Researching Mortality and Deaths of People Experiencing Homelessness

A pre-research note

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Forty-seven years. The mean age at death. A number of cases are listed next to causes: illness 73, traffic accidents 20, violence 19, overdose 16, drowning 14, hypothermia 14, suicide 12. That is how the federation of organisations in Italy (FIOPSD, 2022) is reporting the number of deaths of people experiencing homelessness: "205 deaths in 206 days". The incidents are collected from the media and not-for-profit organisations. Another example, in Los Angeles, the average age at death 48.1 years, on average 36% shorter than a housed person's life. The four leading causes of death (making up 87.3% of cases) are: cardiovascular disease, unknown, acute intoxication, and trauma-related (Hawke et al., 2007). As stated in the Guardian, in the United States homeless deaths have doubled in the last years (McCormick, 2022). Examples illustrated in the article included: A 20-year-old man stabbed to death at the DC's Union Station hub; another young man fatally overdosed after not being admitted to several programmes; and a 60-year old woman perished of hypothermia in a tent encampment in Texas.

This all sounds shocking. Both the numbers and the stories. I have seen it myself when I was working with the Polish migrants on the streets in Brussels. During the four years I was coming back to the field site, four people from 'my group' disappeared and reportedly died. Admissions to the emergency room were a daily occurrence. Some of the people I worked with were my age but looked a generation older. There were around 30 names read (many of them Polish) when I went for an annual commemorative visit to a cemetery (see also: Collectief Straatdoden, 2021). Hospital visits and talking about those who died seem like a regular part of fieldwork in homelessness research, and the daily bread of those working in support organisations. But outside of this field it is often taken for granted. The local newspaper reports on a deadly carbon monoxide poisoning of an elderly couple that tried to heat the shed they made their home. It's such a familiar story, I hardly glance over it.

I started thinking about homeless deaths during my stay in Philadelphia. I was surprised to learn that the city's committee reviews each death on the streets or attributed to a person experiencing homelessness (see also DPH, 2017). I guess, perhaps like a lot of people, I thought "they were just gone". We rarely talk about death. Especially when it comes to phenomena that are complex enough in themselves, like homelessness. I decided to try to talk more. As I was writing my research proposal and taking the first look at mortality research, I encountered a number of issues, which – I can only assume – will become even more complicated during the course of the project. I will summarise them below bundled under five headings: (1) numbers as metaphors, (2) a standardised death, (3) linking data sources, (4) comparison group, and (5) and the results?

Numbers as Metaphors

Not being a doctor or a public health professional and not even dreaming of obtaining any robust data to analyse statistically, I paused on what the data about deaths of some part of the population could be telling us. I have grown suspicious of numbers. Especially in such contentious areas as social problems. A million homeless in America? Twice the standard mortality rate? Forty-seven years on average? Is that true? What does it even mean?

Numbers seem necessary and objective but the production of data may become a "quantifying ritual", where tallying becomes institutionalised but offers no solutions (Jacoy, 2012, p. 398). Once a number appears, it becomes a potential source for everyone and the numbers take lives of their own and are treated as facts. In social policy research, we believe that a 'big' number means a big problem. If the number is 'small', there is a belief in a large 'dark' number that escapes the statistics (Best, 2001). Numbers act as, and are deliberately used as, metaphors (Stone, 2020). Single figures are especially tempting (Neylan, 2005). However, we are very bad at reading numbers and comparing them with each other. A simple transition from thousands to millions is largely estimated by context, but we are often wrong by orders of magnitude (Landy et al., 2017).

A Standardised Death

There's a growing recognition that social inequalities manifest themselves in health disparities. Also within rich societies, there is a huge gap between the groups in both access to health care and health outcomes. Health issues are among the most pressing needs in the homeless population. The problem is likely to get more severe as the homeless population is aging (at least the part of it that we know of).

Mortality is used as a simple indicator of a (sub)population's health condition. WHO compares child mortality, life expectancy, and causes of death as indicators of global health inequalities. Contrary to many other social phenomena, deaths seem like well-defined events, which – at least in rich countries – are pretty comprehensively registered (Sturge, 2022).

Not only is the death itself recorded, but the causes of deaths are also recorded. The International Classification of Diseases (ICD) is a tool to globally standardise and record health issues. Historically, the ICD was intended for recording mortality data. The first classification in 1900 had 191 causes, reflecting medical knowledge of the time (it contained codes such as "want of breast milk", "insanity", "cow-pox and other effects of vaccination"). The ICD has also progressively been used for morbidity data, social security, and insurance purposes. The latest, ICD-11, a 2022 revision, contains some 17 thousand categories.

Standardised codes are used to describe the causes of death on death certificates worldwide. It looks promising, medicine after all is a much more precise science than the messy social sciences. Still, it is difficult to pinpoint one direct cause of a particular death and the entire causal chain of events leading to it. A lengthy and confusing procedure for the certifying physician to establish the underlying cause of death, the train of events leading to death, and other contributory conditions mean many misclassifications and vague reporting (Naghavi et al., 2020; Monasta et al., 2022). The 'actual' cause of death that is registered for comparison purposes (Global Burden of Disease study) might not be the same thing as the immediate cause of death, and it demands the knowledge of an individual's medical history. Even in some OECD countries, concerns remain about the quality of the medical data; there's a high proportion of garbage categories (codes that are too general or codes of diseases that cannot be fatal by themselves). For instance, around 20% of deaths in Poland are registered with codes of low informative value (Fihel and Muszyńska-Spielauer, 2021).

Each subsequent ICD is intended to be better suited for contemporary society and to be standardised globally (Harrison et al., 2021). The newest edition of ICD is interesting because it contains a number of 'social issues'. Stem code QD71 is called "Problems associated with housing", under which: Homelessness, Inadequate housing, and Problems related to living in residential institution are named. It remains to be seen how this will be used in practice. Potentially in the future, the newest ICD-11 could offer another solution to some of the problems I discuss below.

Linking Data Sources

Studying homeless mortality means obtaining data on mortality for the subpopulation of people experiencing homelessness. In theory, this could be done in two different ways:

1. Extracting data on people experiencing homelessness from the general death register; and/or

2. Calculating mortality rate from a database on people experiencing homelessness.

In the first case, however, the housing situation is not registered on the death certificate. That is why, for instance, Brimblecombe et al. (2020) analysed the UK's Office for National Statistics (ONS) mortality data by their postcode to identify the most likely homeless deaths, taking into account only premature deaths, thus under 65 years of age. Thomas (2012) used a similar method for the whole of England and provided several scenarios for different definitions of homelessness. Vuillermoz et al. (2014) performed another study linking two data sources. One was the French population registrar and the other was the data on deaths collected by the voluntary organisation Collectif Les Morts de La Rue. Slockers et al. (2018) were also able to link pooled service providers' data in Rotterdam with the municipal population registration of deaths. Another option is to use data from a subset of deaths. For instance, coroner's or medical examiner's databases are used in many American cities and counties (Hawke et al., 2007). These offices have a responsibility to register suspicious or violent deaths. The coroner's office becomes then the body that determines the homelessness status of the diseased. Similarly, Stanley et al. (2016) used Maryland state's violent death reporting system.

It is clear that since no homelessness status and no housing situation appears on the death certificate, this has to be determined either by the researchers (for instance shelters' postcodes) or by an office like the coroner's.

In the second case, for many reasons (good and bad), we simply do not have such databases. Researchers used available 'homeless' lists (for instance from service providers) and were essentially looking at who from the list had died. This option rests heavily on the type of service provider or organisation which is involved, and therefore the results are biased toward people matching their offer. This kind of data is hardly comparable with that obtained from other sources. Databases of services providing specialised medical support were used in East London (Hassanally and Asaria, 2018), Boston (Baggett et al., 2013), Australia (Brett et al., 2014), and Canada (Hewett et al., 2011). Another project in France looked at the diseased participants in a Housing First programme (Tinland et al., 2021). Dublin Region Homeless Executive collects data that include both homelessness and deaths (O'Carroll, 2021). It was thus also possible to calculate mortality rates for different accom-

modation types; however, selection criteria for these different types of support contain health needs, which means that, again, indicators are hardly comparable.

What this quick scoping review of the literature reveals is that in either case researchers link data from different databases (one on deaths and one on homelessness) in various ways. The problem however remains: the population in question is unstable – people flow in and out of homelessness – and either way, we are back to the messiness of social sciences: What is meant by homelessness here? Would that mean "death on the streets"? Homelessness at the time of death? What kind of homelessness? What types of situations? For how long? How long prior to death?

Homelessness researchers can debate about definitions forever, but once data has to be obtained, choices are often out of researchers' control. On the practical level, thus, homelessness was defined by the kind of data that was available, hence often: a place of residence meant "shelter", and cause of death meant "violent".

Comparison Group

We also know that people who experience homelessness are diverse. Some studies attempted to distinguish between the groups. For instance, they show that young women who experience homelessness have a much higher risk of death than any other group in the homeless population in comparison with their respective housed counterparts (Hwang, 2000; Cheung and Hwang, 2004). This study in Toronto concerned the most vulnerable (shelter users and people not using shelters sampled in meal programmes). Calculations were performed separately for subgroups distinguished on the basis of sex, age, and race. But still, this group was very specific. Even age-adjusted mortality ratios (SMR) were staggering. For instance, it was calculated that the "mortality rate was about 5- to 30-fold higher than expected among younger homeless women" (Cheung and Hwang, 2004, p. 1245). "Than expected" means here: in comparison with the general population of women of the same age in the province of Ontario. It's pretty bad. Is it not sensational? Authors acknowledge that similar studies in other cities arrived at very different results (Cheung and Hwang, 2004). No wonder. For instance, the Philadelphia study was using data from almost a decade earlier than Toronto; it also used a different follow-up period, a city's general population (as opposed to province) comparison group, and was heavily relying on mental health services to describe the homeless population (Hibbs et al., 1994). Does it justify a direct comparison of a few numbers?

Perhaps, as homelessness researchers, we should take a step back. Homelessness could be coexisting with many issues where cause and effect are hard to distinguish – poor diet, no follow-up on treatments, no access to health care, problematic substance use, the experience of violence, extreme stress, and precarity. Is 'homeless' the opposite of' 'housed'? Perhaps it's not that black-and-white?

Morrison (2009) used data of all people presenting to the Glasgow City Council as homeless. This was therefore a pretty diverse group. This personalised information was linked to the NHS Scotland data. Further, a comparison sample was drawn from the socio-economically deprived groups in the city, stratified by sex and age. The comparison population shared thus some of the characteristics of the homeless population. Compared with those in the most deprived areas, individuals experiencing homelessness had a 3.2-fold higher risk of dying. But such was also a hazard for non-homeless individuals living in the most deprived areas in comparison with those in the most affluent areas. Homelessness turned out to be an independent factor in mortality, nevertheless. The author concludes that "homelessness is not simply a misfortune that affects poor people: it is a hazard beyond conventional area-based measures of poverty" (Morrison, 2009, p. 881). Still, after considering prior hospitalisation, the difference in mortality was not as wide, but 1.4 times greater for the homeless population than for the residents of the most socio-economically deprived areas (Morrison, 2009).

I read these results differently. Homelessness actually IS something that happens to people with fewer resources. Chances are that in these most deprived areas, there were a number of people who had experienced homelessness earlier in their lives.

And the Results?

That brings me full circle back to the responsibility of producing the data and presenting the numbers. As mentioned at the beginning, some numbers describing deaths of people who experienced homelessness sound shocking, almost by design.

For presentation purposes, data are usually reduced to simple numbers or indicators. The most frequently used in the abovementioned studies are: the raw number of homeless deaths in a year or other period; cause-specific mortality or the number of deaths; the average age at death; years of life lost due to premature deaths (often in comparison with the general population); and Standardised Mortality Ratios (SMR) – a number indicating how many times greater mortality in the homeless population is from that in the comparison group. However objective and true, all these numbers may be used to (un)intentionally inflate or deflate the emotional load of results.

As indicated above, the control group is crucial for the interpretation of results. Also, the broader the definition (all clients of housing support, all people who died under a shelter's postcode), the more chance we will include people who did not experience homelessness. The narrower the group, and especially using some of the specialised data sources, the more serious it looks – violent deaths, overdose deaths, and deaths on the streets. In the more popular media, these numbers are often presented alongside individual life and death stories (for instance Webster, 2017; McCormick, 2022). These stories are probably also chosen for their ability to evoke emotions.

Presentation of results creates part of the narrative about homelessness, people who experience it, service providers, and institutional safety nets. Sources that focus on premature or violent deaths have the capacity to stigmatise and reduce homelessness to the most severe cases. The handling of data on individuals experiencing homelessness is subject to the risk of 'colonisation' – reducing homelessness to sleeping on the street or invisibilising other homeless situations and groups (such as women, ethnic minorities, and people with no recognised immigration status).

From here we are still left with questions. What's the best way to present data in a responsible way? How not to sensationalise? How not make homelessness associated with violence, problematic substance use, and mental health crisis? What groups should we take for comparison? What then is the purpose of studying homeless mortality? How to talk about deaths and not reduce them to a couple of numbers?

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