



OÉ Gaillimh
NUI Galway



Irish Centre for Social Gerontology

Participant Researcher Briefing Series

No. 1

Health and Health Services

A collaboration as a part of the
Older Traveller and Older Adult Homeless (OTOH) study



Institute for
Lifecourse and Society

What is this brief about?

This Brief focuses on health and health services for older Travellers and older people who have experienced homelessness, and it is a part of the Participant Researcher Briefing Paper Series from the Older Traveller and Older Adult Homeless (OTOH) study. The Series is based on collaborative work between Participant Researchers, who were either members of the older Traveller community or older people who have experienced homelessness, and researchers from the Irish Centre for Social Gerontology (ICSG), NUI Galway.

This Brief presents the perspectives of, and the insights gathered by, Participant Researchers on key aspects of health and health services for older Travellers and older homeless people. It shows why this topic might be important in supporting positive health and for the development of flexible home care models for this group. The Brief describes the findings of two research projects, which explored the following questions:

Project 1: How does older Travellers' health compare to younger Travellers' health?

Project 2: Can experiences of older homeless people help cure the sickness in the health service?

Project 1 was completed by Kathleen Sweeney, a member of the older Traveller community, and project 2 by Rory Carroll and Michael Mackey who have both experienced homelessness.

The Older Traveller and Older Adult Homeless (OTOH) Study

The Older Traveller and Older Homeless (OTOH) study is funded by the Health Service Executive Ageing Research Awards. The aim of the study is to investigate life-course and structural determinants of positive subjective health amongst older Traveller and older homeless people, with a view to centralising the voice of these groups in effective, ethical and rights-based models of home care delivery.

With efforts to improve homecare services for older people in Ireland, there is a pressing need to ensure new reforms are accessible and relevant to the most marginalised older groups. The study focuses on older Travellers

and older homeless adults as two such groups, whose views on health and service access are not always considered. There is also little attention given to marginalised older adults who achieve more positive health outcomes, and healthy ageing biographies, and the ways their perspectives might provide valuable information for improving the design and development of policy and practice.

The study involves a series of research strands that prioritise voice and the 'insider perspective' within the research. This includes focus groups with older Traveller and older homeless adults, and service and advocacy stakeholders working with both groups, consultation forums with older Traveller and older homeless adults and stakeholder participants, in-depth life-course interviews with older Travellers and older homeless adults and, as these briefs describe, participant research training.

What we did

This section is described by ICSG researchers.

Those of us in the research team who were Participant Researchers took part in a programme of researcher training. The focus was on the research process, and on one data-collection method: photo elicitation.

The training involved three workshops held in NUI Galway, between January and February 2020. Participants were recruited through project collaborators and through networks of participants who had already taken part in some aspect of the Older Traveller and Older Adult Homeless study.

In the first workshop, five broad themes which had been developed from earlier phases of research were presented to guide the development of research questions. The five themes were: accommodation and home; health services; social connections; identity; and discrimination. All participants had the option to work in pairs or groups, and two of the individuals opted to work together. This meant that four research projects were to be developed – two of which are described in this Brief.

The second workshop focused on the steps associated with photo elicitation as a research method. The ethical issues of research generally, and those connected with photo elicitation specifically, were also discussed. Participants Researchers were provided with a disposable camera with 27 exposures; one participant opted to use their camera phone to take pictures. Participants were given four weeks to take photographs which they believed addressed their research question. Reminder cards and notebooks were provided to encourage Participant Researchers to remain focused on their research question, to reflect on ethical considerations when taking a particular photo, and to note their thoughts about each photograph.

Why is participant research important and who took part

The research processes and outputs on which this Brief is based aimed to advance the voice of older Travellers and older adults who have experienced homelessness, empowering inclusion and voice to tackle health inequities. It reflected the voice-led approach taken in the broader OTOH study.

This training programme was developed in line with international best practice for the activation and empowerment of marginalised groups of researchers (Fitzgerald and Walsh 2016) and was sensitive to a wide range of abilities and backgrounds.

In addition to contributing to the

overall participatory methodology of the project, there were two important reasons why participant research had to be included. Firstly, this research process provided older people from potentially marginalised sections of society with a way to contribute to the research directly; and secondly, it helped ensure that the overall study was relevant to the lives of older Travellers and older people who are currently, or who have recently experienced homelessness.

The backgrounds and individual profile of the Participant Researchers were diverse. In total, four older homeless people took part, as well as one member of the older Traveller community. Four of the Participant Researchers were male, one was female. For the purposes of this study, an 'older person' is someone aged 50 years or over. Participant Researchers ranged in age from their early 50s to their early 70s.

The third workshop concentrated on how to analyse the photos that participants had taken. Participant Researchers were supported by ICSG researchers to engage in a reflective process where they identified and discussed with the group how each photograph addressed their own research question, as well as considering how it fed into the broader aim of the OTOH study. Contributions from other Participant Researchers also informed the analysis. Participant Researchers' comments were recorded and transcribed and it is these materials along with Participant Researchers' notes that are used for the findings of this Brief. Drafts of the Brief were sent to Participant Researchers for review, and follow-up telephone calls were organised to confirm whether or not they would like to change any of their contributions, and to discuss and agree recommendations based on their work in conjunction with ICSG researchers.

What we found: In the Participant Researchers' Own Words

Project 1: How does older Travellers' health compare to younger Travellers' health? – Kathleen Sweeney

This section is described by Kathleen, with editorial support from ICSG researchers.

I am in my early fifties and am a proud Traveller woman from Galway. I am a mother of five and a grandmother of four. I am an activist who focuses on actions for Travellers in my community to be treated as fully equal. I also work as the Coordinator of Galway City's peer-led primary health care programme for Travellers and I care deeply about health care access for Travellers. I was born and raised in Galway city and this is where I live today with my family. I am aware how important it is to look after my health as my mam died in her early 50s and my dad in his early 60s. I would like to see my grand children grow up to be adults with the help of God.



Findings

Photo 1: Pathways to well-being

This photo shows that Travellers have their own dedicated counselling service. This was set up because the standard counselling service wouldn't have been accessed by older Travellers because of stigma and

discrimination. However, rates of depression and suicide are really high among the Travelling community. We've seen so much suicide in our community. To the outside world it's not seen as a problem, but we see it as an epidemic. So, something had to be done around mental health services. This service was set up in Galway city so that Travellers, both young and old, could avail of this service, and not feel excluded. Also, the younger generation is accessing the relevant services for mental health, and they're now educating the older Travellers on how to access these services.

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Photo 2: Traveller rights are human rights

This picture shows a group of Travellers and it's about Travellers fighting for their rights in Ireland's society. We shouldn't have to campaign, and we shouldn't have to lobby. Our basic human rights are a right to health, the right to education, the right to housing. But we have to fight to have these rights given to us and we shouldn't have to in this day and age. And it's not only about accessing services; it's about accessing services with good outcomes.

Nomadism is a big way of life for the older Traveller in Ireland and what has changed and had a big impact on mental health was the anti-trespass legislation to stop the nomadic way of life that Travellers have. This has caused high levels of mental health problems in our community because now Travellers feel stranded. It's much worse for older Travellers. That's all they talk about. They felt so free being able to go from place to place. One older Traveller woman said to me: 'I feel like I'm in prison in my own house'.

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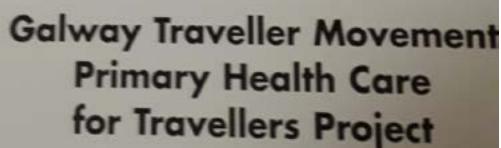


Photo 3: Health from the grass-roots

This picture shows a poster for a peer-led community organisation which was established to address the health inequalities that Travellers face.

It was set up in the year 2000 to train and educate mainly Traveller women. These workers then help to educate older Travellers on their health needs. This is necessary because older Travellers tend to believe in (folk) cures. They're more religious so they often leave their illnesses in God's hands and don't access health services.

These women who are primary health care workers act as the link between the HSE [Health Service Executive] and the Travelling community, bringing issues in the community back to the health service. This makes sure that if services need to be re-designed, this can be done using information coming from the primary health care workers, at grassroots level.

Discussion

This section is described by ICSG researchers, with contributions and guidance from Kathleen.

All three of these photographs relate to the research question of how older and younger Travellers' health compares. They show that older and younger Travellers have had different life experiences, particularly relating to nomadism and education, and this has an impact on their health. Older Travellers' memories of 'life on the road',

the loss of this cultural practice and the feeling they then have of being trapped in their homes impacts the mental health of older Travellers in a way that it doesn't impact on younger Travellers. Younger Travellers being more educated means they have more education around health. It also means that they are more integrated with the settled community. For these two reasons, younger Travellers tend to be less intimidated by doctors and nurses and are willing to ask more questions. Traditionally, older Travellers would never question doctors as they saw them as superior to them. Younger Travellers, especially those who work as community health workers, therefore play an important role in helping older Travellers understand their health, and in accessing effective health care. The community focus of Traveller culture as well as the respect Travellers have for their elders are both important resources which could be used for the improvement of health care for older Travellers.

Project 2: Can experiences of older homeless people help cure the sickness in the health service? – Rory Carroll and Michael Mackey

This section is described by Rory and Michael with editorial supports from ICSG researchers.

Rory: I've spent most of my adult life in and out of homelessness, although I don't really see it that way as the whole of Ireland is my home. As I believe strongly in economic equality and don't approve of the Irish political leadership, I feel it is important to question all state institutions including the health system. But the problem with this is I need the health system because I've so much wrong with me. I worked in construction my whole life so I've a lot of aches and pains.

[ICSG researcher note]: As of April 2020, after this research was conducted, Rory received an apartment from Galway City Council and has left homelessness.

Michael: I left homelessness in 2007 when I got an apartment from Galway City Council, after having spent approximately 20 years without a home. Since then, I spent twelve years as a member of the board of the Galway Simon Community and was

involved with a number of other European groups who lobby for an end to homelessness, such as FEANTSA. I feel strongly that homeless people, particularly older homeless people should be involved in all decisions which impact on them.



Findings

Photo 1: 'Knock it!'

[Rory] What this picture was meant to convey is that this building is so dilapidated. I've been over in the hospital these two years in various outpatient departments and it's always the same story. It's so old, it's overcrowded, there's no ventilation. There could be thirty people in the same waiting room and you're worried about getting a secondary infection. It's not just me. Everyone I'm talking to in these waiting rooms is saying the same thing; even the doctors say to me they don't want to go out there. Hospitals used to be caring, healing environments but that's all gone. If it was down the Docks, people would say it should be knocked. It wouldn't be acceptable in Calcutta; it

shouldn't be acceptable in Galway. The new primary care clinic in Doughiska is great; it's a beautiful clean place. Why couldn't they do that with the hospital? So that's the service they're offering and it's totally unacceptable so I'm refusing all care now. Even with three major conditions, I'm still going to turn my back on the health service. Until they build a new hospital that's fit for service, I'm done with them.



Photo 2: 'Is it worth it?'

[Rory] I've deep vein thrombosis. I can walk maybe 20 yards. The nearest I'd be able to be dropped into hospital is a couple of hundred yards away, when I get a lift off the Simon Community. So it would take me an hour to get through the car park and I'd have to rest. I'd be out in the car park for at least an hour before I'd make it to

the door of the outpatient clinic. If it wasn't for Simon Community and Cope [COPE Galway] I'd never get to see a doctor. When I hurt my leg the Simon nurse came out to me twice a week; the Simon have been great for helping me with my health.



Photo 3: 'Unsettled Bed'

[Michael] These are two chairs, I fall asleep on them. I don't like to sleep upstairs because I have a fear that something might happen, and if I'm downstairs I could be near the door. I've been really sick in the past, with the likes of pneumonia and I would struggle to get downstairs. I've fallen a couple of times coming down.

When I got lung cancer, they got me a chair-lift but I don't particularly use it. I'm afraid because I've had a few heavy goings-over. It's all to do with homelessness really and my bi-polar disorder. It impacts how I feel about my home.

I feel a bit unsettled in my house; I'd be much happier on the ground floor. When I saw the house first I said I'd take it but I knew something wasn't right. I took it because I knew otherwise I'd end up back on the streets. I tried to get a transfer to a one-bedroom bungalow but the Council won't give it to me.

I go off everyday. If I had a home that met my needs, I'd feel more settled. It would have a big impact on my lifestyle. I'd feel more secure. I'd give myself more freedom to spend more time there.

Discussion

This section is described by ICSG researchers, with contributions and guidance from Rory and Michael.

Older people, especially those that have been through many years of homelessness have experienced a lot of health care. For this reason, they can

offer advice on how it should be changed for people like themselves and for others who have a lot of health care needs, or others who are marginalised. With this in mind, Rory and Michael's main insight is that the environment is very important, whether it's the hospital or other health care environment, or the home environment, which is a key part of the foundation of well-being.

However, Rory's experience with the hospital environment has left him feeling even more marginalised because of how it has been designed. With a large car park in front, which he has to cross (and has great difficulty in doing so), Galway's hospital appears not to have been designed with either the car-less or those with mobility issues in mind. In addition, the dark, dilapidated and overcrowded hospital interior is thought to be more 'toxic' than therapeutic as a healing environment.

Furthermore, Michael's feelings about the unsuitability of his home are important. His home may suit someone else but because of his personal situation and experiences he feels unsettled there. For him it is difficult to get enough sleep there, or even to relax there during the day, which drives him to get out of his home as much as he can. For him, this had led to some poor health outcomes, meaning the unsuitability of his home environment, as he sees it, is having a negative impact on his health. Although Michael is yet to receive much home care there, the fact that he feels so unsettled there means home care delivery in that setting would be made more difficult.

For both participants, environments are seen as being essential to feelings of health and well-being. Both participants' photographs illustrate the particular need for a person-centred approach to designing home and health environments for older homeless people so as to maximise what is often termed a person-environment fit.

Conclusion

This section is described by ICSG researchers, in consultation with the Participant Researchers.

Bringing together findings from the two projects presented in this Brief, both projects highlight the importance of temporal context. For Project 1, structural issues have notable impacts on the capacity of Travellers to maintain health and well-being into older age, and to access health services. In Project 2, mental illnesses contributing to homelessness, and physical and mental illnesses or injuries arising out of having spent a long time in homelessness result in negative health legacies, even long after older people have exited homelessness. In addition, evidence is provided that life-course experiences of homelessness impact on how environments, such as institutional health care environments, or home environments are viewed. Furthermore, the lens through which these Participant Researchers view these environments impacts on their capacity to maintain health and well-being.

Leading on from this, for both groups, environments are key to good health and well-being. Older Travellers often feel 'trapped' by their bricks and mortar homes which they cannot escape by going 'on the road' due to the numerous state-sanctioned barriers to this cultural practice. Mirroring this, Michael highlights the importance of a suitable home environment to optimize his cognitive well-being.

Finally, for both groups it would appear important to be sensitive to the dynamics between these marginalised older people and health care professionals. There is a great power distance between these two groups and as such, this impacts the nature and quality of their interactions, with the potential to positively or negatively impact the health of older Traveller and older adults who have experienced homelessness. As can be seen in one of the recommendations below, Kathleen felt that older Traveller women, in particular, should be treated with sensitivity in health care settings as the power differential is stark.

Recommendations and messages

This section is described by Participant Researchers with editorial supports from ICSG researchers.

- Extra resources for the Community Health Worker Programme to help improve the health status of older Traveller men in particular, for example by recruiting and training more male workers.
- Travellers should be part of the decision-making process when delivering services to older Travellers
- Health care delivery to Travellers, particularly older Traveller women, should be culturally sensitive
- Funnel the provision of health care through organisations such as the Simon Community and Cope who have built up relationships with older people experiencing homelessness
- Provide more care in modern primary care units which feel like healing environments and are more accessible
- Once people leave homelessness, they should still have access to homeless services which can positively impact on their health and well-being, as quite often they are still dealing with legacy issues arising from having been homeless
- Older homeless people should be allowed and encouraged to make decisions which impact their own health and well-being. They should be asked 'What would you like to do?'

This Brief has been co-produced by:

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About the OTOH study: This Brief is an output of the Older Traveller and Older Adult Homeless (OTOH) study – 'Life course and structural determinants of positive subjective health among older adult Travellers and homeless people: A voice-led approach to addressing health inequalities in community care'. The study team comprise of Dr. Brídín Carroll (post-doctoral researcher), Prof. Kieran Walsh (Principal Investigator) and Co-Investigators Prof. Diarmuid O'Donovan (Queens University Belfast), Prof. Thomas Scharf (Newcastle University), Prof. Anne MacFarlane (University of Limerick), and Prof. Eamon O'Shea (NUI Galway).

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For further information, please refer to <https://icsg.ie/our-projects/otoh/>, or contact:

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