

Service provision for older homeless people with memory problems: a mixed-methods study

Jill Manthorpe,^{1*} Kritika Samsi,¹ Louise Joly,¹
Maureen Crane,¹ Heather Gage,² Ann Bowling³
and Ramin Nilforooshan⁴

¹National Institute for Health Research Health and Social Care Workforce Research Unit, King's College London, London, UK

²Surrey Health Economics Centre, School of Economics, University of Surrey, Guildford, UK

³Health Sciences, University of Southampton, Southampton, UK

⁴Surrey and Borders Partnership NHS Foundation Trust, Chertsey, UK

*Corresponding author jill.manthorpe@kcl.ac.uk

Declared competing interests of authors: none

Published February 2019

DOI: 10.3310/hsdr07090

Scientific summary

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Health Services and Delivery Research 2019; Vol. 7: No. 9

DOI: 10.3310/hsdr07090

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Background

There is little evidence about the circumstances and needs of older people who are homeless and have memory problems in the UK, although the subject has received some attention in the USA and Australia. Over a decade ago, audits undertaken in different parts of England suggested that 10–16% of older homeless people had 'serious memory problems' or were described as 'have memory problems/are prone to wander' (UK Coalition on Older Homelessness. *Audit of Older Homeless People September 2007: Summary of Findings*. London: Housing Learning and Improvement Network; 2007). These audits relied on staff observations, not those of mental health workers or clinical examinations; various lower age limits were applied (from 45 to 60 years); and resident profiles were unavailable. Multiple and long-standing health conditions were suggested as contributing to the problems reported: long-term alcohol misuse, untreated human immunodeficiency virus infection, vascular disease and head and chronic brain injury.

Little has been reported about problems faced by older homeless people with memory problems, the services and support they receive, and if their needs are met. This may be because they are reluctant to engage with services and difficult to assess and help because of persistent heavy drinking, or because they have behaviour that people find challenging, or other physical health problems, or because they neglect themselves. Furthermore, there is little information about the help available to homeless-sector staff working with this group, and their experiences of accessing services on their clients' behalf. Many older homeless people with memory problems are reportedly unable to live independently, and suitable long-term housing is hard to find.

We designed a 24-month study to investigate these gaps in greater detail. Four under-researched questions were identified as the study aims:

1. To what extent are hostel staff aware of memory problems among their older residents and their prevalence? What impact does this have on their practice or service? How do hostel staff respond to residents' memory problems?
2. What 'service pathways' exist for older homeless people with memory problems? What are their service experiences?
3. What are the gaps in service provision for such individuals, and what are the costs of providing services for them?
4. How do older homeless people with memory problems perceive their quality of life (QoL), and how can this be evaluated? Does this differ from that of other older people and other older homeless people? What are the implications of this for agreeing desirable outcomes from services?

Methods

Work package 1: literature reviews

The research started with two literature reviews (A and B).

Literature review A investigated the prevalence of memory problems among older homeless people. It found that previous studies of the physical and mental health of older homeless people have collected data on memory problems using varied definitions and in different ways, either as a focus or in combination with other conditions. Older homeless people in these studies were recruited from diverse settings, such as day centres, street provision, hostels and clinics. Few studies included service evaluations and trials of interventions; there were also few accounts of practice, service commissioning decisions and outcomes.

Literature review B, published in *Aging & Mental Health*, included a narrative systematic review of QoL instruments used in assessing people with dementia (all types) to assist the research team in selecting optimal measures for their aims and to address issues and life areas that are of particular importance to homeless older people (Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M, *et al.* Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health* 2015;**19**:13–31). It noted the presence of a large body of literature in this area, but found few measures based on rigorous conceptual frameworks. Many QoL measures were based on proxy assessments rather than self-reports from people with dementia. All measures were tested on selective samples only and in just a few sites. Their general applicability remains unknown and their predictive validity is largely untested.

Study design

The study was designed in two phases: (1) a quantitative element to examine the prevalence of memory problems among older homeless people living in hostels and the extent to which homeless-sector staff are aware of and respond to these problems, and (2) a longitudinal case study phase to investigate the more specific questions related to pathways into care, services and support received and their costs, the gaps in services that existed and how these areas could be developed, and how older homeless people with memory problems perceived their QoL.

Recruitment and data collection

Ethics approval was obtained from the London and South East Research Ethics Committee in April 2014 (14/LO/09373) and fieldwork began in May 2014. Several hostels were contacted and, ultimately, eight were recruited from four main sites (Central London, South London, North East and Midlands). Details of hostel services and commissioning or funding arrangements were collected in interviews with managers. Sixty-two residents were recruited for the first phase. Once study details had been explained and informed consent had been obtained, baseline interviews were conducted, at the end of which the Six-Item Cognitive Impairment Test (6-CIT) was conducted. There were many varied challenges to recruitment and data collection, related to the way the study was introduced to study participants, to ongoing and multiple service changes in the hostel sector, and to the complex histories of the participants being recruited. A consultant psychiatrist and his staff team conducted short 20-minute Addenbrooke's Cognitive Examination III (ACE-III) assessments, or the Montreal Cognitive Assessment (MoCA) for those who found ACE-III too burdensome. In the end, 48 ACE-III assessments were conducted and one participant was administered the MoCA. Data were entered into the software SPSS version 22 (IBM Corporation, Armonk, NY, USA) and open-ended responses were entered into the software NVivo 10 (QSR International, Warrington, UK) so that categories and themes could be coded and identified. Descriptive profiles of participants were identified in interviews and using client records, including age, sex, ethnicity, education and work history, housing and homelessness history, activities and family/social contacts, income, management of everyday tasks, physical and mental health problems, head injuries, use of alcohol and drugs and service use 3 months prior to the baseline interview.

All baseline participants were allocated to one of three groups based on decisions made by the research team psychiatrist, using the cognitive assessment, and the history obtained regarding participants' lives, alcohol use and other physical and mental health conditions. The groups were 'memory problems', 'borderline' and 'no memory problems'. Follow-up interviews were conducted at 3 and 6 months with these participants and we aimed to obtain as complete a data set as possible. Fifteen participants (24%) were lost to follow-up and 47 participants were included in the case study analysis. Complementary sources of data were sought and, in total, we obtained interviews with 44 key workers, four external workers and eight hostel managers, as well undertaking analyses of hostel records of the 47 case study participants and the medical records of 30 case study participants.

We also estimated the costs of the services used and compared how these differed between those who had and those who did not have memory problems. To do so, details of the pathways of participants through different health and social care services, and the service use of each participant during the 6-month period following recruitment, were collected and documented as precisely as the available data would allow. The utilisation of a large number of services was included, and categories were informed by the Client Service Receipt Inventory. The unit costs of all services (2014–15) were obtained from validated national sources, applied to each service for each participant and summed to give a total service use per participant during the 6-month period. Summary statistics were calculated across all participants for each service use item and for groupings of services. Specific statistical tests were also conducted. The level of significance was set at a p -value of 0.05. Associations were also explored between service groupings and memory problems using Spearman's rank-order correlation. Ten other participant characteristics with the potential to influence service use costs were identified, and the associations between each of these characteristics and each cost grouping were explored using Spearman's rank test, the Mann–Whitney U -test and the Kruskal–Wallis test. All 10 variables were then included in backward stepwise regression modelling to explore the independent predictors of each cost item.

Findings

The hostels were very different in terms of their physical conditions and accessibility and the services that they offered to residents. Links with primary care and mental health services varied markedly between hostels. Some staff had substantially more sector experience than others, but high levels of staff turnover were reported. Training levels and availability varied, and differences existed in the extent to which hostel staff were permitted to access local NHS and local authority courses.

The team collected detailed demographic information, education experiences, employment history, homelessness history, physical health status, mental health status and substance misuse problems from the 62 older homeless people interviewed at baseline. Although some of those interviewed had relatively stable lives, had worked for years and had become homeless for the first time in later life, most had unsettled histories, had left school early without qualifications and subsequently had experienced long periods of unemployment, intermittent employment and homelessness. The sample tended to be 'young-elderly' homeless people, the majority being aged in their fifties, with a high prevalence of physical health problems, depression, alcohol and drug misuse problems among them. Differences in age cohorts were apparent; those in their early fifties were more likely to have left school early and to have first become homeless as teenagers or in their twenties, and were heavy drinkers and illicit drug users. Many in this group consumed super-strength lagers and beers, drinking > 50 units of alcohol per week at the time of the interview. There were differences by cluster site: those in North England were more likely to have stable histories and to have first become homeless after the age of 50 years, and to have remained in their hostels for longer periods, whereas many in the London sites had experienced homelessness intermittently or continuously since early adulthood.

It is well known that advancing age is the greatest risk factor for developing dementia, yet one of the key findings of our study is that memory problems were prevalent among large numbers of older homeless people in hostels: 47.6% of hostel residents were assessed as having memory problems, and a further 19% were deemed to be borderline. The median age of those with memory problems (groups 'memory problems' and 'borderline') was just 60.4 years. Hostel staff were relatively proficient at identifying hostel residents who were having memory difficulties. They were in regular contact with residents and were able to recognise when residents were confused or were struggling to carry out everyday activities.

We analysed the health and social care needs of the hostel residents, and their QoL and housing outcomes, drawing on information gathered over 6 months from multiple sources. We found that many older homeless people in hostels required substantial help and support to manage everyday activities of daily living and their health problems, especially those residents with memory problems. Hostel staff often provided a great deal of help to some older residents, often beyond the remit of a 'hostel worker'.

Many acted as advocates and took on roles that family members or social care staff generally provide to older people with health and support needs living in the community. In some cases, the local authority had undertaken an assessment of need and had organised a care package. In such instances, home care staff provided help to these residents; but this was not always the case, partly because of a lack of engagement of some residents with support services in conjunction with high thresholds of eligibility for local authority support, meaning that only those with very great levels of need were eligible.

We further analysed the costs of use of health and social care services, residents' unmet needs, challenges along the health and social care pathway and housing options. In terms of cost evaluation, information on service use by homeless people is rarely available, and, although this was a small sample, the data we obtained were detailed and unique. Service use data were available for 47 participants. There was variability in service use among the sample, but general practitioner services were the most frequently accessed. The median cost of service use over a 6-month period (2014–15) was £1454, but the mean was much higher than this (£2975), reflecting the small number of high users of local authority care services and in-hospital care. The proportion of the group with memory problems who had some form of mental health service use during the 6-month study was higher than that in the borderline or no memory loss groups (39%, 29% and 24%, respectively). However, the proportion of total costs accounted for by mental health services was < 5%. The reasons for the use of mental health care are not known, and may have been depression or other mental health conditions rather than memory loss. Participants with memory problems used emergency and out-of-hours services more than those without memory problems, but there was no other association between cognitive status and service use cost categories. Owing to much variability in service utilisation at the individual level, a larger sample would be required to gain definitive results. Many challenges along health and social care pathways were identified: difficulties in keeping appointments, comorbidity and alcohol problems, variability in presentation, lack of flexible dementia support and treatment, the need for residents not to be drinking at the time of assessments, inflexibility of services and the dual reluctance of services to engage with homeless people and of residents to engage with services. The lack of housing options for this vulnerable group was also highlighted.

Discussion and implications

We discuss the study findings, specifically in relation to comorbid physical health problems of the sample, histories obtained of head injuries, current and historical mental health problems, alcohol use, use of illicit drugs, literacy problems identified and varied hostel provision across all sites. We also identify the strengths and limitations of the study. Our study presents new information about older people with memory problems associated with dementia, about older hostel residents and about services for both groups. We have established baseline information and tested different methods and data collection approaches. The evidence from this study is that hostels are not suitable accommodation for people with dementia. Although some hostel staff possess skills and great competence in supporting residents for whom memory problems are having an impact on their lives and well-being, a hostel is not a long-term solution or care setting. There is a strong case for seeing hostels currently as part of the 'dementia care workforce' in the absence of suitable permanent housing or homes for these hostel residents. Likewise, there is a strong case for including hostels as part of the local housing with care economy or system and involving them in strategic planning, training and communities of practice. Local and national dementia strategies and services need to better acknowledge the existence of older homeless people with dementia, which should involve providing them with services, support and a place to call home.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme of the National Institute for Health Research.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

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The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 11/1017/04. The contractual start date was in January 2013. The final report began editorial review in January 2018 and was accepted for publication in September 2018. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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