

**Partnering to Provide Palliative Care: The lived experience of carers accessing after- hours palliative care support provided by a non-government organisation in partnership with a regional local health district.**



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## ABBREVIATIONS

<b>HMCN</b>	Hastings Macleay Clinical Network
<b>LHD</b>	Local Health District
<b>MNCLHD</b>	Mid North Coast Local Health District
<b>NGO</b>	Non-Government Organisation
<b>PCOC</b>	Palliative Care Outcomes Collaboration
<b>RRCBP</b>	Rural Research Capacity Building Program
<b>SPCS</b>	Specialist Palliative Care Service

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## ABSTRACT

### **Aim:**

Caregivers are fundamental to achieving effective home based palliative care. The burden on carers is often greatest after-hours when the usual sources of specialised care are not routinely accessible. A lack of after-hours home visiting palliative care support services outside of metropolitan areas means that many rural people experience frequent unplanned hospital admissions or are unable to die in their preferred place of care. The aim of this study was to explore the experience of carers receiving after-hours visiting palliative care provided in partnership between a Local Health District (LHD) and Non-Government Organisation (NGO) in rural and regional NSW.

### **Method:**

A hermeneutic phenomenological approach with purposive sampling of 10 bereaved carers who accessed after-hours palliative care support was adopted. Data was generated through semi-structured interviews. Inductive thematic analysis was used to identify the essential meanings of the experience.

### **Results:**

Emergent themes included collaboration, anticipatory care, accessibility and perceptual transformation. Carer's experiences of the partnership arrangement were positive, with effective communication, an anticipatory approach to care and access to after-hours support identified as facilitators that enabled death at home.

### **Conclusion and Implications for Practice:**

The continuity of service afforded by this partnership were perceived as crucial by carers to facilitate successful home care of the dying and post- bereavement outcomes. The strengths and challenges relating to this partnership model will inform future palliative care service development and practices that are scalable to other services, with potential applications being extension of packages from terminal and deteriorating phases to unstable phases.

### **Key words**

Palliative Care, carer, after-hours care, non-government organisation, partnership, rural.

## EXECUTIVE SUMMARY

### Recommendations

1. Review existing partnership arrangements between the Mid North Coast Local Health District (MNCLHD) and Silver Chain with the aim of expanding current scope of eligibility criteria to after-hours care. This will address recommendation three of the 2018 Palliative Care Service Development Guidelines (1) and will include:
  - Access for patients in the unstable phase
  - Access to overnight urgent respite packages to provide additional support for carers to reduce after-hours hospital presentations.
2. Establish the Compassionate Communities Public Health Initiative 4 in the MNCLHD, via identified champions such as palliative care volunteers, interested community members and local government. This will assist in meeting the wide-ranging needs of the dying, develop community capacity and death literacy and promote consumer representation in this area. As per the Australian Commission on Safety and Quality in Health Care Standard 2: Partnering with Consumers (4) and the NSW Health Recognition and Support for Carers Key Directions 2018–2020 (5) reforms are needed to ensure meaningful consumer and carer engagement
3. Adoption of a district wide approach to assessing carer support needs via the use of validated tools such as the Carer Support Needs Assessment Tool (CSNAT) or the Caregivers Burden Scale in End of Life Care (CBS- EOLC) to become embedded in clinical practice (6).
4. District wide review of current carer medication safety and education packages, in conjunction with national strategies that address consumer misconceptions about opioids and administration of medications by lay carers in the community setting.

### Context

With projected population growth, increasing incidence of chronic disease and mounting pressure on public hospital resources, the need for effective home based palliative care is evident both nationally and world-wide. With most people preferring to die at home, there is increasing recognition of the central role that carers play in reducing unplanned hospital admissions and facilitating end of life care at home. The burden on carers, particularly in rural and regional areas, can be at its most extreme after-hours, when access to General Practitioners (GPs) and the Specialist Palliative Care Service (SPCS) is not available.

In 2015, the MNCLHD partnered with Silver Chain, a not-for-profit Non–Government Organisation (NGO), to provide after-hours Last Days of Life home support packages in the Hastings Macleay Clinical Network (HMCN). Research to investigate the carer’s experience of similar partnership models is scarce but necessary to develop sustainable models of care and effective stewardship of health resources.

## **Implications**

As well as addressing the identified gap in the literature, this study has implications for policy and clinical practice. This study demonstrates the value of continuation of flexible palliative after-hours care into the future and highlights clinical practice opportunities in relation to inter-organisational and patient communication, anticipatory care and the need for formal assessments of carer support needs via the use of validated tools. As demand for health services increases, evaluating and adapting current models of care will reduce the burden on acute services.

## **Approach**

The research aim was to explore the lived experience of carers receiving after-hours palliative care support provided in a local health district and NGO partnership model. Hermeneutic phenomenology was used to guide the study. Semi-structured interviews were conducted with ten recently bereaved carers and inductive thematic analysis identified the essential meanings of the caregiving experience. Ethics approval from the North Coast New South Wales and Silver Chain Human Research Ethics Committees was granted in July 2017.

## **Findings**

Four interrelated themes defining the participants experience emerged:

### **Collaboration**

Collaboration defines the carer's experience of the teamwork between themselves, the SPCS and Silver Chain to keep their loved one at home for end of life. Carers reported that this collaboration enabled them to feel confident and supported in their role. Communication, an anticipatory approach to care and round the clock support were identified as facilitators that supported death at home.

### **Anticipatory Care**

Anticipatory care involves preparing for and being responsive to the continually changing needs of patients and carers due to disease progression. In home based palliative care, anticipatory care assists in the reduction of acute admissions and contributes to carer confidence and involves access to equipment, education on medication administration and preparation for home death.

### **Accessibility**

This theme highlights that for all participants, the knowledge that they could access palliative care around the clock contributed to their sense of security and confidence, particularly in rural areas where on call GP's and access to a palliative care physician are not available. As well as providing reassurance, access to well-coordinated and continuous care in the home setting was seen as fundamental in reducing preventable admissions to emergency and acute services.

### **Perceptual Transformation**

This theme demonstrates how caregiving at home was experienced as a profoundly meaningful endeavor which, despite its challenges, resulted in perceptual transformation of self and the role of palliative care. Carers described a willingness to repeat the journey for other loved ones with the knowledge that access to 24-hour specialist support was available.

## INTRODUCTION

Caring for someone who is dying is not a subject that is easily raised in Australian society, leaving many unprepared for the overwhelming physical, emotional and psychological challenges it entails. Lack of access to after-hours palliative care support in rural and regional areas compounds these challenges and means that many people die in acute settings (7). In 2015, the Mid North Coast Local Health District (MNCLHD) partnered with Silver Chain, a not for profit non-government organization (NGO) to provide after-hours care to palliative patients in the last days of life. This report explores the lived experiences of carers accessing support within this model of care.

This report summarises qualitative research undertaken by the researcher whilst a participant of the Rural Research Capacity Building Program (RRCBP) sponsored by the Health Education & Training Institute and the MNCLHD. These findings will be of relevance to clinicians involved in the care of people with life limiting illnesses, community and hospital health service managers and policy makers and researchers who recognise the need for review of existing models of care to support an increasingly ageing and sick population, without placing undue burden on hospital resources.

## BACKGROUND

While 70% of Australians say they want to die at home, only 16% do so (7). The NSW Agency for Clinical Innovation (ACI) Fact of Death Analysis established that in NSW between 2011 - 2012, people who were in their last year of life were admitted to hospital on an average of four occasions, utilising 984, 000 bed days at an estimated cost of over \$900 million (8). It is widely recognised that caregivers are fundamental to achieving effective home based care and make a remarkable economic contribution to the health care system (9), however carer fatigue is a significant factor in admissions to hospital in the last days of life (10). Whilst the role of carer is often willingly undertaken, caregiving can entail significant emotional, physical, financial and social impacts on carers (11). Despite The 2018 National Palliative Care Standards (12) advocating the importance of supporting carers, resource issues in rural and regional areas add to the challenge of providing optimal support, particularly in relation to access to after-hours palliative care. This compromises the carer's ability to keep the patient in the home environment, creating conflict between the patient's preference for a home death and the carer's uncertainty about their ability to cope.

### Local Context

The MNCLHD expects to experience a projected population growth of 21% from 2011 – 2031, with an 88% increase in the 85+ age group (13). This, combined with the increasing incidence of chronic disease means innovative models of care that balance responsiveness to individual needs with effective use of scarce resources are vital to keep pace with this growing demand. The NSW Government Plan to Increase Access to Palliative Care (2012-2016) highlighted the fact that people in regional and rural areas are particularly affected by a lack of 24-hour support for carers (14). To address these issues, the NSW government advocated for adopting a combination of organisations to be responsible for palliative care, including Non-Government Organisations (NGOs) and private providers. To achieve this, the MNCLHD partnered with Silver Chain, a not-for-profit NGO to provide Last Days of Life home support packages. Commencing in 2015 in the Hastings Macleay Clinical Network (HMCN), these seven day packages, funded by the Ministry of Health 'wrap around' existing Local Health District (LHD) specialist palliative care services (SPCS), to coordinate round-the-clock

support to patients, their carers and families. While the SPCS continues to provide palliative support from 0800 to 1630 seven days a week, each Silver Chain package, available in the last seven days of life, in addition provides:

- An Assistant in Nursing to provide personal care and respite for carers during the daytime.
- A Registered Nurse home visit to provide clinical care during the evening, with overnight support via telephone or video after 11pm.

Medical governance remains with the GP or treating specialist. Palliative care patients in phase 3 (deteriorating) or phase 4 (terminal) as prescribed by the Palliative Care Outcomes Collaboration (PCOC) are accepted for referral (see Table 1). The common language of PCOC is used by both the SPCS and Silver Chain to facilitate effective clinical handover (15).

**Table 1: PCOC Phase Definitions:**

Phase	Definition
<b>Stable</b> (Phase 1)	Patient problems and symptoms are adequately controlled by established plan of care and <ul style="list-style-type: none"> <li>• Further interventions to maintain symptom control and quality of life have been planned and</li> <li>• Family/carer situation is relatively stable and no new issues are apparent</li> </ul>
<b>Unstable</b> (Phase 2)	An urgent change in the plan of care or emergency treatment is required because <ul style="list-style-type: none"> <li>• Patient experiences a new problem that was not anticipated in the existing plan of care, and/or</li> <li>• Patient experiences a rapid increase in the severity of a current problem; and/or</li> <li>• Family/ carers circumstances change suddenly impacting on patient care.</li> </ul>
<b>Deteriorating</b> (Phase 3)	The care plan is addressing anticipated needs but requires periodic review because <ul style="list-style-type: none"> <li>• Patients overall functional status is declining and/or</li> <li>• Patient experiences a gradual worsening of existing problem and/or</li> <li>• Patient experiences a new but anticipated problem and/or</li> <li>• Family/carers experience gradual worsening distress that impacts on the patient care.</li> </ul>
<b>Terminal</b> (Phase 4)	Death is likely within days
<b>Bereavement</b> (Phase 5)	The patient has died. Bereavement support provided to family/carers is documented in the deceased patient's clinical record.

Adapted from: M. Masso, S. Frederic, Allingham, M. Banfield, C. Elizabeth, Johnson, T. Pidgeon, P. Yates & K. Eagar, "Palliative care phase: inter-rater reliability and acceptability in a national study", *Palliative Medicine* 29 1 (2014) 22-30.(15)

At the time of writing this report, the NSW Government has allocated an additional \$20 million to continue the Last Days of Life Home Support Service for a further 2 years.

## LITERATURE REVIEW

### Carers Experience of Receiving After- Hours Palliative Care

Despite widespread advocacy for after-hours services as the gold standard (16-18) and several international studies reporting high carer satisfaction with after-hours telephone advice lines for palliative patients and their carers, (19-21), a literature search of the databases Medline, Cinahl, Embase and Nursing@Ovid for papers dated 2000 – 2017 (in English) resulted in few papers that specifically evaluate the experiences of carers receiving an after-hours visiting palliative care service, particularly in collaboration with a public-private partnership model.

In a 2016 Cochrane Review by Shepherd et al (22), it was noted that there was a lack of data on the impact of home based end of life services on caregivers available and this was recommended as an area for future research. In three trials reviewed by Shepherd et al, nursing care was available for 24 hours if required, however the interventions were provided from public hospital based services that



provided community outreach (23). The study concluded that all trials highlighted the need for access to 24-hour care.

Innovative models in the UK that use a partnership approach with NGO's include the Midhurst Macmillan SPCS. This programme is a community based SPCS that is jointly funded by the UK National Health Service and Macmillan Cancer Support (a registered charity) providing care in conjunction with primary health care teams. This programme provides 12 hour visiting care access and after-hours telephone support. In a study by Noble et al (2015), bereaved carer satisfaction was examined using a retrospective postal questionnaire (24). Carers were very positive about the support received from this partnership, the confidence this promoted as the disease progressed and the reduced need for admission to hospital. Carers articulated the wish for a full after-hours service to be made available. A study by King et al (2004), examined family carer's experience of after-hours visiting community palliative care in the UK using semi structured interviews and thematic analysis (18). Models of care to provide these services were various, including access to 24-hour district nursing services, night-sitting services and specialist telephone advice from Macmillan nurses and hospice-based specialists. Carer's experiences were generally positive. Of the few negative experiences identified, poor communication and inflexibility of service provision were raised as issues by carers.

Similarly, there is a lack of studies in the Australian context that examine the experiences of care givers with access to after-hours visiting palliative care support. While some Australian studies have reviewed the impact of telephone advice support on carers (25, 26) Thomas et al (2010) evaluated how the needs of family carers were met by three home based SPCS, from the service perspective, rather than that of the carer (27). Of the three services that provided home based palliative care, two metropolitan services were able to offer visiting after-hours palliative care support (not in collaboration with an NGO), while the regional centre did not offer after-hours care. Access to this level of support was identified by the regional site as pivotal if they were to improve palliative care service delivery and adequately support carers.

### **Effect of After-Hours Care on Keeping Patients at Home**

Several studies demonstrated that programs offering after-hours palliative care access to carers increase the time spent at home and reduce the number of inpatient days (21, 28), as well as increasing the likelihood of dying at home compared with usual care. In a study by Ahlner-Elmqvist et al (2004), the proportion of time spent in hospital for those receiving after-hours support was 18%, compared to 31% for those not receiving after-hours care. Of those receiving after-hours care, 21% of patients did not require hospitalisation at all (29). The same study reported that significantly more patients died at home in the group receiving after-hours care (45%) as compared to the group receiving conventional care (10%).

The Marie Curie Cancer Care Programme is a UK charity that launched its 'Delivering Choices' Programme in 2004 to provide at home care for palliative patients. This programme includes community service models that provide 24-hour care through partnership with services such as the NHS, local authorities and independent partners (24, 30). Purdy et al (2015), reported that those patients accessing this program were at least 30% less likely to die in hospital or have an emergency hospital admission in the last 30 days of life than those who did not (31). In a similar study of the same programme, for those who accessed the services, the percentage of home deaths rose from 19% in 2005–6 to 42 % in 2006–7 (32). In regards to hospital admissions, the authors reported a statistically significant fall in average number of admissions. Carer experience was not evaluated.

In the Australian context, a systematic review comparing rural and remote caregivers needs in the palliative setting compared to the urban setting, found that although caregiver needs are similar in both settings, reduced service availability in rural areas negatively impacts outcomes for rural communities, resulting in rural families being more likely to access emergency departments services than their urban counterparts (33).

In the grey literature, Palliative Care Australia published an article in which the Director of Hospice Care Services for Silver Chain reports 70% of Silver Chain's palliative care patients in Perth WA, die in their own home (34). This is a reflection of the WA State Government decision to primarily invest in a community care solution for palliative care. The article also reports that Perth has Australia's lowest number of inpatient palliative care beds per head of population, reflecting the merit of the community solution.

## Research Aim and Question

The aim of this study is to explore the lived experience of carers receiving after-hours visiting palliative care support provided in a partnership model between a regional local health district and a not for profit NGO, as well as gaining an understanding of the effect this support has on the carer's ability and willingness to keep loved ones at home for end of life care.

The research question is:

What are the lived experiences of carers accessing after-hours palliative care support delivered by a non-government organisation in partnership with a regional local health district?

## METHOD

### Methodology:

This qualitative study was guided by the principles of hermeneutic phenomenology. Phenomenology is concerned with the description of the lived experiences of individuals (35) and recognises that people's realities are influenced by the world in which they live (36). These lived experiences contribute meaning to each person's perception of a particular phenomenon, concept or idea (37, 38).

While the epistemology of phenomenology focuses on revealing meaning, variations exist in philosophical assumptions and methodologies to analyse data (39, 40). Hermeneutic phenomenology reflects a constructivist ontology in which multiple realities are recognised that may vary across cultural, social and political contexts (41). This methodology acknowledges the prior personal or expert experience of the researcher as necessary to the analysis with interpretations being co-created by a combination of the experiences articulated by participants and the knowledge and reflexivity of the researcher (42, 43).

Given the intensely personal nature of carers recalling the recent death of a loved one, the recognition that the carers social and cultural contexts create multiple realities and the researcher's prior knowledge and insight into the phenomenon, a hermeneutic framework was chosen to provide a theoretical underpinning to the study. This creates reflective insights that provide greater understanding of the carer's experience that is of clinical relevance and can be used to inform policy and practice around the provision of patient and carer centred palliative care. Results and discussions

are collectively reported as findings to reflect the iterative nature and holistic overview of the methodology.

## **Ethics Approval**

Ethics approval was granted via the NCNSW Human Research Ethics Committee (HREC no. 525N) on the 4<sup>th</sup> July 2017 and Silver Chain Human Research Ethics Committee (EC App 112) on 12<sup>th</sup> July 2017. An application to vary the interview period to March 2018 was approved by both committees in October 2017. The words carers and participants are used interchangeably throughout the report, with the use of pseudonyms to maintain confidentiality.

## **Recruitment**

Purposive sampling was used to recruit bereaved adult carers of palliative patients in the HMCN who had accessed Silver Chain Last Days of Life care packages, in which the patient had died between 6 weeks to 3 months prior to interview. Guidelines on interval from death to interview were reviewed (44) and expert advice obtained from the HMCN Palliative Care Bereavement Counsellor and Mid North Coast Cancer Institute and Wauchope Palliative Care Unit Social Worker.

Deceased patients who had accessed the after-hours packages were identified via the HMCN Community Palliative Care Service 2017 Register of Deaths. All carers had consented to be registered on the Community Health and Outpatient Care electronic medical record as a contact person and their details were cross checked with the patient's electronic medical record to ensure they were the primary carer. The care of the patient did not need to have been exclusively at home and selection was not restricted to patients with malignant diagnoses only. Gender or ethnicity of the carer did not impact inclusion. Carers that had been identified as an extremely high risk for complicated bereavement on the initial Bereavement Risk Assessment (see Appendix 1), such as those with previous suicidal ideation, multiple complex bereavements or death of a child or young person, were excluded from the study, as this was assessed as requiring increased specialised resourcing for counselling support. Due to safety considerations, any carers for whom a significant alert had been identified on the Work Health and Safety Checklist were excluded (for example, a history of violence or aggression).

Participants who met the inclusion criteria had a letter of invitation and Participant Information Sheet (see Appendix 2) mailed to their home address by the lead researcher. All participants were informed that interviews would be audio recorded, assured their data would contain no identifying information and would remain confidential in accordance with the Australian Code for the Responsible Conduct of Research (45). Carers were aware they could withdraw from the study or cease the interview at any time with no explanation or ramifications for future relationships with either organisation.

A total of 25 letters were sent with ten carers responding, all of whom met the inclusion criteria. The participants' ages ranged from 36 to 75 at the time of interview, with a mean age of 57 years. Two carers identified as having had prior nursing experience. All of the patients had home deaths and had identified home as their preferred place of care. The mean length of packages accessed was 5.7 days, with one carer accessing 2 packages over the course of the illness. No patients were hospitalised while receiving a Last Days of Life package. Data saturation was reached after 10 interviews.

**Table 2: Participant Characteristics:**

Demographic Data	Value
Total Number of Participants:	10
Sex: Male/Female:	3/7
Age (years):	
30-49	3
50-69	5
70-89	2
Relationship to Patient:	
Spouse	5
Child	4
Other	1
Diagnosis:	
Malignant	8
Non-Malignant	2
Home Death	10
PCOC Phase	
Deteriorating	2
Terminal	8
Length of Package	
<2 days	2
2-5 days	6
> 5 days	2

Consent was obtained in writing prior to commencing the interviews.

Semi structured interviews were conducted by the lead researcher and took place September 2017 and March 2018 in the participant's home (n=4), the Port Macquarie Community Health Centre (n=4) or Kempsey Community Health Centre (n=2), according to participant's preference. Participants were able to bring a support person with them, though none chose to do this. Mean length of interviews was 51 minutes.

At the end of the interview, ongoing counselling, if not already accessed, was offered to all participants via the HMCN Palliative Care Bereavement Program. Three carers had already been referred to the counsellor at the time of interview and one was referred with their consent as a result of expressed need during the interviews.

Thematic saturation was reached after ten participants had been interviewed. This was determined through initial analysis of the data at the end of each interview and collaborative analysis with the researcher's mentor.

## Data Analysis

The interview schedule (see Appendix 2) was developed to be consistent with hermeneutic principles. This enabled participants' experiences to be explored with further interpretation based on the researchers theoretical and personal knowledge. Initial piloting of questions occurred in conjunction with the HMCN Palliative Care Bereavement Counsellor and the Wauchope Palliative Care Unit Social Worker. Open ended questions were designed to reveal relevant information comparable across interviews, while maintaining flexibility to ask questions in any order appropriate to the understanding of the individual experience. Contextual probes were used to elicit more details about the experience as needed. Participants were given the opportunity to express thoughts, feelings and ideas to allow recall of events from their own perspective and were provided an opportunity to express views on topics not included in the interview guide. Audio recorded interviews were transcribed verbatim by the lead researcher. To preserve confidentiality, participants and transcripts were de-identified by the use of a participant code number. Field notes (46) were kept by the researcher as a means of recording contextual information and to assist in data interpretation.

In keeping with this methodology, initial data immersion through repeated listening to audio recordings and iterative reading of transcripts facilitated preliminary understanding of the data (36). First order constructs (participants' ideas expressed in their own words) were identified using a numbered line by line approach for each text to highlight text segments and assign a code. A total of 51 initial codes were identified. Each code was extracted with its associated text from all interviews into a table for analysis. Second order constructs (using the researcher's theoretical and personal knowledge) involved an iterative process whereby identified themes and sub-themes were checked with the raw data to maintain fidelity to the participants' constructs, identify interrelationships between themes and

relationship of themes to the literature (41, 47). A coding table was developed to record data indexed under each theme for each participant (see Appendix 3).

## Reflexivity

As a novice in the process of hermeneutical phenomenology, the researcher engaged in a process of collaborative analysis (48) with the research mentor. The researcher and mentor independently reviewed the transcripts. Collaborative analysis was then used to discuss initial codes, validate coherence of themes and guard against bias. The researcher utilised the consolidated criteria for reporting qualitative research (COREQ) as a guide in reporting this research (49).

Clancy (2013) describes reflexivity as “the process involved in developing an awareness of self, personal beliefs and opinions and how these impact on the conduct of the research and data analysis” (50). Reflexivity was regarded as an important element in designing and implementing this research and to this end, a hermeneutic perspective, in which the researcher engages reflexively with her own preconceptions and interpretations, was adopted.

The researcher is a female Clinical Nurse Consultant in Palliative Care who has extensive clinical experience in the delivery of palliative care in home and hospital settings. This involves regular contact with dying patients and their caregivers who may be distressed or bereaved. The researcher has personal experience of being a carer for close relatives who have experienced home deaths and advocates for facilitation of preferred place of care for palliative patients and their carers. Awareness of the impact that professional and personal experiences may have on data collection and analysis meant the researcher employed *hermeneutic alertness* (36), to reflect on the meanings of situations, rather than accept assumptions and pre-conceptions that may not reveal the data. This was facilitated by close adherence to the research methodology, design of the interview guide, recording of field notes and a research journal and regular reflection with the academic mentor to identify potential bias. The researcher had phone contact only with three of the participants prior to the patient’s death in relation to operational matters such as arranging urgent home visits by a palliative care nurse in times of crisis, but was not directly involved in the care of any of the deceased patients.

The researcher has completed post graduate studies, including a Master’s degree in Palliative Care, however does not have any previous formal research experience. Participation in the Health Education & Training Institute RRCBP provided opportunities for training in question formulation, research conduct, sampling, interview techniques and research methods. As a clinician and past carer, the RRCBP provided an awareness of reflexivity that served as ‘a bridge’ between clinical and personal experience and the the development of clinically relevant research (51).

## FINDINGS

The analysis generated four major themes: Collaboration; Anticipatory Care; Accessibility and Perceptual Transformation. Although the themes are independent, they are also interconnected and are discussed in relation to existing literature.

### Theme 1: Collaboration:

***“Everybody was on the same page. We all had the same goal, we were all heading in the same direction and that was keeping Mum comfortable and pain free, supporting the family.” Lara***

The theme of collaboration describes the partnership between carers, the SPCS and Silver Chain to achieve the common goal of patient comfort. Carers perceived the collaboration, integration and communication between the SPCS and Silver Chain as being well coordinated and cohesive:

*“We didn’t realise they were two different organisations initially until it was explained when talking to us.” Jason*

Inherent in the collaboration of formal supports and carers is the ability to communicate and connect while acknowledging the advocacy of the carer (52).

## **Communication**

Communication between nurses and carers in regards to the care of a dying loved one is both complex and highly sensitive. This study provided insights, both positive and negative, about aspects of communication. Central elements in this subtheme were provision of consistent information from both teams and the varying information needs of carers regarding what to expect in the future. For Lara, the individualisation of the communication with both teams to her own situation was very important in feeling her concerns were heard.

*“They listened to me, they just didn’t go off this script and treat all people the same...they actually listened to what I had to say.” Lara*

For Angela, feeling that her questions were answered and that both teams were well-informed and providing the same information created a sense of confidence.

*“I always had a list of anything that I wanted to talk about and anything I asked about was always addressed.” Angela*

Communication also extends to clinical documentation and clinical handover. The literature reports carers and patient’s reluctance to repeat their stories (53). In this study, participants felt the nurses were familiar with their situation and needs, creating a sense of security.

*“Yeah it was pretty flawless if you know what I mean. The records were kept and they were aware what had happened the night before or the day before and I couldn’t fault that in any way whatsoever.” Jill*

However, not every carer experienced clear communication. Angela had a difficult journey with her husband being too young to access support packages through My Aged Care. Access to the National Disability Insurance Scheme (NDIS) support was also declined, as there was a misperception by NDIS that palliative care teams routinely provide personal care assistance. Angela expresses her frustration below:

*“I was trying to say I’m saving the government tens of thousands of dollars by doing it all myself and all I’m asking is for someone to come in 3 days a week for an hour to help me shower (him).” Angela*

To assist Angela, the SPCS arranged for a referral to Silver Chain to provide urgent daily support for personal care and an evening RN visit on a temporary basis until further assistance could be sourced. After two weeks, as Angela’s husband did not enter the terminal phase and the package was due for review, a communication breakdown between the two services occurred where the SPCS had wrongly assumed that Silver Chain would notify the carer of plans to review or terminate the package. Angela takes up the story again:

*“There was a communication breakdown between palliative care, Silver Chain and myself in regards to (Silver Chain) pulling their service, which caused an awful lot of distress to me... I was told Silver Chain was pulling their service with next to no notice. So that was the closest I came to having a breakdown.” Angela*

Fortunately, alternative assistance was arranged and later as her husband entered the terminal phase, Angela expressed satisfaction with the collaborative efforts of the SPCS and Silver Chain.

*“So I had the Silver Chain AIN come in the morning, palliative care came around 11 or 12 to do the syringe driver, then I had the Silver Chain RN come in around four or five o’clock. So if I had something I needed help with, I had the help there.” Angela*

While provision of information is an essential component of communication and reducing carer stress, this study found that the readiness of individuals to engage in sensitive discussions to prepare for what to expect, varied between carers and even over time with the same carer. For Karen, it was felt that receiving information made her feel better equipped to deal with potential scenarios that may arise.

*“I think worst case scenario prepares you, whereas if they give you the worst case and it doesn’t happen your sort of sitting there thinking thank God that didn’t happen.” Karen*

For Angela, however, knowing the worst case scenario created more distress.

*“I’m a person who likes to be prepared, but there were that many things that could go wrong with (him). I think it would stress me out more, to think of everything that could go wrong and how I’d plan for it...So sometimes I think, yeah, they tried to over prepare, when sometimes you just need to let it go.” Angela*

The differing needs in carers requirement for information is an expected finding. In order to be psychologically prepared for the future, most carers prefer to receive information that explains what happens as the disease progresses (54). According to Friedrichson (2006), central tenets of being psychologically prepared include anticipation (knowing what may happen), expectation (adapting to what will happen) and prevention (avoiding unnecessary events) (55). However, information provision needs to be adapted to the carer’s preference and level of knowledge, with nurses remaining open to engage in these discussions and to reiterate information when required.

## **Carer as Advocate**

Having a strong commitment to care at home resulted in carers becoming advocates for their loved ones. Advocacy and care coordination require the carer to serve as a communication intermediary between the patient and formal supports, navigate complex systems of care and seek information to ensure needs are met. Participants appreciated recognition of their role, particularly in relation to fulfilling the wishes of their loved ones. The home based setting allowed the carer to maintain control, with the SPCS and Silver Chain providing the support, education and preparation needed. Lara explains:

*“...they were really nice, really respectful I guess of what I wanted and didn’t want. They weren’t pushy. They didn’t step over my lines; lines I’d made in the sand.” Lara*

Karen also described a sense of partnership and teamwork through participation in shared decision making:

*“They (the SPCS and Silver Chain) made us feel well and truly involved and let us be involved with sitting with everything. You never missed out on one thing.” Karen*

These findings are consistent with the literature. Carers value being recognised for the unique knowledge they possess about the patient and their specific needs. Home as the locus of care creates a shift in the relationship between nurses and carers, in which the nurse acknowledges the significance of experiential, individualised knowledge of the caregiver and their wish to act as full partners in the care of the patient (56).

## **Connection**

The building of rapport and trust between the carer and nurses created a connection that laid the foundation for collaboration. This connection produced a sense of security in the nurses’ knowledge and capacity to deliver expert advice. Participants observed that when nurses demonstrated sensitivity to their needs, this mitigated feelings of isolation and distress. For some carers, the connection was perceived as the SPCS and Silver Chain becoming like an extended family.

*“You build up a rapport with the palliative care nurses that are coming regularly and they become, well you know, almost at the point of them feeling like friends or family.” Lisa*

This corresponds with findings in previous studies (57,58) in which carers and nurses experienced supportive, cooperative connections as they met the care needs of the patient. However, these findings are not universal, with other studies (58, 59), noting carers perceive emotional support to be minimal or absent. It is essential to acknowledge that the connection created between carers and nurses may define perceptions on how care needs are met. In a study by Linderholm & Friedrichsen (2010), carers felt isolated and disempowered when they did not establish a connection with nurses (60). Wälivaara et al (2013) describe the dynamic in the home setting in which the nurse is invited into the family’s daily life and highlights the trust this generates and its implications in fostering a positive partnership (61).

Interestingly, for some carers the sense of connection was created directly as a result of the SPCS and Silver Chain nurses being part of the rural community, suggesting not just a sense of common experience, but also of accountability to the carer and patient. Jill, who lives on a rural property, explains her initial reticence at being introduced to the Silver Chain service and a new nurse:

*“I was kind of expecting the same nurse but then I got a phone call to say.... there’d be another one, so I was kind of like “oh no” but once again those fears were just unfounded. She was a local, she lived not far away from us and she was just kind of brilliant really because we as a family were really kind of losing it.” Jill*

Jason, who also lives on a rural property, discussed the reputation of the palliative care team in the community and stated:

*“There was a connection there ...she knew palliative care was a really good team in Kempsey so she was quite happy to have them coming out here and being of comfort.” Jason*

In a review of the literature, Lauder et al (2006) analysed rural nursing and the theory of social capital to reach a better understanding of the theory’s applicability to nursing (62). The researchers established that rural nurses who lived and practiced in the same communities as their patients are able to generate more trusting relationships with patients because of the common understanding of their communities. While numerous definitions of social capital have been proposed in the sociological literature, Putnam, Leonardi & Nanenetti (1993) define social capital as:



*“Those features of social organization, such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated actions”.*(63)

This definition highlights the concepts of trust and community as a determinant of connection. Particularly in rural areas, the trend for family members relocating to urban areas means this connection is extended to include other integral community members and community groups that provide a non-medical support network (33). This has a ripple effect for the broader rural community as participants use their experience and knowledge to support others with dying loved ones as part of a caring network (64). These connections and the concept of social capital are important as palliative care services move towards a public health approach to palliative care (64) and advocate for the development of the Compassionate Communities Movement (65,66) to grow community capacity to support carers in keeping dying loved ones at home. This social capital creates connected communities that understand the deficits and strengths of rurality, making them effective in advocacy and lobbying from a community development perspective.

## **Theme 2: Anticipatory Care:**

***“She sat us all down and spoke to us about what was going to happen and you know, explained everything and what dying would look like and that sort of stuff.” Jason***

Anticipatory care involves preparing for and being responsive to the continually changing needs of patients and carers due to disease progression. In home based palliative care, anticipatory care assists in the reduction of acute admissions and contributes to carer confidence. The use of advance care directives, NSW Ambulance Palliative Care Plans and anticipatory prescribing are all facets of anticipatory care with the patient at the centre of the decision making process. Collaborative discussions also occur with the carer in order to manage change, prevent crisis and reduce carer stress.

The intensity and duration of care can be highly variable across the course of the illness, requiring tailoring of anticipatory care to the individual circumstances. The caregiving trajectory in patients with cancer tends to be non-linear (67) and characterised by rapid transitions over a relatively shorter time frame, requiring intense but brief periods of engagement with formal supports. The carer's needs in managing patients dying at home with non-malignant diseases is less clearly recognised and warrants further investigation, particularly in reviewing models of care that provide a focus on after-hours supports for end of life care only.

The unmet needs of carers have been well documented (68, 69) and include unmet practical needs (respite, financial, personal care and symptom management education), as well as significant emotional needs, with the prevalence of anxiety and depression among palliative carers in the year prior to the death of a cancer patient as high as 46% and 39% respectively (70). This can result in negative health outcomes, including prolonged and pathological bereavement (71). Embedding the use of validated and comprehensive assessment tools (such as the Carer Support Needs Assessment Tool (CSNAT) or Caregivers Burden Scale in End of Life Care (CBS-EOLC) as part of routine clinical practice to assess carers needs will enhance anticipatory care and ensure both services are more responsive to the needs of carers as well as patients (6).

Carers are often challenged with the continuous adjustments needed as they witness the deterioration of the patient. As Jill explains:

*"You'd adjust to one change and then accept it and then there'd be another so it was just, yeah, kind of I don't know, like a snow ball coming down that got bigger and I couldn't...you just have to go with it." Jill*

Many of these changes in the patient's condition required specialised equipment to assist in managing at home. Having equipment supplied by the SPCS free of charge as the patient's condition changes is part of anticipatory care and was appreciated by carers.

*"Like I had a sling hoist, which palliative care paid for the rental of ... There's no way that all the equipment that I was using, there's no way I would've been able to afford to hire that, so it would've been a huge financial burden to have had to either bought or hired that equipment." Angela*

Carers also valued the specific education provided by the SPCS and Silver Chain on symptom management and nursing skills.

*"Both teams would show us how to bathe him and turn him and change him and do all that." Carol*

*"She taught me, she said watch how I do this so if it (sub –cutaneous line) comes out in the middle of the night, she said you can call us and we'll talk you through it ....so she showed me how to put it in and what to kink to be able to use that if I needed." Angela*

Education on medication administration by carers is an essential aspect of anticipatory care and keeping loved ones at home, particularly as the patient enters the terminal phase. Many lay carers reported subcutaneous medication administration was a source of anxiety in their role as carer. An unexpected outcome highlighted the importance of clear communication and reassurance in regards to the use of medications, despite local practices of formal medication education. Lara disclosed:

*"I found it really hard to give her extra Serenace or extra Midazolam or extra anything else. I really struggled with that, um and I'm not sure why I felt like that because I knew the doses she was getting would've been, like they were never going to kill her...so I don't know, it's just a thing I had." Lara*

This was an unexpected finding. As per local practice with all carers, Lara had been well educated on the use, effects and safety of the medications by the SPCS and Silver Chain via both verbal and written information with an endorsed medication safety program (72). This program provides a safe framework to assess a carer's preparedness and ability to administer subcutaneous medications. Lara also had previous experience in administering these medications in a nursing capacity. While nursing experience afforded professional insights that assisted her ability to advocate and navigate the health care system, it did not help Lara in feeling confident or prepared in the administration of these medications to a loved one. In an Australian study on nurses as carers, Quinney et al (2017) recommended caution in presuming the experience for nurses who are carers is homogenous, regardless of the background of their experience (73). The dual responsibility of nurse and carer exposes individuals to anxiety and conflict, including reluctance and fear of medications, both despite and as a consequence of their professional context. This highlight the importance of anticipating and alleviating fear or concerns around medication administration for all carers.

Anticipatory care and planning for home death was facilitated by coordination of timely information from both the SPCS and Silver Chain and allowed carers to access support at the time of the death. Preparing carers for what to do following a home death requires sensitive communication and a practical plan, particularly in rural areas for deaths that occur after-hours when there is no GP available. Despite the nature of these conversations, carers appreciated the opportunity for open and consistent communication from both teams:

*“That information, we were grateful for it...it gave us that option to feel as though we had control over her comfort I suppose. We were very happy with that information. Not happy in what it was offering, but happy in the fact that we were given it. It’s important that we were given it.” Jason*

Again, this is well substantiated in the literature (54, 74), with caregivers wanting nurses to initiate and navigate conversations around death and dying. Ideally, carers preferred that the conversations take place over time, allowing for gradual adjustment, with the option of being re-visited to seek further clarification. Carers preferred clear, direct and simple language with the avoidance of euphemisms that could be misinterpreted (55).

### **Theme 3: Accessibility:**

***“I was very pleased to know that there was help on hand, if you like, 24/7. Otherwise it would have been an ambulance to emergency. As it was explained to us, it was (the SPCS) during the day and at night time it would be Silver Chain, so I thought that’s good, yeah. And they’d probably get there as quick as any ambulance.” John***

Despite rural palliative caregivers reporting similar levels of burden of care as their urban counterparts, rural caregivers are more likely to use acute care services due to a lack of access to specialised palliative care support, respite and personal care assistance, particularly in the last days of life (33). In this study, access to the Last Days of Life Support Packages provided participants with a sense of reassurance and confidence, allowing them to continue caring at home and avoiding unplanned hospital presentations.

#### **Reassurance**

For all participants, the knowledge that they could access palliative care around the clock contributed to their sense of security and confidence, particularly in rural areas where on call GP’s and access to a palliative care physician are not available. Carers shared statements of feeling well supported, knowing they could depend on the nurses for help at any time:

*“You do need that ongoing support during the night...well when they’re in hospital or another care unit, well they’d have 24-hour care, but not here. In the home you need that sort of professional monitoring and care and someone you can call when you’re not sure what’s happening.” Glen*

Long waiting lists and specific criteria for referral, mean many rural palliative patients do not qualify or cannot access care packages in a timely manner through established mechanisms. Due to the nature of the Last Days of Life packages, day time respite, personal care assistance and symptom control support can be accessed quickly when it is most needed. Participants found this particularly reassuring.

*“I understood there were three lines of support for me...if I wanted help in washing him or to have a break, they would assist with doing that. They would also come and visit us of a night and also there was a number for me to contact them throughout the night.” Jill*

*“...oh my God I can breathe! Someone is here to help me.” Carol*

While the reassurance of being able to contact palliative care after-hours is well documented in the literature (27, 53, 58), some studies (75, 76) document carers reluctance to contact after-hours services due to anxiety about the legitimacy of their need. While this was not the case in this study,

participants did report a sense of hypervigilance and anxiety about whether they were providing adequate or appropriate care, contributing to a sense of conflict and self-doubt. Accessibility to 24 hour support from formal services directly impacts the confidence of the carer and their willingness to maintain care at home (77, 78), as Karen affirms:

*“So if they hadn’t of been there to reassure us that we were doing an amazing job (crying) every time they came here...you know, you are not doing anything wrong, you can’t do anything wrong. They kept reassuring us, through the night to just ring Silver Chain.” Karen*

The notion of ‘doing everything right’ is well reported in the literature, with fear and uncertainty related to disease progression and lack of knowledge to cope with unanticipated circumstances the most prevalent concerns (79).

## **Hospital Avoidance**

As well as providing reassurance, access to well-coordinated and continuous care in the home setting is fundamental in reducing preventable admissions to emergency and acute services (31, 77). While the commitment to care at home is often made willingly, carers describe a high degree of associated burden, with related fatigue, anxiety and sleep deprivation being a significant factor in admission to hospital in the last days of life. This is particularly exacerbated by the lack of overnight respite packages. John explains:

*“I had to sleep with one eye open, like I was on watch all the time. Probably the only thing that anyone could’ve done for me was to sit beside her and let me get some sleep at night. Give me that break. Somebody to go on watch for me so I could go off watch.” John*

While access to respite and support are required at the end of life, a lack of access to these services in rural settings prior to the terminal phase, means many carers experience social isolation, exhaustion and put their own health at risk, resulting in admissions to acute facilities for respite well before the terminal phase. Access to overnight urgent respite packages to provide additional support for carers or after-hours access to symptom management for those patients in the unstable phase may reduce these hospital presentations.

For some carers, access to the after-hours team was essential in preventing potential use of ambulance and hospital resources in what were the last moments of life.

*“Mum had a really shocking bleed where she was vomiting the biggest blood clots I’ve ever... like placenta...and we thought this was it. Silver Chain had left. We thought that, you know, how can anyone survive a night through this? So we rang Silver Chain and they came back. They came back (crying). They were amazing and she made mum comfortable, calmed us down...once she explained to us what was going on and all that sort of thing it was a lot easier.” Karen*

*“We rang Silver Chain quite a few times during that (final) night and without that...yeah, she would definitely have had to go into hospital.” Lisa*

A lack of confidence in the hospital system was the driving force behind some participant’s commitment to keep the dying person at home. Angela perceived home as safe and recognized access to 24-hour support as vital in fulfilling this commitment.

*“I was fearful of him in hospital and of things that could go wrong because of neglect... I think if I didn’t have that support (access to 24-hour palliative care), I might’ve done it and then that*

*would've been worse because I'd be living with that guilt that I put him into hospital. He died at home where he was comfortable, where he was peaceful, where he wasn't stressed out."*  
Angela

The literature underscores the importance of round the clock availability by formal palliative services as indispensable in avoiding hospitalisation (31, 77). A further positive effect of this care is that people are able to die at home in accordance with their wishes (80). In the event of a home death, accessibility to 24-hour palliative care services means that legal obligations relating to assessment and documentation to verify death (enabling removal of the deceased from the home) can be attended when the carer is ready, even if death has occurred after hours. For all carers, the reassurance of being able to contact either the SPCS or the after-hours service after the death was particularly comforting.

*"...when he died I called the Silver Chain number and said could you ask (After Hours Nurse) if he could come to the house to do the verification certificate? So it was good having that because if he didn't do it then it would've had to have waited till.... I called the funeral director so it was like midnight before they took his body away. So it was just good having that kind of backup in the evening."* Angela

#### **Theme 4: Perceptual Transformation:**

***"Having both services there is the difference between being able to do this or not. So these services between Palliative Care and Silver Chain make it possible for people that have the desire to support their loved ones at home. It would be the difference."***  
Angela

Finding meaning in experience is central to an individual's ability to adjust and cope in the context of caring for a dying loved one however, the ability to cope is predicated on the carer's perception that resources to support coping are available (81). In the context of this study, with access to round the clock support, caregiving at home was experienced as a deeply meaningful undertaking, which, despite its challenges, lead to perceptual transformation on the role of Palliative Care and resilience.

#### **The Role of Palliative Care**

With the introduction of palliative care often associated with imminent death, carers recounted that it was very confronting to try to comprehend the concept of palliative care, while simultaneously processing the need for such a service:

*"In a way it's like confronting the ultimate fact....and I think all the way through it, I found myself not confronting the issue."* Glen

This was not an unexpected finding and is consistent with attitudes recognised in the literature (54, 82) relating to the wider societal stigma surrounding death and dying. Participants perceived that palliative care was negatively associated with reduced hope and withdrawing of care, making avoidance and resistance common reactions. While many view palliative care as a euphemism for death (54), through collaboration with the SPCS and Silver Chain teams, participants in this study were able to transcend this perception to reframe and achieve a greater understanding of palliative care. Jill explains:

*“I think we associate palliative care with the end bit, the death and things like, it’s the journey for the patient and their family to make it as uplifting and nice and as comfortable as possible... I just feel grateful that I didn’t go with my initial view of what palliative care was and allowed those prejudices to be broken down with seeing what happens.” Jill*

## Resilience

According to Limardi et al (2015), resilience is ‘the ability to adapt or improve one’s own conditions following experiences of adversity’ (83). The end of life care delivered by caregivers is a form of adversity because it involves practical and emotional difficulties, as well as anticipatory grief. As a result of the experience, carers described a resilience and willingness to repeat the journey for other loved ones in future with the knowledge that access to 24-hour specialist support was available:

*“If somebody asked me again can you care for me through this? I would say yes I will. Because as bad as what it is, I will because I know I’ve got you guys there to help, to be a phone call of a night time, yep easy.” Karen*

Positive effects associated with caregiving are reflected in the literature, including increased self-esteem (84) and an increased sense of capability (85). Being able to fulfil promises provided a sense of meaning and privilege. Lara shares her reflections on the experience:

*“I think being able to keep my promise to Mum and knowing that in the last days of her life she wasn’t in relentless pain and that she died at home with people that love her...I think I did a good job. And having the palliative care team and the Silver Chain team, it’s the difference between it being a reality and something that you just hope could happen.” Lara*

The importance of humanity’s capacity to find meaning in suffering is well documented by Frankl (86) and is reflected in later studies (85) that discuss the sense of comfort derived by carers from knowing they had done all they could. Supporting carers, particularly with the reassurance of availability of after-hours care, enables carers to focus on the positive meaningful aspects of caring, reducing the potential for complicated bereavement (87):

*“...in the end (he) got exactly what he wanted and I was able to fulfil his wishes and without both of those services that would have been unobtainable. Now I’m quite at peace that, yes, he got to stay at home and be surrounded by family and yes, it was traumatic when he passed. But it was fast and it wasn’t painful and I felt at peace with how it went down.” Jill*

## STUDY STRENGTHS & LIMITATIONS

**Study Strengths:** This study contributes to the limited qualitative research on bereaved carer’s experience of receiving after- hours palliative care support provided in partnership with a regional LHD and NGO. Carers were interviewed between six weeks and three months’ post death of the patient, ensuring carer recall of events was as accurate as possible and a richer account of the lived experience. Participants varied in age range and relationship to the deceased and while it may be argued that the small sample size may have limited the extent of the findings, this provided the researcher with the ability to explore data depth and complexity, rather than focusing on data breadth. Strict adherence to hermeneutic phenomenology methods followed by independent and subsequent collaborative analysis with an experienced research mentor in regards to coding and emerging themes ensured rigor and credibility in the conduction of this research.

**Study Limitations:** Although broad purposive sampling was adopted, the experience of carers in this study may not be widely generalisable. Seven out of ten participants interviewed were female (possibly reflecting the carer population in general), however according to the findings, both men and women reported similar perceptions. Malignant diseases were strongly represented (80% of sample) and lack of ethnic diversity among responding participants (all Caucasian) means that the experiences of these carers may not be typical of other racial and cultural backgrounds. While the study was not restricted to patients that had a home death, all participants cared for a loved one who died at home. This may represent a self-selection bias towards those carers who had a strong commitment or other supporting factors that facilitated a home death. The experience of carers who accessed a Last Days of Life package, but for who the patient died in hospital has therefore not been captured. This may have highlighted circumstances or information that may have informed the study. Given that participant's accounts are based on memories of a particularly emotional and sensitive nature, it is possible that carer's interpretations of phenomena are subject to change over time and with further reflection. The researcher's professional role of Clinical Nurse Consultant in Palliative Care in the SPCS involved may be seen as a risk for bias in the recording of findings. To this end, negative experiences of carers were actively sought out and reflexive practices such as collaborative analysis, journaling and adherence to the methodology ensured fidelity to the participant's experiences.

## CONCLUSION

Findings from this study conclude that:

An integrated partnership model between local health districts and non-government organisations to enhance access to palliative care services is achievable, effective and sustainable in the rural and regional setting.

Participants reported that the access to 24-hour care, anticipatory care, clear communication and close collaboration between the SPCS and Silver Chain as essential in avoiding unplanned hospital presentations and facilitating death at home for their loved ones. Use of validated tools for the early identification and assessment of carers emotional and physical needs are required to further enhance responsiveness and anticipatory care.

Many rural palliative patients do not qualify or cannot access care packages in a timely manner through established mechanisms. The Last Days of Life packages ensure respite, personal care assistance and symptom control support can be accessed quickly when it is most needed.

The establishment of the local health district and NGO partnership places the MNCLHD in a position to further promote a public health approach to palliative care, via the Compassionate Communities Program. The experience and knowledge gained by carers keeping loved ones at home with access to 24-hour support generates social capital and caring networks that enhance community capacity, death literacy and promote consumer engagement.

Despite the use of an endorsed carer medication safety program, the administration of opioids and other medications at the end of life can be a source of distress and anxiety for some carers and requires ongoing meticulous preparation and education from both the SPCS and Silver Chain services.

Regardless of the challenges involved, the journey of caregiving at home was viewed as profoundly meaningful, affording new perceptions, personal growth and the willingness to undertake the caregiving journey again with the knowledge that access to 24-hour specialist support was available.

## RECOMMENDATIONS

Recommendations and priorities developed as an outcome of this research include:

1. Review of existing partnership arrangements via convening of a working party with the MNCLHD and Silver Chain with the aim of expanding the current scope of eligibility criteria to include access for patients in the unstable phase and overnight urgent respite packages. This will provide additional clinical support and respite for carers to reduce out of hour's hospital admissions.
2. Establishment of the Compassionate Communities Public Health Initiative in the MNCLHD to promote social approaches to dying, death literacy and bereavement as routine in local communities.
3. Embedding the use of district wide validated tools, such as the Carer Support Needs Assessment Tool (CSNAT) or the Caregivers Burden Scale in End of Life Care (CBS- EOLC) to assess support needs for carers and plan services accordingly.
4. A district wide review of current formal packages on carer education on medication safety and administration, particularly in relation to the use of opioids and other medications in the home that may induce carer anxiety and impact bereavement morbidity.

### Recommendations for Future Research:

Areas for future quantitative research include service outcomes, such as hospital avoidance, cost/benefit analysis and impact on home death rate with this model of care. Further qualitative research in to the carer's needs and experiences in caring for people dying of a non-malignant condition at home is warranted as the intensity and duration of care may highlight specific support needs, particularly in the rural and regional setting where access to support and respite services are limited.

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## APPENDIX 1

### Appendix 1- Bereavement Risk Assessment Form

 		MRN: _____  Name: _____ D  CP: _____
<b>RISK FACTORS FOR COMPLICATED BEREAVEMENT</b> <b>OUTCOMES CHECKLIST</b>		
<input checked="" type="checkbox"/> <b>Pre-death</b> <input checked="" type="checkbox"/>		
<b>Characteristics of the bereaved</b>		
<input type="checkbox"/> <b>The bereaved is:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> A child</li> <li><input type="checkbox"/> An adolescent</li> <li><input type="checkbox"/> A young partner</li> <li><input type="checkbox"/> An elderly partner in a long term relationship/marriage</li> <li><input type="checkbox"/> A partner in a relatively new/unrecognised relationship</li> </ul> <input type="checkbox"/> <b>The bereaved has experienced:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Cumulative multiple losses</li> <li><input type="checkbox"/> Multiple stressful situations (see notes)</li> <li><input type="checkbox"/> A family history of mental illness</li> </ul> <input type="checkbox"/> <b>The bereaved appears to have:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Few adequate coping mechanisms</li> <li><input type="checkbox"/> High pre-death emotional distress</li> </ul>	<input type="checkbox"/> <b>The bereaved:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Demonstrates signs of poor initial adjustment to the death (see notes).</li> <li><input type="checkbox"/> Expressed dissatisfaction with their care giving role during the deceased's illness</li> </ul>	
<b>Characteristics of the deceased</b>		
<input type="checkbox"/> <b>The deceased is:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> A child or adolescent (see notes)</li> <li><input type="checkbox"/> The parent of young children</li> </ul>		
<b>Character of interpersonal relationships</b>		
<input type="checkbox"/> <b>The bereaved:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Lacks social support</li> <li><input type="checkbox"/> Feels unsupported</li> <li><input type="checkbox"/> Feels support is antagonistic or unsympathetic</li> <li><input type="checkbox"/> Feels dissatisfied with help available during the illness</li> <li><input type="checkbox"/> Is isolated (see notes)</li> <li><input type="checkbox"/> Has an ambivalent or conflictual relationship with the dying person (see notes)</li> <li><input type="checkbox"/> The death ends an unusually close/exclusive/dependant marriage/relationship</li> </ul> <input type="checkbox"/> <b>The family appears to:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Lack cohesion</li> <li><input type="checkbox"/> Have poor communication</li> <li><input type="checkbox"/> Have difficulty resolving conflict</li> </ul>	<input type="checkbox"/> <b>The bereaved:</b> <ul style="list-style-type: none"> <li><input type="checkbox"/> Is isolated after the death (see notes)</li> <li><input type="checkbox"/> Has reduced social support after the death</li> </ul>	
<b>Characteristics of the illness &amp; nature of the death</b>		
<input type="checkbox"/> <b>The deceased died from an inherited disorder (see notes)</b> <input type="checkbox"/> <b>The deceased died from a stigmatised disease</b>	<input type="checkbox"/> <b>The illness was lengthy and burdensome.</b> <input type="checkbox"/> <b>The death was sudden or unexpected</b> <input type="checkbox"/> <b>The death occurred in traumatic circumstances</b>	
<b>Risk assessment: High Moderate Low</b>		
<b>WHS Alert: No</b> <input type="checkbox"/> <b>Yes</b> <input type="checkbox"/> <b>Specify</b> _____		
<b>Name of deceased &amp; Date of Death:</b> _____		
<b>Relationship to deceased</b> _____		

Referred to:	Yes	No
Volunteer for routine short term follow up/phone contact	<input type="checkbox"/>	<input type="checkbox"/>
Client Consent for referral	<input type="checkbox"/>	<input type="checkbox"/>
Volunteer for long term follow up /home visits	<input type="checkbox"/>	<input type="checkbox"/>
Client Consent for referral	<input type="checkbox"/>	<input type="checkbox"/>
Bereavement Counsellor	<input type="checkbox"/>	<input type="checkbox"/>

## APPENDIX 2 – Interview Schedule



### INTERVIEW SCHEDULE

NB: The following outlines questions that will be utilised in an order that best suits the participant and situation. The interview will be participant centred and the participant may wish to discuss other issues.

Date:

Time:

Location:

Participant Number:

Consent Form Signed: Y

#### Introduction:

Thank you for agreeing to be interviewed today. As you know today's interview will be audio recorded and all data will be de-identified. If at any time you feel uncomfortable or you want to stop the interview, please let me know. Please also let me know if there is a question you don't want to answer.

#### Setting the Scene:

As you are aware from the Participant Information Sheet I am interested in exploring the question:

*What are the Experiences of Carers Receiving After-hours Palliative Care Delivered by a Non-Government Organisation in Partnership with a Regional Local Health District?*

Today, I would like to have a conversation with you about your experiences in receiving after-hours palliative care support and the effect this partnership has had on your role as a carer.

(If necessary and not already known, the following clarification questions may be asked: Carers age, relationship to deceased, deceased's diagnosis -malignant or non-malignant only).

Q 1: Tell me how you came to be in the role of carer?

What do you see were the main issues you faced in your role of carer?

Q 2: Can you tell me about how the concept of after-hours care was introduced to you and what your initial thoughts were?

Q 3: Tell me about your experience of receiving after-hours care.

Q. 4: How did you find various aspects of the care packages – such as personal care, RN evening visits, practical and emotional support and symptom control?

Q. 5: In your opinion, how did the partnership between the MNCLHD and Silver Chain work in respect to meeting your needs as a carer?

Q. 6: How do you feel your questions and concerns were addressed and did you feel communication about sensitive matters was attended appropriately?

Q. 7: Were there any hospital admissions during the time \_\_\_\_\_ was receiving after-hours care? If so, are you able to tell me more about that?

Q. 8: Did the assistance of after-hours care enable \_\_\_\_\_ to die in the place of their preference?

Q 9: What do you feel went well with the support you received?

Q 10: Is there anything you feel that could have been improved or done better?

Q 11: If you didn't have access to after-hours care, how would this have affected your role as carer?

Q. 12: Is there anything else you would like to discuss in relation to after-hours palliative care that I haven't asked you about?

Prompts and probes will be used to gain further information and a clearer picture of what the participant is describing. Examples such as the following may be used:

Can you tell me a bit more about .....

How did ..... come about?

How did you feel about ....?

What would you do differently.....?

Ending:

Do you have any questions or any further comments? Thank you for participating in this interview. Your confidentiality will be maintained. If you would like to speak to me again, please contact me on 0418 971 359, however with your permission, I'd like to contact you by phone in the next 24 hours to thank you again and check on your welfare.

## APPENDIX 3 – Sample Coding Table

Theme	Code and Definition	Sample Quote
<b>Collaboration</b>	The partnership between carers and the SPCS and Silver Chain.	<p><b>P10, p 4, lines 22-24.</b> “So palliative care would actually ring mums doctor and speak to her personally and say look we want to try this and the doctor was in agreeance and would have a script and palliative care would let us know that the script was ready so we could go up and get it”</p> <p><b>P3, p5, lines 5-9.</b> “a pump was inserted in (her) and it was ongoing and in between follow up with morphine and being a registered nurse, well I’m not registered anymore, I was given that, if you like, permission, to give it with the backup of the palliative care team.”</p> <p><b>P8, p6, lines 6-8.</b> “She showed me how to give the morphine because he had one drip in his leg and he had the pump and she said this is what you’ve got to do. She showed me how to unlock things and turn pumps off.”</p> <p><b>P3, p9, lines 18-19</b> “I remember on one occasion both the LHD and Silver Chain Nurse was there making her comfortable”</p> <p><b>P5, p4, lines 25-26.</b> “Everybody was on the same page. We all had the same goal, we were all heading in the same direction and that was keeping Mum comfortable and pain free, supporting the family.”</p>
<b>Accessibility</b>	Access to 24 hour care provides reassurance and avoids unplanned hospital presentations.	<p><b>P1, p6, lines 10 – 14.</b> “You do need that ongoing support during the night. Knowing it’s there. When they’re at home. Well when they’re in hospital or another care unit, well they’d have 24-hour care, but not here. In the home you need that sort of professional monitoring and care and someone you can call when you’re not sure what’s happening.”</p> <p><b>P2, p3, lines 1-3.</b> “But just to know that just one step behind you, if something did go amiss or you were struggling that there was something there behind you to help you.”</p> <p><b>P4, p4, lines 17 &amp;18.</b> “It was good to just get the reassurance at night that she was still ok and comfortable.”</p> <p><b>P4, p6, lines 1-5.</b> “It was reassuring when they’d come in the day and fix up the medications for the day and then one would come back at night just to check again. It was reassuring to know that they could just look and say that Mum looked comfortable and such.”</p> <p><b>P1, p5, lines 13, 14, 15.</b> “They were there whenever needed. And from what I remember there was no difficulty in contacting</p>

		<i>anyone or getting anyone here or getting back up over the phone.”</i>
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