

HOMELESSNESS – PALLIATIVE CARE ON THE FRINGES

Where would you like to die?

'I would like to die at home' was a wish that 75% of people expressed in over 33 countries (Gomes et al, 2013). But where is home? A park bench, a doorway, a friend's couch, substandard accommodation or a cosy bed in warmth and security! Homelessness in Australia is categorised into three types: Primary – sleeping rough, Secondary – couch surfing, emergency accommodation, Tertiary – boarding houses, caravan parks that fail to meet minimum community standards (Macwilliams et al, 2014).

In 2011 the number of homeless people identified in the Census totalled 105,237 (Australian Bureau of Statistics (2012) cited by Macwilliams et al 2014). Homeless people suffer higher rates of mortality and die younger when compared to similar age groups of the general public. This is attributable to their lifestyle that exposes this vulnerable group to more complex and increased risk factors of poor nutrition, hygiene, and sanitation, leading to poor physical and mental health, drug, and alcohol dependency (Webb et al, 2018, Sumalinog et al, 2017).

The prevalence of chronic conditions such as heart and liver disease, cancer, diabetes, HIV, TB, hepatitis and sexually transmitted diseases are all associated with homelessness and leads to extreme health inequalities in this under-serviced population (Shulman et al, 2018). Homeless individuals have higher rates of hospital admissions and emergency presentations, yet in the last year of life up to 50% do not engage with primary care services (Hudson et al, 2016).

Providing palliative care to this marginalised group becomes challenging and problematic not only by the very nature of their transient lifestyle but also a distrust of mainstream healthcare systems, health professionals and the experiences in their lives that have brought them to be homeless. The reasons that people become homeless are multifactorial, often deep rooted and their pathway into this way of life diverse. Factors attributable to homelessness result largely from limitations of social housing, inadequate welfare administration and support, and personal vulnerability (Webb et al, 2018).

Tri-morbidity is a term equated to the homeless as they endure physical and mental health issues as well as substance misuse. Trauma, abuse, detrimental childhood experiences, dependency and neglect are but some of the cause factors leading to tri-morbidity. Mental health issues such as anxiety and depression, obsessive-compulsive disorder and poor coping mechanisms are twice as prevalent in this cohort than the general population. Homeless people are prone to experiencing psychoses of up-to 15 times more than the general population (Webb et al, 2018). These factors lead to social exclusion from mainstream society and reluctance to engage with healthcare provision.

Much of the literature agrees that homeless people are reluctant to access health care services because of the hostile, uncaring attitudes of health professionals experienced towards them. This response feeds into the stigma of being homeless and their lack of self-worth and eventuates in distrust of authority and health providers (Canadian Medical Association (CMA), 2011, Webb et al, 2018). Other barriers are rigid health care processes that become inflexible to accommodate and service the health needs of this marginalised complex group. Fear of losing control in formal environments, mental health issues, drug and alcohol dependency and finding food and shelter all destabilise the priority for seeking medical assistance when poverty and survival are negotiated on a day to day basis.

The most challenging population to assist in dying is the homeless because of the nebulous nature of their unpredictable, precarious lifestyle that does not conform to mainstream society. The need to support this group at the end of their lives surpasses the need of the general population because of the hardships and suffering they have already endured in their lives. Purely being homeless signifies less capacity to cope than others (CMA, 2011).

Providing care to the Homeless that embraces the ethos of holistic palliative care is challenging, has no perfect model of care that achieves this, but there are many attempts worldwide to try and meet these challenges. Although approaches vary there is consensus that health provision needs to be flexible, innovative, non-judgemental and multiskilled with strong links to palliative support and education (Macwilliams et al, 2014, Traynor, 2019, Webb et al, 2018).

Supporting homeless people at the end of their life, means to respect their wishes, values and choices and support them in the place they choose to die. This may not align with some of our own beliefs and ideas but for health care professionals to truly support homeless patients at the end of their lives and respect their choices, we must set our own values aside. We need to be flexible and prepared to work outside the mainstream health models and bring the service to the place where they feel most comfortable (Klop et al, 2018, Macwilliams et al, 2014).

Homeless people generally feel more comfortable and accepted in the shelters provided. They are amongst friends, outreach workers provide care, support and can build trusting relationships over time. They choose to die in shelters that they feel are their home rather than dying in hospitals where they feel judged and tolerated amongst strangers (Hudson et al, 2016). To die in hospital would only add to their suffering so they choose to die at 'home' (CMAJ, 2014).

There is high symptom burden amongst the homeless at end of life because of the tri-morbidity that they endure. This presents complex challenges in managing symptoms especially amongst those with addiction and mental health problems. Managing symptoms to relieve pain and suffering without supporting addiction is a delicate balance. Mental health issues add another layer of complexity impacting effective and open communication through distrust or psychoses. This exemplifies the need for a multiskilled team approach (De Veer et al, 2018, Traynor, 2019).

Throughout the literature some studies undertaken interviewed a few homeless people exploring what was important to them at the end of their lives; they wanted compassion, not to die alone and be in familiar surroundings. Some worried about what would happen to their bodies, funeral arrangements and if their family would be notified. In some of the homeless shelters the outreach workers would even attempt to complete a living will or advanced care plan for homeless individuals so that there was some record of their wishes (Hudson et al, 2016, Klop et al, 2018, Webb et al, 2018).

Outreach workers provide care and support but often feel overwhelmed and ill equipped when someone dies or is in the palliative stages of their life. They felt unskilled in knowing how to recognise and look after a person in the terminal stages of disease, how to engage in difficult end of life conversations and ultimately care for them and felt a hostel was not the most appropriate place to die (Traynor, 2019). The stress burden on outreach workers is extremely high, homeless people have erratic, challenging behaviours and their lives are chaotic. They can be difficult to manage and exhausting (De Veer et al, 2018). Palliative education and support for outreach workers and volunteers has shown to be effective, changing some of their views that hostels and shelters are an appropriate place for the homeless to die. This is because they feel comfortable and see it as familiar and 'home' and through education and team support the outreach workers feel better equipped and supported to look after them (Klop et al, 2018).

Quote from a homeless person:

"End of life. What end of life are you talking about? ...I'm on the street and nobody cares about me". (Hudson et al, 2018).

To deliver good palliative care is complex and highly challenging but it is encouraging that projects worldwide are trying to improve end of life care for this very disadvantaged group. Raising awareness and understanding of the suffering they endure and the reasons that have brought them into homelessness will hopefully help to change attitudes and care delivery within healthcare systems.

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