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Homeless in Europe

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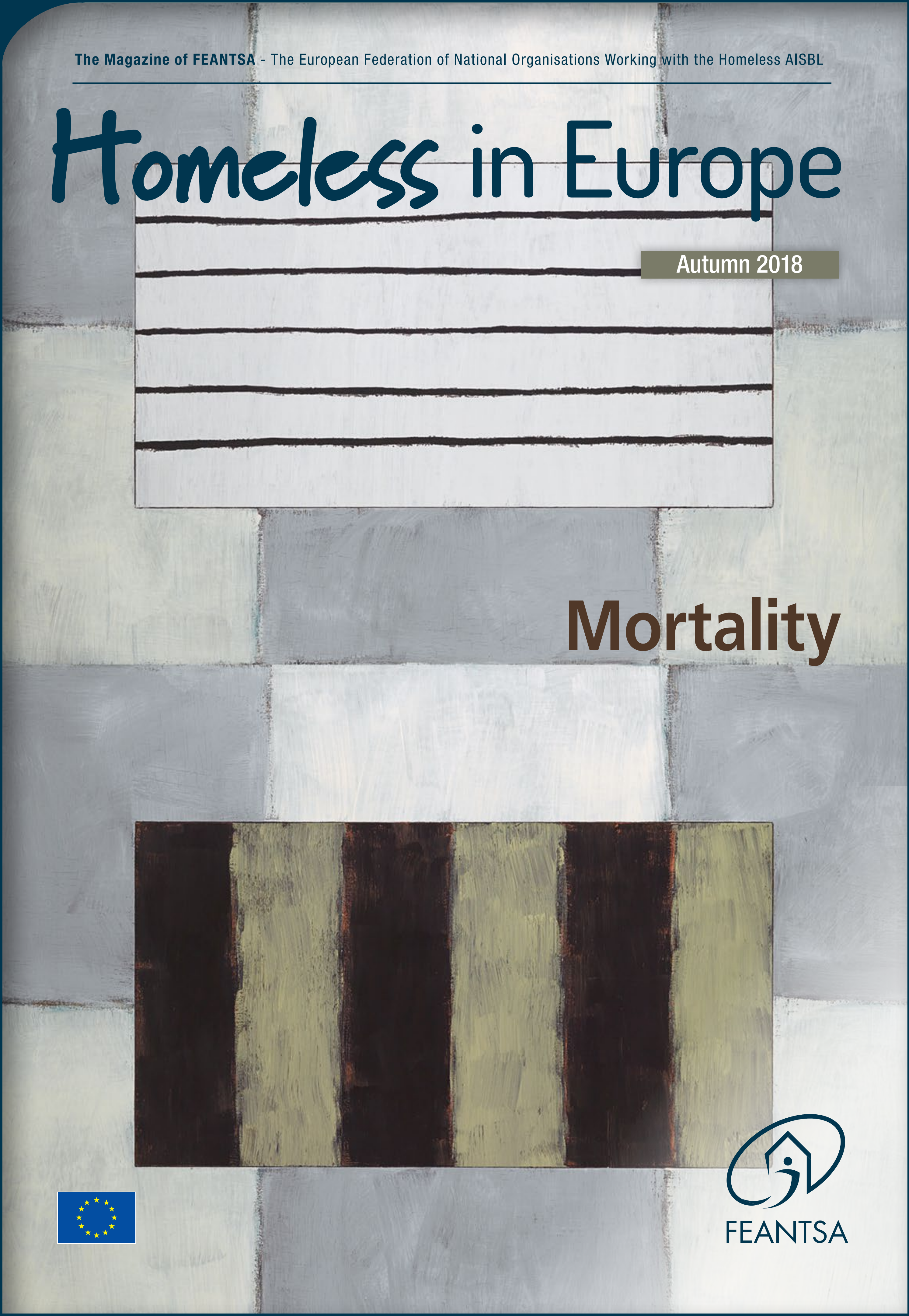
Mortality



FEANTSA

IN THIS ISSUE

Mortality and Homelessness

By **Dalma Fabian**, *FEANTSA Policy Officer*

Thousands of homeless people in Europe are at risk of dying prematurely. The true number is most often unknown as the experience of homelessness is not necessarily recorded on death certificates. As a result, the huge impact homelessness has on people's health and wellbeing, morbidity and mortality often go unnoticed.

That is why we decided to dedicate this issue of Homeless in Europe to raise awareness of the extremely high rates of multiple morbidity and extreme low age of mortality among homeless people. People experiencing homelessness face excessive health inequalities: they have high rates of chronic mental and physical health conditions which are often accompanied by substance abuse problems. While they are the most in need of care, homeless people are the least likely to get them because of the several barriers they face when accessing healthcare.

The statistics are striking: in England, the average age of death for homeless men is 47 years old and for homeless women, it is even lower at just 43 years old. This is compared to 77 years old for the general population. In Denmark, people who live on the street die an average of 20 years earlier than the general population. In his article, Robert Aldridge, one of the authors of the recent Lancet study, highlights that homeless women are 12 times more likely to die than other women of the same age in the general population and men are eight times more likely to die. The article also identifies social and health interventions which are effective in improving the health of homeless people. One such intervention is the provision of housing which is clearly a major social determinant of health. As Nicolas Clement, former President of Morts de la Rue puts it, homelessness is what kills and life on the street is the main cause of death for homeless people. Even if we improve healthcare and make it accessible, available and adequate for people experiencing homelessness, their health outcomes will not improve if they do not have safe and secure housing. Espacio Salud implemented by RAIS in Madrid, responds to this need and offers an innovative housing model bridging social and healthcare as well as palliative care, as explained by Jorge Ferreruela Diaz and Rafael Fernández Manda in their article.

The reality is that people experiencing homelessness are very sick and suffer from life-limiting illnesses which indicates a clear need for palliative care for this population. Palliative care is about meeting the biopsychosocial needs of patients facing serious life-threatening diseases and their caregivers. Palliative care is a human right implied from the international human right to health. But so often homeless people are either very far from receiving access to mainstream palliative care or are even denied it. One of the most important access barriers is stigma and the fear of being discriminated and treated with lack of respect because of their homelessness.

What comes across from the articles written in this issue by authors from around Europe is that a multidisciplinary and partnership approach brings greater benefits for homeless people with a life-limiting illness. In addition, psycho-social support was found to be a crucial part of a comprehensive care delivery for people who are homeless and suffering from a terminal illness in a study by the Universitat de Barcelona which is summarized and reviewed here by Laura Guijarro and Joan Uribe.

LETTERS TO THE EDITOR

We would like to give you the chance to comment on any of the articles which have appeared in this issue. If you would like to share your ideas, thoughts and feedback, please send an email to the editor, emma.nolan@feantsa.org

Anna Klop's article shares a Dutch example of how effective cooperation between the homeless and the palliative care sectors allows professionals to share their specific expertise and to learn from each other. The article also highlights the importance of including experts by experience with their unique perspectives in any consultation or services.

One obstacle for providing quality end of life care for homeless people is the lack of knowledge about their end of life preferences, concerns, needs and wishes, as explained by Wendy Ann Webb in her article. This also shows how crucial it is to look at one's end of life care needs in a social context and recognise the complexities of being homeless.

Last but not least, prevention. We have included a valuable suicide prevention toolkit developed by Homeless Link. The homeless sector has an important role to play in suicide prevention, with so many homeless people at risk and often un-supported. Homeless sector staff therefore need to be trained in suicide prevention and organisations should be aware of how to prevent suicide. It is an inspiring example that can be replicated elsewhere.

Homeless people approaching their end of life should be supported to enhance their quality of life. Resources should be available to help homeless people understand their rights related to end-of-life care, and also to help them voice how they wish to be cared for, by whom and where, and what their wishes are for before and after they die are.

Many homeless people have experienced multiple loss and grief that change their perspective on death and dying and make it even more difficult for them to communicate about this. Leaflets can guide staff on how to initiate conversations about being homeless at the end of life.[1] Homeless sector workers should also be trained so that they understand how important their role can be for homeless people who are dying and that they are better equipped to meet the end-of-life care needs of their clients/users. Staff in homeless services and service users should also be given support to help them cope with the loss of service users, often to a violent death.

Bereavement services should be accessible for homeless people to help support them when needed. In several cities across Europe, public memorial services are organized for homeless people who have died to honour them. This is important in itself and also to raise public awareness about homeless deaths. We hope that this issue will also draw attention to the urgent need to increase access to healthcare and support for homeless people to approach end of life with dignity.

> "Palliative care is a human right implied from the international human right to health. But so often homeless people are either very far from receiving access to mainstream palliative care or are even denied it."

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[1] https://www.dyingmatters.org/page/homeless-people

Life's hard and then you die – with no choice and no voice: Exploring end of life priorities within the homeless population in the UK

By **Wendy Ann Webb**

Wendy Ann Webb is a Doctoral student at the University of Worcester in the UK. Her PhD is exploring end of life priorities within the homeless population. Here she discusses the background to this research and the philosophy underpinning it. Data are currently being analysed and will be reported separately in due course. Associate Professor Theresa Mitchell is the Director of Studies for this PhD. Dr Brian Nyatanga and Dr Paul Snelling are PhD supervisors.

> "[P]eople have come to expect to have choices around the end of life care they may receive. However, people experiencing homelessness do not generally hold the same expectations."

END OF LIFE PRIORITIES

End of life priorities could be defined as the issues and concerns deemed as most important to the person considering end of life. Over recent years, end of life priorities and preferences of the general population have been the focus of much attention in the United Kingdom (UK) as elsewhere in Europe and indeed throughout the developed world. The evidence suggests that most people would prefer to die at home, free from pain with family nearby (1–3). The evidence also points to the importance of peaceful acceptance of death; spiritual concerns being addressed; relieving stress on family members; avoiding a prolonged death; and achieving a sense of control (2,4,5). It has been demonstrated that there are many diverse factors affecting end of life priorities and decision making including; culture and ethnicity (6); spiritual beliefs (7); sexual orientation (8); and personality (9). Research into the preferences of people experiencing homelessness at end of life is sparse. What is known is largely based on research conducted in North America. The exception being a study conducted in the Republic of Ireland (ROI) (10). Some particular and unique concerns and fears were expressed by homeless people in these studies (10–18). People experiencing homelessness want to be accepted and cared for by non-judgmental professionals (15,16,19). They also want to die in the same way that they have lived (20). They are more likely to want to receive CPR (17,18,21) and are happy for medical staff to act as surrogate decision-makers (18,22). Some also voiced a desire to reconnect with estranged relatives (13,14). The assumption that the findings of these North American studies are transferable to the homeless population in the UK should be avoided. There is therefore a distinct call for further research 'outside of North America that provides a platform for the voices of homeless people' (22 p15).

NO CHOICE AND NO VOICE

Choice, dignity and respect have been widely promoted as the core principles underpinning high quality end of life care. As such, in the UK, national campaigns (24) promote discussions around end of life preferences. Individuals are encouraged to record their end of life care preferences: particularly their preferred place of care. And as a result, people have come to expect to have choices around the end of life care they may receive. However, people experiencing homelessness do not generally hold the same expectations. Even in the UK, where healthcare is still free at the point of need, they often have trouble accessing regular healthcare services. They have even greater difficulty accessing specialist palliative and end of life care services. The barriers they face regarding access to end of life care in the UK are well documented (23,25). Many homeless people die alone on the streets in undignified situations. Or else they die in hostels without adequate specialist support. They have been described as the 'doubly disadvantaged': a population having 'no choice and no voice' (26). Healthcare services in the UK are therefore now being encouraged to find creative solutions to address these stark inequalities (25) so that this vulnerable population may receive the same high quality care at end of life that the rest of the population have come to expect.

ENGAGEMENT AND COLLABORATION

As a result of the Care Quality Commission document highlighting gross inequalities in end of life care for marginalised groups (27), many hospices in the UK have now employed 'engagement officers' to address some of the barriers to accessing care. This is a positive step which has resulted in hospice staff and hostel staff meeting together to discuss how to collaborate more effectively. However, there seems to be an underlying assumption, that in the absence of appropriate alternatives, hostels are probably the most appropriate places for people experiencing homelessness to be cared for as their health deteriorates and as they move towards end of life. The problem is, this is an assumption without an evidence base for we still do not know what matters most to individuals experiencing homelessness when they consider their own end of life. End of life preferences, concerns, needs and wishes within the homeless population in the UK have not yet been sufficiently explored and we cannot simply assume that they will automatically reflect those of homeless populations in North America or the ROI. Neither can we assume that they will mirror those of the general population: people who have a home, supportive networks and adequate resources.

RESEARCH UNDERWAY IN THE UK

In the UK, there have been no published research papers to date specifically exploring end of life preferences within this marginalised group. Therefore, this qualitative PhD research project (28) is underway. 21 older homeless participants have taken part. Each participant has been interviewed in depth by an experienced palliative care nurse about important matters of life and death. The questions have been carefully selected to help the participants to talk about their lives, including general priorities in life, and then their concerns, preferences and priorities around end of life. A broad range of open questions were used in the audio-recorded interviews so that participants could explore what is important to them. Data are currently being analysed and findings will be published in due course. It is hoped that the findings will help to bridge the current gap in knowledge and inform new service provision.

This UK research project is underpinned by the philosophy of Maurice Merleau-Ponty (29): the French C20th philosopher who introduced holistic concepts to the philosophical debate of the day. He understood the complexity of human life and experience. His holistic philosophy of 'embodiment' reveals how life experience is multi-sensory, has intertwined physical, psycho-social and spiritual components and always unfolds within a context of time and space. Life is always lived from a unique perspective. According to Merleau-Ponty, a view is always a view from somewhere specific. His philosophy is of immense significance and value in this project exploring end of life preferences within the homeless population. It provides an ideal lens through which to view, discuss and offer an interpretation of the perspectives of the homeless participants. Let us now explore the reasons for this.

THE IMPACT OF HOMELESSNESS ON END OF LIFE PRIORITIES

Merleau-Ponty was Professor of child psychology at The Sorbonne in the early 1950s. This may explain his early understanding of the way that adverse childhood experiences (ACEs) affect the way a person learns to see the world. Decades before it had entered mainstream thinking, Merleau-Ponty understood how past experiences impact upon physical, mental and spiritual health and upon the way we interpret reality and make decisions. He understood about ACEs which are now a familiar concept within social work, mental health, inclusion health and addiction services and are a known risk factor for homelessness. Many people experiencing homelessness have a history of ACEs including abuse, trauma and loss. Many homeless people also feel constrained by their circumstances. Mental illness and addiction issues are prevalent in this population and these illnesses can place further restrictions on the choices available to a person experiencing homelessness. Merleau-Ponty's philosophy helpfully outlines the concept of 'situated freedom'. For example, when people long for a different path in life but feel constrained by the circumstances in which they find themselves: circumstances beyond their control. According to Merleau-Ponty, this is situated freedom: something that most, if not all, homeless people will have experienced. His holistic philosophy helps us to appreciate how the experience of homelessness is likely to impact on the individual's outlook. It helps us to recognise how the embodied-psycho-social-spiritual experience of homelessness can affect the way the whole world is perceived. Additionally, it facilitates an understanding that homelessness is likely to impact upon the way that decisions are made, and future priorities are determined.

CONCLUSION

The lens of Merleau-Ponty's philosophy is a powerful tool to be used in research around homeless health, which is why it has informed and influenced every methodological decision that has been made and is also being used as a framework to organise the findings of the study. His philosophy is capable of sharpening vision relating to the impact of homelessness on decision-making and health behaviours. It clarifies the importance of exploring end of life priorities with this population of society before attempting to plan services to meet their needs. It also highlights the importance of seeking to understand the specific socio-cultural embodied perspective of people experiencing homelessness here in the UK.

All of life's experiences unfold within a specific context of time and space and there is a clear call to explore end of life priorities within the UK homeless population. This PhD responds directly to that call in the hope of influencing service provision for this doubly disadvantaged group of society.

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Dying on the Streets in France

By **Nicolas Clement**, *former President of Le Collectif des Morts de la Rue*

DYING ON THE STREETS?

Since 2002, *Le Collectif des Morts de la Rue* has been releasing the figures on how many people died whilst homeless in France over the previous year. For several years, this figure has hovered around 500 people. Each time, there is outrage in the media. But should there really be? Can we actually say this number of deaths is high? Even if it is estimated that this figure is actually more than 6 times higher, which would be 3000 deaths per year.[2] But even at levels like this, it is difficult to judge whether it is actually high or not. As a matter of fact, there have not been *any* counts of the number of homeless people in France since 2012 and the French office for national statistics, INSEE, has no current plans to do any. It is also the case that it takes such a long time to design and carry out a study of the same type as the one in 2012, if the decision to carry out the study were made today, the results would not be available until 2022 or 2023. And it will actually be even later given that nothing has (yet) been put in motion. In the meantime, we have to make do with guessing: it is assumed, as a result of the huge increase in the number of migrants, that there has been the same increase in the number of homeless people, as well as a significant change in their profiles (the proportion of people who were born outside France already reached 53% in 2012; it is now likely to be closer to, if not higher than, 60%). As such, we don't know which population to measure the number of deaths against. And so it is very tricky to establish whether this number of deaths is high or not.[3]

ARE THINGS GETTING BETTER?

In any event, the stable number of deaths against the backdrop of the rise in the number of homeless people would seem to suggest an *improvement* in the situation. Two factors contribute to this: improvements to temporary accommodation on the one hand and the changing population on the other. Every year, and rightly so, charities hotly criticise the closure of winter shelters and the fact that numerous people are forced to return to the street. Nonetheless, under every successive government,[4] the number of temporary accommodation spaces has continued to grow. In 2004, there were 51,103 bed spaces in temporary accommodation and 110,000 in 2015,[5] which represents an increase of 115%. INSEE counted the number of homeless people in France, at more or less comparable times of year, between 2002 et 2012. The number went from 86,000 to 141,500, a 65% increase.[6] Accordingly, the proportion of people accommodated increased massively, going from 59% to 78%, while the number of people who were not accommodated stayed about the same, around 30,000. Safer conditions, that are also attributable to a marked improvement in the quality of temporary accommodation units, all this contributes to constancy in the number of deaths counted and with it, given that the number of homeless people has sharply increased, an improvement in their situation. The second factor that contributes to this improvement is the change in the profile of homeless people with, in particular, a huge increase in the number of migrants, a population that is generally young and in good physical health.[7]

YOU DON'T GROW OLD ON THE STREET!

This improvement is also demonstrated by the increase in the average age of death. For homeless people, it is still shockingly constant at around 50 years of age, but for people who have stable accommodation, the average age of death increases to 61.6 years, which means almost an extra 12 years of life. And this is very consistent with the changing demographics of people on the street: with an almost identical number of rough sleepers (and therefore without accommodation), the number of deaths has remained stable, while life expectancy has increased significantly with improvements in service provision.

WHAT ABOUT WOMEN?

It is quite striking to think that the proportion of women among the rough sleepers who die is very small, as they only make up 9.2% of the total. But that is completely in keeping with the social makeup of life on the street: while 38% of homeless people are women, they make up only 5% of rough sleepers and 9% of people in night shelters that they have to leave in the morning.[8] This is another demonstration of what common sense leads us to believe: the main safeguard we need is a roof over our heads. Support services cannot stop there but this step is vital.

> "But the main cause of death – we hope that we have shown that – is life on the streets itself. It has to be said and said again – the street kills!"

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[1] This article is mainly based on my experience as president of the *Collectif des Morts de la Rue* from 2015 to 2018, but it also uses research I carried out to publish « une soirée et une nuit (presque) ordinaires avec les sans-abri » [An (almost) ordinary evening and night with rough sleepers] (Editions du Cerf, Paris, 2015). Its conclusions are my own.

[2] A study by CepiDC for 2008-2010 came up with, by matching the data on deaths held by *Le Collectif* and by INSERM-CepiDC, a multiplier of almost 6 in order to come to the 'real' number of deaths. It should nevertheless be noted that this estimate is based on data that is almost 10 years old and, at the same time, the quality of *Le Collectif*'s research and surveys has gotten better. This matching needs to be updated but it is very likely that the multiple has gone down.

[3] When we are dealing with a subject that is as divisive as determining the level of poverty and exclusion, given the amount of money spent on doing so, it is very disappointing not to be able to measure the extent of the phenomenon. This knowledge is nonetheless vital, both to good economic governance and in order to put a stop to delusions and, with them, populism.

[4] This growth has not always been at the same rate but the direction has always been upwards.

[5] Sources: Report by the Court of Auditors: La politique publique de l'hébergement des personnes sans domicile [Public policy on accommodation for homeless people]. November 2011; website: gouvernement.fr/action/l-hebergement-et-le-logement-des-personnes-en-difficulte.

[6] And, actually, this increase is lesser because the 2002 figure was an underestimate, leaving out, as it did, a large number of non-French speaking foreigners, who are counted in the 2012 study.

[7] Even though their mental state can be delicate after the ordeals they have been through to get to France, and even though the very harsh way they are treated (or rather, not treated) can lead to real breakdowns.

[8] Françoise Yaouancq, Alexandre Lebrère, Maryse Marpsat, Virginie Régnier, Stéphane Legleye, Martine Quaglia: L'hébergement des sans domicile en 2012: des modes d'hébergement différents selon les situations familiales, [Homeless accommodation in 2012: Different types of accommodation according to family makeup] *INSEE Première*, 1455, July 2013.

MORE VIOLENT DEATHS

But what do homeless people die of? Is it different from what housed people die of? The main thing to note is that, in almost 50% of cases, the cause is unknown and it is therefore difficult to carry out much analysis. Of those whose cause of death is known, around half die violent deaths, with a lot more murders, accidents and drownings than among the general population - but significantly fewer suicides.[9] Life on the streets is dangerous and these violent deaths are the clear consequence of that. Of course, the younger people are, the more often their main cause of death is violence rather than illness. But this phenomenon is compounded among migrants (there are a lot of accidental deaths in Calais when trying to cross over to England,[10] and, since last year, around Ventimiglia and while crossing the Alps) and among children in shanty towns (fires, accidents, etc.)[11] In this last case, it is inferred (too quickly!) that shanty towns are unsafe (which is correct) and they therefore need to be evacuated at once (and that is what is incorrect: being evicted over and over again without real alternative solutions is actually very damaging; it stops people adaptating to the area and families making it safer, which creates realities that make accidents very likely).

The quality of accommodation or, at least, in the case of shanty towns, stability, are therefore two important conditions for an improvement in homeless people's lives.

DO THEY GET ILL JUST LIKE EVERYONE ELSE?

Among the other half of those for whom we know the cause of death, we see more or less the same illnesses as among the general population, with two differences: they affect them rather less frequently than the general population and the age at which these illnesses arise is generally *very premature*. Age of death is very relevant to this second point. As regards the first point, we find several things that are counter-intuitive, such as when alcohol is involved. When we think about life on the street, we very often associate it, quite naturally, with excessive consumption of alcohol. For some people, this is not wrong and we can all picture that drunk shouting on a street corner. But this image does not apply across the board, it is linked to a kind of distorted reality related to the over-exposure of homeless people: a man on the street with a can of beer in his hand will be seen as an alcoholic; a man at home, listening to music in a comfy armchair, on his third whisky, will on the contrary be thought of as an aesthete and a man of good taste. In actual fact, contrary to popular belief, it becomes apparent that homeless people are *lower consumers of alcohol* than the general population of the same age.[12]

Another specific cause of death is the cold (should we think of it as an illness or a cause of accidental death?). This is much higher than for the general population who are practically never affected in this way, but it still remains marginal. And looking at deaths in terms of seasons does not allow us to pin down winter as a cause. Once again, the reality is very far from popular belief but, of course, if we think about what would happen if the winter shelters no longer existed, the situation would be very different.

WHAT CARE CAN ROUGH SLEEPERS RECEIVE?

Le Collectif des Morts de la Rue launched a study of the ways in which homeless people are treated in care-giving structures. The initial results are complex. Treating homeless people 'normally' is often inappropriate (recommendations like 'bathe your feet regularly' or 'have an injection every morning at home' are almost surreal), but in other cases we find 'alternative' actions that really take people's lives into consideration (such as, for example, an adapted prognosis that allows for a longer care and treatment package than medically necessary in order to give the person some 'breathing space' so they can get their strength up).

Progress still needs to be made and it will be important, for example, to look at how 'no charge prescriptions' will work for these populations. But the main cause of death – we hope that we have shown that – is life on the streets itself. It has to be said and said again – the street kills! And accommodation is absolutely necessary if we really want homeless people to have a life expectancy that is close to that of the mainstream population.

SURVIVING – OR THRIVING?

Even so, we can't just stop once the person has been provided with a roof, otherwise, the search for a sense of purpose which basic questions of survival put on the backburner will come back with a vengeance and will be the cause of numerous suicides or drive people to a slow death after a struggle with depression. Finding meaning in a life that everyone has judged as worthless is a big part of regaining confidence and managing to believe in yourself again. The charity *Les Petits Frères des Pauvres* understands this well, as demonstrated in its instructive slogan, 'give flowers before you give food'. This shows how material things, which are doubtless important, cannot take precedence over something deeper that gives meaning to our existence. The charity *Un Ballon pour l'Insertion*,[13] which organises self-rediscovery breaks for vulnerable people has also internalised this crucial factor: through letting them take part in sport and surpass themselves, it allows people to change the way they see themselves, to rethink themselves and, ultimately, to be able to *take the lead role in their lives* again. Lives that get longer but above all, *fuller*.

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[9] The subject of suicide is controversial because the statistics from other countries do not lead to the same conclusions; what's more, some deaths that are recorded as accidents could be suicides that are not recognised as such. But that is also true of the general population. This debate is outlined in the report on *Le Collectif*'s study « dénombrer et décrire » [Count and describe] published in November 2017 and accessible on the website of *Le Collectif*.

[10] 81 deaths between 2012 and 2016 while trying to cross over to England.

[11] 35 migrants under 15 years old died between 2012 and 2016; all of their parents were foreigners.

[12] François Beck, Stéphane Legleye et Stanislas Spilka: L'alcoolisation des personnes sans domicile : remise en cause d'un stéréotype [Alcoholism among homeless people: challenging a stereotype, *Revue Economie et Statistique [Review of Economics and Statistics]*, 391-392, 2006. The growing proportion of migrants coming in the main from Muslim countries should not reduce this trend, on the contrary.

[13] On the charity's website, several short videos, made by the participants on each break, show better than a long speech could the effect these initiatives can have on people and on the image they have of themselves: www.unballonpourlinsertion.org

Espacio Salud: an integrated model for palliative care

By **Jorge Ferreruela Diaz** and **Rafael Fernández Manda**. *RAIS*

HOMELESSNESS AND HEALTH IN SPAIN

The determining role that social factors have on health is an indisputable fact which is based on innumerable scientific evidence. The **World Health Organization (WHO)** defines the social determinants of health as the circumstances in which people are born, grow up, live, work and age.

Living without a home is a constraint on the health status of people. The three dimensions of well-being (i.e. physical, mental and social), identified by the WHO as a good state of health, are threatened by the experience of homelessness.

Although there is no specific research in Spain on the impact of homelessness on the health of people who experience it, some data from the **Survey of Homeless Persons conducted in 2012 by the National Institute of Statistics**[1] indicate the worst health status and the worst conditions of life that can favour it:

- 41.4% of people in a situation of homelessness considered that their state of health is not good.
- 30.7% of people experiencing homelessness claimed to have a serious or chronic illness.
- 19.8% of people experiencing homelessness reported not having a health card, this implies a barrier to their access to the health system, proper care and monitoring of health.

The barriers that hinder the access to health services as well as the monitoring of a homeless person's health are many: The complexity of access to health rights, the lack of accommodation that guarantee a space for rest and medical recovery, the lack of a family network and/or support that provides assistance and emotional support, the affordability of medicine, the inflexibility of care networks which usually make it difficult to access combined profiles (convalescents, drug addicts, mental health, etc.). This highlights the need for flexible resources to promote timely responses to the complex health needs of this group.

The perceived health of people indicates the important impact that homelessness has on physical well-being. It is difficult to have healthy habits concerning food, hygiene and rest when a person is in this situation. These same conditions obviously influence the possibility of facing the end-of-life process of palliative people in conditions of dignity and quality.

The control of symptoms, which is key for the intervention in palliative care and convalescence, is very difficult to deal with if the patient does not have an address. The homeless, once discharged from the hospital, usually return to a shelter or similar or to the street and in none of these cases can the specific and necessary support for their final life process be provided. Mostly, these situations involve difficulties in adhering to treatment since continuous care is abandoned, the patient relapses and keeps returning to the emergency services.

ESPACIO SALUD (HEALTH SPACE)[2]

The service

In 2011 **RAIS** observed a reality that has not been addressed neither by the public sector nor by civil society organisations that worked with homeless persons in these processes. Due to the lack of attention to this group RAIS has developed a campaign with the slogan "The hospital discharge is bad news if you live in the street" which is a project that first opens in Madrid – including palliative care in 2014- and will be replicated further in the cities of Murcia and Córdoba.

Espacio Salud is a programme which responds to the detected needs. It applies a methodological change in its approach and implements an innovative housing model. Both aspects are aimed at acting as a bridge between social and health care networks, improving the health (symptoms) and care for palliative homeless people as well as promoting improvements in their general situation through a process of rising social mobility.

It is being developed in apartments, avoiding the concept of a centre, in order to be as close as possible to the idea of a traditional apartment. Although the apartments are located in social action centres, each one of them has an individual and independent entrance from the shared community space to promote the feeling of belonging to the community. It is not a parallel resource to the hospital centres, but we make use of the network of standardised health services such as citizenship in general.

Palliative care and the end-of-life stage

Persons under **palliative treatment** need references within which they can move while at the same time the functioning of the programme has to be consistent with their treatment and degree of autonomy. It is necessary to match those aspects of their lives that can give them an identity with those that challenge their mourning process at the end of their lives. With a person-centred model, working to improve the quality of life, responding to individual needs as required, without losing the intervention focused on the present, on the experience of now. Based on an absolute **respect** for autonomy during the end-of-life stage and on the **belief** that all persons have a dignified life/death, the right to equal treatment and non-discrimination. Guaranteeing access to and exercising

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[1] http://www.ine.es/dynt3/inebase/es/index.htm?padre=1870&capsel=3249

[2] https://raisfundacion.org/en/right-health

of citizenship rights and generating a sense of social belonging.

In order to prepare the end-of-life process, we are providing for all the needs of the fundamental dimensions: symptom control, psychological, spiritual, emotional support and grief support with the aim of achieving and maintaining the highest quality of life for those who need it. It is important that each person is the protagonist of his or her process, making decisions that they consider appropriate, choosing the best way to spend the last moments of their life with support and closeness. According to this focus, it is necessary to start the palliative treatment well in advance, not delaying it to a near-death phase of the disease.

> "The control of symptoms, which is key for the intervention in palliative care and convalescence, is very difficult to deal with if the patient does not have an address."

The wish expressed by people who learn about the prognosis of their terminal illness requires professionalism, moral maturity and extraordinary sensitivity so that the patient's request can be fulfilled. We ensure that each person can freely control their body and their life when freely choosing the way to die. To carry out this work, a **professional multidisciplinary team is required**:

- From a **health perspective**: registered nurses and nursing assistants address symptom control, search for comfort, pain relief, nutrition, supervision of pharmacological treatments, mobilisations, accompaniment, etc.

- From a **social perspective**: professionals in psychology, occupational therapy and social work provide person-centred support in order to develop and accept grief respecting each person's pace, recognising their state of mind, helping to overcome fears, being readily available, providing all possible comfort, listening, creating areas of reflection concerning family relations and, whenever possible, facilitating family reunions.

Furthermore, at **community level**, we are developing a network that joins the forces of other services and entities at our disposal. Continuous coordination with the home-based health care teams (ESAD) for symptom and treatment control, and with the Spanish Association Against Cancer where people participate in workshops and support groups with psycho-oncologists.

The intervention is not a product of intuition, nor of the state of mind at a particular moment, but rather of a cautious and informed reflection which is discussed and shared among all team members, considering and aware of the preferences of each person. It focuses on:

- Offering a secure space providing comfort care;
- Ensuring health monitoring, adherence to treatment and pain control;
- Guaranteeing access to resources and services made available by the public health system for citizens for the home-based treatment of people receiving palliative care;
- Psychologically and emotionally accompanying the gradual acceptance of the patient's palliative reality;
- Supporting the resumption and/or improvement of family relations and other support;
- Guiding leisure time activities;
- Informing about and supporting in the preparation of advance instructions to choose which type of medical care patients would like to receive at their end-of-life stage;
- Guiding on economic and legal arrangements;
- Encouraging areas of autonomy.

Main results and challenges for the future

In **Espacio Salud**, 25 people have been accompanied in their end-of-life process; during this time, they have spent an average of 3.4 years on the street. The percentage has been shared equally between men and women. The palliative processes were cancer related. According to the National Institute of Statistics, life expectancy at birth in Spain is at 83 years; seven people have died before reaching the age of 50 years and 16 have died before the age of 66 years, which indicates a decrease in life expectancy of almost 20 years.

As a challenge for the future, this programme has to be reinforced and expanded across Spain by providing a **specialised response that combines social and health intervention**, offering a space of security, rest and stability that contributes to the improvement/stabilisation of health. In doing so, space is essential to ensure the coordination between social and health services in order to guarantee accessible and continuous treatment of patients in palliative care. It is necessary to accompany the patients during their end-of-life process respecting the principles of security, dignity and stability.

Stronger Together in Palliative Care for the Homeless

The use of consultation between professionals from different disciplines to improve palliative care for homeless people

By **Hanna Klop**, **Bregje Onwuteaka-Philipsen**, *Amsterdam Public Health Research Institute (APH), Department of Public and Occupational Health, Expertise Centre for Palliative Care, VU University Medical Centre, Amsterdam, Netherlands* and **Jaap Gootjes**, *Hospice Kuria, Amsterdam, Netherlands*

INTRODUCTION

Palliative care for seriously ill homeless people is offered late, if given at all. In order to improve this palliative care, a collaboration between the hospice and social care has been set up in Amsterdam. We have investigated whether there is a need for this consultation for other organizations and situations in the Netherlands.

EXISTING COLLABORATION IN AMSTERDAM

Five years ago, a collaboration in Amsterdam between Hospice Kuria (a high care hospice where homeless people are regularly admitted), the social care of HVO Querido (an organization with multiple locations for short-term and long-term shelter care and home support), and the Salvation Army started. Within this collaboration, social workers can request nurse consultations from Hospice Kuria about palliative care for homeless people at an early phase. Subsequently, the Kuria nurse visits the patient and advises the social worker. This allows the patient to remain in their familiar environment for as long as possible. If the care becomes very intensive, the patient can be admitted to Hospice Kuria. Then, the professionals of the social shelter advise the hospice nurse on how to deal with the patient. These shelter professionals have often known the person for a long time. As a result, they can give more insight into the history, behaviour, and needs of the person (see Box 1 with practical example).

As a result of this reciprocal exchange of knowledge and experience, referred to in this article as 'consultation', both professionals working in social (shelter) services and professionals working in the hospice or in a nursing ward are being better equipped to provide good palliative care to people who are homeless. In addition to this, the patient who is homeless is already familiar with the hospice nurse and the hospice.

Box 1. Practical example of consultation

54-year old Harry has been with a social shelter in Amsterdam for more than five years. His care provider, a social worker, is familiar with his long history of homelessness, and notices that he is very tired. His sitution continues to deteroiorate and the Municipal Health (GGD) doctor and the social shelter team are discussing his situation. They indicate that they expect Harry to probably have no more than six months to live. Harry indicates that he would like to stay with the social shelter for as long as possible. The social worker calls a nurse from Hospice Kuria and explains the situation. The hospice nurse then goes to visit Harry. She gives the social worker, the GGD doctor and nurse advice on palliative care, allowing Harry to stay as long as possible at his familiar place of residence. When Harry's disease progresses, he is transmitted to Hospice Kuria. His social worker visits him regularly and gives advice to Kuria's nurses and doctor. This advice is for example about dealing with Harry's alcohol addiction, his need for self-control, and his wish to stay in touch with friends.

Palliative care is an approach that, according to the World Health Organisation (WHO), improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

Homelessness is defined in various ways in the Netherlands. *Actual homelessness* is used by the Dutch Statistical Office (CBS). This concerns more than 30,000 people who live on the streets, or stay in a social short-term shelter, or are sleeping rough. *Residential homelessness* concerns residents of 24-hour shelter facilities. In this article, we use the definition of homelessness by which we mean both residential and actual homelessness.

OUR RESEARCH PROJECT

To get more insight in whether the above approach might be useful elsewhere, in our research, we examined whether there is a need for consultation specifically aimed at palliative care for the homeless in the Netherlands. As a part of the project, in 2016 focus group meetings were organized with 19 professionals (4 focus groups with *a.o.* nurses, physicians, street pastors, social workers) and 15 people who were homeless or who stayed in a nursing ward (2 focus groups). In the following sections we describe the results of these focus groups. We discuss what makes palliative care complicated for this target group, what homeless people think of the idea of consultation, whether professionals need consultation, what challenges exists for developing consultation, and what is needed besides a consultation for providing good palliative care.

WHAT MAKES PALLIATIVE CARE FOR PEOPLE WHO ARE HOMELESS COMPLICATED?

> “Furthermore, homeless people want to be taken seriously and they want tailored care.”

The focus groups showed that people who are homeless and in the palliative phase have complex problems and specific care needs. They often have a long history of physical disorders, in combination with problems concerning housing, income and debts, addiction, psychiatric disorders and / or intellectual disabilities. Their disease course is also often unpredictable. For professionals, it is frequently difficult to estimate the life expectancy of a homeless person when seriously ill. Besides this, at the end of life there are often transitions between settings; for instance, from night shelter, to emergency admission to a hospital, to a nursing department.In our focus groups, homeless persons themselves have indicated that they experience that many professionals have insufficient knowledge about specialist (medical) care and the characteristics of the target group. Professionals often know a lot about problems in one discipline, but not in another. In the last phase of life, addiction to alcohol and / or drugs is often still present, and pain management can be difficult. Also, aggressive behaviour and care avoidance behaviour occur regularly. This is behaviour that professionals from outside social shelter or mental health care have less experience with. Furthermore, it often happens that someone who is homeless or has no contact with family and friends.

WHAT DO HOMELESS PEOPLE THINK OF CONSULTATION?

Homeless participants often suggested practical consultations during the focus groups, such as with a social worker or an expert by experience who helps them to express their needs. In addition, they saw consultation as a good way to train professionals to show understanding and attention, something that, according to them, not all caregivers are good at. Furthermore, homeless people want to be taken seriously and they want tailored care. If professionals start working more together, they believe there are more opportunities to offer appropriate care because professionals can learn a lot from each other.

DO PROFESSIONALS NEED CONSULTATION?

Professionals indicated the need for consultation on how to deal with problems that occur at the end of life. Professionals saw the consultation of added value in the area of sharing specific expertise and knowledge that they formerly would have had little or no access to; they see it as a means to connect medical and social professionals. This bundling of knowledge is essential due to the complexity of problems among homeless people. Above that, professionals need a better recognition of the palliative phase of a homeless patient. The consultation function can help to accomplish this. Finally, the consultation can also contribute to raising awareness and creating openness to discuss the end of life through providing information, training or coaching in delivering tailored care.

HOW CAN THIS CONSULTATION BE BEST ORGANIZED?

Professionals often mentioned that the practice of palliative care for homeless people differs per city, professional, and organization. Much depends on the expertise and knowledge already present. It is important to adjust the consultation according to this expertise and knowledge. Therefore, it is necessary to assess at a local level what is needed for consultation and how it can be financed. A point of attention is that this consultation will be tuned in with existing consultation functions for palliative care which are not specifically aimed at the homeless by providing them with basic knowledge about the target group in the palliative phase, and by informing them about the new specific consultation function. Box 2 gives an impression of the aforementioned subjects that are regularly overlooked and where a consultant could help.

Box 2. Subjects for consultation and knowledge

- Multi-problem and diversity of the target group. E.g. complex somatic problems in combination with addiction or intellectual disabilities.
- Cultural and religious differences. E.g. insight into culture and religion so that needs are better understood.
- Care avoidance. Recognition and dealing with care avoidance and refusal.
- Illnesses and diagnoses. Specific clinical pictures that are characteristic of the target group in the final phase of life.
- Pain treatment. E.g. pain relief in case of addiction problems.
- Discussing the palliative phase with the person who is homeless. Discussion is sometimes difficult, e.g. because of fear of death or no confidence in the professional.
- Addiction and substance use. Knowledge about how to deal with addiction and substance use and the course of the palliative phase.
- Process of dying. The process of dying is often complex due to the above subjects.
- Aggressiveness and behavioural problems. Many professionals have little experience with this type of behaviour.
- Use of volunteers. Advice on how volunteers can be deployed specifically for this target group.
- Aftercare for professionals and fellow patients. For professionals because they have provided intensive care, for target group due to small network and relationship with fellow patient.
- Funeral, commemoration and rituals. Dignity is very important for the target group.

Participants of our focus groups mentioned various characteristics that a good consultant ideally has. A good consultant connects organizations and disciplines, takes initiative, represents multiple organizations and knows the practice from the inside. A low-threshold consultant who is flexibly accessible is of added value, given the problems and the lifestyle of the target group.

WHAT IS NEEDED IN ADDITION TO CONSULTATION FOR GOOD PALLIATIVE CARE TO THIS TARGET GROUP?

A knowledge platform where knowledge is shared with other professionals was also mentioned by participating professionals in the focus groups as something needed in practice. It can ensure that professionals are generally better and more broadly informed, also from the angle of other disciplines. For people who are homeless, the deployment of an expert by experience appeared to be important. This person would be able to assist them when they are seriously ill, for example in contacts with care providers.

CONCLUSION

There is a need for a reciprocal form of consultation regarding palliative care for people who are homeless. Professionals in social care who provide care to incurably ill homeless people want to know more about palliative care options. Professionals who offer palliative care to homeless people in hospices, nursing homes and hospitals, in turn, need advice on how to deal with this target group. Homeless people see consultation as a means to better align palliative care with specific individual needs and often complex problems.

Palliative care for homeless people.

Original Report by Bernat Carreras, Jordi Valls, Sylvia Regueiro, Ivette Morilla, Joan Uribe, Cristian Ochoa. Anuario de Psicología, Universitat de Barcelona (2017) Volumen 47, (pp. 95-106)

https://www.sciencedirect.com/science/article/pii/S0066512617300144

Review of the article by: **Laura Guijarro** and **Joan Uribe**

The lack of access to housing has increased in Europe since the beginning of the economic crisis and the subsequent refugee and migration crisis. Lack of housing is associated with greater health problems and higher premature mortality, especially in the homeless population. In the United Kingdom for instance, the life expectancy of the general population is 77 years, while in the homeless population it is 47 years for men and 43 years for women. In Denmark, people who live on the street die an average of 20 years earlier than the general population (Feantsa, 2015).

Although the interest in palliative care (PC) and in offering a dignified death to people has been growing in Europe in recent decades, in the homeless population it remains a need not yet covered.

This study examines the quality of PC, its degree of development in Catalonia, and highlights the program promoted by the La Caixa Foundation, directed by the Catalan Institute of Oncology (ICO) and endorsed by the WHO. This program has promoted the creation of 42 psychosocial care teams (EAPS) to complement the care provided by the healthcare teams of the Spanish National Health System to patients with advanced diseases and their families. Some of these EAPS (constituted of psychologists, social workers, doctors, pastoral agents and volunteers) extend their work to more specific and vulnerable populations such as the homeless.

The first part of the article it is about homelessness, the different situations people who are homeless can find themselves, and the risk factors that can lead to homelessness.

The second part presents the health variables (comorbidity and mortality) and covers the main concepts of PC in general, as well as the palliative needs of homeless people.

Finally, in the third section shares the concrete experience of clinical psychologists who work with homeless patients with advanced or chronic diseases.

1. HOMELESSNESS

To provide a better understanding of homelessness, the authors present the typologies of homelessness and residential exclusion established by FEANTSA in 2005. The ETHOS typology covers all living situation which amount to homelessness including: the 'roofless', who sleep rough; the 'houseless' who have a place to sleep but only temporarily in a shelter; and those who living in insecure or inadequate housing.

The authors describe the situation of homelessness at a European level, highlighting the work of Busch-Geertsema, et al. (2014), that analyzes the evolution of homelessness in Europe, noting an upward trend in the last 5 years in almost all European countries.

Regarding Spain, it is noted that Catalonia, with 21.3% of the state total, is the autonomous community where most homeless people live. In the specific case of the city of Barcelona, there is an upward trend, with around 3000 homeless people (with almost 1000 living on the streets) according to the count carried out by the XAPSLL in 2017. There is greater political will to end homelessness supported by the Barcelona City Council's Plan for the Fight against Homelessness 2016-2020. The survey shows that the profile of homeless people has demographic characteristics that are increasingly similar to people "integrated" in society (with an increase in homelessness due to non-payment, housing losses and unemployment) and analyzes the causes, situations, and events that can lead a person to end up in a homeless situation.

2. PALLIATIVE CARE FOR HOMELESS PEOPLE.

Lack of housing is associated with greater health problems and sometimes it is even the direct cause of mortality, as well as of complexity of treatment or recovery. Some homeless people, particularly those who sleep rough and those using shelters for long term, are affected by multiple morbidity, including drug and/or alcohol abuse, and mental and physical health problems. According to the study of Uribe and Alonso (2009), the most prevalent diseases in homeless people are in this order: musculoskeletal disorders, cardiovascular disorders, mental disorders, drug addictions, neurological disorders, digestive disorders, and respiratory disorders.

The authors show that among homeless people there is less use of health services and that, in addition, providers of these services often lack the resources and flexibility to care for these people. That is why they propose to have a protocol for homeless after hospital discharge, as well as having specialized centers with sufficient resources, as is also included in the National Strategy for Homeless People.

The main objective of palliative care is to reduce the symptoms and pain and to provide comprehensive care including physical, psychological, and/or spiritual care. Palliative care should cover the full evolution of the disease, provide care to both the patient and their caregivers, and should respond to any needs they may have. In the case of palliative care for homeless people, it is necessary to start the approach well in advance in order to guarantee interdisciplinary care. It must be considered that homeless people are extremely vulnerable and also more likely to suffer discrimination or to experience barriers to access to health care due to their socio-economic situation, the presence of diseases such as HIV, a history of addictions, etc.

Despite the fact that palliative care is a universal right and that homeless people have special needs, the report concludes that today most homeless people die without any support. The authors refer to a FEANTSA report (2015) in which they analyze some of the barriers faced by the homeless when they attempt to access care at the end of their lives. These include: overly strict hospital norms, lack of confidence in the health system, and difficulty in accessing residential palliative care since the services are not provided in residential centers of a temporary nature.

3. OUR EXPERIENCE: ATTENTION TO THE PSYCHOLOGICAL NEEDS OF HOMELESS PATIENTS IN SITUATIONS OF ADVANCED CHRONICITY AND/OR END OF LIFE

An interdisciplinary approach is needed, bringing together expert professionals in end-of-life care and expert professionals working with homeless people, so that care for these people is as comprehensive as possible. That is why there has been a confluence between the team Serveis Socials Sant Joan de Deu in Barcelona and the psychosocial care team (EAPS) of the Parc Sanitari Sant Joan de Déu. The result of this collaboration between professionals are presented in the article. The collaboration agreement between both teams lasted 2 years (from August 2015 to August 2017) and during that time specialized psychological care was provided to homeless users of Social Services by a clinical psychologist from EAPS. The patients treated were not only patients at the end of their lives, but also complex chronic patients (PCC), having multimorbidity, advanced fragility, or a clinical condition that involves demanding management. Within the CCPs mainly the MACA subgroup have been served (patient with advanced chronic disease). In the two years of collaboration, 21 patients were attended over a total of 142 residential places divided into two centers, one with 52 places and the other with 90 places.

The authors report that one of the main difficulties was to publicize the psychological care service, so one of the objectives was to publicize the criteria for referral and that workers could detect in the centers those residents with advanced disease that could benefit from specialized psychological care. The referral, therefore, always started from the worker or social educator of reference. The referral criteria were divided into: presence of advanced disease, affective symptomatology, anxious symptomatology, substance use, and problems of adaptation to the disease. Almost all the referred patients presented one or more psychiatric diagnoses, dual diagnosis being the most common comorbidity.

The visits were made in the two residential centers of Sant Joan de Déu Serveis Socials, and in the social inclusion flats also belonging to Sant Joan de Déu Serveis Socials of Barcelona. Group treatment sessions focused on both users and professionals of the centers were also carried out.

The report concludes that there is a significant gap in terms of psychological care for homeless people with advanced disease and a great lack of knowledge of homeless health. It is therefore necessary to establish alliances between palliative care professionals and professionals in the field of homelessness. Having a referral protocol for homeless people after hospital discharge, as well as specialized centers and flexible health care are among other proposals proposed by the authors.

> “Palliative care should cover the full evolution of the disease, provide care to both the patient and their caregivers, and should respond to any needs they may have.”

Inclusion health - understanding extreme health inequity and what works to reduce it

By **Robert W Aldridge**, *Institute of Health Informatics, University College London*
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> "Housing within an ordinary community setting should be an overriding policy objective of inclusion health."

"Social exclusion is deprivation upon stilts".[1] This was the turn of phrase adapted by Michael Marmot in an accompanying commentary to our recent systematic review and meta-analysis of morbidity and mortality in homeless individuals, prisoners, sex workers, and individually with substance use disorders in high income countries.

Prior to our review much was known about the association between deprivation and health outcomes, using measures such as neighbour deprivation and occupational status, not least because of the work of Michael Marmot. However, these existing measures of deprivation are often collected on housed populations and therefore do not provide evidence on the extent of health and equity experienced by populations who are subjected to deep social exclusion.

In preparation for a series in The Lancet on inclusion health we performed a rapid review of the morbidity and mortality literature in this area and found extensive evidence on the highly overlapping nature of inclusion health populations, which in this instance focused on homeless individuals, prisoners, sex workers, and individually with substance use disorders. The literature also indicated at severely increased mortality in inclusion health groups in comparison to the most deprived populations in the general population.

Our rapid review did not identify any previous systematic attempt to summarise morbidity and mortality for inclusion health groups and we therefore decided undertake a full systematic review and meta-analysis. We looked at studies published between 2005 and 2015 and included results from observational, interventional studies and prior systematic reviews and meta-analysis. We decided to focus on high income countries - those that are wealthier as defined by the World Bank[2] - as we believed that the risk factors for poor health in these countries were most comparable.

Our view highlighted the extreme extent of inequity faced by inclusion health populations.[3] We found that women in these groups were 12 times more likely to die than other women of the same age in the general population and men were eight times more likely to die. We also looked at the underlying causes of these deaths. Injuries, poisoning and other external causes of death - in men and women - were found to have the most extreme risk of death. Whilst these causes were associated with the highest risk, we found that relative mortality was increased across all sub-categories for we had sufficient data to analyse, including infections, mental health and behavioural disorders, cancers, and cardiovascular disease.

When we examined the volume of previous research that had been taken in each of these groups of disease, we found that infectious diseases and Mental and Behavioural disorders were the two most studied ICD 10 categories. Injury and poisoning only accounted for a small amount of the extracted data despite being in the group with the highest relative increased mortality risk.

Some caution is required interpreting our summary estimates of relative mortality. We found a great deal of variation in the outcomes across the different groups, but we were unable to fully explain this variation with additional statistical analysis. We were therefore unable to understand why health outcomes varied which is an important area for future research. Our review only looked at published research and we limited our search to results from 2005, and as a result we will therefore have missed literature published outside of the academic arena and we were unable fully examine how changes in mortality have occurred over time.

Linked to the systematic review on mortality was an accompanying paper that aimed to identify social and health interventions with evidence for improving the physical and mental health of inclusion health groups.[4] In this paper we found evidence for a broad range of interventions that worked at the individual level. Case management was shown to improve care coordination and mental health and outcomes. Contingency management (ie, vouchers or incentives), motivational interviewing, and cognitive behavioural therapy were found to have some benefits for substance use disorders and in therapeutic communities for reincarceration. Existing studies showed that disease prevention can be achieved through a harm reduction including, for example, needle and syringe programmes, substitution programmes, and safe injecting site programmes that can reduce risk behaviour, risk of blood-borne viruses, and overdose risk.

Individual based interventions will improve the health and well-being of those receiving these interventions, but wider social, economic, housing, education approaches that tackle the root causes of exclusion are required if we are really going to make large improvements for inclusion health. Our review found less evidence of what works in these areas, but policies that focus on reducing poverty and deprivation, particularly among families and young children at risk of maltreatment, are those that are likely to have the greatest impact.

Housing within an ordinary community settings should be an overriding policy objective of inclusion health. This means that housing should be open-ended, flexible and coordinated. People should be given the option of staying in ordinary housing - with appropriate support if and when required - rather than being obliged spend periods in other communal settings, particularly if this is against their wishes.

Barriers in accessing health, and non-health, services are a key problem for inclusion health populations. A effective way identify and accelerate the removal of these barriers is to involve and work in close collaboration with people with experience of social exclusion. As part of our review, we undertook an engagement event with experts by experience - individuals with experience of social exclusion, such as homelessness, addiction, or incarceration. Working with these experts barriers to accessing services were identified, including administrative and documentation requirements (such as proof of address), language, culture, and even fear of the service. Luck was often described as the way these barriers had been overcome, but better care coordination and the use of peer advocates were identified as systematic ways to improve access. The experts also emphasised the importance of non-healthcare related interventions - the most important of these was housing.

To move things forward we proposed priority areas for further work. Inclusion of populations are often absent from routine administrative data collection - an issue that should be addressed as without these data these groups will remain invisible to politicians and policymakers and therefore too easily ignored. Such data will also enable the monitoring of outcomes over time to facility a better understanding of what is improving their outcomes at the regional, national and international level. Additional evidence on upstream interventions, such as employment and education, that are likely to be beneficial to inclusion health populations needs to be generated as a matter of priority.

Our studies therefore highlighted the extreme inequity of inclusion health, along with evidence on what can be done to start to improve this situation, and the areas for further research. Tackling this problem requires the organised efforts of society, and as Michael Marmot concluded "We need the involvement of society as a whole to tackle the causes of the causes of social exclusion and its dramatic health consequences. This approach might save money and it is the right thing to do."

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How can we prevent suicide in homelessness services?

By **Tasmin Maitland**, *Head of Innovation and Good Practice, Homeless Link*

Homeless Link is the membership body for organisations ending homelessness in England. We commissioned 'Suicide prevention: Guidance for homelessness services'[1] in response to concern from our members about the challenges and anxieties their teams were facing around suicide risk. These conversations raised two main areas of concern: how to assess and reduce the risk of suicide in services, and how to support staff teams following a death by suicide. This article outlines the key elements of our guidance and how we hope it will be used to prevent suicide in homelessness services.

SUICIDE AND HOMELESSNESS – AN INCREASED RISK

There were 5,965 suicides registered in the UK during 2016.[2] People who are homeless will often be in more than one group with a high risk of suicide including, for example: "men, people who self-harm, people who misuse alcohol and drugs, people in contact with the criminal justice system".[3] The trauma of being homeless and related issues, such as poverty and isolation, also increase risk. As a result, the homelessness sector has a vital responsibility for suicide prevention, yet many organisations are unsure of their role.

Where suicide prevention rests at the level of individual support work and risk assessment, there are rarely specific training and protocols in place. This means that often support workers lack confidence to talk about suicide and may feel anxious that raising this issue could increase the risk of self-harm or a suicide attempt. They may seek to make a referral to mental health services, only to find that their client does not meet the threshold for statutory support, and not know how else to proceed, exacerbating anxiety for both worker and client.

We recommend that organisations take a strategic approach that makes suicide prevention a shared responsibility and part of everyday practice, rather than something that individual workers only face in a crisis. By doing this, staff teams will be able to have conversations about risk and safety, knowing how to follow protocols to escalate any concerns and being confident that they are doing the right thing to keep people safe.

DEVELOPING AN ORGANISATIONAL APPROACH

Homelessness services should create a Suicide Prevention Protocol specific to their context, e.g. thinking about the particular issues arising in an accommodation project or day centre. The protocol helps to create a consistent approach across teams and reinforce a shared understanding of their role. The objectives of a protocol are to:

- Promote good practice in suicide prevention across the organisation
- Be aware of the wider causes of suicidal thoughts and feelings, including mental ill health and, therefore, to provide a safe and welcoming environment for all service users
- Provide a framework to enable staff to feel empowered to talk to individuals about how they are feeling and then develop an appropriate safety plan
- Provide guidance to staff on referrals for specialist assessment and intervention as part of the safety plan
- Ensure that all team members are proactively engaged in suicide prevention and, where appropriate, they record details of discussions and serious incidents to promote organisational learning.

The Department of Health strategy 'Preventing suicide in England'[4] recommends that local areas establish a Suicide Prevention Partnership, bringing together a wide range of agencies, including the voluntary sector. Homelessness services should join these partnerships, as many of the issues affecting the people they support will overlap with the work of other local agencies, e.g. police.

SAFETY PLANNING

The introduction of a local Suicide Prevention Protocol has to be accompanied by training for staff, as it is their ability to have compassionate conversations that will reduce the risk of deaths by suicide. They must be able to ask about mental health symptoms or thoughts of self-harm in a calm and supportive manner, creating an environment in which people feel able to disclose suicidal thoughts and feel that

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[1] www.homeless.org.uk/suicide-prevention

[2] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesintheunitedkingdom/2016registrations

[3] 'Local suicide prevention planning: A practice resource', Public Health England, October 2016 www.gov.uk/government/publications/suicide-prevention-developing-a-local-action-plan

[4] www.gov.uk/government/publications/suicide-prevention-strategy-for-england

these will be taken seriously. Staff will be supported in this by clear, low threshold processes to escalate concerns to managers, as well as knowing how to involve health services when needed.

We hope that these conversations form part of a wider shift towards psychologically and trauma-informed working in the homelessness sector, with collaborative safety planning as a core part of the support offer. The process of developing a safety plan usually takes place over a period of time, as trust and rapport develops. Suicide is a sensitive topic and staff should allow a person to tell their own story as far as possible, calmly asking open questions and looking at strengths – what makes them feel hopeful, what reminds them of their reasons for living, what comforts them – as well as asking about past or present suicidal thoughts and previous self-harm. As well as training, staff may initially need additional support from their manager to plan for and reflect on these conversations. Over time, their skills and confidence will grow as these conversations become a natural part of their support, the need for crisis management will reduce, and the topic of suicide create less anxiety.

Each person's safety plan should be developed in collaboration, drawing on the individual's internal resources and external support when they experience suicidal thoughts and feelings. It is also important to engage other professionals supporting the person, such as the Community Mental Health Team or a keyworker from drug and alcohol services. Where appropriate, and where consent is given, it can be helpful to engage with friends or family members.

Key areas to cover in the safety plan include:

- What helps the individual to manage suicidal thoughts or feelings in their experience? What coping strategies have been useful in the past/what support is needed?
- What is the best course of action for them in the event of a crisis? What will they want to do when they experience suicidal thoughts and feelings?
- Who do they prefer to speak to when they have suicidal thoughts or feelings? This may include a friend or relative, a staff member in your project, another professional or a telephone helpline.
- Which other agencies can they contact or who are they happy to be contacted by staff on their behalf (such as support or advice lines, Mental Health Teams or Emergency Services)?
- Depending on circumstances, service users may be able to identify a safe place to go.

Staff should also know the emergency protocol if there is an assessment of immediate suicidal intent. This will may mean contacting the duty worker at a GP surgery or Community Mental Health team or calling the emergency services. Consent should be sought for referral when possible or local procedures for overriding consent followed where there is significant risk of harm. All actions should be documented.

RESPONDING AFTER A SUICIDE

Services have told us that their staff struggle to cope after a suicide. Teams may feel unsupported, unsure of how to manage their own emotions and therefore struggle to support others. There may be anger towards the organisation, focused on a lack of management support or failure of prevention. It is vital that the organisation responds to the needs of staff quickly, with the protocol setting out clear steps for the responsible manager. Support for staff may include offering compassionate leave, clinical supervision or referral to counselling. There should be a serious incident review to look at what lessons can be learned and make recommendations.

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It is equally important that the organisational protocol sets out how the people using their service will be informed and supported. Where staff are anxious about discussing suicide, this reluctance may well increase after a death, resulting in a lack of communication to other people about what has happened. This may be influenced by the misguided assumption that people using homelessness services are more likely to respond to bad news in destructive ways (e.g. substance misuse) than the staff team hearing the same news. As a result, staff may avoid sharing information to reduce these perceived risks. However, not keeping people informed and supporting them in their grief contributes to an environment in which people do not feel able to disclose thoughts of suicide, thereby reducing the opportunities to prevent future harm.

This issue was highlighted by the charity Groundswell, whose partner project with *the Pavement* magazine included a feature edition on suicide.[5] Peer journalists spoke to people homeless in London and found that many of them had lived in services where someone had died by suicide, or had themselves felt suicidal, but had not been offered support. Groundswell's work highlights the need for staff teams to be trained and for organisations to raise awareness of how to prevent suicide, with the full involvement of the people using their services.

CONCLUSION

The homelessness sector in England should be playing a key role in suicide prevention, as the people we work with are often at high risk, yet too often they are not getting the support that they need. By taking an organisational approach and implementing local suicide prevention protocols that include staff training, safety planning and improved communication, we can improve our response and reduce the risk of suicide in our services.

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[5] http://groundswell.org.uk/what-we-do/information-for-action/from-the-ground-up/

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