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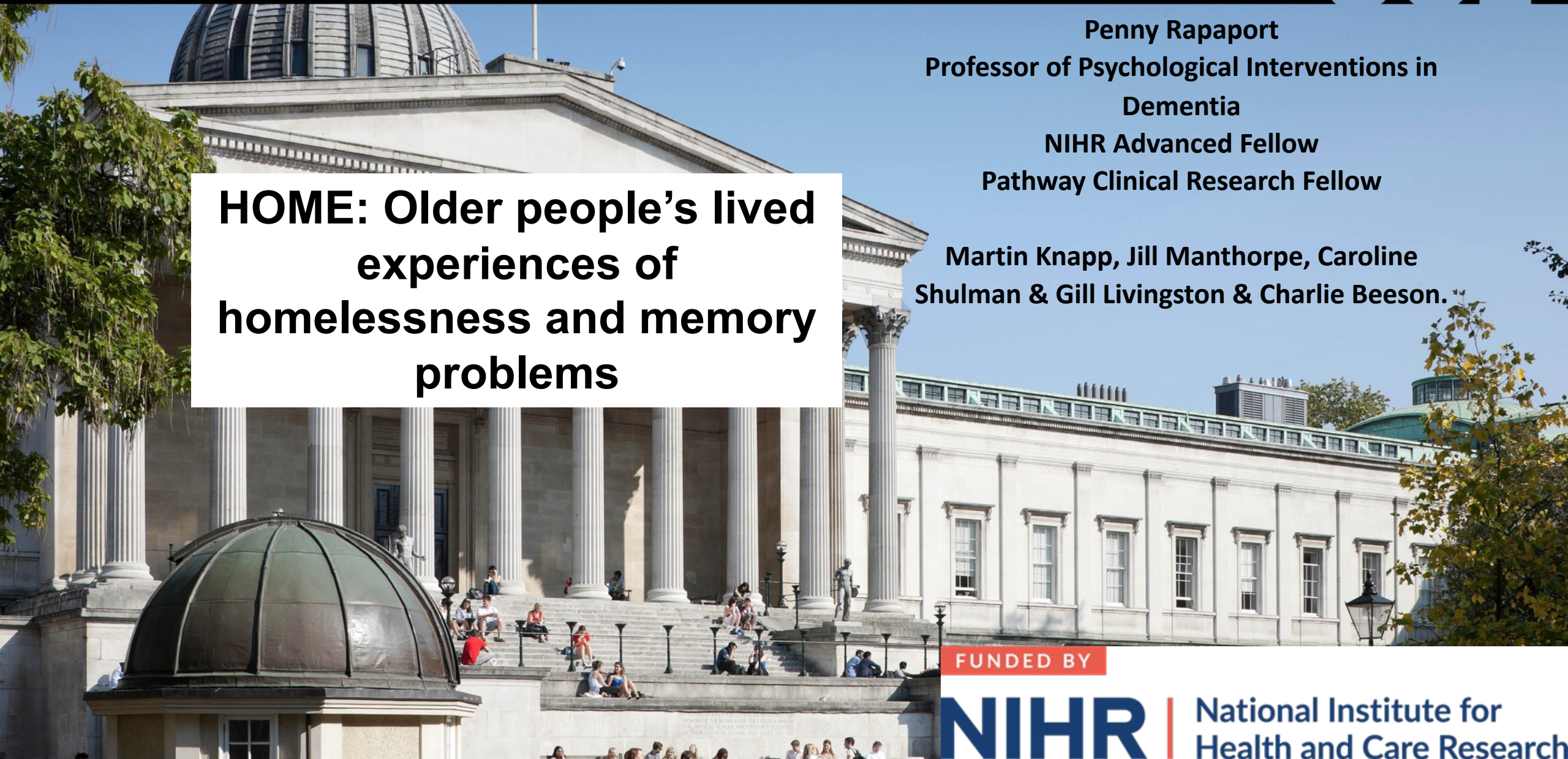
HOME: Older people's lived experiences of homelessness and memory problems

Penny Rapaport
Professor of Psychological Interventions in Dementia
NIHR Advanced Fellow
Pathway Clinical Research Fellow

Martin Knapp, Jill Manthorpe, Caroline Shulman & Gill Livingston & Charlie Beeson.



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What are we doing?

1

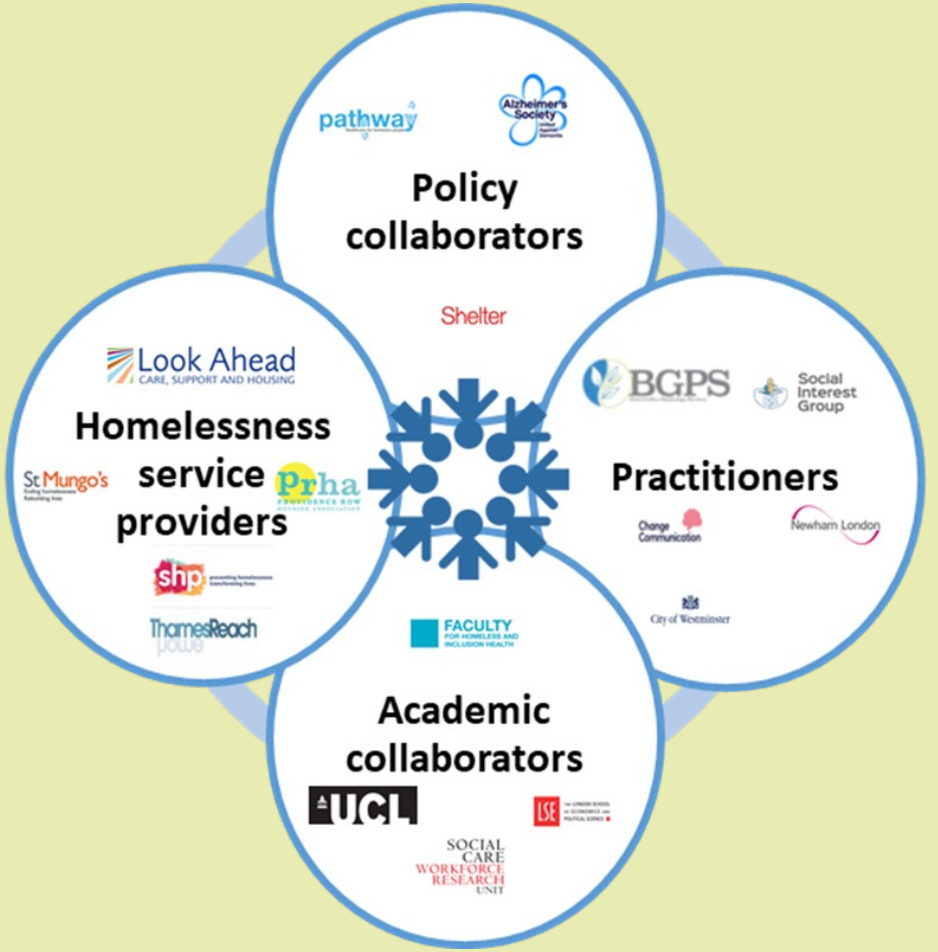
Exploring how stakeholders experience care and support for older people experiencing homelessness and memory problems.

2

Focusing what works and what gets in the way and what are meaningful outcomes for this population.

3

Using what we learn to influence policy and to codesign and test a support intervention for hostel workers.



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Why are we doing this work?

- Those experiencing homelessness, despite multiple vulnerabilities are largely absent from dementia policies[2]

- The older homeless population living with memory problems is growing[3], yet their complex health, housing and care needs remain largely unmet[4].

- There is widening inequality in dementia[5] – The most deprived fifth of adults are 50% more likely to develop dementia than the fifth least deprived.

What do we already know?

Hostel residents with memory problems are more likely to[4]:

Stay more than 2 years

Need more social & personal care

Use more emergency services

Need more intensive support

Most research addresses risk factors and prevalence

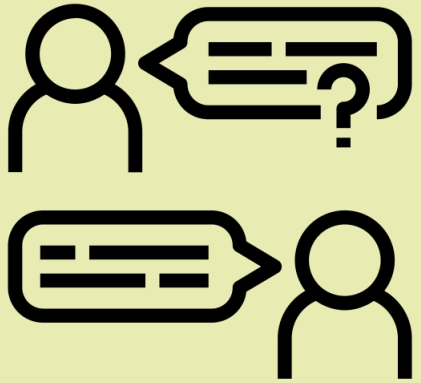
There is a critical gap in understanding how to support older people experiencing homelessness and memory problems.

What did we want to explore and consider?

1. The lived experiences of older people experiencing memory problems and homelessness.
2. How staff currently support older hostel residents with memory problems.
3. What factors determine current support.
4. What facilitates positive and meaningful outcomes for staff and residents.

What have we done? (work package 1)

- 49 interviews with15 hostel staff and managers, 17 people aged 50+ living with memory problems and experiencing homelessness and 17 health and social care practitioners.
- Ethnographic ‘participant observations’ with 13 older people (2 hostels / 1 care home), 29 hostel staff, 7 health and care professionals.
- 60 observations over 36.2 hours (range 5-210 minutes).
- Observed welfare checks, discussions between older people and key workers, visits by care workers, communal mealtimes, group-based activities, health checks, hospital and future accommodation visits, and team discussions.
- We conducted a reflexive thematic analysis[6] informed by a critical realist perspective[7].

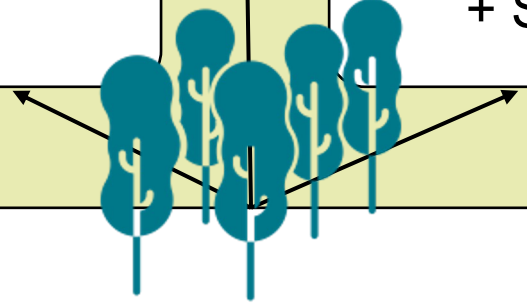


What did we find?

- Cognitive difficulties are missed
+Staff support from a distance

-Population are not taken seriously
+ Staff advocate & persist

- Filling in gaps: missing narratives
+ Staff help with remembering



Can’t see the wood for the trees

“People who've got a long history of homelessness, multiple disadvantage, so homeless, drugs and alcohol, physical health issues and workers around them not being able to see the wood for the trees - Could it be this? Could it be this? Could it be this?” *Specialist practitioner*

Lived experiences of memory problems

- Disorientation and getting lost
- Communication difficulties
- Functional difficulties
- Lack of awareness and insight
- Memory and paranoia
- Distress behaviours
- Self-reliance
- Social isolation
- Difficulties processing and understanding

Hostels are not safe

"He will believe whatever he's told if someone goes up to him. Like you said this, you said you would lend me your card, he questions himself. And I think sometimes he feels pressured that he did say it when he might not have at all." *Hostel Worker*

Hostels are not a home

"it's very variable from what I understand, I have to say, whenever I see residents in their rooms, it always looks like, you know, it's always a really unpleasant environment it's just undignified and not good"

Homelessness Clinician

Vulnerability and risk of exploitation

Lack of appropriate housing

"He was not the only gentleman with memory problems. We couldn't move him anywhere. We tried and tried and tried. And eventually we started the process to move him into a care home and he just went straight down hill and died." *Hostel worker*

Falling through gaps in services

"Rather than continuously trying to drag people into systems that don't fit them and just disadvantage you further when they don't fit. Because then they [don't attend] and get struck off and then you start all over again." *Homelessness clinician*

What helps?

I think before you can't assume that someone's going to, having been on the streets for several years, just going to pop out to the GP, going to go to an appointment, you need to be bringing that stuff here and creating a trusting relationship first and then people will go out. (Practitioner)

Bespoke accommodation

What helps? Flexible support

What helps? Time to get to know people

You need to take a longer time to make them feel comfortable and reassured and to express themselves as they see it and that their thoughts on their own experiences are valuable and matter, because I think that often people who really feel they're not listened to. (Hostel worker)

On site care and support

I think for the hostel staff again it just it feels like actually there's somebody here who's got a little bit of capacity to be able to have traction and to have the time to liaise over these cases that we didn't have before. (Practitioner)

What helps? Specialist input

Supportive & consistent relationships

What helps? Meaningful interaction

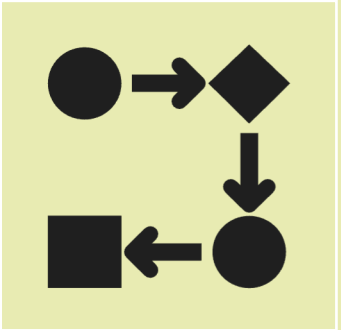
Collaborative integrated care

You know, for a start, I want to be able to do ordinary day by day things… we are always watching films and laughing and joking, have the door open, know what I want, not to be ignored in here.

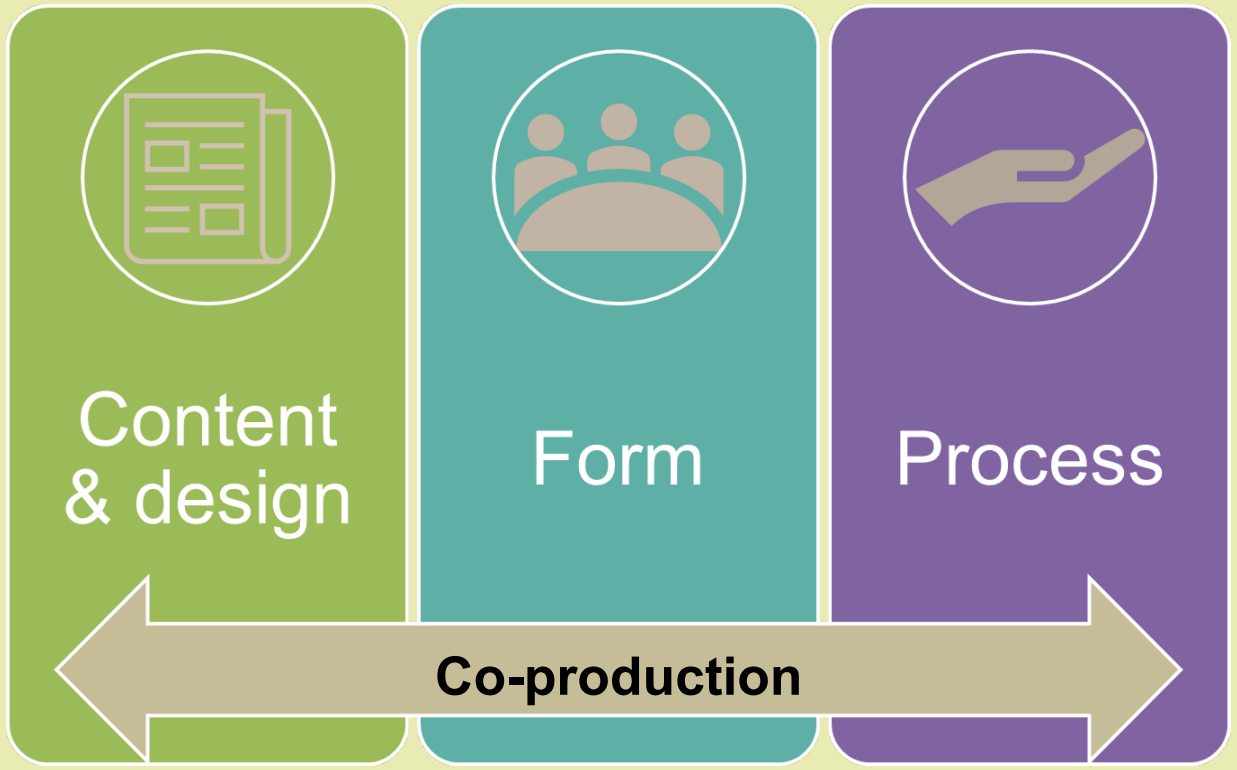
(Hostel resident)

Summary from qualitative study

- Interventions to improve the care and support of people experiencing memory problems are needed and should reflect the complexity of lived experiences.
- These findings should target health, housing and care policies to ensure that the needs of this population are better met.
- The coproduced intervention to support staff in hostels should:
  - Support staff to collaborate with outside agencies, especially around move on.
  - AND focus on how staff can understand the individual and identify and respond to residents' unmet needs.

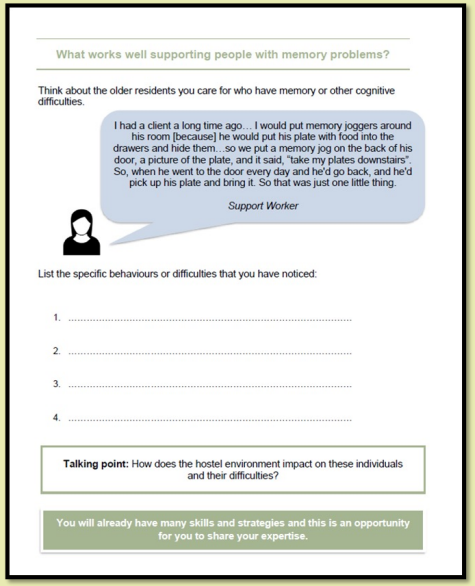


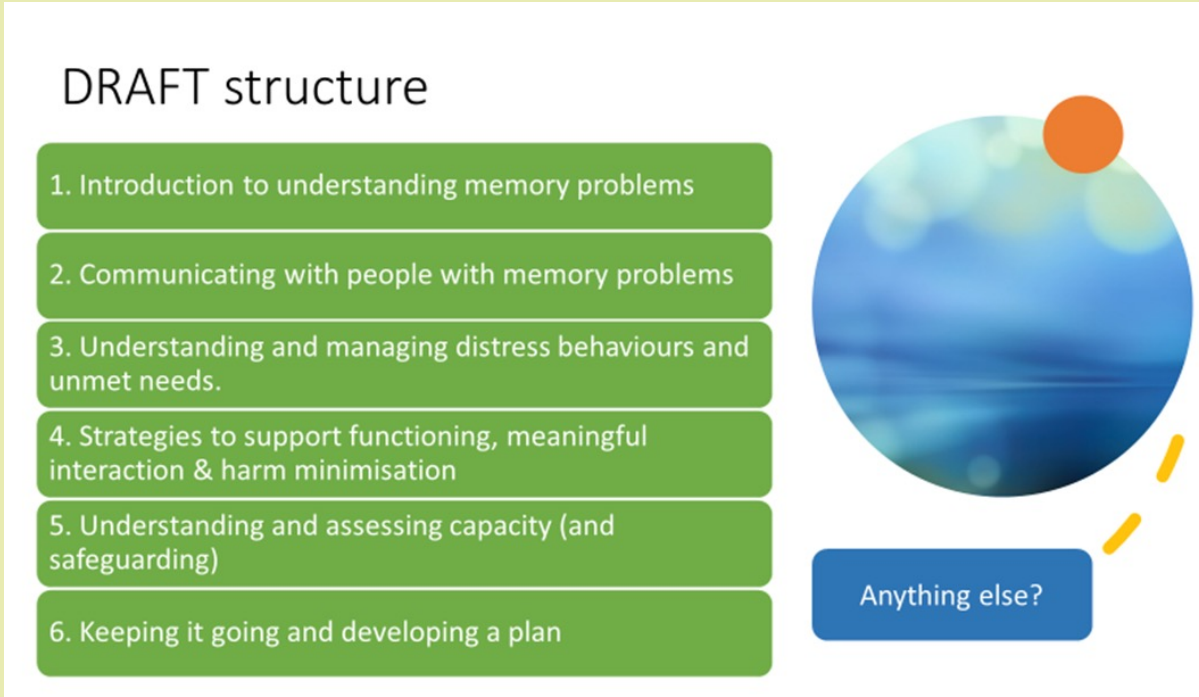
WP2: Coproduction and initial testing



Draft intervention

- 3 face to face workshops with experts by experience, hostel staff and managers
- Followed by - Online meetings with staff in homelessness / commissioners and academics
- Draft structure coproduced incorporating findings from WP 1 refined iteratively:
  - Manual based but individualised
  - 6-8 staff in a group
  - All staff / managers attend where possible
  - Collaborative and reflective
  - Facilitated by trained RA and hostel champion
  - 6 sessions 2hrs (including break)
  - Meeting with managers to embed and troubleshoot
  - Monthly support sessions in hostel





Initial Pilot

- 10 staff members were identified and approached, and all consented to the study.
- 8 people completed all sessions (or provided with 1:1 catch up).
- 1 person consented to the study but was not able to participate due to not working on Wednesdays and no catch-up sessions were offered.
- 9 people attended at least 1 session.
- Reasons for non-attendance included sickness or hostel emergencies
- 1 person attended session 1 and 2 only due to not being located at the hostel on a permanent basis.

Reflections on delivery

Booking the slot in the team meeting might have worked well to get people to attend

There is a wide range of skills and abilities among staff so needing to tailor information for everyone

Encouraging staff to use their own examples helped

At times it was challenging when new staff members would join the group without the foundations of earlier sessions

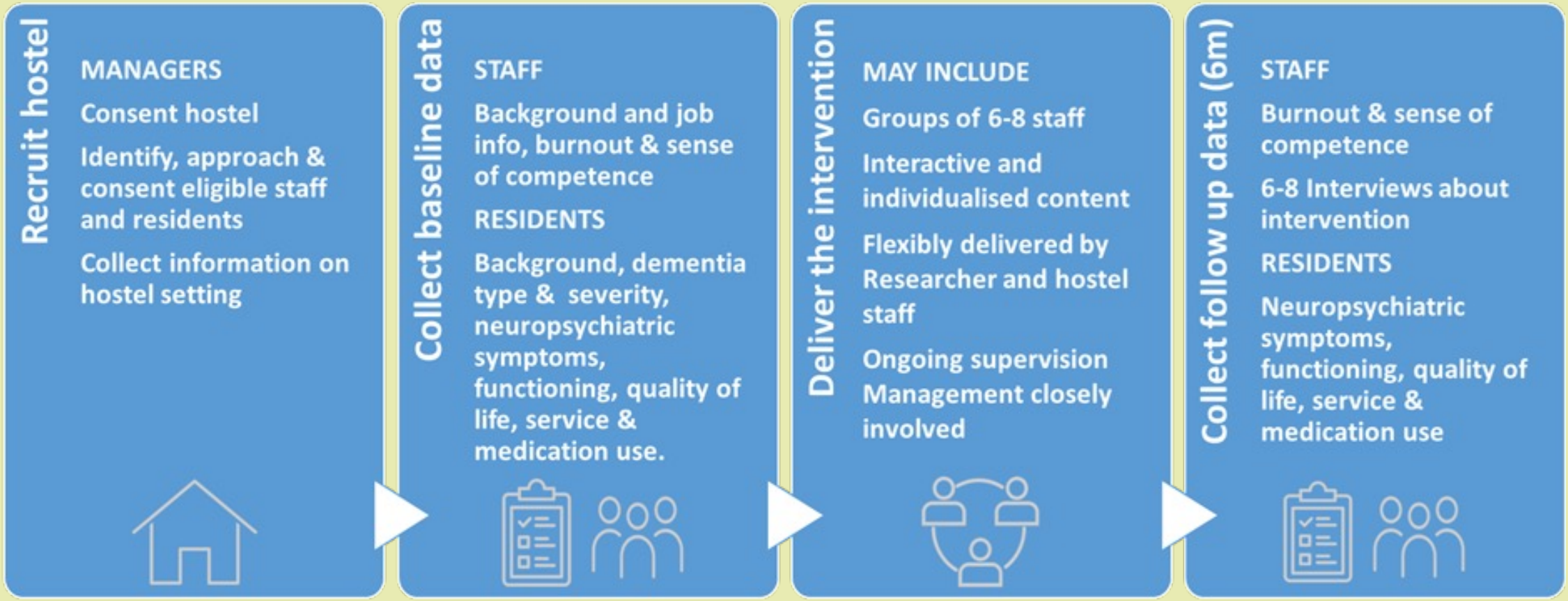
Need more time to reflect and go over between session exercises

Challenge for staff facilitating in terms of their time

Main refinements:

- Flexibility in delivery
- More support for hostel to deliver
- Reducing content in each session
- Simplifying exercises
- Tweaking facilitator training

Work package 3: Feasibility trial



Aim to establish, can this be done, how do people find it and to understand how to test more broadly.

Plan to recruit 40 older people with memory problems and 40 staff members

Progress so far (hostel 1)

9 out of 11 hostel staff members recruited (1 not eligible; 1 did not consent)

8 out of 12 eligible hostel residents >50 years with memory problems consented (2 declined; 2 could not be found by researcher to speak to)

10/11 staff members completed at least 4/6 sessions (includes 1-to-1 and group catch-ups)

8/11 staff members completed all 6 sessions (includes catch ups)

6 out of the 8 hostel residents with memory problems followed up at 6 months post baseline (1 person missing; 1 moved to care home)

8 out of 9 staff members followed up at 6 months (1 person left service mid-intervention)

Learning, challenges and reflections from intervention in hostel 1

Complex, loud environment often with emergencies made intervention delivery challenging at times

Busy work environment meant little time for between session tasks

Sense that some content not as effective or understood (e.g. trauma informed care)

Varying feedback on usefulness of stress reduction components

Shortened manual from pilot allowed more time to reflect

Hostel champions reported a positive experience co-facilitating

Difficulties implementing post-intervention hostel 'Action Plans'

Progress so far (new hostels)

Hostels 2 and 3 (recruitment in progress)

18 hostel staff consented to participate so far (none have declined to participate) across both hostels. Approximately 20 eligible hostel staff in total

One hostel champion trained to co-facilitate the intervention in each hostel. Plans to start intervention in both hostels in January 2025

4 hostel residents with memory problems consented so far (out of possible 13 eligible residents across both hostels)

1 resident has declined to participate. All others approached so far expressed an interest

Facilitators trained from 2 new hostels in other organisation, due to start recruitment there in early 2025

Challenges and learning in hostels 2 and 3

High staff turnover

Potential under-estimation of number of older people with memory problems

Advantages of having established neuropsychological clinicians and services associated with hostel

Find out more and get in touch / involved

https://www.ucl.ac.uk/psychiatry/research/mental-health-older-people/home

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RESEARCH Open Access

A qualitative exploration of older people's lived experiences of homelessness and memory problems – stakeholder perspectives

Penny Rapaport[1*], Garrett Kidd[1], Rosario Espinoza Jeraldo[1], Ava Mason[1], Martin Knapp[3], Jill Manthorpe[4,5], Caroline Shulman[2,6,7] and Gill Livingston[1,8]

Abstract

Background The numbers of older people experiencing both homelessness and memory problems are growing, yet their complex health, housing and care needs remain undelineated and unmet. There is a critical gap in understanding what can improve the care, support and experiences of this group. In this qualitative study we explore how stakeholders understand memory problems among older people in the context of homelessness and consider what they judge gets in the way of achieving positive outcomes.

Method We conducted reflexive thematic analysis of qualitative interviews (n = 49) using a semi-structured topic guide, with 17 older people (aged ≥ 50 years) experiencing memory problems and homelessness, 15 hostel staff and managers, and 17 health, housing and social care practitioners. We recruited participants from six homelessness hostels, one specialist care home and National Health and Local Authority Services in England.

Results We identified four overarching themes. The population is not taken seriously; multiple causes are hard to disentangle; risk of exploitation and vulnerability; and (dis)connection and social isolation. The transience and lack of stability associated with homelessness intensified the disorienting nature of memory and cognitive impairment, and those providing direct and indirect support required flexibility and persistence, with staff moving beyond traditional roles to advocate, provide care and safeguard individuals. Memory problems were perceived by frontline staff and older people to be overlooked, misinterpreted, and misattributed as being caused by alcohol use, resulting in pervasive barriers to achieving positive and desired outcomes.

Conclusions Efforts to meet the needs of older people living with memory problems and experiencing homelessness and future interventions must reflect the complexity of their lives, often in the context of long-term alcohol use and current service provision and we make suggestions as to what could be done to improve the situation.

Keywords Memory problems, Ageing, Homelessness, Inclusion health, Qualitative

*Correspondence:
Penny Rapaport
PRapaport@ucl.ac.uk

Full list of author information is available at the end of the article

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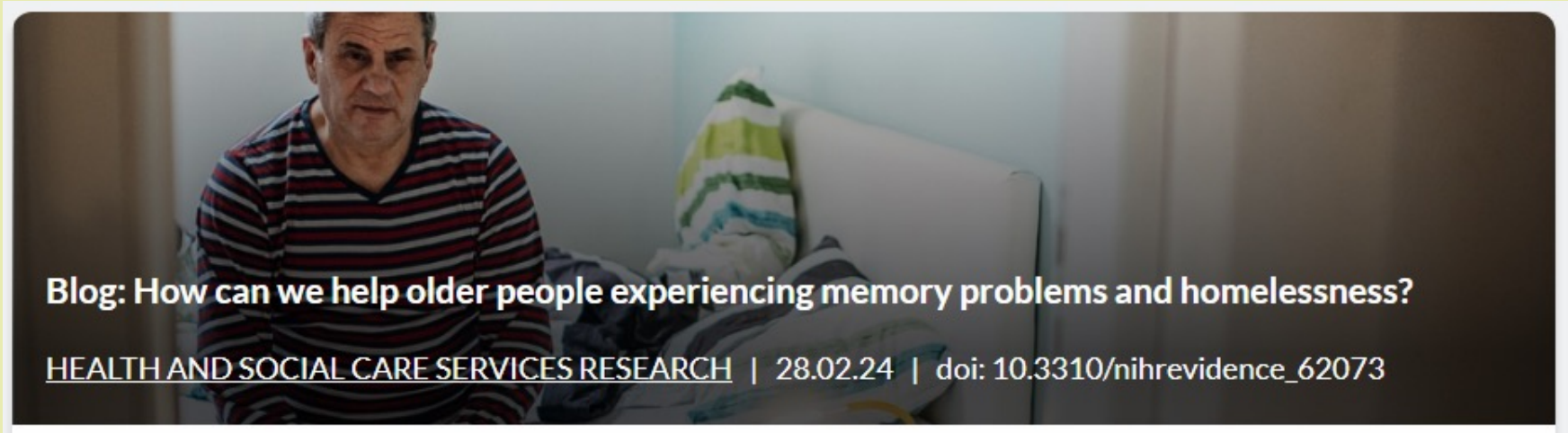

p.rapaport@ucl.ac.uk

Due March 2025

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References

1. Equality and Human Rights Commission. England's Most Disadvantaged Groups: Homeless People. 2016.
2. World Health Organization. Dementia: a public health priority: World Health Organization. 2012.
3. Ennis N, Roy S, Topolovec-Vranic J. Memory 2015;23(5):695-713.
4. Manthorpe J, et al. Health Services and Delivery Research 2019;7(9). National Institute for Health Research.
5. Cadar D, et al. JAMA psychiatry 2018;75(7):723-32.
6. Braun V, Clarke V. Qualitative research in sport, exercise and health. 2019 Aug 8;11(4):589-97.
7. Houston S. Br J Soc Work 2001;31(6):845-61