things. It looks pretty tidy in here but if you get down to it it's not. It's not as clean as I'd like it to be but it's just bloody hard work. I just can't do it."

(Int. 17, male, age group 60 – 69; living alone)

"I need to get a new bulb. I sent people out getting new bulbs for it and not successful so far so I just have to take each day as it comes."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

Interviews with older people living with spouses uncovered some areas of support which would almost certainly have gone unmet without a co-resident carer and which were often little things that made life easier, more comfortable and fulfilling, and which gave people the feeling that they were well taken care of. Examples included: help to put hearing aid wires back in place, reminding them of medication and helping with drops, going with them to hospital appointments to provide company and moral support, frequent washing of bedding where health problems led to it being soiled every day, being able to sleep during a long bus journey when travelling with a spouse. Related to this and of relevance to both ADLs and IADLS was the advantage that co-resident support was also flexible and could be provided as needed. For example, partners could be on hand to help with putting on shoes and socks when needed but to allow the older person to do things for themselves when they could, enabling them to maintain some independence with support.

Needs for social interaction and companionship

One of the most frequently and openly mentioned needs was in relation to social interaction and companionship. Unlike needs for ADLs, which people were somewhat reluctant to admit, participants described how lonely and isolated they felt and how much they missed having someone to talk to, if possible in person. Participants mentioned a range of situations with regard to loneliness, from not having any close friends, not receiving any Christmas cards or birthday cards, not being able to go out meaning they felt cut off from society, unfriendly neighbours, their family being unwell or too busy with their own affairs to visit them. Some felt lonelier at specific times of the day, or on days where they did not have any scheduled activities (e.g. day centre).

Loneliness and isolation made participants feel bored. Their days felt long, and some just watched TV for company and to pass the time. Some people were desperate for social contact, much more than for having a clean and tidy home or garden. Telephone friends were valued, but others wanted more face-to-face contact and someone to visit them at home.

"I ain't got nobody I'm entirely on my own, it if weren't for her [her neighbour] doing my shopping, I'd go hungry... I tried to get somebody to come and talk to me for an hour, that's all I ask for, nothing. I ain't got nobody, it's terrible."

(Int. 3; female, age group 80 – 89; living alone in council accommodation; recently widowed)

"Very, very, very, lonely. It's awful. I said to them [the recruiter] yesterday, I was looking forward to you [the interviewer] coming because it's somebody to talk to."

(Int. 14; female, age group 80 – 89; living alone in 'Independent Living' accommodation)

Surveys conducted with older people have also found a high level of concern about loneliness. According to the English Longitudinal Survey of Ageing, 1.2 million people aged 65+ in England are persistently/chronically lonely²². In a 2015 survey conducted for the Centre for Ageing Better, nearly a quarter (24%) of those aged 50 and over said they felt a lack of companionship some of the time and 5% said they felt this often.²³

In some cases, it was just company that people desired, but in other circumstances they wanted the support in dealing with the challenges of life and discussing issues which arise.

"It's the fact that I haven't got anybody. If something crops up that I've got to deal with, I've got nobody to ask and some of it I don't know."

(Int. 14; female, age group 80 – 89; living alone in 'Independent Living' accommodation)

Participants most at risk of social isolation and loneliness included:

- those without a supportive family;
- those living on their own;
- those whose spouse, partner and/or close friends or neighbours had died;
- those unable to go out independently (usually those with high care and support needs);
- those previously busy with a fulfilling job/social life: they had to adjust to life without these (though some of them also had networks from the past that they could access to counter isolation); and
- those who felt too exhausted or in too much pain to engage in any activities or hobbies.

"It's getting there and I know I just don't have the energy. That's the other thing I have, I seem to have waves of tiredness...Oh God, it's not a lot of fun getting old."

(Int. 7; female, age group 80 – 89; living alone)

²² source: Marmot, M., Oldfield, Z., Clemens, S., Blake, M., Phelps, A., Nazroo, J., Steptoe, A., Rogers, N., Banks, J., Oskala, A. (2016). English Longitudinal Study of Ageing: Waves 0-7, 1998-2015. [data collection]. 25th Edition. UK Data Service. SN: 5050, <http://dx.doi.org/10.5255/UKDA-SN-5050-12>. Figures extrapolated to national population using latest ONS Populations Estimates.

²³ Later life in 2015: An analysis of the views and experiences of people aged 50 and over: Survey Topline Results, Ipsos MORI research for the Centre for Ageing Better, December 2015, <https://www.ipso-mori.com/Assets/Docs/Polls/sri-centre-for-ageing-better-topline-2015.pdf>

Not everyone living alone with care needs experienced loneliness. People who had continued to live in the communities in which they had lived for many years and who had strong networks of friends and connections built up over the years were less vulnerable to social isolation and loneliness. Examples of these types of connections countering isolation even among people living alone included:

- maintaining contact with friends from school days by phone and meeting up regularly;
- continuing to meet with friends from a sports club (e.g. golf or tennis) even when they could no longer play; and
- continuing to attend clubs or churches which they had been involved in for many years.

Where people lived with partners, the support offered was not just practical but also included companionship and moral support which made social isolation and loneliness less likely.

4.3 Even when needs are met, in full or in part, sources of support were often precarious

Many participants relied on neighbours, friends and family to meet some of their needs related to ADLs and IADLs, such as weekly shopping, cooking, taking them to medical appointments, DIY, managing finances and doing their paperwork. These sources of support were informal, provided by people who sometimes were also getting old and/or had other caring responsibilities or health problems of their own. At times, these sources of support were unstable, unreliable or unsustainable. This on occasion led participants to be without support for some of their needs, or to have to find alternative support networks at short notice, because their usual helper was unwell or had someone else to look after who needed all their attention. The precarious nature of some of these support networks worried some participants, particularly when combined with uncertainty about how their needs would develop in the future.

"I suppose my fear is, I feel, I've got certain vulnerabilities that I could be fine today and then next week I'm back in hospital with something else, and the outcome being you don't know, or I don't know."

(Int. 9, male, age group 80 – 89; living with partner in own home)

His wife (who is his carer and in her late 70s) then commented:

"I couldn't manage him when he was really poorly, if he was like that again, I know I wouldn't be able to manage, no."

(Wife of Int. 9, male, age group 80 – 89; living with partner in own home)

"Well I take it as they come. I don't know what the future's like, whether I can cope with it in half a year's time I don't know. I just cope with it one day after the other."

(Int. 6; male, age group 80-89; lives with wife in own home; carer for his wife who has dementia)

Support networks of family and friends were, by nature, precarious, even when participants lived with their main source of unpaid support. They could all end up in crisis if their care needs escalated to the point where their support network could not cope, or if their sources of support became unwell. What made a difference was the number, resilience and availability of the sources of support: how many people shared the caring responsibilities, whether they were in good health, how much time they had to support the participant, whether they were working and looking after a family of their own as well

as caring for them, and where they lived. This clearly points out the importance of support for unpaid carers – which other studies have also shown.

Where people lived alone, the precarious nature of their care was already evident to them. For example, being reliant on a neighbour calling in to help them if they fell, not being sure when the person who helps with their heavy shopping like milk and potatoes would happen to drop by and offer to get them. A few participants also felt guilty about constantly having to ask their friends and neighbours for help, and this generated frustration, especially among people who used to be very independent:

"One of the worst things about my situation is that I'm an independent minded person and I find myself having to ask somebody to help me have a shower, will you go shopping for me, will you go and get some cash for me, all the time. Asking, asking people to help you do the most simplest of things and you can't do them yourself and I can't even ask my son. That's very sad."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

Where the older person lived with their spouse who was currently providing a good level of care and where day-to-day needs were met, the support was precarious because of its reliance on one person. They were aware of this but had not yet experienced unmet needs.

There was also evidence of the impact that caring had on the co-resident carers, for example having to give up their work to deal with the level of care needs or having to take on responsibilities for areas of life which they did not feel comfortable with (such as household finances).

4.4 The changing boundaries between met and unmet needs

Resulting from the precarious nature of support, and the changing nature of care needs, the extent of people's unmet needs for care fluctuated over time. When participants first developed needs, or when their care needs increased, it could take time for their support to be put in place or adjusted to the required level. Sometimes it was not adjusted and participants just struggled in silence, or they learnt to manage without (more) support, or they got better. These moving trajectories were usually marked by injuries, accidents, or illnesses, for the person with care needs and/or their (unpaid) carer. Sometimes the changes were in the control of the older person, and sometimes they resulted from events outside their control. Unmet need represents the gap between the needs and the available support. Unmet need develops when care needs increase or the supply of appropriate support decreases (or both). Unmet need can be reduced or avoided where need decreases or the supply of support increases. Sometimes changes in need and the available support happen simultaneously and sometimes they do not. The speed of change can also vary from gradual to sudden events. Examples from the in-depth interviews which illustrate this include:

- A man with very high level of care and support needs – met by his wife - when he had cellulitis and septicaemia. His condition had improved meaning he relied less on his wife at the time of the interview. But she was getting older and weaker and this impacted on her ability to provide the low to moderate level of care he still needed.
- A woman who was cared for by her husband (following hip surgery that went badly wrong). Initially she had managed with two sticks with difficulty. Months or years after the surgery the hospital provided her with a wheeled trolley tray (wheeled zimmer with two trays) which had made a huge difference to her mobility round the house, though she still needed care from her husband. After several years he became ill and died quite suddenly. After his

death, she broke her shoulder twice and had to spend time in a care home. As she started living on her own, her son had arranged an hour of paid care per day and a cleaner for a whole day a week. What had been a period of crisis after the husband was ill and died, had led into a period of having ample care at home – more than she felt she currently needed now she had recovered from her accidents.

- A woman who broke her leg and had ‘self-imposed’ unmet needs: she refused adaptations (stair lift) after a serious accident, because she wanted to learn to manage. Her condition improved over time, and she further reduced the care she was getting (getting rid of cleaner and care line), because she was determined to cope without.

05

WHY ARE
SOME
NEEDS
UNMET?



5. Why are some needs unmet?

Summary

A wide range of factors were found when exploring the causes of unmet needs, and most were unrelated to local authority funding for care and support. They included:

- 1) A lack of planning ahead for care needs in old age, driven by the unpredictability of care needs and low awareness of how the social care system works.
- 2) Not wanting to be a burden on others.
- 3) The costs, affordability and willingness to pay for care services, which many participants found expensive. This led people to delay their use of these services until they could no longer cope.
- 4) Frustrating interactions with local authorities, marked by long waiting times for equipment and adaptations, services arranged for self-funders being seen as poor value for money, and unwillingness to provide information and advice to people who do not meet the eligibility criteria for local authority funded support.
- 5) A lack of bespoke information and advice, especially with regard to access to adaptations and equipment. Participants needed help promptly, usually as a result of an accident or illness, but did not know who to contact, or which organisation was best placed to resolve their issue.
- 6) Some needs being things which cannot be met by the services or adaptations in the social care system.
- 7) Difficulty accessing existing sources of information, advice or support, because this usually involved making numerous phone calls, and some felt unable to make these calls independently.
- 8) A high level of resilience, combined with a strong aspiration to remain independent, leading some people to postpone or refuse help, or certain type of help, for as long as possible.
- 9) A lack of confidence to do things for themselves (e.g. for fear of falling), or to speak up, ask for help and manage the person helping them. This usually affected the oldest age groups, and those with the most severe care needs. This was sometimes linked to having adaptations or aids which were not enough to fully meet their needs.
- 10) Reduced mobility and limited access to public transport, which impacted on people's ability to go out, shop, socialise and attend appointments. Participants who had a car and were able to drive, or lived near a bus stop and had a free bus pass, were more independent and reported fewer unmet needs.

5.1 Lack of planning ahead

Evidence of the extent to which people planned ahead for developing care needs in old age was patchy. A few participants appeared to have planned ahead financially to cover the costs of potential care needs: they were usually the most well off, and/or people who had developed a progressive long-term condition in their young age, such as MS. More evidence of planning ahead was found with regard to housing: some participants had moved to a stair-free or more accessible home, a home that was warden controlled, warmer, or nearer to their family. Sometimes this was in response to developing care needs, in other cases this was in anticipation. Many more participants said they would consider moving home if their accommodation became less suitable or if their care needs developed. A few participants had set up power of attorney.

Very little evidence was found of couples planning ahead to allow one of them to cope after the death of their spouse, and examples were cited of recently widowed participants struggling with day-to-day activities that their spouse used to deal with. In one case, this led the participant to decide to move to a (self-funded) care home. In another case, the participant relied on a neighbour to deal with her finances and pay bills on her behalf. Another widow found herself cut off as she could not drive and used to rely on her husband to take her to places – a responsibility now taken on by her sons, who had to fit it within their busy lives. While participants found a way forward, they were not always satisfied with the solution for a range of reasons, such as:

- it was not reliable enough, or not sustainable in the long-term;
- the quality for the support did not match their expectations; or
- it affected their relationships with other family members, and made them feel like a burden.

Overall, reasons for not planning ahead for developing care needs in old age included:

- being on low income for most of their life, or not working and living in a low income household. This greatly limited their ability to save for old age;
- participants' mindset, living for the moment and preferring to deal with issues if/when they arise;

"But I haven't really planned ahead for anything, no, because, no, I'm a get up and do what you're doing today sort of person,"

(Int. 8; female, age group 60 - 69; living alone for a long time)

"I have left everything on my God and I am happy, I think of the good thing not the bad and I've left my past behind and I'm thinking about the present, only the present. What will happen in the future, I don't know, only my God knows... I don't plan anything"

(Int. 23; Female, age group 90+; living alone in supported living accommodation; interview conducted with a translator)

- the unpredictability of care and support needs. Sometimes participants' care needs had come about quite suddenly and unexpectedly – breaking a leg, hip surgery going wrong. In other cases, there had been longer term problems but their conditions had deteriorated unexpectedly;

"You can't plan anything. No, it's just how your body is at a particular time."

(Int. 5; female, age group 80 – 89; living alone for a long time)

- a belief that care and support services are free at the point of access like the NHS, including equipment and adaptations. This lack of understanding of the social care system is in line with public perceptions²⁴;
- an expectation that they would die very soon after their spouse.

"She says that when her husband passed away she thought she will also go soon but now she realises that life is getting more, problems are increasing day by day".

(Int. 22; Female, age group 80 - 89; living alone in supported living accommodation; recently widowed; interview conducted with a translator, words here as spoken by the translator)

5.2 Not wanting to be a burden

A common reason for needs not being met were that participants said they did not want to burden their family (for those who had one), or did not want to make a fuss or create trouble for others around them. They also expressed concerns about being a burden on the state or services. Reasons for this included:

- not wanting to 'feel like a burden' on others – this was less about the actual burden their need for help might put on people but more about how it affected their identity;
- children or grand-children living far away and having busy jobs or responsibilities which made it difficult to provide support;
- children or grand-children having problems or challenges of their own to deal with, such as illness or disability, which meant they could not help, or which made some participants reluctant to ask them for help; and
- feeling that older people are considered a burden on public resources, or that it is their responsibility to look after themselves.

This caused people not to ask for help at all or to limit the extent to which they called on the help which was available to them.

"So there's help. If I want it and if I ask for it, I'll get it, but I tend not to ask for it because I think, well, everyone's got their own lives and they're doing something for themselves. I've always done things for myself."

(Int. 8; female, age group 60 - 69; living alone for a long time)

²⁴ Public Perceptions of the NHS and Social Care Survey. Ipsos MORI research for the Department of Health, July 2015. <https://www.ipsos-mori.com/en-uk/public-perceptions-nhs-and-social-care-survey-3>

"[I get] Occasional help from my children but I'm a bit proud really and I don't like to mither them. They have actually got their own lives to lead and I never ever want to feel I'm a burden."

(Int. 1; female, age group 60 - 69; living alone for a long time; suffers from arthritis and has damaged knees)

"At the moment, as I say, there's loads of little jobs that I need to get done and I don't want to ask my son. He knows that I need things doing, but he's physically, at the moment, just not up to anything because of these headaches. So I don't ask him."

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

"I'm constantly being told about the burden we are upon the state aren't we? We're responsible for all the expenses and the health service and we're running away with all the money and so on and so forth. Make you feel like a bit like a parasite."

(Int. 2; female, age group 80 – 89; living alone in own home)

Concerns about asking for help and avoiding being a burden on family were more important for those living alone. Where participants lived with co-resident carers (usually their husband or wife), they recognised the burden this put on their partners but it was less likely to involve unmet need since the care could be provided anyway without it being asked for. These participants and their co-resident carer were not in receipt of any local authority funded support, and two of them had not contacted their local authority for help.

There were also situations where, by moving closer to family members, older people could feel that receiving help from their family was less of a burden on them, thus enabling them to access the support they needed:

"My kids moved round here and my son said let's see if we can find something round here because they were getting me things, helping me do things, I was getting a little bit needing help and that's why they moved me here so it's easier for them as well."

(Int. 13; female, age group 70-79; lives alone in own home, wording as spoken)

These findings align with previous research which identified ambivalence among older people who may prefer care from family or friends but feel guilt for the burden placed on them.²⁵

5.3 The costs, affordability, and willingness to pay for care and support

The costs and affordability of care and support services was found to be too high by some participants, who said they could not afford them at all, or could not afford more of them than they currently receive. These costs put them off from buying (more) support/equipment/adaptations privately until there was a desperate need for it. Indeed, as care needs can be unpredictable, some preferred to keep their savings to cover their care needs if they escalated, even if it meant living with low levels of unmet needs in the meantime. This tension over whether more care was needed enough to justify paying for more is well illustrated by this quote:

²⁵ De Sao Jose, J., Barros, R., Samitca, S. Teixeira, A. (2016) 'Review: Older persons' experiences and perspectives of receiving social care: a systematic review of the qualitative literature' Vol 24 (1): pp1-11 Health and Social Care in the Community.

"Well you have the Linkline and actually I never think of asking more help really, because as it is it's enough help as it is, more help means more to pay out so, I just simply can't."

(Int. 6; male, age group 80-89; lives with wife in own home; carer for his wife who has dementia)

Similarly, some participants said they would need their children to help pay for their care costs if their care needs increased. They tried to cope without this financial support for as long as possible, again resulting in some low level unmet needs, or they received unpaid care from their family.

Finally, a few participants reported that some of the care and support services available appeared very expensive, and did not seem good value. They didn't feel that they needed these services enough yet to justify the costs, even if they had the money available, so they postponed the use of these services until they really needed them in the future. Some had tried some of the services on offer and found that the standard was not good enough (e.g. house cleaning, safety alarm, meals from frozen meal provider), and they preferred to do things themselves, or go without (putting themselves at risk) even if they struggled or felt very tired as a result. In other cases, they relied on unpaid care from family in order to avoid paying for outside services.

"I certainly feel that Susan should be relieved somewhere, but, then again, she's a very exacting taskmaster and she likes things done properly, and I'm not sure that this is necessarily cheap."

(Int. 20; male, age group 80 – 89; living in own home with partner)

A small number of participants had been told about Attendance Allowance and other benefits they could claim, and received help (e.g. from Citizen's Advice, their local library or the Red Cross) to fill out forms and apply for these benefits. This had made an important difference to the amount of help they could afford. Proactive signposting of these benefits was really appreciated, especially as some of them opened the doors to other benefits or pension credit.

5.4 Interactions with Local Authorities

Mixed experiences were reported when it came to interacting with local authorities.

Some participants had not contacted their local authority: they did not think they would be eligible for help, they did not feel they needed help, they preferred to manage things independently or (more rarely) they did not know that their local authority might be able to help.

Among those who had contacted their local authority for help, some were very pleased with the outcome. They received the adaptations they needed (e.g. bath boards, rails), and on a few occasions they received more help than they asked for, which they welcomed.

"I've got to shower in my bath, and about a year ago I thought, wait a minute, anyway, I got on to social services and they supply things to help don't they? A guy came round and put me a seat in the bath, brilliant. Sit down, do my hair and it's all done."

(Int. 11; male, age group 80 – 89; living alone in own home)

Generally however, interactions with local authority were often described as frustrating (even among those who had also had positive experiences), for a range of reasons.

A couple of participants had contacted their local authority to ask for information on paying for care and support services and to enquire about eligibility criteria. They wanted to access information and advice so they could plan ahead, but their local authority refused to provide it, saying that they would do a financial assessment when they needed care. The two participants found this unhelpful as it meant they did not know what to expect going forward and how to plan ahead for their care needs.

"Now I've been trying to get from social services who pays for what if this happens. Can I find out? No. What they're saying to me is, if you need it, we'll do a financial assessment. But I want to know before I need it. Can I find out how this system works? No. I've got all the information, but there's nothing in black and white, you do this, do that, but they don't actually give you any facts and figures and this is a problem."

(Int. 11; male, age group 80 – 89; living alone in own home)

Other reasons for being disappointed with their local authorities included:

- The local authority agreeing to fund certain things (equipment or adaptations) that the participant did not consider important but not others that mattered more to them. This meant that the support provided was seen as not personalised, and that the user had to find other way of having some of their needs met;
- A long waiting time for adaptations or equipment, which put some participants in difficult situations that affected their health, well-being or dignity (e.g. need for a commode, need for a downstairs toilet, need a grab rail to get in and out of the shower or bath), and resulted in some care needs being temporarily unmet;
- The local authority refusing to come and conduct a face-to-face assessment, as the participants' needs were not considered severe enough when they were screened over the phone. This meant participants had to find ways of meeting their care needs themselves – though some of them did not know where to look nor how to go about it;
- Local authorities arranging support on behalf of self-funders that was considered poor value for money. This resulted in one participant saying she preferred to stay away from them and organise her support herself, as much as she could.

Case study A (Interview 18): Dorothy

Dorothy has care needs as a result of MS, arthritis, and more recently falling down when getting up at night, leaving her with a fracture which is taking a long time to heal. She cannot go out unaccompanied as she loses her balance. She often feels weak and exhausted. She has had contacts with her local authority on more than one occasion, and is frustrated by each encounter.

The local authority has in the past agreed to arrange care on her behalf (she is a self-funder), but Dorothy did not feel this provided good value for money.

'I had the balance problem and I wasn't supposed to have a shower on my own so they [the local authority] got a social worker to come to be here and it was pointed out that this person couldn't do anything to help me if I had fallen. All she could do is contact emergency services. So this ended up with me paying £17.50 an hour for somebody to come and sit here and watch telly while I had a shower and the only thing that she was required to do was call 999 if I had a fall. To me that seemed a completely unacceptable way of spending money.'

More recently Dorothy asked an occupational therapist (OT) to visit her to advise on where to fix some grab rails inside her home, as she finds it harder to move around. The OT went through a check list over the phone and decided that Dorothy did not need a home visit. However, when Dorothy mentioned to the OT that the wooden rails by the steps in the garden were rotten, the OT sent someone to have a look at these rails, and fixed a galvanized rail. While Dorothy welcomed the new rail to help her access her garden, she did not think it was a priority as her fracture would not allow her to access the garden for a few more months.

'It would be more helpful if the occupational therapist had come to advise, oh, if you put a hand rail here, I mean a grab bar here, or a grab bar there you would be safer in this area but they just went through the list through the house. [...] how soon did they think I would be able to go out in the garden after a fractured foot, you know? But then they did it. It's quite nice but I would have benefited more greatly if an occupational therapist had come and advised on where grab bars could go indoors.'

Following her fall, Dorothy's GP referred her to social services, asking them to provide her with a commode as a matter of urgency. It still took many weeks before social services got in touch with her, collected payment and arranged for a commode to be delivered. By that time, Dorothy was about to buy one online as she could not cope any longer.

Resulting from these contacts, Dorothy does not trust her local authority any more:

'I'm very cynical about anything the local authority can do.'

5.5 Some needs can't be met

Some health conditions greatly affected participants' lives or left them in a lot of pain. These health conditions meant that some needs could simply not be met, or so participants believed. Examples included:

- Experiencing levels of pain which could not be relieved. For example, a participant was in so much pain that she was unable to engage in hobbies or activities;
- Not being able to have a bath or shower owing to a health condition;
- Help with hobbies and activities for fun not being something which either services or adaptations could help with.

"Well when I say the things I can't do, is not the sort of thing that would then, you could get help for. For example, I used to enjoy baking, you're not going to get help with that are you?"

(Int. 2; female, age group 80 – 89; living alone in own home)

Similarly, some participants had lifelong friends or a spouse who had died. While some of them mentioned having a befriendee, these could not replace lifelong relationships. Similarly, receiving help from friends and neighbours was not considered the same as having a close supportive family living nearby – something which not all participants had.

5.6 Lack of bespoke information and advice

Lack of timely and bespoke information and advice was brought up by participants as a major cause of unmet needs. Overall, participants' understanding of the care and support system was low. This meant that many participants did not understand the eligibility criteria for local authority funded care or did not know how the care and support system worked and how to access help for the specific issue that they faced.

Indeed, many participants had come across specific issues they needed help resolving, promptly, usually as a result of an injury or illness. Examples of these issues often related to a need for equipment, aids and adaptations:

- Needing a commode and having little money to buy one privately. The participant found it difficult to find out whether it was possible to get one free of charge and how to go about it, without having to wait for months;
- Needing advice from an Occupational Therapist on where to fix some grab rails inside the house and not knowing where to get impartial advice if the local authority will not visit their home, and not knowing who could fix the rails for them;
- Needing a grab rail to get in and out the shower/bath following a fall and not knowing who to contact as they kept being passed on to other services or organisations. This participant lived in warden-controlled housing.

In other cases, participants had concerns about future needs but were not sure about how to plan ahead. A widow was concerned about who would look after her affairs and health and well-being if she loses mental capacity as she has no family. She had been told a power of attorney costs £250 to set up with a solicitor and was concerned about this cost.

The type of tenure affected the specific problems people had to deal with regarding aids and adaptations, and their information needs. Those who lived in their own property usually needed advice from an occupational therapist, or help on how to get the adaptations completed privately if they could afford it. For people living in council housing, the issue

was usually more about getting hold of the right point of contact within the local authority, and the waiting time for the aids and adaptations to be provided. People renting privately seemed to have little control over their living environment and needed advice on how to handle their situation with their landlord.

The timeliness of the response was very important to participants, but it took them a lot of time to get their issue resolved (or not). At first they did not know how to go about resolving them and it had taken or was taking them a while to find a way forward because they did not know who to ask for information and advice, or the organisation(s) they contacted referred them to somewhere else, or (more rarely) they did not get back to them.

Not knowing who to approach in the first place was common among people who were not familiar with the care and support system. Although participants were familiar with charities such as Independent Age and Age UK (which is unsurprising as they facilitated the recruitment of participants), their awareness of how and where to access personalised and bespoke information and advice was low, especially with regard to adaptations and equipment.

Case study B (Interview 15): Albert

Albert has lived by himself for the past 13 years. He has siblings and a son who live nearby, who he relies on for support when needed. Due to a bout of ill health including COPD and arthritis, Albert hasn't worked for the past 15 years. His illness was steady up until three years ago, when it started to worsen.

"Well, it [my health] stayed steady up until three years ago and then I started having heart problems, which has just escalated in the last six months and why I've just had the pacemaker fitted."

Because of this, he is still learning to adjust to his situation and establishing what tasks he needs help with. Day-to-day he has not been able to do much, but he is determined to do as much as he can for himself.

"Well, I really try to do everything on my own that I possibly can. I do have, now and again they give my house a thorough clean, one of the family, but I do try to keep it all clean myself. But, like I say, at this moment now I don't know how much I'm going to be able to do, so things are really up in the air at the moment."

He doesn't currently receive any paid care and support; he relies on help from his family when needed, and has a good relationship with his local GP who phones him every now and again to check up on him. He does however acknowledge that his care and support needs have gradually increased, and he has not always received the right support straight away.

Although he is very satisfied with the care and support he receives, he would like the burden to be taken off his family. He wants to rely mainly on himself but doesn't know where to get information about care and support.

"I've never turned to professional help, no help, other than the doctor, obviously, because she knew about my condition, other than the family, other than, I've never asked for any help off a, for a professional, no, but one of the reasons is, well, now, is because I don't know how to, to tell you the truth. I don't know who you ask, yeah."

"I may need something for the shower now and things. I'll have to look into that, I suppose, but I don't know how you do it, but there must be a way. That's what I'm lacking, is information. If I had the information, I'm quite capable of knowing what to do with information, but I just don't have the information."

In contrast, the few participants who used the internet found it much easier to find relevant information and lists of local services that could help them.

"Well, I'm able to ask for things and make my own arrangements and do some phoning and get on the internet and check things. A lot of people, I'm one of the rare people, really, at my age group, who does use a computer. Not very well, I might add, but I can use it, yeah."

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

A handful of participants had not had any contact with their local authority social services: they did not know that they might be able to help them, nor how to contact them. This situation, however, only affected a minority of people. Many

mentioned using telephone helplines from Age UK, Independent Age²⁶, Silver Line or Citizen's Advice, but they were not always clear about who these organisations were, what each of them could help them with, and who their first port of call should be for the specific difficulty they faced, meaning it took them longer to get their issue resolved.

A few participants were especially concerned about the trustworthiness of private service providers and the information they supplied. This happened when the information, advice or service was not provided by charities or organisations they were familiar with. Such concerns were usually caused by previous bad experiences with unscrupulous contractors, or having heard of others in such situations, and tended to affect the most vulnerable participants. When buying goods or services from an organisation or a person they had not heard about before, participants did not know whether they could trust them. Leaflets from private companies advertising care and support services coming through the post were moderately helpful: people still had to make a judgement call to decide whether or not it was safe to follow them up. The risk of strangers taking advantage of them made it harder for them to get their needs met.

5.7 Difficulty accessing sources of information and advice

Once participants knew of organisations they could contact to deal with the issue they were facing or get the information they were after, the complexity of the system for care and support meant that contacting these organisations was often just a first step to get an issue sorted – the person on the phone would talk them through their options but they still needed to act upon the information provided, and/or follow up with relevant professionals or organisations, which took time (and some of these issues could not wait) and effort (and many lacked energy or felt very tired).

Being given phone numbers to ring was considered moderately helpful, for two reasons. First, being passed from one person or one organisation to the next to get an issue resolved was found frustrating, especially when it involved repeating a story many times. Second, a few people mentioned that they no longer felt comfortable making phone calls: they lacked the confidence to do so, or they did not know how to explain their situation over the phone within a short amount of time, what to say and what questions to ask. They preferred someone else to make phone calls on their behalf, or information being provided to them face-to-face in a calmer, less stressful environment that would give them time to articulate their thoughts and absorb the information provided. This was especially the case for the older age groups and for those with more severe care needs.

Overall these difficulties meant that it took people longer to get their need met when a need arose, and the protracted journey to get an issue resolved frustrated them.

There was evidence of GPs offering support and advice and signposting people or facilitating access to services which could help with their health and care needs – for example courses on living with certain conditions. Supportive GPs were also seen as a source of reassurance and support and their role was appreciated. There was little evidence of GPs helping older people to access social care services or supporting them in accessing information, though one participant had been referred to social services by her GP for equipment.

²⁶ This was expected, as recruitment was carried out through these two organisations.

5.8 Resilience, identity and independence

A high level of resilience was common to many participants, even among those who were clearly struggling. They aspired to maintain their independence, and managing to remain independent gave them pride and was part of their identity.

"I come from a family that my grandfather used to say, you've got to have grit. Well I happen to have it and that's it."

(Int. 3; female, age group 80 – 89; living alone in council accommodation; recently widowed)

"I won't have anything that defeats me."

(Int. 5; female, age group 80 – 89; living alone for a long time)

"That's our philosophy. Bash on, no matter what the difficulty."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

Their determination to be resilient and their aspiration to maintain their independence had important implications. It led some participants to postpone help until it became absolutely necessary, or to find coping strategies. Examples of coping strategies included:

- stocking up on groceries before the person doing the weekly shopping goes away on holiday;
- not cutting nails so that one can still grab jigsaw pieces and do puzzles when unable to grip;
- hanging out two to three items of clothing at a time, and sitting and resting before hanging out the next two, because reaching up to the line is difficult or painful; and
- finding a new way to put the duvet cover on.

In one case, the determination to regain independence led the participant to refuse equipment and adaptations that had been suggested to her by the local authority after an accident.

"I refused it [stair lift] and sent back a lot of other stuff [e.g. equipment to tilt bed] that they gave me... because I was determined to get better. So it was hard work but I was determined that I would get as good as I could get, if I can"

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

The rationale for refusing or postponing help, and for designing coping strategies, was that among those who valued their independence, getting help with care needs tended to be considered as undermining people's independence. A handful of participants equated help with having someone dictating their life, or someone making decisions on their behalf despite them having the mental capacity to make their own decisions.

"I've seen in others where their life's been taken over by help, and I don't wish that, either. I wish to be independent, and help when I really need it would be wonderful, would be great, and I'd really appreciate, but I would not like anybody coming in my life and dictate what my life is to be. That is what I do not want."

(Int. 15; male, age group 60 – 69; living alone; has had COPD and arthritis, and has recently got a pacemaker inserted)

Help was also seen by some participants as being suitable for people older than they were (or felt they were). They expressed the feeling that they were not yet old enough for certain services or equipment or that they still felt young.

"I'm thinking oh, that's, my cousin's got one [care alarm], she's 90, do you know what I mean? I'm thinking do I need that yet? So I'm trying to stave it off for a little while longer."

(Int. 13; female, age group 70-79; lives alone in own home)

"Well, they did give me a booklet with all sorts of information in. As I say, I found the home help for myself. But a lot of the things, they were too, how can I put it? I didn't feel that old then, if you know what I mean. I still had a youngish outlook and I still wanted to do the things I've always been able to do."

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

Even where people had suitable help or adaptations they could limit their use of these to avoid developing dependence on them.

Underlying these attitudes and behaviours was the perception that getting help or using adaptations could be a slippery slope: it could lead people to need more help because they would lose the habit of doing things for themselves. It could also lead people to become dependent on the help provided, and being left unable to cope if the help or support temporarily stopped. Finally, a few participants thought that not having help kept them busy and active, and that they would not have anything else to do otherwise.

"Independence is a very precious thing, and I think perhaps there's a danger that if you are coping and you then ask for some help, you might become for want of a better word, addicted, utterly dependent on it, that if for some reason that help, for any reason was suddenly withdrawn, you'd become so dependent upon it, would you be able to go back to coping."

(Int. 2; female, age group 80 – 89; living alone in own home)

The interviews did show instances of where receiving care could help maintain independence rather than undermine it, for example if it enabled people to stay in or return to their own home or live by themselves and where the care was provided in such a way that it re-enabled them. Although provided privately (rather than through NHS re-ablement) someone who suffered an accident after being widowed and had to spend time in a care home, was able to return to her own home and regain some independence with the help of a resident carer who came from a private company to stay with her for two weeks to help her get back on her feet. Since then she had carers for an hour a day and said:

"Having the carers in, helps me to keep my independence, but also it means I can do, live here, I can do what I like when I'm here. I don't want to go in a home again. I've been in there, done that one."

(Int. 24; female; age group 70-79; living alone in own home)

These findings point to a high level of resilience among some participants, determined to cope no matter what to remain independent. This was found among those with both low levels of need and high levels of care need and with varying levels of support. Still, this resilience and their aspiration to remain independent should not overshadow the extent of their unmet needs. A lack of support for certain ADLs or IADLs still affected their quality of life and well-being, and made them more vulnerable. In many cases, they would have welcomed some personalised, well-targeted and respectful support that helped them maintain their independence, and interventions to counter their loneliness or isolation. The quotes that follow show the ambivalence in the participant's mind: as the interview unfolded, she showed resilience and determination at times, but also acknowledged the difficulties and challenges she faced.

"I'm determined not to let it get me down. I'm not the incurable optimist, but I'm not a pessimist either. Just get on with it really."

"I feel I am slowly getting slower, I'm not improving in any way at all. I'm just coping, that's the word isn't it? Just managing really."

(Int. 2; female, age group 80 – 89; living alone in own home)

5.9 Lack of confidence

While some participants showed high levels of resilience and determination, others lacked confidence. This tended to affect those in the older age groups, or those with more severe care and support needs. This lack of confidence affected them in many ways.

Those who felt physically frail, unstable, or who had experienced a fall often lacked confidence to do things for themselves such as going out independently (especially when the rain made pavements slippery), or having a bath or shower while there wasn't anybody else at home, because they worried about losing their balance and falling down. This lack of confidence impacted on people's mobility and on the activities they could engage with.

"She says she is being advised by neighbours that she should come out, walk a little bit but she doesn't go because she is worried about falling, so she just stays indoors."

(Int. 22; Female, age group 80 - 89; living alone in supported living accommodation; recently widowed; interview conducted with a translator))

"I don't get out as much as I would like in the bad weather. I have a horror of it being slippery underfoot because I wouldn't have a cat in hell's chance."

(Int. 1; female, age group 60 - 69; living alone for a long time; suffers from arthritis and has damaged knees)

This lack of confidence also led to situations in which suitable adaptations or aids were available to the participant, but they still did not meet their needs because of a lack of confidence in using them. This was particularly common in relation to bathing adaptations (as described by Clara in case study D).

Others lacked confidence to ask for help and to speak up for themselves, especially over the phone. They struggled to express the issues they were facing, or the help they needed, and would have benefited from an advocate. As explained in section 5.6, poor experiences with contractors for home improvement, DIY or gardening were reported, resulting in people feeling fearful of ending up in similar situations again. These participants needed support to identify reliable and trustworthy sources of help, managing the source of help, making sure they deliver what and when they should, as well as

checking their bills, as they found these things difficult. A fear of strangers coming into their home and taking advantage of them was also mentioned. As a result, some participants preferred to go without the help they needed to save them the challenge of having to find and manage someone they could trust, even when they could afford to buy some help.

"She is afraid that people like that, can steal, they can harm, physically harm, so she is very scared to have that kind of help from someone she doesn't know. She hasn't thought about it but she is scared of strangers coming to her house and she thinks that her area that she lives most of the people are like that, so she is very scared."

(Int. 22; Female, age group 80 - 89; living alone in supported living accommodation; recently widowed; interview conducted with a translator)

In contrast, having confidence had a significant impact on participants' lives. It helped them access support, stand up for themselves, and deal with nuisance calls or visits. Confidence and resilience usually went together, and those who had them usually bounced back well after a problem, while others did not and tended to feel stuck.

"If people come trying to sell you anything, they haven't got a cat in hell's chance with me. I might be old but I'm not daft. I won't have anything that defeats me. I'll try it."

(Int. 5; female, age group 80 – 89; living alone for a long time)

One participant gave an example of seeing an older man with his carer in a coffee shop regularly. She thought that knowing about care providers might be useful to her in the future so she approached the carer and obtained the details of the provider. When she came to need care services some time later, she had the information she needed to contact a provider she had identified and chosen herself. She now has support from that company daily and is very satisfied with the service they provide.

5.10 Reduced mobility and limited access to public transport

Mobility was a major issue for people with care needs. This impacted on mobility within the home as well as ability to get out. Being able to get out was highly valued because of the practical need to get out to go to the bank and shops, but also because of its impact on well-being. A participant with relatively low levels of need who was still able to go out most days expressed the view:

"I think it is everything to be able to get outside the front door"

(Int. 16; female, age group 70 – 79; living alone in privately rented accommodation)

In contrast, someone whose care needs were greater and now went out once a week or less (dosed up on painkillers) described how:

"I don't pop out, it has to be a carefully planned affair."

(Int. 2; female, age group 80 – 89; living alone in own home)

Being unable to go out of the home unsupported, and not having easy access to public transport, impacted hugely on people's ability to get their needs met, because they needed help from others for a lot of day-to-day activities such as shopping, health appointments and engaging with hobbies or socialising.

A few participants no longer had access to a car because they had lost their licence due to a health problem or problems with their eyesight, or because they could no longer afford one. In other cases, their spouse used to drive them to places but he or she had died. Where this happened, they reported a sudden and significant impact on their independence and mobility:

"It was a lot of money to have parked in there just to drive up and down. I had to get rid of that. That was a big blow."

(Int. 5; female, age group 80 – 89; living alone for a long time)

"When her husband was around they had their own car, he used to drive her, now she has to be dependent."

(Int. 22; Female, age group 80 - 89; living alone in supported living accommodation; recently widowed; interview conducted with a translator)

In contrast, fewer unmet needs were found among people who were still mobile. In particular, having a bus stop located close to the front door with good transport links, a free bus pass, or a car were highly valued.

"For me and a lot of old people, the free bus pass, without it, a lot of old people wouldn't get out at all, because bus fares are costly. That's one of the things to me, I do feel I would hate to lose"

(Int. 2; female, age group 80 – 89; living alone in own home)

The importance of good community transport was highlighted by many participants. In fact, one of them was campaigning for the community transport service to cover their area, and another one had decided to move to a smaller property with better links to public transport.

Those who could still drive or had access to good public transport could go to the shops, and socialise without having to rely on people coming to visit them in their home. Going out gave them company and it helped fill their day, meaning they felt less bored and isolated – even if it was just a trip to the supermarket. Overall, this mobility meant a lower level of unmet needs. In addition, they could drive to places for pleasure, for example to go sight-seeing or go out with family members for fun. Concern was expressed that if they were no longer able to drive they would become cut off.

"That's my one salvation in life isn't it, I love my driving."

(Int. 9, male, age group 80 – 89; living with partner in own home)

Where participants could not drive, coach trips organised by voluntary organisations for older people could enable them to get out, go on outings or even holidays and meet other people. However, restrictions on taking wheelchairs on coaches and difficulties of transporting mobility scooters meant that for those with severe mobility problems, even with access to a car or coach trips their mobility was restricted.

Participants described how the weather and seasons could impact on their ability to get out. This was related to the impact of cold weather on a heart condition, or concern about slipping in wet or icy weather.

Within the home, participants reported on using sticks and zimmer frames. However, even with these adaptations they faced mobility difficulties because of the difficulty of carrying things while using them:

"My son bring me a frame for me, Mum walk with a frame, I say I walk up with frame how can I take me anything, my telephone, water, after cup of tea, how can I take it?"

(Int. 22; Female, age group 80 - 89; living alone in supported living accommodation; recently widowed; interview conducted with a translator, words as spoken by the translator).

Where they had been provided with a suitable trolley or where someone had adapted a frame with a tray, this made a huge difference to their mobility in the home and was really valued.

06

THE IMPACT OF UNMET NEEDS



6. The impact of unmet needs

This chapter explores the impact of unmet needs on participants' mental health, well-being, health and dignity. It is important to note that it was very difficult to establish a causal link between unmet needs on one hand, and mental health and well-being on the other, because participants did not look at their life in isolation. There were many factors that impacted on participants' mental health and well-being, and it was not always possible to distinguish what was caused by unmet needs, or by other issues. Therefore the findings that follow need to be considered in conjunction with other factors, such as getting older, and general life circumstances. In addition, well-being is a broad concept that encompasses a range of different factors and attributes. The term is highly subjective, and the interviews also explored how participants defined well-being, and the perceived positive and negative contributants of this. On the whole, participants focussed on more positive aspects of well-being, in line with our approach in the secondary analysis. However, as described in section 6.1, the interviews also uncovered evidence of mental health conditions. Although mental health and well-being are associated, there is an argument in the 'dual continuum' model that they are independent and so we discuss links between unmet need and well-being and between unmet need and mental health conditions separately²⁷.

The link between unmet needs and well-being was formally explored by the secondary data analysis. The measure used in the secondary analysis was CASP-15 which explores four dimensions: control, autonomy, pleasure and self-realisation, and therefore includes both hedonic and eudamonic aspects. The focus in the secondary analysis was not on the absence of mental health problems but on subjective mental well-being in older age with a focus on positive and beneficial aspects of well-being, not just the absence of negative factors²⁸. More detail on well-being and links with social care can be found in the secondary analysis report.

²⁷ Slade, M., Oades, L., Jarden A. eds. (2017) Wellbeing, recovery and mental health. Cambridge University Press.

²⁸ Wiggins,R.D., Netuveli,G., Hyde,M., Higgs, P. and Blane,D.N., (2007) 'The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: a combination of exploratory and confirmatory approaches. Social Indicators Research. Vol 89 (1): pp 71-77.

Hyde,M., Wiggins,R.D., Higgs,P., and Blane,D.B. (2003) Researching quality of life in early old age: the importance of the sociological dimension. Social Policy and Administration. Vol 37 (3): pp 239-252.

Summary

Unmet needs impacted on participants in different ways, but primarily on their mental health, well-being, health and dignity.

Signs of poor mental health were apparent in participants, with some feeling that their lives were no longer worth living, or that they were not coping, but simply existing. However, experiences differed: while in some cases participants had had long-term mental health conditions that were exacerbated by their social care needs, others were beginning to feel increasingly worried and anxious about the future and their deteriorating physical and mental capacity. These issues negatively impacted on their mental health.

Many participants felt bored, and lacked mental stimulation, and this negatively affected their sense of well-being. Most often it was because tasks, hobbies and activities that previously came with ease were found to be increasingly challenging, if not impossible.

Conversely, where participants were continuing to engage with their interests and hobbies, or had a distinct purpose through volunteering and helping others, it was considered to have a positive impact on their well-being. Additionally, having things to look forward to, such as belonging to a community, and maintaining good relationships with family and friends, were found to enhance participants' sense of well-being.

When asked about what 'well-being' meant to them, participants most often associated it with being able to socialise and being independent. Some participants alluded to services or initiatives that had helped to alleviate feelings of loneliness, including telephone befriending services, time banking initiatives, and support groups or day centres.

As well as impacting on people's mental health and well-being, and increasing their social isolation and loneliness, in certain cases, participants' unmet needs affected their health and dignity.

Participants mentioned having falls, postponing medical appointments, wetting themselves at night, and washing less frequently than they wanted - often due to not having the right equipment, or more frequent support.

6.1 Links with mental health

The feeling of 'just existing'

Some participants reported signs of poor mental health, such as depression, pessimism, worry and anxiety affecting their sleep and their eating habits. In fact, some participants openly said they were waiting or hoping to die, because they felt that their life was not worth living for.

"I'd just like to die I think, it's the only way out because there's no life."

(Int. 14; female, age group 80 – 89; living alone in 'Independent Living' accommodation)

"Just put me in a box and forget.... Just wonder if it's worth carrying on sometimes. Or you just sit, you know, and eat yourself silly."

(Int. 19; female, age group 70 – 79; living alone in council accommodation)

They spoke of not coping, but just existing. It was hard to determine whether they felt like this *because* of their unmet needs, or owing to other circumstances, or both. However, it was evident that lack of support, loneliness and social isolation had a considerable negative effect on people's mental health.

"You don't [cope], you exist. You just exist. It's an existence. I'll tell you what I think, I consider this house a coffin with a door. Do you understand that? You can get outside from it, but apart from that I might as well be in a box. No entrance or anything. Because you've no life. Imagine if you didn't see a soul all day, you couldn't go out and you just sat in a room on your own, all day. Not just a few days, forever. It takes a hell of a lot of putting up with."

(Int. 5; female, age group 80 – 89; living alone for a long time)

Occasionally, these issues were related to long-term mental health conditions which were exacerbated by the current social care needs and could be mitigated by factors outside of social care. For example, a few participants described the effect the weather had on their mental health – however, this was not something that could be controlled.

"Well I have, winter nearly killed me because I get SAD [seasonal affective disorder] and just, by the time January came I was just about ready for cutting my throat. I like to hibernate in winter, I go to bed about nine o'clock, just so that I can get away from the darkness. The darkness upsets me. So now I'm beginning to come to life. I'm feeling a lot better because the sun's shining, the Spring's on its way. And you probably noticed all my daffodils and everything, and the tulips.... I've had it all my life as far as I know."

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

"I've somehow got to get motivated. But I think I suffer from SAD. When the weather brightens up I brighten up."

(Int. 1; female, age group 60 - 69; living alone for a long time; suffers from arthritis and has damaged knees)

As described in the previous section, winter weather also impacted on older people's mobility which may have exacerbated the effects of SAD on their well-being.

Worries about the future

Additionally, some participants were worried and anxious about the future, even if their mental health and quality of life were good at the moment. Among other things, the types of issues people were worried and anxious about were:

- their health problems **significantly deteriorating** and not being able to plan for this, or not knowing whether they will be able to afford or get help when their care needs increase;
- their **memory getting worse**;

"Well, as I say, over the last few years I've noticed my old memory's going a bit, but then everyone says theirs are the same. ... short term memory loss comes in quite quickly now. And I might, I don't know if it's because I'm noticing it more because of my friend's rapid degeneration with her Alzheimer's [...]."

(Int. 8; female, age group 60 - 69; living alone for a long time)

- losing mental capacity – particularly thinking about who would look after their care and finances if they could no longer deal with it themselves.

"Well the big thing is this paperwork worrying. Because, I'm not sleeping so well and I lay awake for hours and hours. But it's on your mind. That's my big worry. In case, as you're getting older, there's things I'm going to come across that I won't be able to deal with, what we were just talking about. That is my worry. My biggest worry."

(Int. 14; female, age group 80 – 89; living alone in 'Independent Living' accommodation)

6.2 Links with well-being

Boredom and lack of mental stimulation

Throughout the interviews, it was clear that **many participants felt bored and not mentally stimulated**. This happened because the tasks, activities and hobbies they used to engage with and which had given them purpose and fulfilment became more challenging or impossible to do as a result of getting old, developing care needs, or not getting enough help towards them. When this happened, they reported **sadness and frustration at the inability to carry out tasks and activities that they could previously do with ease**, which in turn had a negative impact on their well-being. Having something to look forward to was really important to help participants keep up with some of the difficulties they were facing day-to-day, though many reported that they did not have anything to look forward to.

This is backed up by The UK Inquiry into Mental Health and Wellbeing in Later Life²⁹, which identified older people's participation in activities (social, cultural and political) as a crucial factor contributing to their well-being.

Case study C below illustrates a participant's frustration at being unable to do certain activities and how this impacted on her well-being.

²⁹ Age Concern England (now Age UK) and the Mental Health Foundation launched a UK Inquiry into Mental Health and Wellbeing in Later Life in late 2003, which was published in 2006, because of a shared concern that mental health in later life is a much neglected area.

https://www.mentalhealth.org.uk/sites/default/files/promoting_mh_wb_later_life.pdf.

Case study C (Interview 2): Emily

Emily's husband died about over 20 years ago and she has been living alone since then. She has one son who lives relatively close and grandchildren who visit and help when they can.

Emily's care needs started around seven years ago and have got progressively worse. She can get out of the house but it has to be planned; she has to take her painkillers and wait for them to take effect before she can get out. In the last five months, she has used a stick to walk when she goes out.

She described her life as 'boring'. Her interests were walking and travelling and she cannot do those now, and she also had penfriends who she used to write to, but they have now died.

"[My day-to-day life] is boring. Well I cannot do the things I used to do. It's as simple as that really. Well I was a very keen walker. I liked to go on holidays. I liked to go shopping outside of Manchester using the public transport because we have free transport, so I made full use of that, can't do that now, because I'm not as mobile as I was."

One of her hobbies was gardening and she can't do that anymore. She also used to enjoy baking and cooking for fun and can't do that anymore either. To make matters worse, the funding for two of the activities she could still do has been withdrawn, which further limits her hobbies.

"After I retired I used to be, I had my voluntary work. I joined a writers' group. I went to floral arrangement class. So I had those things, which I don't have now, and they're not available anymore."

She belongs to an Independent Age book/research group, which she enjoys, but this is not enough to make up for the hobbies she can no longer engage with.

When asked what had a negative impact on her well-being, she described how she was frustrated with the things she was no longer able to do.

"Negative would be all the things I can't do, and when you say negative I mean mine is more frustration than, negative, it's just the things I can't do".

Despite all these challenges and frustrations, when asked about her well-being overall (which she described as her outlook) she said:

"Mentally I suppose I'm fortunate. Medically no I wouldn't, no, I'm, out of ten I would only put myself at four or five, but mentally I'd put myself at probably nine."

Boredom and lack of mental stimulation made participants feel worse because they had no distraction from the difficulties they face, nothing to help them escape from the reality temporarily.

"Some days, you just feel absolutely defeated. I've got a friend who had a brain tumour and we talk about it, her problems and mine. And we both say the same. You wake up some mornings and you think, oh, go away. You don't want to answer the phone, the TV's a bore because it's the same old thing, and you think, what the hell am I going to do today? And you can't think of anything that'll make you feel better. You feel so low."

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

Importance of hobbies in maintaining well-being

Linked to the above findings, the importance of continuing their hobbies or maintaining links through past hobbies was highlighted as having a positive impact on well-being. Even if they didn't do each activity or hobby as fully as they did in the past, continuing to complete at least part of a hobby was considered to be beneficial. For example, some participants described how they were continuing to run a bowls club, meet friends weekly for a coffee at the golf club, and meet friends from the tennis club despite no longer playing. Continuing with these hobbies, or simply keeping in touch with these hobbies if they could no longer fully engage with the activity, helped to improve participants' mood. It gave them something to look forward to, helped them maintain friendships and made them feel more connected within their local community.

"Many years ago, before I had my health problems, I was playing tennis three times a week, on the parish council for a while, so I was quite involved in all sorts of things, but then in 2014, I had this health problem, so I hung up my tennis racket. I still run a carpet bowls club on a weekday afternoon at the Parish Centre, which the parish asked me to do in the year 2000."

(Int. 11; male, age group 80 – 89; living alone in own home)

Sometimes new hobbies had been taken up for fun, or for therapeutic reasons, such as joining a choir because they thought singing would be "good for the brain".

"Well, yeah, the last four years David's not been very well because of his hip replacement that went wrong and he had the hip replaced five times, and all the operations and the infections, then it went to his brain and he's now got this mild dementia. And when the doctor said, it's good for David to sing, it's good to sing for the brain, I thought, right, I'm going back to the choir and he can come with me. So we've been doing that."

(Int. 20; wife of male, age group 80 – 89; living with wife in own home)

It was clear that there was a sense of sadness amongst those who were unable to take part in their hobbies anymore. One reason for giving up a hobby or activity was the sense of letting others down if they were to perform it to a poor standard. Quite often, the people who said this had participated in these hobbies for a large part of their life, and they did not want others to see their deteriorated ability, they did not want to embarrass their partners or fall short of people's expectations of them.

"I think I am getting to the stage where my memory isn't good. I do try, I'm playing bridge tomorrow afternoon and I'm going to cancel my bridge from now on because I used to be quite a good bridge player, you wouldn't believe it, but I was, and I don't want to embarrass people or to let people down."

(Int. 7; female, age group 80 – 89; living alone)

"My body told me when to stop. [...] If I did go back, I wouldn't play as I used to, and I would be letting my partner down, so I thought no."

(Int. 11; male, age group 80 – 89; living alone in own home)

The unpredictability of health and care needs also impacted on people's ability to take part in hobbies and interests. For example, trips offered by organisations for older people had to be booked and paid for in advance. This could put people off booking when they did not know how they would feel that day, or when they had to arrange their lives round medical appointments.

Other factors that had a positive impact on people's well-being

In addition to hobbies, having a purpose, especially to help other people, had a significant positive impact on people's well-being. For example, people spoke about becoming a befriender to someone of a similar age, and donating books to charity. Even the idea of doing this could contribute to their well-being, and part of planning for their future. For example, someone spoke of intending to volunteer to sit with families of people living with dementia; having been through the process themselves they wanted to help and believed they could be of benefit to others in a similar situation.

"In fact, it's given me such a boost that this Signpost for carers, I offered the other day to help out with them, because I can go and sit with someone who has got dementia and give, say, the wife or the husband some time off. They could go have a shower or a bath or anything they want. So, I'd have to be trained for it. [...] The thing is, I'll just say, 'I lost my husband to dementia', end of story. That'll be all they know. So, they will know that I know what they're going through."

(Int. 4; female, age group 70 - 79; living in own home; was carer of partner that recently died; recovering from an accident)

Despite their care needs, volunteering was at the forefront of some participants' minds. One was able to continue with his volunteering activities thanks to the help of his support worker, who could accompany him as necessary. A retired teacher was very motivated to do some volunteering in school but could not get out of her home without help, due to mobility issues – she found this sad and frustrating:

"I'm an able person. I used to be a teacher. I could still go in to school and help children learn to read or that sort of thing, but I can't access. I can't get up the stairs, I can't, I mean, it's very frustrating. (...) I'm still quite capable of teaching. That's sad because you know, there's so much funding pressure on schools now and any voluntary help, schools voluntary help, like I can provide... It's very difficult because most buildings don't have good access unless they're a new build."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

It was not just helping as a volunteer, but also being able to offer support to friends and family members which contributed to a sense of purpose. Participants described how they helped family members, for example one spoke about giving a lift to her daughter, another described being able to help with odd jobs for his wife who was not as strong as he was, and starting to take a role in helping his wife with household cleaning.

Religion, and belonging to a community such as a church was also stated by a few participants as contributing to their sense of well-being. Several expressed enjoying going to church and mentioned prayer.

"So I try to be as positive as possible, and if someone say something or do something that I don't like, I say a short prayer for him and for myself."

(Int. 6; male, age group 80-89; lives with wife in own home; carer for his wife who has dementia)

"I like going to church, it gives you a feel of belonging to something, yes. I also belong to a prayer group."

(Int. 24; female, age group 70-79; living alone)

Additionally, good and close family relationships enhanced participants' well-being. They took pride in their children and grandchildren, their achievements, and the relationships they had with them. For some, strong family relationships helped them keep up despite the difficulties they were facing. They also offered the possibility of support with aspects of life (apart from meeting care needs) which could contribute to well-being such as going on holiday together – enabling them to get away and give them confidence. However, those who did not have a good or close relationship with their family reported feeling very sad about it, and those who did not have any family sometimes envied those who did.

"They [my grandchildren] like me to come up, I'm sitting there and they're asking me everything, how to do this, how to do that. And I, and they say ... come and sit in the kitchen on a chair and guide us like this and like that. But I ... like that."

(Int. 23; Female, age group 90+; living alone in supported living accommodation; interview conducted with a translator)

"I just love my grandchildren and my kids so much that, and I think I do actually want to be around. I wish I'd listen to people more when they tell me I've got, still got plenty to offer."

(Int. 1; female, age group 60 - 69; living alone for a long time; suffers from arthritis and has damaged knees)

There was also evidence of participants building relationships with other people, outside their families, which contributed to their well-being. For example, ensuring their relationships with carers, cleaners or people who helped them with jobs was friendly and offered the opportunity for social contacts as well as service delivery.

This project aimed to explore the links between unmet need for care and well-being. However, the research also highlighted that care needs themselves impacted on people's well-being, regardless of whether they were met. At the same time the in-depth interviews showed how many other aspects of life affected participants' well-being in ways which were totally unrelated to their care needs. Concern about the problems faced by family members (e.g. mental health problems among their children), unresolved grief for bereavements years before, or tensions or conflicts within families had negative impacts on well-being. Anxieties about upkeep of the home could have negative impacts on well-being, while ability to make home improvements which enhanced the quality of their living environment improved well-being. For older participants with care needs, their unmet care needs were not necessarily the primary driver of their well-being. The interplay of these multiple factors which impact on well-being may help explain why the regression analysis found no

clear link between unmet need and well-being, when controlling for other factors. By exploring people's lived experiences of unmet need using a qualitative approach, the links between unmet need and well-being become clearer.

6.3 Social contact and well-being

When asked what the word 'well-being' meant to them, and how they would define it to others, participants usually associated it with two themes: being able to socialise, and being independent. As mentioned in chapter 4, many participants were quick to acknowledge that they felt isolated or lonely – unmet needs for social contacts were common among our participants. The lack of hobbies and activities that they could participate in contributed to the issue. Participants explained how their loneliness affected their well-being. For example, they remarked that they could feel the benefits of interacting with others for a while after the interaction was over.

"Well the more company I get, the better I am.(..)I know how I am the next day after I've had a talk to people."

(Int. 3; female, age group 80 – 89; living alone in council accommodation; recently widowed)

They also described how socialising with others 'made them think' and mentally stimulated them, something that they didn't necessarily experience on a regular basis but wanted to.

"Well, I think socialising helps you mentally, conversation, to make you think. Yeah, that's why it's always nice to interact with others, but I suppose that, at the moment I'm not having a lot of it, and this is what I'm saying. I hope at the end of all this I get some help from somewhere and actually get round to my friends."

(Int. 15; male, age group 60 – 69; living alone; has had COPD and arthritis, and has recently got a pacemaker inserted)

Those who had lost close friends and family reported how acutely they missed them: they missed the purpose, the company, the laughs, and the moral support they got out of these interactions.

"It's the loneliness that does it, as much as anything. If you've got somebody to talk to or something that you're looking forward to. Because we were always going abroad, or something and with loads of things, functions and things with our hats and we were always involved with them all, so when all that finishes it's as though you, you might as well not be here. You sit here all day. I've nothing to look forward to, nothing. And it's company you'd miss. People. But there's nothing you can do about it. They're not here anymore."

(Int. 5; female, age group 80 – 89; living alone for a long time)

"My fast friend, she died three months ago. She had a cancer. She was very helping. Another friend and her, on Sunday they used to have lunch with me. I used to cook for them ... some nice food and we would clean the kitchen together. It happened every week but for the last year it's all gone. Ah, my friend died and then, after that it's gone. She used to help me with things, we would do our shopping together. I feel more isolated now."

(Int. 23; Female, age group 90+; living alone in supported living accommodation; interview conducted with a translator)

The definition of unmet need used in the secondary analysis did not include social isolation or loneliness as a type of unmet need, which may also partly explain the lack of association between unmet need and well-being in the regression analysis. In the in-depth interviews where loneliness was regarded as an unmet need as well as consequence of other unmet needs, it became clear how this aspect of unmet need had detrimental impacts on well-being.

Factors helping to combat loneliness and social isolation

Although loneliness and social isolation were frequently mentioned as key determinants of well-being, people alluded to several factors that made them easier to handle, such as:

- Telephone befriending services, such as Silver Line.

People who used these types of services were very complimentary about them; they appreciated being able to speak to someone whenever they wanted, for advice and support or just to engage in ordinary conversation that they would have been unable to partake in otherwise. They liked the feeling of someone else being 'on the other end of the line' for emotional support. The benefits of this were particularly welcomed by those who were frail and housebound and couldn't attend day centres or groups.

"And I'll tell you who else is good - Silver Line. I speak to them on a daily basis. They are brilliant, not every day, I haven't been but last few days I've been phoning up two, twice a day, not something I would normally do, that lets you know that I'm not so good and I feel like I need something more, someone to chat to, and they're brilliant, they're absolutely magic, Silver Line. And, I even have a pen-friend."

(Int. 10; female, age group 60 - 69; living in own home with partner; suffers from depression and anxiety)

However, whilst telephone befriending services were considered to be good, they weren't always enough and people did desire face-to-face contacts too. One participant liked her befriender but found that she was so much younger than her that it made it harder for them to establish a close connection because their lives were so different. She would have preferred to be befriended with an older person, thinking that they would probably have more in common.

- Time banking

One participant described how she had benefitted from a 'time banking' initiative set up in her local community, built on the principle of each person offering a service, in exchange for withdrawing equivalent support when needed. In this scenario, the participant received face-to-face company from someone who helped her with her gardening, as well as a telephone befriender, and in return she wrote an article for the magazine about gardening.

"What they do with this is, no money is involved, but you do things for people, you give them a time to do something. I've got a lady who comes, and she only lives around the corner as it just happens. She comes and helps me get out and make hanging baskets in the summer, and she's coming around to have a natter with me for about an hour. (...) Then I've got another lady that comes and rings me up from London. (...)

I said well I can't do anything to join in. I was in the garden one day and she said well do something about the garden. So, I've written a thing all about gardening, and that was in the magazine when it was. It comes out a couple of times a year, so my little episode was on gardening. I'm all right on gardening."

(Int. 5; female, age group 80 – 89; living alone for a long time)

- **Support groups/day centres** where they did fit in – although some people did not feel like they fitted in, and this had a negative effect on their well-being. In the main, people felt happy attending these groups, and appreciated socialising with others outside of their own homes.

"I feel happy when I come here. I feel less troubled when I come here. I forget everything..."

(Int. 23; Female, age group 90+; living alone in supported living accommodation; interview conducted with a translator)

"The Seniors Forum was started about six or seven years ago in [town name]. [...] She arranges outings where they're picked up, certain points in [town name], on the coach, so, and so you pay for that, and you're picked up and you're taken to the spot. You're taken around wherever they're going and you have lunch, and it's just a nice time for people to be together and out of their houses."

(Int. 20; male, age group 80 – 89; living with partner in own home)

6.4 Impact on health and dignity

As well as impacting on people's well-being and increasing social isolation and loneliness, in certain cases, **participants' unmet needs affected their health and dignity**.

Examples included:

- falls that could have been prevented if they had had the adaptations or equipment they needed;
- postponing visits to the GP due to lack of transport;
- people wetting themselves at night due to a lack of a commode; and
- not washing as often as they wanted to, or only strip washing, or taking a lot of time to shower and get dressed, due to lack of equipment or adaptations, or lack of support with personal care. This was frequently mentioned.

"I should have had a shower and washed me hair this morning and I thought oh no I can't be bothered. I can manage in the shower it's the drying what tires me out, getting dry when I get out the shower, that bugs me up. But I can't expect somebody to come in to dry me, can I?"

(Int. 12; female, age group 60 – 69; living alone)

On the other hand, other participants talked of how receiving certain types of help affecting their feeling of self-worth. In particular, getting help with personal care was considered difficult to accept, because it was felt to be intrusive and humiliating:

"It is very humiliating. I hate it. I absolutely hate it. Not being able to be, fully able to have a shower safely and dry yourself and get in and out without asking somebody else to help you is horrible. I just find it humiliating that I can't do it myself. (...) There are limits in my mind to how much I can ask somebody to help me do."

(Int. 18; female, age group 60 - 69; living alone in own home; living with MS)

Case study D (Interview 5): Clara

Clara's husband died over 20 years ago and she has been living alone since. She has family who live nearby who she speaks to on the phone every day, but acknowledges they have their own lives too and does not want to be a burden on them.

She has suffered a long period of ill health, including rheumatism, bronchitis, diverticulitis, and weeping eczema, as well as other long-term conditions. She is in severe pain the majority of the time, and doctors have not found any cure for her conditions that work for her as her body keeps rejecting the tablets.

'They've found no cures at all, so you just have to suffer and they tell you it's going to get worse. How much worse it's going to get I can't imagine because I don't know what the hell I'm doing with myself, some days I can't move at all.'

'I've had aches and pains all my life through rheumatism but this is ridiculous the pain here. I'm sat here sometimes and I've got tears streaming down my face with the pain, and there's nothing they can do. Just sit here, until it eases.'

Clara does not think of herself as 'coping', but rather of 'existing'. She finds this hard to comprehend as she has always been a very active person with many hobbies, however the pain she is suffering means she is unable to plan anything in advance and has had to give up many of the activities she used to enjoy, which impacts on her well-being, both mentally and physically. Doing simple tasks such as making a cup of tea can take up to half an hour, but she tries to manage. She used to be an avid gardener but can only 'potter about in it now'.

'The pain is indescribable and there's no cure for it, and there's very little help. Now I've got that to start with. I've been a very, very active person, I've always been. We used to be dancers, we used to dance, we even taught it. I'm a bridge player, which I can't do any of these things now, nothing. Because I can't pick things up. It's just as though your body's just a frame as though you're just walking about, and I used to say, and we were always with people, I used to take about 30 odd pensioners on holiday, two or three times a year. I've always been a very active person, and with people. Then you finish up like this. It's not a life, it's an existence.'

She used to attend a day centre but has now chosen not to anymore, due to the unpredictability of her conditions, her inability to sit down for long periods of time, and difficulty getting into and out of the car. She described her difficulties using the bath.

'I've got a fantastic bath, I've got a bath with a seat on it, which lowers you down into the bath. But I've not got the confidence to do it on my own. I just have a wash down because nobody comes to help me, and I just haven't got the confidence to do it.'

Clara has enquired about this with Age UK (referred to as Age Concern), but they haven't been able to help her as they have been fully booked.

'I have enquired several times about it, but they all say oh well we don't do that, or that's not on the list. Age Concern and that, they don't do this, they don't do that. Then they sometimes say well you have to pay for that. Well that's all right, but they're all booked up.'

07

CONCLUSION



7. Conclusion

7.1 How care needs develop and how they are met

The qualitative research enabled us to explore how people's needs had developed over time in a way which was not possible in the quantitative analysis. This demonstrated that while some people experienced a sudden onset of care needs after a specific health care crisis, for others needs developed gradually over many years. This could simply be as a result of ageing, or as a result of long-term chronic conditions or disabilities which had been manageable but which were complicated by the process of ageing. Participants received help with the difficulties they faced from a wide range of sources including formal services to help with personal care and jobs around the house, co-resident family members, family living elsewhere and various charities and support groups. The range of support available to older people with care needs impacted on the extent to which needs were met now and the sustainability of the support.

7.2 The extent of unmet need and hidden unmet need

The quantitative research showed that more than half of those with care needs had unmet need for at least some of their needs. The qualitative research showed that on the whole participants had their basic needs met, and that they did not always describe unmet needs for ADLs themselves in that they were fed, washed and dressed. However, participants' accounts demonstrated that this was sometimes at the cost of exhaustion or pain, or that it took a long time for them to complete these activities. Under the Care Act definition, where needs can only be met by an older person in this way, this is a sign of an unmet need for care³⁰. Still, it is important to bear in mind that these interviews were conducted by researchers and not by social workers: quantifying the amount of time, degree of pain, or the difficulty in carrying ADLs and IADLs that were unacceptable to formally qualify a need as unmet based on the Care Act definition was beyond the scope of the project.

Furthermore, participants described how the care they received was not always appropriate or sufficient. The qualitative research also uncovered areas of unmet need which could not be fully explored in the quantitative research and which also relate to the Care Act definitions of care need. This includes, having a lack of social contact and not being able to pursue hobbies and interests as a result of their care needs. We found that unmet needs are hidden in that older people do not always acknowledge their unmet need for support with the basic needs of daily living, because they do cope, however this does not mean they have no unmet needs. At the same time the quantitative approach, which did undercover these types of unmet need, is less effective at leading to an understanding of unmet needs related to the isolation and social impacts of care needs. By using these two methodologies, this research has uncovered a more rounded and nuanced picture of unmet care needs.

³⁰ In the Care Act, an adult is to be regarded as being **unable to achieve** an outcome if:

- the adult is **unable** to achieve it without assistance;
- he/she is **able** to achieve it without assistance **but**:
 - doing so causes them significant pain, distress or anxiety;
 - doing so endangers or is likely to endanger health or safety;
 - he/she takes significantly longer than would normally be expected.

7.3 The precarious nature of support and the transition from needs being met to unmet and vice versa

Unlike the quantitative analysis, which looked at care needs at particular snapshots in time, the qualitative interviews allowed us to explore how needs and support had developed over time and participant concerns and plans for the future. What this showed was that the situation was not static and participants could move in and out of situations of unmet need as their condition worsened or improved and the support available to them increased or diminished. A key element in this was the precarious nature of support, particularly unpaid support from family, friends and neighbours. Where participants were heavily reliant on support from one person this could lead to intermittent unmet need, or the possibility of serious future unmet need if that support was no longer available. Among those living alone, examples were given of care needs being unmet when their support was temporarily unavailable. Even among those living with a partner and whose care needs were currently fully met, it was clear that an increase in their care needs or the loss of their partner would have serious consequences. Among those who had recently been widowed, the implications of this were already evident. Furthermore, the interviews also uncovered unmet need for support among those who were providing care to a partner, which contributed to the precarious nature of this support.

7.4 Predictors of unmet need

The quantitative research identified unmet needs among all groups of older people, with few clear predictors of unmet need (among those with care needs). The key factors linked to unmet need were being younger and previously healthier, living alone and being widowed. There was no evidence that levels of wealth predicted future unmet need. The in-depth interviews have allowed us to understand more about these findings. Our research found evidence of people delaying their use of social care, because they wanted to save their resources for when their needs were greater or because they didn't feel old enough to use certain types of services such as care alarms or stair lifts. This may partly explain why unmet needs were found to be greater among relatively younger people in the quantitative analysis.

The number of participants living with co-resident partners or family was small in our qualitative sample. These cases showed the benefits of living with someone, particularly a partner, in meeting care needs on a day-to-day basis. This included providing support that the older person may not even have realised they needed as well as flexible support which could adjust according to need at that particular moment. Co-resident carers also offered companionship and more general support. Where older people did not have a partner, they became reliant on care from wider family members or paid providers. Concerns about being a burden on their children, grandchildren, friends and services more generally could make them reluctant to seek help at all, or to limit the help they requested even when the offer of unlimited help was there. Furthermore, financial concerns could lead them to limit or prevent their use of paid care services where they were not eligible for local authority support or believed they would not be. In some cases, participants stated that they could not afford the care at all, and in other cases it was about priorities, given their current level of need.

The research also uncovered other barriers to accessing social care including difficulty of finding out information about available services, a lack of information which was specific to their circumstances and could allow them to plan and access support, and challenges associated with navigating phone calls and reaching the help they had identified. Difficulty accessing local authority support included local authorities not offering assessments, delays in providing equipment or support, or older people believing they would not be eligible for help from the local authority so not contacting them.

7.5 Resilience, coping and identity

The quantitative research showed that there was no clear link between unmet need for care and well-being. Discussion with stakeholders and a reference group of older people at Age UK suggested that in some cases the ability to cope, show resilience and maintain independence could have positive impacts on well-being even in the face of unmet care needs. Furthermore, older people's views on coping could lead them to deliberately leave some needs unmet. Therefore, the qualitative interviews drew out participants' views and experiences on these issues. This confirmed the importance of maintaining independence. Across the sample, considerable determination and resilience were demonstrated by participants. Older people delayed accessing services or help from families to maintain their independence, they limited their use of the support they did have and they adapted and used strategies to cope when support was lacking. Participants described not only the value of independence to them now, but also concerns that seeking help could lead to dependence which could exacerbate the problems which the support, adaptation or change to housing was intended to help with.

Independence was seen positively by participants. In contrast the term 'coping' was sometimes used to mean just about managing and a potential indication of unmet need. There was also evidence that in some situations, receiving social care support was a means of maintaining independence, rather than a challenge to it.

Resilience and independence were also associated with a confidence that the older person could manage despite challenges and that they could still speak for themselves. Where older people with care needs had lost confidence, this was linked with unmet need either because they needed more support than was available for tasks such as getting out of the house or bathing, or because they did not have the confidence to access the services or help they needed.

7.6 Mobility

The ability to move safely around the house and to get out of the house to run errands, socialise or for fun was an important theme that emerged across the interviews. Where participants had maintained their mobility through appropriate equipment and adaptations at home and access to a car or accessible and affordable or free public or community transport, this meant they were less likely to have unmet need for mobility and they had fewer other unmet needs as they could get to the shops and appointments. Furthermore, it reduced social isolation and had positive impacts on their well-being.

7.7 Social isolation

There were older people in the sample who described serious levels of isolation and loneliness often through being confined to the house, having no visitors and through friends and neighbours having died. Loneliness could be regarded as an unmet need in itself but also an indication of unmet need for support, particularly with mobility.

Access to support from family or paid care and support workers provided benefits beyond the tasks being completed as they also provided company and someone to see. Therefore, by meeting needs with other types of difficulties, need for social contact could also be met, even where this was not the prime reason for the support.

As described in the following section, there were strong links between social isolation and well-being, suggesting that social isolation may be a mediating factor between unmet needs and well-being.

Not everyone we interviewed did experience social isolation. Maintaining social ties from before care needs developed and living with other people seemed to reduce the risk of isolation.

7.8 Unmet needs and well-being

A key finding from the quantitative research was that there was no clear link between unmet need for care and well-being. In contrast, the qualitative research demonstrated a number of important links between unmet need and well-being as experienced by older people. This included the impacts of not keeping their house as they would wish, not being washed as well or as often as they wished, being reliant on a less interesting diet than they were used to when they could cook themselves. The interviews also showed that lack of mobility and isolation and lack of access to hobbies and interests and the associated loss of independence were the aspects of unmet need for support which had the strongest link with well-being. Owing to the limitations of the available data, these dimensions of unmet need could not be captured by the definition of unmet need used in the quantitative research (CASP-15), which could explain why the quantitative research found no link between unmet needs for care and well-being.

Interestingly, loneliness and social contacts were included in the quantitative model predicting well-being, alongside unmet need and they were not found to be significantly related to well-being. One possible explanation for the lack of a link is that other aspects of life which were not measured in the quantitative analysis and which are in many ways unrelated to unmet need also had important links with well-being, as described in the interviews. Another explanation is that it is the level of need itself, rather than the extent to which it is unmet which has the greater impact on well-being. Where people experienced severe pain, this had a detrimental impact on well-being, regardless of whether help with daily activities was received. Finally, the qualitative interviews have provided evidence to support the hypothesis that in some cases maintaining independence and managing without support themselves can have a positive relationship with well-being (the direction of causality is not always clear).

These findings should not lead to the conclusion that unmet need for care does not matter for the well-being of older people. Rather it shows the complexity of well-being and the fact that in seeking to improve the well-being and quality of life of older people, their whole life circumstances and approach to life need to be considered. The same way of meeting care needs may have very different links to well-being for different people.

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

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