Palliative Care
NEW SOUTH WALES

Homelessness and Palliative Care

A Scoping Study in Regional, Rural and Remote NSW

Emma Scott-Stevenson
Policy Officer, Palliative Care NSW

Megan Asbury
Deputy CEO, Palliative Care NSW

Contents

Acknowledgements

PCNSW would like to thank the participants of the regional, rural and remote interviews for the input provided to this study.

Suggested citation

Scott-Stevenson, E and Asbury, M (2024). '*Homelessness and Palliative Care: A Scoping Study in Regional, Rural and Remote NSW*', Palliative Care NSW, Sydney.

02

Background

Palliative Care NSW (PCNSW) completed this scoping study to examine the availability and accessibility of Palliative Care services for homeless individuals within regional, rural and remote areas of New South Wales (NSW). This study builds upon the findings of the previous scoping study *Homelessness and Palliative Care: A Scoping Study in Metropolitan Sydney* (Metropolitan study), conducted by PCNSW (2022) as part of a National Project by Palliative Care Australia (PCA). While the first study shed light on the barriers that inhibit or prevent access to Palliative Care by those experiencing homelessness in Metropolitan Sydney, regional, rural and remote areas of NSW face unique challenges and therefore required additional investigation.

The stakeholders who participated in the Metropolitan study (PCNSW, 2022) had expertise across a range of professions within health and social services in Metropolitan Sydney, and many had experiences with either providing or sourcing Palliative Care for homeless clients and patients. The key findings from the first study highlighted disconnections between health and social services, a lack of available and accessible Palliative Care services for homeless patients, barriers that prevent homeless patients from accessing Palliative Care, and barriers that prevent healthcare providers from delivering care to homeless patients. The study also found homeless patients were seldom provided with the same person-centred and holistic approaches to care as non-homeless patients, as a result of their unstable and transient living conditions. The study provided new insights and highlighted existing gaps in care for this vulnerable population. People experiencing homelessness in regional, rural and remote NSW face similar barriers when attempting to access Palliative Care, though often with additional challenges of isolation, limited healthcare resources and services, and limited literacy of Palliative Care (Smith, 2019). This study seeks to improve upon the dearth of research on how Palliative Care is currently accessed by and provided to people living in insecure housing or experiencing homelessness outside of Metropolitan areas in NSW. The NSW Health *End of Life and Palliative Care Framework 2019-2024* specifically refers to people experiencing homelessness in *Priority Five*, highlighting the need for equitable access to Palliative Care for vulnerable populations.

Palliative Care is defined as "the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life" (International Association for Hospice & Palliative Care, 2018). The *Exploratory Analysis of Barriers to Palliative Care: Issues Report on People Experiencing Homelessness* (Australian Government Department of Health and Aged Care, 2019) states that Palliative Care should "be strongly responsive to the needs, preferences and values of people, their families and carers; be available to all people with an active, progressive, advanced disease, regardless of diagnosis; and affirm life while recognising that dying is an inevitable part of life". Palliative Care is also recognised as a human right under Article 12 of the International Covenant on Economic, Social and Cultural Rights (United Nations General Assembly, 1966), which outlines the broader human right to health. The World Health Assembly (2014) also determined that Palliative Care is "an ethical responsibility of health systems", and the International Association for Hospice & Palliative Care (2018) suggests that governments should take measures to ensure access to adequate Palliative Care for vulnerable groups.

The Australian Institute of Health and Welfare (AIHW) (2023) uses the terms 'regional', 'rural' and 'remote' to refer to "any area outside of Australia's major cities". The Local Health Districts (LHDs) located within these areas in NSW include Hunter New England LHD, Northern NSW LHD, Western NSW LHD, Far West LHD, Murrumbidgee LHD, Southern NSW LHD and Mid-North Coast LHD. Residents living in regional, rural and remote areas of NSW "face unique challenges due to their geographic location and often have poorer health outcomes than people living in metropolitan areas" (AIHW, 2023). The AIHW (2023) also states that "people living in rural and remote areas have higher rates of hospitalisations, deaths, injury and also have poorer access to, and use of, primary health care services than people living in major cities". People living outside major cities in NSW have a lower than average life expectancy of 81.7 years, compared to the average life expectancy of 84.5 years for those living in Greater Sydney (AIHW, 2023).

Homelessness in NSW

Chamberlain and Mackenzie's cultural definition of homelessness (1992) was used for the purposes of this scoping study. This definition presents three different forms of homelessness: *primary*, *secondary* and *tertiary*. *Primary homelessness* is experienced by individuals who live in unconventional accommodation, for example sleeping rough, in cars, or in improvised dwellings including sheds or garages. *Secondary homelessness* is experienced by individuals who move frequently from one temporary accommodation to another, for example emergency accommodation or temporarily staying in accommodation which is not their own, including the homes of friends, families or others. *Tertiary homelessness* is experienced by individuals who live in accommodation which falls below minimum community standards, for example in boarding houses or caravan parks (Chamberlain and Mackenzie, 1992).

During the 2021 Census, the Australian Bureau of Statistics (ABS) recorded estimated levels of homelessness, categorising the data by 'Homelessness Operational Groups' and 'Other Marginal Housing'. Both categories are relevant to Chamberlain and Mackenzie's cultural definition of homelessness (1992). According to the 2021 Census, a total of 122,494 people were recorded as being homeless across Australia (ABS, 2023). NSW reported the highest number of homeless individuals out of Australia's states and territories, recording 35,011 people experiencing homelessness during the survey (ABS, 2023). ***Table 1*** presents this data by area of remoteness in NSW. An additional 32,929 people were also recorded as living in 'other marginal housing', which is presented in ***Table 2*** by area of remoteness in NSW. When these two totals are combined, an estimated 67,940 people were recorded as either experiencing homelessness or living in marginalised housing in NSW, on the night of the 2021 Census (ABS, 2023).

As outlined in the Metropolitan study (PCNSW, 2022), people who are homeless typically face a complex range of issues which impact their health and wellbeing. Homeless individuals face higher rates of health issues and premature death than non-homeless individuals (Smith, 2019). Death resulting from 'unknown causes' occurred "60 times more frequently for those who were homeless" (Smith, 2019), with the average life expectancy for homeless individuals estimated to be only

44.5 years of age (Knaus and Evershed, 2024), which is significantly lower than the Australian national life expectancy of 83.2 years (AIHW, 2023). Premature deaths can result from “adverse life events”, as occurrences of suicide, accidental overdose, homicide and life-threatening accidents are significantly higher amongst homeless populations (Smith, 2019). The increased exposure to death resulting from these occurrences can lead to further trauma amongst homeless communities, as they are faced with the threat of premature death to both themselves and those close to them (Kenney, 2019). Such trauma can substantially impact the likelihood of these individuals seeking the healthcare they require, extending to Palliative Care.

As also identified in the Metropolitan study (PCNSW, 2022), homeless individuals face unique barriers when accessing Palliative Care services. People experiencing homelessness are more likely to prioritise their day-to-day needs, such as sourcing food, shelter and personal care, rather than addressing less immediate concerns, including more complicated health care (Australian Government Department of Health and Aged Care (DoHAC), 2019). Unstable and inadequate living environments can also impact access to Palliative Care, as prerequisites of permanent residences or particular housing standards may prevent individuals from receiving the care they need (DoHAC, 2019). The prevalence of mental health issues and substance use amongst individuals experiencing homelessness can also impact their access to Palliative Care, as well as “disparities in social status”, including “lifestyle and education level”, “fear of stigma and judgement” and “distrust of institutions and authority” (DoHAC, 2019).

Table 1: Homeless Operational Groups Based on Remoteness Areas of NSW During the 2021 Census

		Homeless Operational Groups						
		People Living in Improvised Dwellings, Tents or Sleeping Out	**People Living in Supported Accommodation for the Homeless**	**People Staying Temporarily with Other Households**	**People Living in Boarding Houses**	**People in Other Temporary Lodgings**	**People Living in ‘Severely’ Crowded Dwellings**	**Total:***
Remoteness Areas of NSW	**Major Cities**	407	3,680	2,273	8,317	999	12,678	28,348
	Inner Regional	306	1,153	1,385	446	359	1,462	5,165
	Outer Regional	77	188	379	61	64	476	1,248
	Remote	63	15	25	10	4	19	139
	Very Remote	47	0	19	10	0	0	75
	Total:*	963	5,043	4,100	8,842	1,427	14,640	35,011

*The 2021 Census data was altered randomly prior to public release to ensure confidentiality, meaning that totals may not match exactly. The data provides a general estimate of homeless and marginal housing populations in NSW.

(Australian Bureau of Statistics, 2023)

Table 2: Other Marginal Housing Groups Based on Remoteness Areas of NSW During the 2021 Census

		Other Marginal Housing			
		People Living in Other Crowded Dwellings	**People in Other Improvised Dwellings**	**People Marginally Housed in Caravan Parks**	**Total:***
Remoteness areas of NSW	**Major Cities**	25,645	109	680	26,434
	Inner Regional	3,218	185	1,467	4,870
	Outer Regional	1,009	116	170	1,295
	Remote	51	161	11	223
	Very Remote	29	71	0	100
	Total:*	29,956	642	2,331	32,929

*The 2021 Census data was altered randomly prior to public release to ensure confidentiality, meaning that totals may not match exactly. The data provides a general estimate of homeless and marginal housing populations in NSW.

(Australian Bureau of Statistics, 2023)

Method

In early 2023, PCNSW contacted health services in regional, rural and remote NSW to interview Palliative Care health workers about their experiences working with clients who were homeless. The interviews (n=8) were semi-structured and conducted by phone to enable the study to cover as many locations as possible without the limitations of travel. The unique challenges faced across diverse regions and populations in NSW are addressed in this study.

Significant care was taken when planning and conducting this study as people experiencing homelessness are considered part of a vulnerable population. Homeless individuals can face discrimination as a result of their housing status, and can be vulnerable to exploitation due to their insecure accommodation or their history of trauma (Homeless Hub, 2024). Additionally, individuals facing both homelessness and a terminal or life-limiting illness are at an even greater risk of vulnerability or exploitation. Care was taken when developing this study to prevent any unintentional harm to this population.

Participation in this study was voluntary. It should be noted that the sample was therefore not necessarily representative of all Palliative Care health workers in regional, rural and remote settings. Recruiting participants for this study was challenging. Multiple health services were contacted in each regional, rural and remote LHD, though not all services that were contacted were able to participate. While some participants requested to be included after they had seen the findings of the Metropolitan study (PCNSW, 2022), others were contacted directly either by phone or email and provided with a basic outline of the study. Despite enthusiasm to participate in the study, high workloads and a shortage of staff in regional areas meant that it was difficult for participants to find the time to be interviewed, as it required flexibility and rescheduling to accommodate their workloads and timetables. As a result of this, we were unable to find an available participant from Mid North Coast LHD. Health workers from the remaining regional, rural and remote LHDs were able to participate in the study, including: Northern NSW LHD, Hunter New England LHD, Western NSW LHD, Far West LHD, Murrumbidgee LHD, Illawarra Shoalhaven LHD and Southern NSW LHD. Participants were screened prior to the interview to ensure they had experience caring for patients experiencing homelessness while requiring Palliative Care services.

The qualitative data collected was analysed thematically to better understand how Palliative Care is provided to homeless patients with a life-limiting illness, as well as the barriers participants faced while trying to provide care and how the patients' housing situation impacted the care they received. The definition of homelessness used within this study (Chamberlain and McKenzie's cultural definition, 1992) was explained to each participant prior to the interview. The interviews were recorded with permission from each participant for the purpose of data accuracy, and were revisited while analysing the findings of the study. The participants were also assured that all information would remain confidential and be de-identified for use in the study.

Preliminary Findings

The data collected throughout this study highlights the difficulties faced by both the patients experiencing homelessness and the health workers caring for them. The findings from this study suggest that there is an opportunity for significant review of current policies regarding how care is provided to this vulnerable population, as well as how the health professionals caring for these patients can be better supported.

When asked about providing or sourcing Palliative Care for individuals experiencing homelessness, one participant explained that "it was difficult because I didn't know what to do for them", and another stated it was "really complex, and really hard for both the patients and clinicians as well" (Interviews, 2023). Others described their experiences as "stressful", and "difficult, due to access to the patients' dwellings and [concerns for] nurses' safety" (Interviews, 2023). Feelings of stress and uncertainty were common amongst participants, and these themes arose multiple times throughout the study.

Current data indicating that residents in regional, rural and remote areas typically have poorer access to healthcare and may be required to "travel long distances or relocate to ... receive specialised treatment" (AIHW 2023) was reinforced by the study participants. They explained that the lack of resources, staff and specialist health care services in regional, rural and remote areas makes it difficult to provide Palliative Care in these locations. These issues are compounded when the patient is also at risk of, or experiencing homelessness (Interviews, 2023). Multiple participants also explained that they had encountered patients with life-limiting illnesses who had lost their homes or living arrangements as a direct result of their deteriorating health (Interviews, 2023). One participant explained:

> *"In the later stage of life-limiting illnesses when I connect with the patients to provide Palliative Care services, and they're no longer working due to their deteriorating health, homelessness really becomes an issue."*
>
> \- Interview, 2023

When some patients find that there is "nowhere else to go" and they have no family or friends to turn to for help, they can find themselves living in their cars, tents or caravan parks instead. The participant further explained that “it does come to the crunch in the end if you don’t have family or your own home”. When asked how they provide care to patients in these difficult settings, one participant stated, “well, we do what we can” (Interviews, 2023).

In regional, rural and remote areas of NSW, participants described the increasing rates of homelessness they have witnessed. While the reasons for these increases varied depending on location, there were reports of rising homelessness due to natural disasters, the impacts of COVID-19, rising costs of living, and limited available housing for rent or purchase at accessible prices. Participants explained that when patients are living with a life-limiting illness, it is even more difficult to find appropriate housing that can accommodate their reduced mobility needs as their illness progresses. Participants specifically described the floods in Northern NSW and the bushfires in Southern NSW that they said had left “thousands” of people homeless (Interviews, 2023). One participant explained that many residents who were made homeless as a result of the floods in Northern NSW were relocated to emergency accommodation referred to as “pods” (Interview, 2023). Although this accommodation is temporary (NSW Government, 2023), the participant explained that the people living there are “grateful to have them”, and features such as air conditioning and minimal staircases in the ‘pods’ are especially helpful for Palliative Care patients and older people (Interview, 2023). However, the participant also described the negative implications for individuals residing in this type of emergency accommodation long-term. They explained that the ‘pods’ are “removed from the general communities” and lack the social and cultural supports which had previously existed in the area for residents (Interview, 2023). They also believe that the community is experiencing significant post-traumatic stress as a result of the natural disasters, as well as the fear of facing homelessness again in the future due to further natural disasters that could occur in the region (Interview, 2023). The combination of these challenges can have significant impacts on members of the affected community and are additional pressures to people also living with life-limiting illnesses. These issues can make it even more difficult for healthcare workers to provide holistic Palliative Care services to members of this population.

Barriers to Providing Care

In general, there appears to be a lack of formal policies and procedures for healthcare workers to follow when caring for a Palliative patient experiencing homelessness.

When asked if there were existing policies that outline how to appropriately care for homeless patients, the participants generally indicated that they were not aware of formal procedures to be followed in their services, and most used an ad hoc approach to these cases. One participant explained that they refer homeless patients to their service’s Palliative Care social worker, who can support them as their illnesses progress. Others said they “just worked it out as [they] went”, and “just ran with it and did the best [they] could” (Interviews, 2023). Their responses suggest that there is uncertainty regarding the approaches they should take and the procedures they should follow while caring for patients experiencing homelessness. This lack of established policies and procedures within services is concerning considering the prevalence of homelessness, particularly in regional areas of NSW. With an ageing population, and women over 55 becoming increasingly at risk of insecure housing and primary homelessness (NSW Parliament Legislative Council, 2022), this challenging care setting is only likely to worsen in the coming years. The impacts of increasing and widespread natural disasters will also continue to challenge the provision of high-quality Palliative Care for patients and families, alongside ensuring a safe and secure workplace for healthcare workers (KPMG, 2023).

Despite the lack of formal guidance, the participants suggested that they adopt a flexible approach to care in regional, rural and remote locations. One participant stated that:

> *“There are no set guidelines that I’m aware of, but there might be some sort of policy. I guess our practice is seeing what the patient wants and trying to help facilitate access to housing if that’s what they need.”*
>
> \- Interview, 2023

Most participants provided examples where they had found non-typical ways to provide homeless patients with care. One participant explained that they would try to “think outside the box” and ensured that their management was informed about all attempts they made to provide their patients with care (Interview, 2023). These non-typical methods led to one homeless patient being provided with medical supplies they would not have otherwise been able to access, as the participant was able to coordinate supplies for the patient with a hospital willing to help. The participant also described how they received support from their management when presenting them with the difficulties of this particular case, and after checking that all other options had been exhausted, the management told the participant:

> *"Well, we've got a duty of care, what else can we do."*
>
> - Interview, 2023

This serves as one example of the commitment of the healthcare providers in regional, rural and remote areas, which became evident throughout the study. Participants also described the ways their services had been able to alter medical equipment used when providing care to patients living in temporary or emergency accommodation.

Other barriers often began early in the referral process when accessing primary care. It was noted that before patients can access a General Practitioner (GP) service there is often a requirement to provide formal documentation, including identification, Medicare cards and a proof of address. While these documents can be easily provided by patients in secure housing, patients facing homelessness can struggle to meet these same requirements. This issue was also prevalent in the Metropolitan study (PCNSW, 2022), and was identified as a significant barrier to homeless patients accessing care. Similarly, it was found in this study that while some policies appeared to be sound in theory, they could be unrealistic or unattainable in practice. One participant explained that in their region, patients "need a GP because the model of care is centred around the GP" as "the GP has medical dominance in the community" (Interview, 2023). If a homeless patient does not have access to a GP, the participant explained they will try to arrange a GP for the patient despite feeling that they are not supposed to do this, stating that it could be viewed as "approving one doctor over another ... but we're not supposed to do that" (Interview, 2023). "Bending the rules" and collaborating with primary health providers that understood the challenges of providing care to homeless patients often served as solutions to these hurdles (Interview, 2023).

Participants also discussed the challenges associated with identifying Palliative patients and obtaining referrals in order to provide them with specialist care.

> *"There are lots of people living in the street, but they're not linked with our services. They might have a Palliative diagnosis, but no one has referred them to us, and we can't be involved if they have not been referred to our service. There might be a lot of people in the street who would benefit from Palliative Care."*
>
> - Interview, 2023

Most Palliative Care services in NSW require a referral, so when there are barriers to accessing these GPs or other specialists, it subsequently prevents them from accessing the care they require moving forward. This issue of health workers having to choose between 'bending the rules' and denying care to patients facing homelessness was also explored in the Metropolitan study (PCNSW, 2022). Ultimately, it was found that "health providers acknowledged that although they were putting their job at risk, they felt they were unable to refuse medical care to a person in need" (PCNSW, 2022). When health workers are unable to bypass restrictive policies, they are burdened with the concern that these patients will not receive necessary care.

Another issue that arose multiple times throughout this study were the difficulties participants faced maintaining the safety of themselves and their patients while providing care in unstable and inadequate living environments. Some of the environments encountered by participants included damaged rental houses with broken walls and mould, temporary living structures with dirt floors, cars, and accommodation frequented by acquaintances with a history of violence. The participants also explained that they were often required to attend residences in pairs as a safety precaution, but that this was not always possible due to staffing limitations. Another participant described the difficulties associated with safely storing medication while patients were living in transient or shared accommodation, especially in environments where children were also present. The participants depicted the stress experienced while attempting to maintain the safety of themselves, their co-workers and their patients. In some instances, the participants were unable to provide quality care safely in these environments and were required to offer care from the local hospital instead.

Due to the limited number of specialist health services available in regional, rural and remote areas of NSW, emergency departments play a crucial role in providing homeless patients with Palliative Care, often in a crisis situation when there are no alternative services available. One participant described how they had negotiated with the manager of a motel providing emergency accommodation after devastating floods hit the region, as to whether they would allow a patient to die on their premises, in an attempt to provide the patient with a comfortable space for their remaining days. Unfortunately, the outcome was that the patient eventually needed to be taken to the local emergency department so they could access necessary care, but this was done as a last resort. The participant explained that despite this occurring regularly due to some patients having no other option, there could be disputes between Palliative Care services and emergency departments about the burden this places on hospitals due to limited resources and beds. The difficulties that arise when emergency departments are relied on to provide Palliative Care to homeless patients were also explored in the Metropolitan study (PCNSW, 2022). The transient care provided in these settings often means that high quality, patient-centred care is not possible, and homeless patients with a history of trauma can also find it difficult to remain in these environments long-term. There are still significant issues with relying on emergency departments to provide this care, especially in hospitals with limited available space and resources.

The often tenuous links between health and social services were mentioned as another barrier to care, with appropriate social services support found to vary depending on the location in NSW and often limited in available resources. Some of the services that participants had collaborated with included Housing NSW, My Aged Care and Link2Home. Participants also explained they were able to collaborate with individuals such as Social Workers, Aboriginal Liaison Officers and Parole Officers in particular cases, to support patients. Most of the services listed by participants focused on securing housing and funding support to access necessary healthcare services. In some cases, services also focused on providing case management and advocacy services for patients, but these were often not in close collaboration with Palliative Care services. There was a heavy reliance on support from Housing NSW and My Aged Care, though these services were also limited in the assistance they could provide. These limitations often revolved around available supported housing and access to funding for patients. When asked if there were any services they could collaborate with to support homeless patients, one participant explained that they “don’t tend to have typical homeless shelters” in their surrounding areas (Interview, 2023). A lack of available and accessible emergency housing makes it difficult for healthcare providers to assist patients to die at home or in a place of their choosing, and places an extreme burden on the emergency departments and hospitals in these areas. The participants expressed a need for greater support in regional, rural and remote areas, with one participant stating that “if we had more support, we could do more” (Interview, 2023).

Barriers to Receiving Care

Due to the unstable and transient living situations of some homeless individuals, participants had faced difficulties ensuring these patients received continuous and holistic care. With no fixed address, patients found it difficult to maintain contact with Palliative Care health workers and services, especially if they regularly moved between different forms of accommodation. Many of the participants said they primarily relied on the patient arriving at the service independently. It was acknowledged that it could be difficult for homeless patients to make their own way to regular appointments to effectively manage their symptoms, but that "when things get bad enough, they'll present to the emergency department, even if it's really difficult for them to get there" (Interviews, 2023). In these circumstances care is rarely person-centred, and it is imperative that greater support is provided to ensure continuous care can be delivered across various settings, particularly for this patient population. *Priority Five* of the *End of Life and Palliative Care Framework* (NSW Health, 2019) outlines that access to quality care must be equitable, and specifically highlights the needs of people experiencing homelessness, as well as those located in regional areas. Extra support for these populations is required to achieve this goal, due to the additional challenges they face while attempting to access necessary care.

Another challenge associated with insecure accommodation is that patients are often not able to make necessary adjustments to meet their reduced mobility needs (Interviews, 2023). Aids and equipment are commonly used to support individuals receiving Palliative Care in their homes, including handrails in bathrooms to prevent slipping, and ramps to replace stairs that are no longer accessible. In housing where these adjustments were not possible, the participants found it difficult to ensure that the patients both received adequate care and would remain safe while by themselves.

Some participants had also encountered patients experiencing homelessness as a result of losing accommodation provided through employment packages. Following the diagnosis of a life-limiting illness, one patient had been terminated from his position and lost his allocated accommodation in the process. One participant explained:

> *"He went from having stable accommodation and a job, to nothing. They basically just said to him 'Look, you don't work for us anymore, get out'."*
>
> \- Interview, 2023

The participant further described the stress the patient had endured in the months following, explaining that he "stayed anywhere he could" while also experiencing a life-limiting illness. Eventually the community nurses were "lucky" to find emergency accommodation that the patient could stay in, with basic furniture generously provided by a friend of the patient. This example highlights the need for greater support for people diagnosed with life-limiting illnesses while living in employer-provided or temporary accommodation, as they face a greater risk of sudden and unexpected homelessness.

Another participant described how patients staying in emergency motel accommodation after losing their homes to natural disasters were required to vacate their allocated rooms over the weekend, so the rooms could be rented out to paying customers. In one case, a participant explained that a patient with a life-limiting illness was forced to sleep in their car while the emergency accommodation was unavailable over the weekend (Interview, 2023). It is quite clear that homeless people are not being afforded the right to die in their place of choice, which is another goal included in the *End of Life and Palliative Care Framework* (NSW Health, 2019). It appears that this constant transient accommodation impacts on patients receiving high quality Palliative Care with continuity and flexibility across multiple settings, and causes further challenges as patients are forced to find alternative places to stay despite being allocated emergency accommodation.

Grief and bereavement are also an often-overlooked aspect of Palliative Care. While ensuring carers have safe and secure housing after a patient dies is definitely outside the scope of Palliative Care services, the inextricably linked issues should be noted here. The *End of Life and Palliative Care Framework* (NSW Health, 2019) specifically mentions the importance of carers being "recognised, valued and supported" and states they should receive the "services and support they need to carry out this role". Participants described examples of carers facing homelessness following the death of the patient they were caring for, highlighting the need for greater support for this population.

Carers can find themselves in difficult circumstances when they take on the responsibility of caring for their loved ones. According to the ABS (2019), there were 2.65 million people in Australia who served as either a primary or other carer providing “informal assistance” to individuals requiring care. The ABS (2019) states that the lives of primary carers are “often significantly impacted by their caring role”, and “employment status varied with the hours of care per week that a primary carer was providing”. As the number of hours of care provided by primary carers increased per week, the number of primary carers that were employed decreased. Additionally, “the majority of primary carers (79.1%) resided in the same household as the person for whom they provided the most care” (ABS, 2019).

Participants explained that “a lot is left up to the family or primary carer”, and that there are many people who “leave their family to go and care for their sibling or parent with a life-limiting illness”, in areas where services can’t provide 24-hour Palliative Care (Interviews, 2023). In one case, a primary carer had faced homelessness following the death of the patient they were caring for, as their supported accommodation had been provided under the patient’s name only. The carer was required to reapply for supported housing under their own name, but the waitlist was so long that the carer could not be provided with new housing before they were required to leave the old one. The participant further explained that they had witnessed both patients and carers facing extensive waiting times for priority assisted housing, and that patients with life-limiting illnesses often do not have the ability to wait for these long periods. Overall, participants expressed feelings of helplessness at the amount of time their patients had spent waiting for supported housing while actively living with life-limiting illnesses, as well as the impacts on carers facing homelessness after they had spent extensive time caring for their loved ones, often while still grieving the loss of their loved ones.

Opportunities for Improvement

Prior to this study, the availability and accessibility of Palliative Care services for homeless individuals in regional, rural and remote NSW was largely undocumented. The approaches taken by health workers providing care to homeless patients in these regions was also largely unknown. The experiences described by the study participants suggest that they have faced many challenges while providing Palliative Care to patients facing homelessness. These challenges are amplified by their remote locations and often limited access to specialist care. The findings of this study provide opportunities for improvement regarding the support of both Palliative Care providers and homeless people with life-limiting illnesses in regional, rural and remote areas of NSW.

During the interviews, participants were asked what changes they hoped to see in response to their concerns and the challenges they had faced. They explained that with greater funding and support in regional, rural and remote areas, they would be able to better provide care to vulnerable patients. They expressed frustration at the barriers that prevented them from providing person-centred and holistic care to patients experiencing homelessness, including staff shortages and limited access to specialist Palliative Care services in these areas. They also stated that further education for Palliative Care providers regarding the care of homeless patients would be beneficial. With greater support for Palliative Care services in these regions, the current reliance on emergency departments would also reduce, easing the burden on local hospitals to deliver specialist care in transient settings.

Participants explained that the provision of case managers to maintain records of homeless patients receiving care for life-limiting illnesses could be beneficial for both the patients and staff providing care. Some also expressed that they would benefit from a clearer understanding of how patient funding is allocated between services, as well as greater management of patient funding by funding providers.

Challenges for specific vulnerable groups also became clear through the study. Particular concern was expressed for the individuals with life-limiting illnesses that are located in regions prone to natural disasters, as well as those that live in accommodation provided as part of employment packages. Carers that had relocated to live with the patients they cared for were also believed to face additional risks. Patients within these groups were believed to be even more vulnerable to exploitation and homelessness, due to the unforeseen and uncontrollable circumstances that had destablised their housing arrangements. Participants also highlighted the need for greater priority housing support for patients experiencing life-limiting illnesses in regional, rural and remote areas of NSW.

Despite the challenges, the participants were often able to adequately manage and work around these barriers to continue delivering quality Palliative Care services to homeless patients. The dedication of the participants and those within their services to provide homeless patients with care was evident through their descriptions of the creative and non-typical methods they used in unstable and stressful settings. This level of flexibility appeared to be the result of living in regional locations, as the participants displayed a sense of community that is often unique to smaller, more isolated areas. It was inspiring to hear how the participants persevered with the delivery of quality Palliative Care, despite the difficulties they had faced. One participant described how workers at their service had taken it upon themselves to care for a patient's two pet dogs, as the patient declined in health and needed to remain in hospital due to his life-limiting illness. The participants explained that they all tried their best to help their patients who were experiencing both a life-limiting illness and homelessness. This demonstrates the commitment of health workers even when faced with difficult circumstances, but the impact this can have on their health and well-being must also be acknowledged and addressed.

Through this study, it became clear that both homeless patients and health workers have faced many challenges in the access and provision of Palliative Care, in ways that are often unique to regional, rural and remote areas. These barriers continue to impede the accessibility and delivery of care in these regions, and it is imperative that these barriers are addressed in order to ensure equitable access to these services across all areas of NSW.

References

Australian Bureau of Statistics (2023). '*Estimating Homelessness: Census*', as accessed at <https://www.abs.gov.au/statistics/people/housing/estimating-homelessness-census/2021>.

Australian Government Department of Health and Aged Care (2019). '*Exploratory Analysis of Barriers to Palliative Care: Issues Report on People Experiencing Homelessness*', *Australian Healthcare Associates*, as accessed at <https://www.health.gov.au/sites/default/files/documents/2020/01/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-experiencing-homelessness.pdf>.

Australian Institute of Health and Welfare (2023). '*Deaths in Australia*', Australian Government, as accessed at <https://www.aihw.gov.au/reports/life-expectancy-deaths/deaths-in-australia/contents/life-expectancy>.

Australian Institute of Health and Welfare (2023). '*Rural and Remote Health*', Australian Government, as accessed at <https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health>.

Chamberlain, C and Mackenzie, D (1992). '*Understanding Contemporary Homelessness: Issues of Definition and Meaning*', Australian Journal of Social Issues, 27(4), 274-297.

Department of Customer Service (2024). '*Temporary and Emergency Housing*', NSW Government, as accessed at <https://www.nsw.gov.au/emergency/recovery/temporary-housing#toc-at-home-caravan-program>.

Homeless Hub (2024). '*Discrimination*', Canadian Observatory on Homelessness, as accessed at <https://www.homelesshub.ca/about-homelessness/legal-justice-issues/discrimination>.

International Association For Hospice & Palliative Care (2018). '*Global Consensus Based Palliative Care Definition*', Houston TX, as accessed at <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/>.

Knaus, C and Evershed, N (2024). '*What Do We Know About Homelessness Deaths in Australia - And Why is Nobody Tracking Them?*, The Guardian, as accessed at <https://www.theguardian.com/australia-news/2024/feb/06/australia-homeless-population-deaths-numbers-prevention>.

KPMG (2023). '*70 Percent of Australians Impacted by Natural Disasters*', as accessed at <https://kpmg.com/au/en/home/media/press-releases/2024/09/70-per-cent-of-australians-impacted-by-natural-disasters.html>.

NSW Ministry of Health (2019). '*End of Life and Palliative Care Framework 2019-2024*', as accessed at <https://www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf>

Scott-Stevenson, E and Asbury, M (2022). '*Homelessness and Palliative Care: A Scoping Study in Metropolitan Sydney*', Palliative Care NSW, Sydney, as accessed at <https://palliativecarensw.org.au/wp-content/uploads/2022/12/PCNSW_HomelessnessPC_Report_F.pdf>.

Smith, J. (2019). '*The Homelessness, Death and Dying Project: Summary Report*', Parity, 32(6), pp. 4-12.

Standing Committee on Social Issues (2022). '*Homelessness Amongst Older People Aged Over 55 in New South Wales*', Legislative Council, NSW Parliament, Report 61, as accessed at <https://www.parliament.nsw.gov.au/lcdocs/inquiries/2865/Report%20No.%2061%20-%20Homelessness%20amongst%20older%20people%20aged%20over%2055%20in%20New%20South%20Wales%20-%20October%202022.pdf>.

Contact Palliative Care NSW

Phone 02 8076 5600 **Email** info@palliativecarensw.org.au

Office Suite 706, 50 Clarence St, Sydney NSW 2000

www.palliativecarensw.org.au

Palliative Care
NEW SOUTH WALES