STUDY RESULTS

Measuring outcomes of people with dementia and their carers

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Study results summary, Version 3.0
Date: 2 September 2021

WHAT WAS THE STUDY ABOUT?

We wanted to see whether the two questionnaires that the research team based at Personal Social Services Research Unit, University of Kent has developed are (1) easy to complete and (2) measure what they are intended to measure – that is, aspects of people's lives that might be affected by using social care services.

In this study, we were especially interested in social care services that people use when they are living at home, like home care, day activities or support from a carers centre.

The first questionnaire, called **ASCOT-Carer**, looks at aspects of life that are important to family and friends who look after someone. The second questionnaire, called **ASCOT-Proxy**, looks at aspects of life that are important to person living with dementia. ASCOT-Proxy was designed to collect information about someone who is unable to take part in surveys. In this study, we asked family and friends, who support someone with dementia, to fill in the questionnaire.

ASCOT-Carer measure for example:


Self-care


Space and time to be yourself

Safety


Occupation


Participation and involvement

ASCOT-Proxy measure for example:


Cleanliness and comfort


Food and drink

Safety


Accommodation


Participation and involvement

WHO TOOK PART IN THE STUDY?

Inclusion criteria:
A friend or family member of someone living with dementia, who:

- Lives at home (not in a nursing or residential care home)
- Uses at least one type of social care service
- Would not be able to answer a postal or online questionnaire, even with help.

313 Carers

75.7% Females

62.4 years average age

47% of Carers provided **50+ hours** per week of care

41.5% of Carers helped their partner/spouse
48.9% of Carers helped their parent

WHAT DID RESEARCHERS LEARN FROM THIS STUDY?

Both questionnaires have very low missing information. This indicates that carers of people living with dementia in England find the questionnaires easy to fill in. The results also confirmed that the questionnaires are reliable and measure what they were intended to measure. This means that we can use these questionnaires, with confidence, in future research. This will help us to understand whether, when and how different social care services improve people's lives.

In addition, this study has shown that people living with dementia and their carers have high levels of unmet needs even when in contact with social care services. This shows that the needs of people with dementia and their carers are not always being fully understood and addressed. This is an important message for adult social services, social care providers and funders or decision-makers.

We also found that some people are more likely to have unmet needs - especially, people with their own health problems and when the design of the home is not suitable for the person living with dementia. This suggests that social care, healthcare and housing services need to work better together.

MORE INFORMATION

For more information, please visit https://www.pssru.ac.uk/ascot/# and see the sections about the ASCOT tools and Publications.

Alternatively, you can contact the study lead, Dr Stacey Rand by email: S.E.Rand@kent.ac.uk, if you would like to learn more.

We thank everyone who took part in this study. Without your help and feedback, improvements in adult social care would not be possible.

In addition, we would like to thank all participating sites across the National Health Service and adult social care for their help with promoting and recruitment to the study.

Recruitment to this study was supported through the National Institute for Health Research (NIHR) Clinical Research Network (CPMS: 44825) and Join Dementia Research, which is funded by the Department of Health and Social Care (DHSC) and delivered by the NIHR in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.

This research was funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number: NIHR200058). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.