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

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Scientific Summary

Background

There is little evidence about the circumstances and needs of older people who are homeless and have memory problems in the United Kingdom (UK), although the subject has received some attention in the United States (US) 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 ‘have memory problems / are prone to wander’ (UK Coalition on Older Homelessness 2007). These audits relied on staff observations, not those of mental health workers or clinical examinations; various lower age limits were applied (from 45 - 60 years); and resident profiles were unavailable. Multiple and long-standing health conditions were suggested as contributing to problems reported – long-term alcohol misuse, untreated HIV, vascular disease, head and chronic brain injury.

Little has been reported about problems faced by older homeless people with memory problems, services and support received, and if their needs are met. This may be because they are reluctant to engage with services, difficult to assess and help because of persistent heavy drinking, or may have behaviour that people find challenging, other physical health problems, and neglect themselves. Furthermore, there is little information about 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 study aims:

1. To determine prevalence of memory problems and the extent hostel staff are aware of memory problems among their older residents? How does this impact 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 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, and how can this be evaluated? Does this differ from 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 amongst older homeless people. It found that previous studies of 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 or 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 quality of life (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 et al 2015). 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 predictive validity largely untested.

Study design

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

Recruitment and data collection

Ethical 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, 8 hostels were recruited from 4 main sites (London Central, 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 obtained, baseline interviews were conducted, at the end of which the six-item cognitive test (6-cit) was conducted. There were many varied challenges to recruitment and data collection, related to the way the study was being introduced to study participants, ongoing and multiple service changes in the hostel sector, and the complex histories of participants being recruited. A consultant psychiatrist and his staff team conducted short 20 minute Addenbrooke's Cognitive Examination tool III (ACE-III) or the Montreal Cognitive Assessment (MoCA) for those who found ACE-III too burdensome. In the end, 48 ACE-III assessments were conducted and 1 participant was administered the MoCA. Data were entered into software SPSS and open-ended responses into software NVivo so that categories and themes could be coded and identified. Descriptive profiles of participants were identified in interview 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 three months prior to baseline interview.

All baseline participants were allocated to one of 3 groups based on decisions made by the research team psychiatrist, using the cognitive assessment, and history obtained regarding their life, alcohol use, and other physical and mental health conditions. Groups included: "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 dataset 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 keyworkers, 4 external workers, and 8 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 costs of services used and compared how these differed between those who had or did not have memory problems. To do so, details of the pathways of participants through different health and social care services, and service use of each participant over the 6-month period following recruitment were collected and documented, as precisely as available data would allow. Utilisation of a large number of services was included; and categories were informed by the Client Service Receipt Inventory. Unit costs of all services (2014-15) were obtained from validated national sources and applied to each service for each participant and summed to give a total service use per participant over 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 $p=0.05$. Associations were also explored between service groupings and memory problems using Spearman non-parametric correlation. Ten other participant characteristics with potential to influence service use costs were identified and associations between each of these characteristics and each cost grouping were explored using Spearman's rank test, Mann Whitney U and Kruskal Wallis tests. All 10 variables were then included in backward stepwise regression modelling to explore independent predictors of each cost item.

Findings

The hostels were very different, in terms of their physical conditions, accessibility, and services 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, while 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. While 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 experienced long periods of unemployment, intermittent employment and homelessness. The sample tended to be ‘young-elderly’ homeless people, the majority being aged in their 50s, with high prevalence of physical health, depression, alcohol and drug misuse problems among them. Differences in age cohorts were apparent – those in their early 50s were more likely to have left school early, have first become homeless as teenagers or in their twenties, were heavy drinkers and illicit drug users. Many of this group consumed super strength lagers and beers, drinking more than 50 units of alcohol per week at the time of interview. There were differences by cluster site – with those in North England being more likely to have stable histories and to have first become homeless after the age of 50, and 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 hostels residents were assessed as having memory problems, and a further 19% were deemed to be borderline. The median age for 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 on their quality of life 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 due to 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 costs of use of health and social care services, residents' unmet needs, challenges along health and social care pathway, and housing options. In terms of cost evaluation, information on the service use of homeless people is rarely available, and although this was a small sample, data we obtained were detailed and unique. Service use data were available for 47 participants. There was variability in service use amongst the sample, but GP services were the most frequently accessed. The median cost of service use over a six month period (2014-2015) was £1454, but the mean was much higher than this (£2975), reflecting small number of high users of local authority care services and in-hospital care. The proportion of the group with memory problems that had some form of mental health service use during the six month study was higher than for those in the borderline or no memory loss groups (39%, 29%, 24% respectively). However, the proportion of total costs accounted for by mental health services was less than 5%. The reason for use of mental health care is not known, and may have been for depression, or other mental health conditions rather than for 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. Due to much variability in service utilisation at 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, co-morbidity and alcohol problems, variability in presentation, lack of flexible dementia support and treatment, the need for residents to not be drinking at the time of assessments, inflexibility of services, and the dual reluctance of services to engage with homeless people as well as residents to engage with services. The lack of housing options for this vulnerable group was also highlighted.

Discussion and implications

We discuss study findings, specifically in relation to co-morbid physical health problems of the sample, histories obtained of head injuries, current and historic mental health problems, alcohol usage, use of illicit drugs, literacy problems identified, and varied hostel provision across all sites. We also identify 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 out different methods and data collection approaches. The evidence from this study is that hostels are not suitable accommodation for people with dementia. While some hostel staff possess skills and great competence in in supporting residents for whom memory problems are impacting on their lives and wellbeing, a hostel is not a long-term solution or care setting. There is a strong case for seeing them 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.

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