

Experiences of informal caregivers in managing the care and the death in the rural palliative care home setting.



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- Cover image taken from my travel collection depicting “The Journey” sculpture by Fenwick Lawson, Durham City UK of six monks carrying Saint Cuthbert’s coffin to Durham Cathedral – relates to the reverence caregivers reveal about the person and the care they bestow on them, even in death.

CONTENTS

Acknowledgement	2
Abstract	3
Executive Summary	4
Introduction	6
Background	6
Rationale	8
Method	10
Findings	12
Study strengths and limitations	21
Conclusions	22
Recommendations	23
References	25
Appendices:	28
1. Participant information Sheet	
2. Consent	
3. Semi-structured interview questions	
4. Sample of coding table	

ABBREVIATIONS

Cessnock Kurri Kurri Singleton Palliative Care - CKKSPC
General Practitioner – GP
Hunter New England Local Health District – HNELHD
Health Education & Training Institute – HETI
Health Promoting Palliative Care – HPPC
World Health Organisation - WHO

ABSTRACT

Aim

The aim of this research is to explore and describe the lived experience of informal caregivers managing pain and other symptoms in the last few days of life, including care of the dying, managing the death, and the bereavement experience in the palliative care rural home setting.

Methods

Interpretive phenomenology was used to guide the study. Ten semi-structured interviews were conducted with people in their homes in rural NSW. The data was thematically analysed using framework analysis with a Health Promoting Palliative Care (HPPC) theoretical framework.

Findings

Five major themes reflected caregiver experience, 'in it together', 'sense of control', 'developing confidence and ability', 'redefining cultural norms', and 'living with loss'. Caregiver identity and choices were connected to their loving relationship with the patient, which drove their desire to fulfill wishes. A sense of control was gained from staying at home, often driven by hospital and treatment experiences, home being the locus of control. Staged education and support from health professional's increases caregivers capacity and resilience, enabling managing symptoms, medication, the home death, comfort caring for the body and with the body remaining in the home, defying modern cultural norms and perceptions. After-hours contact with palliative care professionals was considered to be essential, as was their connection to the GP's. Family remained the mainstay of bereavement support however other important needs were identified on a personal and public health level; unique rural issues were revealed as well as a plausible rural model of specialist palliative care.

Implications for practice

The findings evidence a rural model of palliative care inherent with the conditions that drive caregivers' satisfaction in achieving a home death, within a legal, ethical and safe framework. The results also evidence the conditions that drive a less satisfactory experience from a caregiver perspective. There are clear indications that a public health approach to palliative care has the potential to improve the bereavement experience for all people living in rural communities, beyond palliative care service involvement.

Keywords

- Palliative care
- Rural
- Home death
- Medications
- Framework analysis

EXECUTIVE SUMMARY

Context

Most people across the western world die in hospital despite their preference to die at home due to a complex range of factors. None the less that a range of community health services are under-funded including palliative care. (Swerissen & Duckett 2014) In rural NSW a palliative care team adopted a Health Promoting Palliative Care philosophy as the basis of practice, introducing a Medication Safety Program in 2008 to support informal caregivers managing care and deaths at home. Research to investigate the expanded role of caregivers in managing symptoms and the home death is scant, leaving gaps in our knowledge and understanding of caregiver's experiences, and the conditions that drive capacity and resilience to achieve the preference of a home death that is safe, legal and ethical with preparation for bereavement. These optimal conditions for caregiver satisfaction revealed a plausible rural model for palliative care service delivery.

Implications

This study has clear implications for practice as resource gaps and inequities in palliative care service delivery have been identified across rural NSW. Equity of access to palliative care has been found to depend on the geographic location where people live, mainly due to the fact that every existing palliative care service has differing models of service delivery based on available resources and budget rather than on the needs of the community. This study has evidenced a rural model of palliative care inherent with the conditions that drive caregiver satisfactions, achieving the death at home, in a safe, legal, and ethical manner. The results also evidence the conditions that drive a less satisfactory experience, from the caregiver perspective. There are clear indications that a public health approach to palliative care has the potential to improve the caregiving and the bereavement experience for all people living in rural communities, beyond palliative care involvement. This rural model of palliative care has the potential to improve equity of access to palliative care and relieve the financial burden of hospital care.

Approach

A qualitative methodology was used to guide the study. The research aim was to explore and describe the lived experience of informal caregivers managing care of the dying, the death, and the bereavement experience in rural palliative care home setting.

Findings: Five themes were identified that together captured the lived experience of the caregivers.

Redefining Cultural Norms

This theme captures the evolving cultural change brought about by people experiencing more control over their lives and deaths. The findings highlight the experience of managing symptoms with caregivers at the forefront of the medication administration, the death, and care of the body after the death. During the bedside vigil two symptoms were the main areas of the caregivers' focus, the pain and the breath. This focus indicates that the palliative care clinical staff need to be skilled clinical assessors and communicators with GP's. The dimensions of hope and dignity are discussed in relation to caregiver emotions and behaviours as emotions were powerfully expressed and ranged from gut wrenching grief to comfort in achieving the patient's wishes. Additionally, there were some unexpected outcomes as discussed in the findings.

In It Together

This theme captures the interpersonal Reorientation of HPPC as it relates to the critical role of caregivers and their identity which in this study is clearly grounded in the relationship with the patient. The caregiver role is fated, evolving as a natural progression in their relationship due to life-changing forces. A range of complex emotions and behaviours are experienced by caregivers and these impact on decision-making, particularly during bereavement. These findings highlight that rural palliative care services supporting stressed and distressed people every day require a specific range of skills, understanding and resources. Rural palliative care teams are more likely to consist of nursing staff with tenuous links to allied health such as Social Workers and Occupational Therapists. While nursing staff may develop skills to respond appropriately and deal with a range of issues they are not trained Social Workers skilled to address the broad range of issues identified in the findings. These findings indicate the necessity for a Social Worker to be situated within the team, integrated as an active team member.

Sense of Control

Hospital experiences were the greatest source of despair due to perceived loss of control. The upheaval of diagnosis, treatments and traversing the health system left caregivers feeling abandoned and seeking control and refuge at home. Partnering with palliative care was perceived as enabling access to supports, staged education, information, and decision-making involving the patient, caregiver and the General Practitioner. (GP). Control of pain was very important, and there was huge appreciation for the power and potency of morphine. Receiving support and involvement in decision-making promoted a sense of control over uncertainty, and enabled the caregiver role in fulfilling the patient's wishes to die at home, with home seen as the locus of control.

Developing Confidence and Ability

This theme captures how the caregivers experience the education and training to administer medications and provide care in the last few days of life, increasing the caregiver's confidence and ability to perform their role, and the patient's confidence in them as caregivers. The importance of access to specialist palliative care staff 24 hours 7 days per week was emphasized, seen as vital for advice and support if they needed it, particularly regarding symptom and medication management. Palliative care's partnership with the GP is highly valued as it is perceived by caregivers to validate the caregiver role and involvement with medications, the end of life phase, and countered the absence of GP home-visiting. Just as caregivers are pivotal to community palliative care, in rural areas the GP figures largely in the palliative care equation.

Living with Loss

This theme captures the bereavement from days to months after the death, who supports the caregiver and how. Just as the diagnosis was a period of upheaval, so is the bereavement. This consists of suffering the loss, with social isolation and identity crisis prevalent, the salves being the support from family and friends, and the comfort of achieving their aims. There are important implications for community development actions, in particular strategies for palliative care volunteers to broaden their reach to include the bereaved, especially those suffering from social isolation, anxiety and depression in rural areas.

RECOMMENDATIONS

1. All rural palliative care teams require a social worker integrated into the team.
2. Financial distress be valued and addressed equally with physical and emotional distress. Palliative care services need to develop sensitive methods to assess and address these issues, with early intervention to prevent crisis situations in bereavement.
3. HNELHD Palliative and End of life Clinical Stream submit position statement to address Government policy in advocacy for people with life-limiting illness and the criteria for access to personal care packages, especially for people under 65 years. The convoluted processes accessing NDIS and MAC need simplifying for time limited people and their caregivers.
4. Locally: palliative care providers brainstorm to develop strategies to unearth caregiver's true and hidden perspectives on the use of morphine, intervening early to improve understanding and prevent the development of guilt and associated complicated grief.
Nationally: professional palliative care organisations, universities, medical associations and health services need to combine efforts to develop public health strategies to counter the morphine mythical misinformation and potential professional and personal crisis. The palliative care movement and GPs need to ensure it is not seen as a form of euthanasia or secretly performing mercy killings or other such activity.
5. Palliative care be especially vigilant for those more isolated rurally, sensitively working with caregivers to develop plans to guide death in a timely manner. NSW Authorised Adult Palliative Care Plans should also be considered.
6. Rural palliative care services have inbuilt professional support and education for staff who constantly deal with stressed and distressed people, including clinical supervision and debriefing.
7. Palliative care services adopt a HPPC philosophy approach whereby the development of a compassionate community is strategised, inbuilt, and on-going, and opportunity seeking to encourage individuals, groups and organisations to effectively develop the community to respond to the broad range of needs of ill and grieving people. Palliative care volunteers are well positioned to undertake this work.
8. That palliative care volunteer services broaden their scope to response to the needs of the bereaved, irrespective of place of death, especially lonely, socially isolated, anxious and depressed people.
9. That governments and district health services consider the identified rural model of palliative care in planning rural models of palliative care. This model is not idealistic, it is possible and plausible, challenging the death denying cultural norms of the past decades, and forms the bedrock of palliative care practice in the HNELHD Cessnock and Singleton LGA's of the Hunter Valley of NSW.

INTRODUCTION

This report summarises the research undertaken by the researcher as a participant of the Rural Research Capacity Building Program sponsored by the New South Wales Health Education and Training Institute (HETI) and Hunter New England Local Health District. (HNELHD) The report highlights the experience of informal caregivers managing symptoms and medications, the death and after death care in the palliative care home setting in rural NSW. These findings should be of relevance to health service policy makers and planners; to rural palliative care service providers; community and hospital health service managers; HNELHD Palliative & End of Life Care Stream; to rural GP's; and to palliative care volunteer coordinators.

Gaps and inequities in palliative care service delivery have been identified in the rural areas of NSW as per the NSW Government Plan to Increase Access to Palliative Care (2012), and occur throughout rural Australia. These gaps and inequities make it harder for Australians to achieve their goals of staying in their home in the last days of life. There are gaps in our knowledge regarding caregiver's perceptions of their role in managing the last few days of life (Gill; Laporte & Coyte 2013; Linderholm & Friedrichsen 2010) at home with purpose designed support such as Cessnock Kurri Kurri Singleton Palliative Care (CKKSPC) Medication Safety Program and home death plan, aiming also to capture the cultural and social context of that care. It is hoped that this study of the lived experience enriches current knowledge, exposing and proposing a rural model of palliative care and positive evolving cultural change.

BACKGROUND

Palliative care is described by the World Health Organization (WHO) (2002) as care that includes coordinated medical, nursing, allied health and pastoral care services, delivered wherever possible, in the environment of the person's choice. It is specialised health care of dying people directed at maximizing quality of life and assisting families and carers during and after death. The WHO's description is the ideal however health service delivery is challenging in rural or less populated areas of many industrialised nations including North America, Canada, the United Kingdom (UK) and Australia. (Herd 1990; Wilkes and White 2005; Madigan et al 2009; Wilson et al 2006; Gill et al 2013; and Burns et al 2015). Yet Australia has been rated in a report by The Economist Intelligence Unit (2015) as second in the world behind the UK in providing a good quality death in the Fact of Death Analysis 2011/12 report. The establishment of specialist palliative care is thought to have contributed to this positive rating however there are further improvements needed for equity and quality in end of life care for all Australians, especially in rural areas. (Burns et al 2015). Despite the fact that 70% of Australians express the wish to die at home figures demonstrate that most people in Australia die in hospital due to a complex range of factors (Swerissen and Duckett 2014) including the biomedical model of care. (Russell and Schofield 1986; Baum 2008)

The NSW Agency for Clinical Innovation (ACI) Diagnostic Report 2014 indicates that access to Palliative Care Services across Australia is inequitable with access to palliative care dependent on the actual geographic location where people live. The NSW Government Plan to Increase Access to Palliative Care 2012 -2016 has been prioritised in an effort to improve equity of access and provide choices as it is recognised that rural services, where they exist, differ widely in terms of staffing, reach, hours and resources. After-hours care or weekend services are unlikely to be provided in rural areas.

In 2007 the CKKSPC identified that existing processes required standardisation to improve medication safety for patients and caregivers, while providing effective symptom control. A literature review undertaken at that time revealed scant recognition of palliative care nurses providing informal training for caregivers to give Pro Re Nata (PRN) (as needed) subcutaneous (SC) medications in the palliative care home setting. One study (Anderson and Kralik 2008) reported on traditional community nursing practices in Australia that included informal adhoc training to palliative caregivers to provide as needed medications by SC injection. These practices are reported to be attributable to the recognition that caregivers are pivotal in providing palliative care at home, service resource limitations, (Wilson et al 2006 and Israel et al 2008) and driven by patient and caregiver requests when dying at home is preferred. (Israel et al 2008; Anderson and Kralik 2008). Palliative care research tended to report the negative aspects of inconsistent practices of caregiver education and support both within and across service providers (Herd 1990; Rose 1997; Israel et al 2008; and Anderson and Kralik 2008) and call for standardised practices, good communication, and access to medications to ensure good symptom control. The lack of formalised processes within NSW for caregiver administered medication became the impetus for the Medication Safety project. In response to this situation the CKKSPC applied Kellehear's (1999) Health Promoting Palliative Care philosophy to clinical practice. This philosophy is based on the Ottawa Charter 1986 five actions for health promotion. The Medication Safety Program evolved and commenced in 2008 providing the tools to address after-hours staff safety; escalation of anticipatory care; and the pre-planning of the expected death. Plans for the death were developed in conjunction with caregivers, General Practitioners and Funeral Directors.

Specialist palliative care nurses remained on-call after-hours via telephone and after-hours home visiting became less necessary. This is now current standard practice in CKKSPC yet nearly a decade of further palliative caregiver research has highlighted that varied inconsistent practices still exist in Australia and reports abound that informal caregivers providing end of life care require structured education and support (Bee et al 2008; Stajduhar et al 2008; Healy et al 2012; Currow 2015) throughout their caregiving time. Indeed administering medications has remained a focus of concern and anxiety for caregivers, especially in the last weeks or days of life. (Herd 2009; Israel et al 2008; Newbury 2011; Healey et al 2012; and Currow 2015)

There is evidence in the literature to support the development of programs such as the Medication Safety program. When palliative care clients choose to remain at home to die there is a need for good around-the-clock pain and symptom control, respect for choice and autonomy, and support for carers. (Gnomes and Higginson 2006; NSW Carers Strategy 2014; and Palliative Care Standards for Providing Quality Palliative Care for all Australians 2005) It is reported that caregivers value their role (Beck-Friis and Strang 1993) and that palliative care professionals understand the pivotal role of informal caregivers in providing care at home (McCarron 2000; Aranda and Hayman-White 2001; McGuire et al 2012). Importantly, McGuire et al (2012) identified that the ethics and safety of informal caregiving means that health professionals need to be the recipients of care as well as the providers of care.

Additionally, a study by Howat et al (2007) found that the involvement of community nurses and specialised equipment was associated with achieving a home death, which is most desirable in a rural area. (Wilkes and White 2005) It was also found that the most common reason for admission to hospital was for symptom control, (Swerissen and Duckett 2015) disappointing those who prefer to be at home, impacting negatively on the patient and caregiver experience with implications for complicated bereavement outcomes. (Connell et al 2010; and Currow 2015)

The fact that not all people have a choice in their place of care and place of death is evidenced by the literature with indications that dying in an institution can be a viable choice, or an only option. (Herd 1990; Currow 2015). Alternatively people who have an informal caregiver and a place of residence are more likely to be able to choose their place of care and where they wish to die. For those from this group who choose to remain at home, the CKKSPC work collaboratively with the patient and the caregiver to implement the Medication Safety Program and develop a home death plan. Regarding palliative care practices, Currow (2015) like McGuire et al (2012) implore us to rethink the whole concept of caregiver support, assessment and education by seriously developing programs that will sustain caregivers and promote their well-being beyond their caregiving experience, providing further impetus for the need for this research.

While it would be reasonable to expect that bereaved caregivers might not want to be involved in research, White and Hardy's (2009) systematic review found that palliative care patients and their relatives, with some studies referring to caregivers, do want to participate in research as long as it is undertaken sensitively. In recruiting participants Robertson et al (1997) argues that grief can be unpredictable so timeframes for caregiver's participation in research about their experience cannot be easily identified. Perreault et al (2004) believe that offering opportunities to caregivers to talk about their experiences is important and Richards and McCallum (1979) state that informed consent and the absence of pressure to participate is of utmost importance thus indicating that participation is rightfully consented by the participant; and (McKissock and McKissock 1991) suggest that researchers prepared to enter the bereaved person's world may assist with their ability to adjust to their loss. Findings from bereavement literature suggest that conducting any part of the research process on significant dates (such as significant dates should be avoided like anniversaries of the death.

The Cessnock Kurri Kurri Singleton Palliative Care (CKKSPC) Service is a component of Hunter New England Local Health District (HNELHD), based at Cessnock Community Health in the Hunter Valley of NSW. The service provides palliative care nursing and social work to people living in the Cessnock and Singleton Local Government Areas (LGA's). The Cessnock LGA is approximately 1,950 square kilometers with an approximate population of 56,000 people. The Singleton LGA has approximately 25,000 people and 4,893 square kilometers. The combined area of 6,843 square kilometers has an approximate population of 80,000 people. There is above NSW state average incidence and cause of death from cancer and cardiovascular diseases. (NSW Department of Health 2010). Both areas have an itinerant populations – Singleton has an Australian Army base and Cessnock has a large maximum-security gaol. Cessnock has a strong mining heritage, along with the timber, dairy and wine industries. Singleton is 45 minutes away by road and has a very rich agricultural history and the mining industry. The rural density varies between Cessnock (28.4 people per square mile) and Singleton (4.92 people per square mile). The Aboriginal and Torres Strait Islander (ATSI) populations are Cessnock 4.8% and Singleton 3.75 % both higher than NSW average of 2.5%. Overseas born population Cessnock 12.2%, Singleton 12.9%. (Australian Bureau Statistics 2011 Census). The areas have both social advantage and disadvantage. (Cessnock and Singleton Community Profiles)

The CKKSPC Medication Safety Program is underpinned by a legal, ethical and safe framework that is mobilised along with a home death plan when care at home is chosen and death imminent. This practice includes:

- Prompts end of life conversations and decision-making.
- A tool to evaluate a caregiver's preparedness to administer subcutaneous medication with pre and post confidence testing.
- A caregiver education program on subcutaneous medication administration with an education checklist.
- A protocol for staff to outline the processes and involve GP's in decision making.
- An inherent right for carer and/or client to change their mind at any time.
- Specific specialised equipment and syringe labelling.
- Daily support home visit by a specialist palliative care nurse.
- Offer of referral for enhanced service through partnership with Non-Government Organisation (NGO) Silver Chain.
- After-Hours phone contact with a specialist palliative care nurse.
- Plan of managing the death at home to guide caregiver/ family and bereavement care.

RATIONALE

Two considerable challenges to palliative care provision in Australia are the ageing population (Australian Institute of Health and Welfare (AIHW) 2014) and the death denying cultural norms (Zimmermann 2007) of Australian society. Given the certainty that we will all die, most likely after the effects of living with long-term chronic illnesses, an even greater challenge is bringing death and dying to the forefront of community consciousness. Public health perspectives of palliative care as espoused by Kellehear (1999) propose that this consciousness would enable people to have more involvement in end of life planning as a natural part of life, gaining more control over their own life, and death, while reducing the financial burdens of current medical practices. These challenges become more complex in rural areas where access to palliative care and resources are much more limited than in larger metropolitan areas. Within this context this study investigated the lived experience of those who have experienced this consciousness, and chose to care for the dying at home, with the support of a specialist palliative care team.

The Cessnock Kurri Kurri Singleton Palliative Care (CKKSPC) specialist palliative care developed the project 'Improving Medication Safety in the Rural Palliative Care Home Setting' (Appendix i) in 2008. The CKKSPC 2013 Annual Report (Appendix ii) states that this program provides a safe, legal and ethical framework designed to support caregivers in the management of care in the last days of life, and death in the home setting. The CKKSPC is a rurally located unit of Hunter New England Local Health District (HNELHD) in New South Wales (NSW). The HNELHD's Palliative Care Clinical Leadership Stream supported the policy development for this practice.

Although medication safety is a priority from referral, the Medication Safety project is a program that is mobilised when care at home is chosen and death is more imminent. It also involves the CKKSPC furthering their partnership with the client and caregiver to develop an individualised plan for managing the impending death. This plan is an essential component in the management of care at home, especially the death. Caregivers are pivotal to that plan.

The Medication Safety Project has been awarded Quality Awards (Appendix iii) and the merits of the CKKSPC service have been reported in both quality award applications (Appendix iv) and in the CKKSPC Annual Report (2013) (Appendix ii). Conversely, the program is not universally supported in the palliative care field, with concerns regarding the impact on caregivers described in studies by Aoun et al (2005) Grande et al (2009) and Thomas et al (2010). CKKSPC evaluations have included caregiver's anecdotal feedback however there has been no specific formalised research process to gain understanding of the caregiver perspective in participating in this program. Therefore it is imperative to understand the challenges, the holistic needs and possible impacts on well-being experienced by caregivers when managing medications and symptoms, the death at home, and bereavement.

Previously reported studies involving palliative caregivers at home examined various aspects of caregiver experience such as (Newbury 2011) who explored caregiver preparedness for home death, and (Wong and Ussher 2009) who explored caregivers' positive experiences caring for loved ones at home. None of these studies focused on the management of symptoms or the actual management of the death. A similar study by Anderson and Kralik (2008) investigated the feasibility of caregiver administration of medication in the palliative care home setting. Although the study found that the access and administration of medication by caregivers to be integral to quality end of life care, the medication in this study was drawn by community nurses, not by the caregiver, and left in the home for the caregiver to administer. This specific difference in practice justifies further research especially amid claims of a legal, ethical and safer framework for practice.

Studies regarding informal caregivers perspectives on injecting subcutaneous medications at home, (Lee and Headland 2003; Healy et al (2012) conclude that formalised programs that support caregivers are valued and needed and call for further research. One study by Israel et al (2008 p395) postulates caregiver's major concerns and suggested a list of interventions regarding "structured support and educational interventions that may provide carers with the skills to empower them in this often necessary role". Given that the CKKSPC program is aligned very similarly with these suggestions, demonstrates an imperative to conduct further research, especially considering none of the studies included care of the dying or management of the death at home. Lees et al (2014) surveyed caregivers via questionnaire on quality of end of life care finding that caregivers need a range of information and support as well as written advice and guidance on what to do when someone dies. Hall (2014) outlines the key factors to assist community nurses with recognising and managing death, and Gill et al (2013) conducted a critical review of predictors of home death however there is very little evidence available regarding the actual experience of managing death at home in the palliative care setting. Many of the studies emphasise caregivers' roles and needs, not how they managed the actual death, or how they felt about that experience, perhaps indicating that the avoidance of research related to death which in turn reflects society's fear of death as espoused by Kellehear (1999; 2005).

Despite this fear and avoidance there is a growing body of evidence that care associated with dying and death needs to be improved. Organisations such as the Public Health and Palliative Care International (PHPCI) indicate that western cultures are blinded towards 'death' and partly attribute this to the biomedical model of care (Russell and Schofield 1986; Baum 2008) where 'health' is a biomedical state to be 'managed' by the medical profession giving rise to Kellehear's (1999) public health model of palliative care where the individual and albeit the broader community is responsible for health and well-being. This model is based on the premise that death, due largely to medical dominance, is over medicalised, and occurring 'unexpectedly' during the dedicated pursuit of treatment and cure, with subsequent significant financial, emotional and social costs. This is consistent with the Grattan Institute's Dying Well Report by Swerissen and Duckett (2014) indicating that most people across the western world die in hospital despite their preference to die at home.

Kellehear (2005) and Smith (2014) postulate that modern medicine and death taboos impact on society, and on the individual, and encourage a counter culture, challenging palliative care professionals to take the lead. Kellehear furthers this with the claims that the denial of death leads to social isolation of the dying, their caregivers, and on those experiencing grief, resulting in a high degree of anxiety and depression during caregiving and bereavement. Kellehear draws attention to the hidden or taboo language around death and dying, believing that this 'softening' or 'avoidance' of language only serves to keep death hidden thus furthering the social isolation and depression. Noonan et al's (2015) study found that it is possible to build 'death literacy' among caregivers and their social networks, engaged in caring for the dying. Noonan et al's (2015) findings pose that death literacy is not only a communicated language, rather it is specific skill set developed around caring for the dying, that builds on personal and community capacity for compassionate care.

Other than the study by Israel et al (2008), recent palliative care research including (Gill et al 2013; Linderholm and Friedrichsen 2010) revealed that there are no specific studies regarding carers perceptions on managing the last few days of life, including symptoms and managing the death at home with purpose designed support such as the Medication Safety Program and home death plan, aiming also to capture the cultural context of that care.

Consistent with the issues mentioned by Aoun et al (2005) Grande et al (2009); and Thomas et al (2010), concerns about the availability of after-hours service provision, the extended role of caregivers into the clinical field with possible negative consequences, after-hours home visiting nurse safety, and anticipatory planning of health care have been raised at a local level. HNLHD Palliative Care Clinical Stream Minutes (June 2010; August 2010)

The NSW Government Plan to Increase Access to Palliative Care (2012) highlighted gaps and inequities in palliative care service delivery in rural NSW. These gaps and inequities prevent people living in rural areas from accessing palliative care and from preferencing where they want to be cared for and where they want to die despite the fact that most Australians prefer to remain at home. Swerissen and Duckett (2014). The National Strategic Framework for Rural and Remote Health (2012) indicated that approximately seven million people living outside of metropolitan areas do not enjoy the same positive health outcomes as Australians in metropolitan areas, and the National Rural Health Alliance (2012) statistics revealed the challenges and inequities in accessing palliative care occur throughout Australia.

In summary, there is evidence that experiencing a good home death depends on the professional support an informal caregiver receives and that the professional support depends on the geographic location that one lives in. Qualitative research to investigate the expanded role of caregivers in managing symptoms and the home death is scant, revealing gaps in our knowledge and understanding of caregiver needs and challenges; caregiver capacity and

wellbeing; bereavement; and the possibility of an emerging culture around care of the dying and death in community. In consideration that the medication safety program was designed for use in rural areas, enabling a home death, the results of this study have the potential to contribute to future palliative care model development across Australia.

Therefore the aim of this study is to understand the lived experience of caregivers managing the care, medications and the death enriching current knowledge, exposing and proposing a rural model of palliative care and positive evolving cultural change.

METHOD

Methodology

A qualitative phenomenological methodology as described by van Manen (1990, 2001) was used to design the study. Interpretive phenomenological enquiry seeks to describe and analyze the lived experiences of people's perceptions, perspectives and understandings of a phenomenon, in the social and cultural contexts that the lived experience occurs in. Interpretative phenomenology allowed exploration of multiple experiences of the same phenomena in an effort to capture how the participants make sense of the experience and the meaning they assigned to those experiences. Use of this method allowed the researcher to draw and interweave description of the social and cultural context into the findings as espoused by Dowling (2007), and draw on the researchers experience, knowledge and presumptions regarding the phenomena of caring for someone who is dying as a valuable guide to the study (Flood 2010).

Additionally, interpretative phenomenology is acknowledged as suitable for framework analysis (Gale et al 2013), a method for thematically analysing the data (Braun and Clarke 2008) and of managing the data of semi-structured interview transcripts. This research, in capturing and interpreting the participant's experience, presents the results and discussion as findings, to represent the whole.

The flexibility of the framework method allowed the researcher to use the HPPC framework (Kelleher 1999) (Appendix V) as a theoretical 'lens', enabling comparison of palliative care policy aims with participant experience.

Ethics

Ethics approval Reference No: **16/04/20/4.06** was received in May 2016 from the Hunter New England (HNE) Human Research Ethics Committee (HREC). An application to vary the analysis to include Framework Analysis (Gale et al 2013) and was approved by HNE-HREC in March 2017. The participants in this study are referred to throughout this report as caregivers and or carers and the term patient has been used to differentiate participants from whom they were caring for. This assists reader understanding while maintaining participant confidentiality and anonymity.

Sample: A purposive sampling method was used to identify a maximum variation sample (Vitcu et al 2007) from the CKKSPC bereavement records. These records enabled identification of potential participants from the study population (Appendix VI) who met the following inclusion criteria: informed, consenting past palliative adult caregivers aged 18 years or over; participation in the CKKSPC Improving Medication Safety Program; managed the death at home; was at least three to twenty four months post death prior to the interview; participated in the CKKSPC bereavement care program; able to communicate in English; thought to be experiencing an uncomplicated bereavement; and thought to be in good health.

Data Collection:

A total of 20 participants meeting the inclusion criteria were identified. Letters of invitation and Participant Information Sheets (PIS) (Appendix VII) were sent, staggered, 4-5 invitations at a time, approximately 1 month apart between June and November 2016. Participants received opt-in Yes or opt-out No reply paid letters and envelopes (Appendix VIII), clearly differentiated by colour to reduce confusion and ensure transparency of the researcher's intent. The invitations informed the potential participants that the researcher would contact them by telephone if no response was received in 3 weeks from posting, and that only 2 attempts would be made to contact them.

Ten participants were recruited in total. Two participants accepted the invitation by returning the Yes letter. Seven participants waited until the researcher telephoned to accept the invitation from the researcher and one participant contacted the researcher and requested to participate after receipt of the invitation. Of the 10 non-participants, 4 did not respond to the letter or the telephone call, three responded no via the return letter and three awaited the telephone call to reply no. The non-participants were 1 male and 9 females.

There were seven females and three male participants recruited: An adult daughter of a father; an adult son of a mother; an adult niece of an uncle; five spouses - one of whom was same sex couple; one carer of English not the first language; and an aboriginal carer. Two of the patients were from English not first language backgrounds. The participant's ages at the time of the interview ranged from 46 to 75 years with a mean age of 61 years. Age only relevant in that the youngest participant had school-aged children and the eldest participant had elderly parents in their 90th years. The timing of the interviews from death ranged from 3 to 18 months, most however, participated between 8-10 months post death.

Ten in depth semi-structured interviews were conducted in the participant's homes. The participants consent was obtained in writing prior to commencing the interviews. The interviews were all conducted by the researcher alone, had a mean length of 60 minutes and were recorded using two audio devices. The semi-structured interview questions were developed with assistance from a representative expert group. All interviews were conducted using the semi-structured interview questions for the non-ATSI pre-prepared list (Appendix IX) as none of the participants identified as Aboriginal or Torres Strait Islander in the records. The interviews explored participant's perceptions and recollections of behaviours from 'becoming' a caregiver through to the bereavement and their future goals. Participants were reminded pre-interview of their rights to confidentiality and privacy, the voluntary nature of participation, that they could stop the interview at any time, and withdraw their consent at any time during the interview. Participants were also reminded of the limitations of confidentiality, privacy, and compulsory reporting responsibilities of the researcher regarding disclosure of illegal activity. (Appendix X)

None of the participants took the option to see a social worker on the day of or post-interview. Emotional responses to the questions were anticipated by both the participants and the researcher, the researcher used skills gained from many years of experience in palliative care to respond appropriately to expressed emotions. In areas of concern to the researcher, discussion and clarification was offered and undertaken post interview.

Data Analysis

The recorded interviews were transcribed verbatim using a transcription service. A research assistant checked the transcriptions against the recordings to verify their accuracy, signing and dating each transcript. The researcher kept a field journal to record important timelines and dates, and to outline each interview with observations, impressions and participant behaviours which was particularly useful during the analysis as emotions and behaviours can be seen and heard, rather than read from a transcript. The researcher became familiarised with the data through listening to the recordings, and reading the transcripts, reflecting and expanding on initial impressions to explore concepts and patterns for consideration during the analysis. Data analysis involved identifying codes inductively as per Braun and Clarke's (2006) thematic analysis and Gayle et al's (2013) framework analysis, coding important aspects, behaviours, values, expressed emotions, places, and interpretations thought to be relevant and important in understanding the phenomena. The flexibility of Gayle et al's (2013) framework enabled the development of a working analytic framework (sample - Appendix XII) to build on both inductive and deductive coding throughout each level of the analysis. In the first level of the analysis the researcher and the research mentor both independently coded the first three interviews. The deductive and inductive codes were agreed upon by the researcher and the research mentor, with valuable assistance and advice from the research assistant. As all interviews were coded the researcher continued to identify codes, and to build on the analytic framework, further defining and refining concepts to develop themes as the relationships and inter-relationships between codes were revealed and evidenced. Kelleher's 1999 HPPC theoretical framework was deductively coded to contribute to the overall coding and theme development strategy, and to organise and manage the data so that the reader can understand the CKKSPC HPPC policy aims and compare how caregivers actually experience the policy in action, in the findings. The research mentor and the researcher agreed on the final themes, and the research mentor reviewed the analytical framework developed with HPPC categories, five themes derived from 68 agreed upon codes clearly defined, supported with excerpts from the interview transcripts. The final framework enabled the observations, relationships, descriptions and interpretation summaries to be explored expanded upon in each category, working the final analysis into a whole as reported in findings.

Reflexivity

The researcher acknowledges awareness that the experience in palliative care developed in 23 years of practice could influence the conduct and outcomes of this research. To this end, the research was conducted by adhering closely to the methodology, discussing issues of concern or possible bias with the research mentor and the research assistant, especially in the areas of testing certainty regarding findings. The RRCBP team promoted awareness of reflexivity as a process of self-scrutiny, acknowledgment of ethical dilemmas, and the researchers 'place' within the conduct of the research, consistent with McGraw, Zvonkovic and Walker (2000). The researcher had not been professionally involved with any of the participants; and has extensive experience with people with life-limiting illnesses, their caregivers and families, and experience working with stressed, distressed, vulnerable, grieving people. The researcher was a novice researcher, highly experienced in quality improvement project management and deeply involved in the implementation of the CKKSPC Health Promoting Medication Safety Program, which could potentially have posed a conflict of interest however the pursuit and adherence of sound professional values and high degree of education regarding research conduct during post graduate Master's Degree, meant scrutinising personal aims regarding conduct of this research. Underlying influencing factors are professional values especially the premise 'do no harm' and the potential for quality improvements.

FINDINGS

Five themes were identified that together captured the lived experience of the caregivers.

Redefining Cultural Norms

Supporting preferences to die at home has the potential to redefine the cultural norms brought about by the Biomedical Model of Care (Russell and Schofield 1986; Baum 2008) that gives rise to death denying health policy, and favours the pursuit of cure. Subsequently society has experienced loss of control over death and dying, resulting in the majority of people in industrialised nations dying in hospital, having failed to respond to treatment. A HPPC service aims to reorient health policy to address this imbalance, setting the HPPC philosophy in action. In this study the caregivers discussed the practicalities and their emotions in managing the care in the last few days of the patients' lives and their deaths, recalling their perceptions of the experience, sometimes faltering with emotion or use of words like 'death' preferring to say 'passed' which is consistent with this study's interview question development 'representative expert group's' advice on suitable language, and is also consistent with Noonan et al's (2015) belief that 'death literacy' needs to be developed in society to bring about a common comfortable language that does not hide death in words, in language or in cultural behaviours. Caregiver language varied however most did 'soften' their words, perhaps in reverence for their relationship with the person who has died.

"Oh yes, they gave me the information on what to do. Under no circumstances ring the police because it becomes quite a different thing. When he went, I rang my doctor and I rang palliative care, and I had already - this sounds macabre - I'd already rung the funeral people prior and so I then rang them and said look, dad's gone now. They then spoke to the doctor.....and they came and got the body. It was lovely...." (Interview 2)

"One minute they've gone to bed with their mum alive. It's the whole thing, you're not trained to - you're never brought up to know how to say it to your kids or whatever". (Interview 5)

In palliative care the terminal phase of the illness is the catalyst for further decision – making; establishing firm preferences, and initiating the formal training that culminates in assessing the caregivers preparedness to manage symptoms, draw and administer medications, manage the death, and the after death care as per the HNELHD Medication Safety for Palliative Carers at Home (2014). A plan is developed with the caregiver as a guide for managing the death – a practical plan for an emotional event. Caregivers described keeping a bedside vigil, sometimes with other family and friends, attending every need of the patient. They describe being unable to leave the bedside, believing it unfathomable that the person die alone or without them. Others describe feeling 'timeless' or "in a daze," without conscious awareness that death may be soon yet subconsciously aware that the patient is dying. Remaining unaware is sometimes preferred.

"I suppose while I was watching, I became aware that this was the eleventh hour..." (Interview 1)

"....she sat down and said.....we really need to have a chat. She was really, really nice about it but where she went was a place I didn't want to be.....I was quite well aware of what was going to happen..." (Interview 8)

"I actually wasn't in there when she actually - well I was in there two minutes later when she passed.so I thought there's no point waking them at 1:00, just thinking of the kids. I had to wake them I suppose about 6:00, I thought I was just waiting around, bloody waiting and waiting and then finally had to tell them. The young bloke couldn't believe it, he actually went in there and saw her. I'm pretty sure (daughter's name) did too, but she's just that two years older and she understood more". (Interview 5)

Just as there is no stereotypical caregiver, there is no stereotypical dying person (Kellehear 1999) each death is unique. Descriptions of deaths varied however there were two common areas of focus, the pain and the breath. Caregivers' perceive that the potential for suffering arises from the loss of dignity and hope, uncontrolled pain, and noisy, productive, gasping for breath in the hours prior to death. The caregivers feel this suffering vicariously by way of their intimate relationship with the patient, the intimacy of which forms the basis of the caregiver role of keeper of dignity and hope.

"I rang them and told them that (patient's name) had passed. I had rung earlier when I was sitting here. He got that funny breathing noise, they call it the death rattle; I had never heard of it before". (Interview 3)

"Knowing that he wasn't in pain and knowing that if it started to escalate I could get it under control made me feel better". (Interview 4)

"I really need to give him this morphine. Because I was worried that he was suffering and I didn't - I just didn't want him to suffer. That was my biggest fear. That was the most overwhelming thing, yeah". (Interview 10)

While most descriptions indicate that symptoms of dying generally respond to medications and other comfort measures, one caregiver described a high level of distress due to noisy, burbling, gasping breathing that required a

change of medication. Although this was achieved with eventual calm, their rural location extended the period of distress due to nurses traveling the distance to their property.

"There's one comment that I need to make there.... on the last day of her life is that she was really struggling; really, really struggling. The fluid was coming up. She was virtually drowning in her own fluid. They have given us the medication for that.... I submitted that and that was working. Then I did it again at night but it wasn't as effective any more". (Interview 7)

Additionally, if for whatever reason the plan for the death is not fully developed there is much reported angst with anger and disappointment looming large. Caregivers can be left with the very difficult task of trying to arrange doctors and undertakers to attend the home during the night. Preparing all stakeholders for the possibility of the death with a practical plan in place for the caregiver to follow is the standard local procedure as this practice supports the caregivers and families more effectively.

"If I would have known this prior to when they said, well it's time that you start organising the funeral because she could pass away this weekend, that was too late. I needed to have that information earlier..... Yeah, I was appalled by that. I thought why are they in that profession. But anyway, in the end it went quite smoothly". (Interview 7)

(Angry) "...because she said can you keep him there 'til the next morning. I thought no". (Interview 9)

For the most part the deaths, and the after death care were emotionally and spiritually comforting, evidenced by descriptions of caring for the body, the calm presence of the body in the home, the comfort with keeping the body at home until 'ready' for separation, and caregivers normalising the experience for other family and friends.

"Because she said he'd be hot and everything. We did all of that and then he settled back down. Afterwards I rang to say that he'd passed away. I actually didn't believe it. I kept holding his chest and checking to see well is he just in a really deep sleep? Has he really gone? I mean I knew....." (Interview 10)

"...that morning that he died it was really - the house was so peaceful. It was. It was like there was something in the house just leaving everything peaceful. He was so peaceful, the baby was so peaceful. I was just here and you could just feel it. It was like there was something in the house wrapping its arms around you. It was the most amazing feeling. I know that sounds ridiculous but this most amazing, beautiful, warm feeling in the home. His passing was beautiful". (Interview 10)

"He had myself and my brother with him. I've seen quite a few deaths. There was no gasping, there were no noises, and I looked and I said, mum, he's gone. He just fell asleep. It was beautiful....My brother and I, we didn't lay him out but we prepared him, got him ready for the undertaker, because palliative care had told us what to do.....you know..... My brother was here so I said come on, we're going to do this for dad. So we did that and straightened him out. Yeah, that was a privilege". (Interview 2)

Caregivers expressed a range of emotions and feelings from disbelief, numbness, sadness, and real gut wrenching, painful grief expressed with emotion and passion. There were tears, laughter and many meaning-making stories. Caregivers expressed a great sense of achievement by knowing and fulfilling wishes, believing that the experience was one of personal growth, improving confidence in themselves. Caregivers were unanimous in stating they would care again, many believing that it was a positive experience, if caring for someone you love.

"I would say that they will learn on their journey that they think it's about the person that's dying. But you learn so much about yourself..... You learn what you're made of - good and bad. You learn that you can be selfish and think if only I could have time out... - in amongst it all. But it's a journey for everyone. It's just not about making that person's journey beautiful; it's about understanding yourself as well". (Interview 10)

"I think I'd have to say that I think it's the finest thing you could do. (Interview 1)

I don't think you can ask a friend to do that, because you live and breathe with that person for however long they're ill. They can't be - I don't even think (wife's name) could be in another room. You have to be right next to them, because they have moments of pain. They have times when they're uncomfortable and I know times when they're stressed and you can't be even in another room and lose that moment". (Interview 1)

"I think it's the finest - for someone you love. I mean, you couldn't do it for anybody else. But for somebody you love, you can't imagine doing anything else". (Interview 1)

There were two unexpected outcomes, the first is in regards to the hospital bed loaned to patient's whose family or friends transport to the home. The findings indicate that the hospital bed is accepted by patients with some foreboding; standing testament to the illness, separating couples, and often surrendered to in the last few days of life. Surprisingly the stock standard hospital bed is assigned a more spiritual than practical connotation. For caregivers the hospital bed is an acceptable space in the home to die.

".....she was sitting upright and she didn't like that bed being in our room, but I said it's not for her it was for me, just in case anything went wrong that we had something. She was still sleeping in our bed, so she was - I think she was confident that this was all going to work and she was going to get better, but clearly she wasn't". (Interview 1)

"He wanted to be home, yeah. They asked me how I felt about that, and I felt good about it because that was his wish...his brother found it a little bit harder than me. Even till now he can come up and he sort of walks to the door.....he didn't think he could go in there.....I said, it's only a room. I said, he didn't pass away in that bed, it was the palliative care bed". (Interview 6)

"That upset him that we weren't sleeping in the same bed anymore. I wasn't too happy about it either, but it happens". (Interview 9)

The second unexpected outcome was the disclosure by two caregivers who believed it was the 'morphine' that caused the death, with a third caregiver bordering on this belief, unclear in her meaning. The root of these beliefs was grounded in their past experiences and assumptions. Surprisingly the disease somehow disappeared from their language, the medication became the 'culprit', and they were willing or unwitting participants remaining silent, their role unspoken and somehow sanctioned by health professionals. Rural palliative care nurses in the CKKSPC generally would expect that these beliefs would be held by the broader public who have not had any prior experience with illness, death or palliative care education. The CKKSPC palliative care nurses spend a great deal of their time dispelling morphine myths and educating patients and caregivers about the medication, its uses, administration, side effects and historical and modern uses. The power of these caregiver's beliefs, despite being the recipients of palliative education and information, hints at a broader public health problem requiring 'national' consideration and attention. Neither education nor medication training unearthed these beliefs which, at the very least may have personal implications for caregivers during bereavement, and for palliative care service reputation.

"...our son, he blamed Midazolam for - I don't know - he thinks that Midazolam speeded up the process, but I think it was that last drug that they gave him. I think everybody's got their ideas about palliative care in that last little bit. Yeah. I've heard a few people comment..... I wanted them to do something because.....we just couldn't bear to see him" (Interview 4)

"Yeah. I'll tell you, I did feel later, I felt guilty because I realised that that was helping him to pass on. I know that they do that in hospitals, the more morphine you give, and the less they eat - because he had decided - he couldn't eat very much at all towards the end, he'd just pick. I'd put a meal and he'd say oh..... I don't think I can eat that. Just eat what you can, dad. Then later I thought oh dear, it's me giving him this morphine that's..." (Interview 2)

"...lined up all the morphine shots and told me what I'd have to do, because now we were just going to make him comfortable. My girlfriend said what are you doing? I said making him comfortable, which means we're putting him to sleep". (Interview 9)

In discussing this further the caregiver explained that the illness had caused a coma-like state initially, not the medication. *"It (the disease) had put him to sleep." (Interview 9)*

The theme of 'Redefining Cultural Norms' is consistent with the HPPC goal of 'Combatting Death Denying Health Policy'. A caregiver in this study who had experienced many close family member deaths from childhood onwards described her experience as *"Too much grief for a young girl to handle, but I did."* This caregiver had developed language and behaviours that she deemed to be realism regarding death.

"Well...being (funeral director name), he came down straight away..... with his off-sider, and they took the body away. (funeral director's name) came in and looked at me and said do we have to meet again like this?.....I said to him, apparently they've got a surprise party arranged for me for next Saturday..... He said well, we'll put him in the icebox 'til next week. My girlfriend just looked and I said well what else do you think it is? She said it's the fridge, the cool room. It's an icebox sweetheart. She looked at me, I said, you know me, realism to the end". (Interview 9)

In It Together

The theme 'In It Together' relates to the critical role of caregivers and their identity which, in this study is clearly grounded in the relationship with the patient. The caregiver role is described as fated, evolving as a natural progression in their relationships due to life changing forces. Caregivers do not strongly identify with the term 'carer' or 'caregiver', as these labels are health professional language associated in their mind with formal payments of which they are quick to disassociate from. The caregivers' use of language and descriptions of their role indicated that caregiving is something they do rather than who they are, and certainly not for payment.

"My husband and I are on pensions, but we manage. We manage quite all right. But no, it's about the person, not about the money". (Interview 2)

"So becoming a carer: who's the carer?I'm the carer. Okay".

"Well, I don't think I - I don't think I ever sort of consciously thought, okay, well, I'm going to care for (wife's name). It just - it didn't occur to me to do anything else.....So it was just one of those fluid situations that you just seamlessly move into without making a conscious decision, all right, then I'm going to do this. You just take it on. It just becomes part of your life". (Interview 1)

"Well I was obviously foremost a partner caring for her wellbeing". (Interview 7)

Most meaningfully, caregivers expressed the view that caring was all about the relationship, about love and care, that love and caregiving are not separate entities but interwoven. Length of time in the relationship was often used to explain the magnitude of their relationships. In this study the caregiver's role evolved seamlessly from being a partner, a child or other relative, and inextricably tied to all further actions, decisions and care – they were in it together.

"I would say it's a beautiful thing to help people that you love". (Interview 10)

"Well I was obviously foremost a partner caring for her wellbeing... So I didn't even see any differentiation between partner and carer, it's just the one". (Interview 7)

"What I did, I did out of love". (Interview 6)

These findings do not equate with the stereotypical caregivers of the past being mostly duty-bound females. Rather the caregiver's in this study were more consistent with Leveque's (2015) claims that modern caregivers are more likely to be employed, younger, and all genders. Brodolini (2001) claimed that gender inequality remained problematic in terms of social and financial values of caregiving in society and Accius (2017) claims increases in male caregivers reflects the diversity of society. This study revealed that despite caregivers not identifying with financial rewards, there is a financial impact causing a great deal of distress for some, and that the impending personal financial loss or crisis is often not addressed until after the death when the impact is compounded with the effects of grief, loss, loss of the patient's income and funeral expenses. While personal financial positions may not be high on the agenda of palliative care providers, and not disclosed by caregivers as a source of distress, for some there is an underlying impending financial threat, which can be experienced more potently during bereavement. This is especially concerning in rural areas where palliative care teams may not be resourced with staff skilled with the expertise to assist with these problems.

"It was really hard. It was really, really hard to have him in the hospital for two months straight" no intervention during that time leads to financial distress complicating the bereavement as demonstrated by following comment.....

"Lost. Concerned about my future, if I'm going to end up losing my house....." (Interview 3)

"...and I'd have to get a loan and do you really want to leave me with a bigger loan than I'm already paying off when you're gone?" (Interview 9)

The suppression of financial concerns seems to go hand in hand with the suppression of a complexity of emotions ranging from containment of emotions, to denial and avoidance behaviours. These behaviours at best seem embedded in the capacity and resilience of caregivers, and at worst, can effectively cause the caregiver to miss opportunities for decision making, important conversations and experiences that in hindsight they wish they had done. Complex because this staving of emotions effectively bolsters their capacity to endure and manage a range of issues and circumstances during a time of upheaval, changed life circumstances and changing relationship dynamics.

"There were 100 things I wanted to ask her about how to cook certain things, but you don't want to put that negative thought into their head, so you don't, well we didn't..... Yes and it's just shattering that (daughter's name) didn't get the opportunity to learn how to cook from her mum. I can cook, but nothing like....." (Interview 5)

"Well, you sort of push it away from you and that's why I was a bit afraid of this interview, because I - well, it's happening. It's all coming back like it was yesterday". (Interview 1)

Avoidance of anxiety, and other painful emotions are thought to drive these behaviours. (Penley; Tomaka and Wiebe 2002) The contemplation of death, and all that it means, may be too disconcerting, overwhelming the caregivers, suggesting that the use of denial bids time for processing painful information slowly, as many participated in decision-making in tandem as events unfolded.

"...just really opened my eyes to the fact that this was imminent. Before that, I knew it was sort of coming, but I probably - not probably - I did push it out of my mind". (Interview 5)

While all caregiver's capacity and resilience is impacted by their health and wealth, two caregivers were diagnosed with life limiting illnesses immediately prior to caregiving, and one afterwards, with subsequent treatments and surgeries, and fated a dual role of patient and caregiver.

".....six months after Dad died I was diagnosed.....So from that day I was diagnosed with it being that bad, I stayed with Mum so she was caring for me kind of thing, like I was still very active and we were helping each other". (Interview 8)

"Now I guess because I've held everything in check for so long that's why the carpal tunneling, the broken wrist and now this..." (Breast cancer) (Interview 9)

The findings from this study indicate the significance of rurality; specifically, that palliative care staffing is often under resourced, especially with allied health resources. Families have to own and maintain a vehicle, be able to travel distances for treatment and check-ups, or relocate to metropolitan centres with subsequent financial challenges and isolation from family supports. Privacy and confidentiality can be challenging as members of the community are more likely to know each other, sometimes exposing caregivers and patients to unwanted attention, indicating that health

professionals need specific strategies to deal with those issues. The skills and resourcefulness of the rural palliative care team need to be diverse, and the relationship with the General Practitioner is ever important as the patient declines. Communication between the GP and palliative care is vital as GP home visits are virtually non-existent.

"We had (name of doctor) but she wouldn't do home visits. I considered that a necessity. Because the last couple of times we had to get Mum to (name of doctor) we had to get her in with a wheelchair". (Interview 8)

"So we lived up here and so we would go down to Sydney. We'd stay at a hotel....would go to those treatments and then as soon as she felt strong enough, we would come back here. Because she always wanted to come back here". (Interview 1)

"I had a few talks with the nurses when she was up in the transition ward, there was a couple of nurses, I already know them, and one of the nurses I actually went to school with. So I've known her for a bloody long time. They kept saying you better do this, you better do that". (Interview 8)

While financial and emotional issues would 'play out' in the everyday lives of caregivers they report being more concerned with the practical day to day care, focusing on the needs of the patient above all else.

"...more worried about him having his nutrition. Trying to make sure he had his vegetables and his gravy and just things that he could palatively enjoy". (Interview 10)

Providing or seeking assistance with personal care can be a dilemma when care giving for a parent or relative of the opposite sex. This is a huge area of concern as support services are in great demand and convoluted access to government programs such as My Aged Care (MAC) and National Disability Insurance Scheme (NDIS) cause some distress, as does waiting times for time-limited people. Such is the resilience of caregivers, faced with such daily challenges, the intimacy of the relationship provoking their role as the keepers of dignity, advocate in decision making and proactive help seeker, and dependent upon community-based services to prevent unwanted hospitalisation.

"....in the morning she'd lay in bed until probably about 15, 20 minutes before the nursing was coming or a friend that could help her in the shower. So our schedule run by clockwork and I mean by clockwork and I stipulated that...." (Interview 8)

"I did need that. Towards the end I needed a hand with him in the showers and that because he was getting too - well I'm not that, you know, and he was getting too hard for me to do..." (Interview 9)

"Mum was a little bit more difficult because she was more on the personal hygiene side where Dad just needed a bottle and nappy wipes and..." (Interview 8)

The theme 'In It Together' is consistent with the HPPC framework (Kellehear 1999 p127) goal of 'Interpersonal Reorientation' that recognises that "people are beings at the centre of a web of human relationships, financial commitments, and institutional obligations. They tend to resist major changes in their lives unless the forces are considerable."

Sense of Control

Hospital experiences were the greatest source of despair from perceived loss of control. This was most sorely felt when patients were told by health professional that there was nothing more that could be done for them, or that they couldn't stay in hospital any longer. Amid feelings of abandonment many sought refuge at home. All caregivers confided fear of hospital or bad experiences in hospital as the driver for the patient preferring to be at home. Many feared death in hospital with perceived lack of control over symptoms, austere clinical ambience, isolation from family and friends, lack of privacy, and depersonalisation. In contrast, home is equated with comforts, family support, and ability to maintain a balance of identity, and just a "little bit of normal".

"He woke up and he said where am I and what am I doing here, get me home. So I had to tell him then what was going on, what had happened, and he said you know my wishes, get me home. He gave them four days to sort out whatever they had to do, and then he was coming home. He would not let me leave". (Interview 3)

"So I just went back in and I sat with my head in my hands..... I just sat with my head in my hands. There was nothing I could do. It's very heart breaking to see that ward. Not only for her....well the treatment in the hospital it was, fair dinkum, disgusting. Absolutely disgusting". (Interview 8)

"I hate the pain clinic. As I said to them, you and I both know that if they've got pain, the pain absorbs it. There is no residue and this man's not acting, so why do you keep doing this? Every time they'd change the meds around that'd muck up everything". (Interview 9)

Partnering with palliative care, from the caregiver perspective, generally came about due to the proactive help-seeking behaviours of the caregivers who describe some reluctance on the part of the patient to accept the service. However, because the caregiver wanted the support they describe a truce like situation occurring, with eventual acceptance. The caregivers did not perceive that there were definitive choices about staying at home, being at home was more

about gaining a sense of control over upheaval, and accessing services was driven by the need for support, gaining a sense of control over uncertainty and the need to fulfil the patient's wishes.

"(Husband's name) didn't want palliative care, but I said yes, get it because I don't know what's going on. I said I don't know what to do if you get really sick. I talked him into having palliative care..." (Interview 4)

"(Wife's name) was a bit - well, she has always been a very independent woman and she didn't think she needed a..." (Interview 1)

Such support as offered by the palliative care team is valued by caregivers faced with continuous adjustments to patients needs due to disease progression and deterioration and with the emotional impact and changed circumstances with home seen as the locus of control. Seeking control may be driven by anxiety as caregiving is associated with high levels of stress, anxiety and depression (Ferrario et al 2004) which may in turn, impact on cognitive functioning (McKenzie et al 2007) indicating perhaps why denial and avoidance behaviours are so powerful.

"I had a migraine - I think it was two weeks before. I couldn't talk, I couldn't do anything. That was when they wanted to know - they said there's nothing that they could do for (husband's name). They wanted to know whether we wanted to put him in respite. I just kept saying - they were ringing and I just kept saying no, he's not going to respite. I said I can't make a decision because I was sick". (Interview 4)

"I just can't recall the process that I went through, but obviously somebody helped me..." (Interview 1)

"But yes, we had both of them. So I had to learn to cook from cooking for two..... to cook for four. It was so difficult because dad was on a particular diet.... and mum was only 32 kilos and I had to build her up as well..... I was on a diet and my husband was on the verge of being a diabetic, so okay. That was a bit of a nightmare but anyway, we worked around it". (Interview 2)

Skilled communication and supports arise as key considerations for palliative care as caregivers describe living with hope. Hope according to (Dufault and Martocchio 1985) is to want something good to happen in the future, often having a confident feeling that it might. When hope was maintained some caregivers describe consciously not speaking of dying and death and subsequently, in hindsight, regret that important conversations weren't had, information and skills weren't passed on, and important opportunities for decision making were missed as the reality of death was not realised verbally.

"It just happened that way. It's funny - it's not funny, but when someone's dying you don't talk about it, because bloody hell, she tried. The hope, first time we've ever believed in one word. Big as a bloody car, the word was. That's all we were doing, was hoping, but I think because it was so advanced from the word go". (Interview 5)

"She was still sleeping in our bed, so she was - I think she was confident that this was all going to work and she was going to get better... Well, I don't know whether it was just family and me had an optimistic view..... or whether we were just not being honest with ourselves. So we bought her home thinking that we can make her better". (Interview 1)

"Well leading up to it (the death), it's always crossing your mind leading up to it. It would cross everyone's mind but mine maybe....." (Interview 5)

For others, as the forces of hope were shifted, and a more 'realistic' awareness dawned, a cascade-like decision-making process evolved between the patient, the carer and palliative care, slowly but surely. Thus caregivers reported that the burden of decision- making was relieved by knowing the patient's wishes, bringing a sense of control to the emotional crisis of the situation.

"He wanted to be home, yeah. They asked me how I felt about that, and I felt good about it because that was his wish". (Interview 6)

"Yeah, knowing what his wishes are and what they were, it helps. If I could give you ladies any advice when you're dealing with families is to make sure that their partners or their family knows what they want to happen afterwards, because it's so much - it makes life so much - just that little bit easier to cope with". (Interview 3)

"No, he wanted to go to the hospital. Because he didn't want us - he didn't want to be a burden to any of us. But it wasn't until probably the last week I think he realised. Because he did pull me aside and had a chat to me. He was happy that he was here. Because he really struggled with it but he was happy. He said he couldn't have been anywhere better". (Interview 10)

The greatest need for control recognised by the caregivers was for control of pain.

"There's no way she could have survived here without palliative care, because she needed the drugs and just a bit of support. It was really handy, otherwise she would have had to be in hospital for ages". (Interview 5)

"As long as her pain was under control, that's all I was concerned about. (Interview 1)

“...if you are so involved as a partner, it's hard to stay calm and not be emotionally involved in it. So all you want to do is just to help to take that pressure and that pain and.....” (Interview 7)

The complexity of emotions and behaviours at the heart of caregiver capacity and resilience while unique in each seems a tenuous coping framework that needs a solid foundation of personal and community supports and professional support from health professionals who understand and are prepared to work with this complexity. The theme ‘Sense of Control’ is consistent with the HPPC goal of ‘Reorienting Palliative Care Services’ to have HPPC education, training, policy and partnership agenda’.

Developing Confidence and Ability

The developing partnership with palliative care means that the CKKSPC needs to be vigilant in establishing clear lines of communication, laying the ground work for decision- making and formally assessing the caregiver’s preparedness to provide care in their place of preference, prior to medication administration training. HNELHD Medication Safety for Carers at Home (2014). Remarkably, caregivers focused somewhat on the details of the illness and treatments during the interviews, with seemingly great recall despite their stated feelings of confusion, and being “in a daze” or other such like emotional states at the time. Indeed during the interviews the focus on detail suggested a mirroring of the avoidance behaviours caregivers reported had occurred during the caregiving. Thus avoiding painful emotions, enabling participation in the interview. The self-reported stress and poor memory are all the more remarkable given that the caregivers are at the forefront of medication management and decision making, especially in the last few days of life.

*“He had diarrhea at home, and nothing would stop it, nothing. He was going to the toilet heaps.....They put him in hospital. They couldn’t stop the diarrhoea, so they just kept pumping him with stuff. He ended up bleeding from the bowel. He’d had a really bad bleed, so they took him down to intensive care. We thought we’d lose him then. He came out of intensive care and he went back to the ward. That was when his blood pressure dropped. Then he came all right. Then he went back to the ward. Eventually he came home and he felt okay. Then it was later he had the - a couple of months later he had the bleed from the bowel. He had to have emergency surgery. They had to take some of the bowel out. He got over that. Oh, he lost a lot of weight. He was on - is it a TPN bag?
.....It was just a horrible year, a horrible year”. (Interview 4)*

“I was very much ahead of the medication, the medication was on the dose, it’s the frequency, even with the chemo drugs and things like that, I knew exactly what was going on”. (Interview 6)

“...well it was good getting the training straight up, early”. (Interview 5)

Caregiver familiarity with medications such as morphine is evidenced by the confident descriptions of assessing and managing pain. Their recall of the formal training was generally accurate in regards to the process, and while the names of some medications were lost, morphine seemed to always be mentioned. There was enormous respect for the perceived potency of morphine with many caregivers reporting initial fears associated with keeping the patient comfortable without overdosing them or shortening their lives.

*“...I was scared I was going to overdose him. I had all these things going through my head. Oh if I overdose him, what’s going to happen to me..... but if I get charged for overdosing my poor husband, what’s going to happen to my kids. That’s the thing that scared me the most and I think that’s why I rang that phone number: should I give him this?
I was just so scared of overdosing him”. (Interview 3)*

Practical strategies were developed by some to manage multiple medications such as photographing the packaging.

“I took - I had to take photographs of all the drugs, because otherwise I couldn’t keep it in my mind, but the palliative nurses were doing all the other drugs”. (Interview 1)

Pain assessment skills were described including recognition of non-verbal pain cues.

“Yes, I learned to recognise it. (Pain) Well, he helped me by looking at me. He didn’t have to say very much, he didn’t have to say anything sometimes, just look at me, and close his eyes and I knew he was in pain, or wince. I was just able to do it”. (Interview 2)

Caregivers described an increase in confidence on completion of the training, especially when other family members or friends were trained with them this enabled them to support one another, and offered a round the clock team approach to the care in the last few days of life.

*“He had the - he had a... A little cannula in... He had four hourly - one was four hours, and I think one was two hours. Somebody stayed up - well, someone slept in. We just swapped around. If he went to sleep we had an alarm on...”
(Interview4)*

*“Yes, I felt confident, especially when my husband, the two of us together, we could do it together. So I knew that we would be able to - whoever did it, we’d be checking - you know what I mean? Two people are better than one”.
(Interview 2)*

“They talked me through everything I asked about and they provided all the advice. I mean, they were wonderful.the medicine was all very confusing, but frankly I just relied on those nurses in the last stages to help me with her”.
(Interview 1)

“Are you tired? He said, yeah, put me - he said but I've got a big pain too. I said alright I'll give you your morphine. So I gave him his morphine and then he said, after he'd had something to eat, put me inside. He didn't eat much. Sit me in the recliner. So we got him all comfortable in the recliner.... I put the blanket over him. He said wake me up at seven for Dr Who. I went in at seven. I couldn't disturb him. I couldn't wake him. Lifted his eyelids, I thought well he's still home”. (Interview 9)

Caregivers appreciated the staged education and information, evolving in line with the care needs of the patient. This staged process affording timely access to the medications, education and professional support which was central to the reduction of pain and suffering, and served to sensitively inform and support the caregiver and the patient as they come to terms with the situation.

“As she deteriorated, the care increased. The nurses seemed to understand that the evolution of the care that was needed and prepared me for it. Yeah. It just became part of life”. (Interview 1)

“...and the whole staff - we had different ones - and I couldn't complain with one of them, because they explained everything. When there was questions we wanted to ask, they answered them”. (Interview 6)

Some caregivers reported that participation in the formal training with palliative care served to increase the patient's confidence in their abilities, reassuring them that their care needs could be managed.

“I can remember him saying well the nurses and the doctors they know what they're doing... then he realised that I could do it. That did make him feel better. Because they have to be confident that the person who's looking after them is going to look after them properly and try and make them as comfortable as they can. So yeah, it's a big thing. It's a huge thing”. (Interview 10)

Effective communication within and between the caregiver, the patient, palliative care and the GP is valued, and the paging service was particularly valued due to round-the-clock access to palliative care support seven days per week, should caregivers falter in their confidence to administer medications, enquire about symptoms, or require moral support. Caregivers believe this access to be vital, assisting them in resolving issues that could potentially be overwhelming, or cause hospitalisation.

“I rang that quite a few times, yes, just to get advice, to let them know how (husband's name) was. They even rang me, which was great. They rang me and the paging number, the person I spoke to asked for my name and the number. Not even two minutes had gone past and someone was back on the phone to me. That pager, that's a lifesaver. That's a lifesaver that one. You don't want to change that”. (Interview 3)

“... that you always know there's something there to fall back on. If you've just got one question, they're only a phone call away”. (Interview 6)

Rural caregivers depend on access to the GP via palliative care – indicating that GPs and Palliative care have a responsibility to develop effective working relationships in rural areas if patient's preferences to die at home are to be enacted. The caregivers in this study valued the GP's involvement as they felt that it validated the end of life phase, their involvement with medications, and the provision of care at home, countering the absence of GP home visiting. Essentially this meant that the patient did not have to visit the GP surgery when physically unable, nor did they need to be in hospital to access a doctor. Just as informal caregivers are pivotal to palliative care, the GP figures largely in the palliative care equation, particularly in rural areas.

“They knew what they were doing. They were confirming everything with the doctor. The doctor was confirming everything with the specialist. So everybody was watching everybody. You couldn't really put a foot wrong with the way measurements were drawn up and the locked box with all the ‘don't need to touch’ unless you really have to drugs”. (Interview 8)

The theme of ‘*Developing Confidence and Ability*’ is consistent with the HPPC goal of ‘Education and Information for Health, Dying and Death’ with promotion of autonomy and empowerment central to the core of its health promoting goals.

Living with Loss

In single words the days following the death were experienced as “numb” “terrible” “busy” and “empty”. A common expression is that nothing prepares you for the bereavement. Most focused on keeping busy, sorting out affairs, some overwhelmed by bureaucracy. Caregivers left no doubt that this is another time of upheaval. No longer did they feel that they could participate socially from the ‘we’ platform, some filling the void with their grandchildren, others returning to work out of loyalty to supportive employers. They describe a growing dread of weekends as their friends and

colleagues look forward to activities while their own life has changed. As expected, there is ongoing grief and feelings of loss amid expectations that feelings may ease over time. Some were really suffering, finding it difficult to participate, their place in the world misplaced, lost to them, their identity in crisis. Simple pleasures once enjoyed now gone.....

"So I take fruit mostly - every - almost every day. So yeah, I think I'm doing okay there. But again, because the joy out of cooking of course is gone, it's just for yourself". (Interview 7)

"I'm just cruising along. Have some really bad days. One of my friends rang up a few weeks back and I was just sitting here balling my eyes out". (Interview 8)

"I find that the Friday is the worst. [Crying] Going into the weekends, where your colleagues are planning the weekend with the family, I just go home with nothing. I find that the hardest. (Interview 7)

".....especially since I had that meltdown a bit because I guess what I did is I kept myself extremely busy immediately after (partner's name) passing to that extent that I probably was burnt out. I was just going like a Bondi tram and it was just probably all hitting me. So they reassured me that it was just the normal process of grieving and to expect it more often. But as time goes it should get lesser and lesser intense". (Interview 7)

"I've been called the merry widow by a couple of supposedly friends..... We went out for lunch to celebrate (son's name) birthday..... We were laughing and carrying on with him..... She was a friend..... really hurt me....I've told her not to ring me or contact me again and I have deleted her off my Facebook". (Interview 3)

Financial distress was prominent for one caregiver in particular who indicated that the GP had been a great source of support, others also indicated supportive GPs.

"But I have had counselling since then. My doctor thought I needed to go and see someone so I have been and seen someone... It's hard. It's hard, very hard. If I knew 12 months ago what I know now, I would have done things a little bit different concerning finances....." (Interview 3)

Many dealt with the circumstances as they always had, referring to past coping abilities or stress responses. Two caregivers accepted counselling when offered by the GP some months after the death. Those more geographically isolated found accessing social supports harder.

"I'm a bit isolated where I am. I'm on 25 acres So it's not something just in town that you can walk in at a neighbour's and have a cuppa sort of thing. So that makes it harder". (Interview 7)

"I think the hardest thing is knowing that he's missing out on (grandson's name). That's one of them really hard things, and the occasions like his first birthday and his christening and seeing him walk and how funny he is". (Interview 4)

"I've thought about going back to work, but I've always had trouble with anxiety. It takes a bit for me to do certain things. I thought about going back to work, and then I had a couple of really bad anxiety attacks and I thought I'll just put it off a little bit. I went to the doctor and he changed my tablets. He's put me on an anti-anxiety medication rather than an antidepressant. I actually went away for the weekend last weekend. I went with another six ladies. Got up on the stage and did some belly dancing, so yeah, I think they're working". (Interview 4)

"I thought I'd be worse than what I was when he actually passed, but it was a comforting feeling knowing that the pain was gone, there was no more agony for him. I got his ashes back. When I brought them home I thought this is going to be so creepy, but it was so comforting to have. They're still here. We were going to spread them, but we just didn't get a date". (Interview 4)

"I've always learnt to manage the grief, because when (brother's name) died you couldn't let it out because you couldn't let the other two boys see....." (Interview 9)

Many however attributed their ability to cope because of their relationship with the patient, the love, the honouring of that love, and the memory of what that person had expected of them. There is evidence of an ongoing relationship that comforts and sustains caregivers during grief. Memories kept alive, a lasting love that both aggrieves and sustains caregivers, motivating them to care for themselves.

"I've still got the same plans as I had before". (Interview 5)

"The future. I've got a selfish thought that goes through my mind every now and again: when mum's gone, my husband and I will just have our time on our own. That's very selfish but it's probably very human. We're tired, but we'll keep going". (Interview 2)

"We're close and after what happened to (husband's name) we're even closer now, which is good, me and the kids". (Interview 5)

"He's still here; we brought him home in the box up there. I go past, I say hello, dad". (Interview 2)

"Just time, I think. It'll never go, every single day I think of her". (Interview 5)

Family and friends are recognised as the greatest social support and source of sustenance along with pharmacy assistants, colleagues; GPs; sporting, undertakers and social groups. There was appreciation expressed for the kindness and compassion of 'others', these acts not unnoticed, however "keeping busy" was the most prominent coping strategy. Stories of meaningful spiritual significance to the caregiver could be referred to as paranormal phenomena (Barbato et al 1999) which are not uncommon in the bereaved. Caregivers draw comfort from these encounters and recited them with wondrous curiosity.

"She's at the moment really missing him because she's in hospital with a broken hip, but she had a beautiful experience. A few days after the operation she was laying in the hospital bed and she said she had her eye closed, but her hand was lying beside her. She said she felt pressure on her hand and she thought oh, who's that and she turned, opened her eyes and looked and there was no one there. The voice said it's all right love, it's only me, I'm staying with you. She said, and then I just closed my eyes and cried and cried. Cried like a comforting - comforting tears". (Interview 2)

*"They came and they asked if we wanted to leave the room, but we were quite welcome to stay. I think we all stayed there and watched what they did. I just said to them he's been really cold, can you put a blanket on him, so they took the blanket. They wrapped it around him, and I thought that's really.....stupid, but they were so nice about it.....Just as they were putting him in the truck a star fell, so it was.....
A star, fell just as they were putting him in. I took that as a good sign". (Interview 4)*

The greatest source of comfort however stemmed from having, incredibly achieved the fulfilment of the patient's wishes. While challenged by grief and learning to live with loss, caregivers all shared their vision for their future, some with trepidation, especially if financial problems existed, however there was a strong sense that their relationship with the person who had died was a spur for living on, that somehow they owed it to the relationship, and would live on both of their behalves.

"He wanted to be home, yeah. They asked me how I felt about that, and I felt good about it because that was his wish". (Interview 6)

"....it was my plan to make that wish a reality for her. That's what she wanted. However it had crossed my mind because during the whole period of her illness, there were very stressful times too". (Interview 7)

"Having (name) at home for that last week, it was amazing. Sometimes it was horrible, but yeah, I would say take them home, take them home for sure". (Interview 4)

The theme 'Living with Loss' is consistent with the HPPC goal of 'Developing and Providing Social Supports, both personal and community' that in this study were essential for caregivers' capacity and resilience to cope.

"I think it's unavoidable that you always have regrets or always have got questions about - should I have done this or could I have done this better or whatever. I think that will always be the case. Maybe a little bit more so when you're at home. But yeah, again, that support network is vital". (Interview 7)

STRENGTHS AND LIMITATIONS

Study strengths: This study provides much needed qualitative research on the experiences of informal caregivers managing symptoms, medications and the home death in rural palliative care. A representative expert group assisted the development of the interview questions. As diverse a group of participants possible was purposively selected. The use of framework analysis as per Gayle et al (2013) enabled both deductive and inductive coding and construction of an analytical framework, with subsequent theme development. All transcripts were verified as true accounts of the recorded interviews.

Study limitations: The study was restricted to caregivers or patients who had died at home. It is not known that if the inclusion of those who preferred or decided to stay at home, but actually died in hospital settings, would have revealed further information regarding the ideal circumstances to remain at home. The small sample size may have limited the gravity and extent of some findings.

The researcher's professional role as a clinical nurse consultant in palliative care may have limited the research in understanding from a nursing perspective, and by professional interests with involvement in the Medication Safety Program development and implementation.

CONCLUSIONS

1. The greatest sources of suffering were identified as loss of dignity, hope and uncontrolled symptoms.
2. Palliative caregiver identity is grounded in the loving relationship with the patient. The caregiver role evolves seamlessly from being a partner, a child or other relative, and is inextricably tied to all further actions, decisions and care – they are in it together.
3. Contrary to death denying social norms, people do want control over their end of life and their deaths.
4. Palliative caregivers become involved in managing and administering medications including opioids long before the need for subcutaneous injections.
5. There is a complexity of emotions both expressed and suppressed during caregiving and bereavement requiring understanding and skilled, sensitive communication and management.
6. The effects of grief are compounded by issues not dealt with, for whatever reasons, prior to the death, especially financial distress.
7. There are gaps in access to personal care services via current government programs of NDIS, and MAC. Time limited people, and people under the age of 65 years are discrimination against. Some patients die before ever receiving a service. These gaps cause emotional and physical distress to caregivers. Maintaining dignity of the patient can depend on access to these services which is currently a convoluted process. Many caregivers and patients experience difficulties traversing this system. The Silver Chain personal care package availability is limited to the last week of life, and depends on rurality and availability of staff across the area.
8. Caregivers in this study have demonstrated that, despite feeling anxious and requiring support they were:
 - Capable and reasonably comfortable to care for the dying.
 - Capable and confident to store, draw, label, administer and tally PRN SC Medications safely and legally.
 - Comfortable with the body in the home after the death, and participation in care of the body.

This comfort depends on the support, staged information and education and access to round the clock advice and support seven days per week to palliative care professionals. Additionally, a practical plan (Appendix XII) to guide the caregiver is essential for caregiver well-being in relation to managing death and after care.
9. Caregivers may not reveal attitudes and perspectives in regard to opioids such as morphine despite opportunities to discuss and or disclose.
10. A range of education and information needs to be available in the home such as written guides. (Appendix XII)
11. The hospital bed has a more spiritual than practical connotation – it is an acceptable space in the home to die.
12. The complexity and depth of emotions experienced in bereavement, along with social isolation, identity crisis, changed life circumstances and financial status indicated that a range of supports including and besides family and friends are needed.
13. Confidentiality and privacy can be at greater risk of compromise in rural areas.
14. There is evidence in this study from the caregiver perspective that hospitalisations and the accessing of treatments such as oncology experienced by the patients caused stress and distress and lingering fear in the caregiver as well. Therefore it is reasonable to assume that caregivers whose relatives die in hospital potentially may experience more trauma or complexity in bereavement requiring support.

In Summary:

This report has identified a Rural Model of Palliative Care with the ideal conditions for improving caregiver well-being and satisfaction in relation to achieving their aims of a home death are:

- The caregiver is caring for someone they love who desires or chooses to be at home.
- Proactive health professionals prepared to refer to palliative care other than at crisis point.
- A proactive caregiver assessed as prepared to manage PRN SC medications, the death and after death care in partnership with the GP, palliative care and partners.
- A practical plan for managing the death has been developed as a guide. May also include a NSW Ambulance Authorised Adult Palliative Care Plan (Appendix VII).
- Written information/guides would be available in the home.
- Support from family and friends.
- Early intervention - sensitive assessment and access to support where financial or other stressors are identified as potential major sources of future distress.

This Rural Model of Palliative Care would consist of:

- A palliative care team with capacity for 7 days per week practice and after-hours access for clinical advice and support.
- A palliative care team staffed at minimum with registered nurses and an integrated social worker who are prepared to pro-actively plan, pre-empting possible needs, rather than reactive crisis management.
- Palliative care staff would be skilled and or developing strategies to address the complexity of emotional and behavioural issues as discussed in the findings of this report.
- The palliative care staff would have opportunities for education, clinical supervision and debriefing.
- Palliative care staff would be skilled, providing staged, skilled education and support; skilled clinical assessments; and links to a broad range of community supports including palliative care trained volunteers.
- The palliative care team would have a very genial professional partnership with General Practitioners and the NSW Ambulance Service.
- The palliative care team would have access to equipment including hospital beds.
- Certain recognizable conditions would prompt referral to community services as soon as possible, involving the social worker to expedite convoluted government processes.
- The palliative care trained volunteers would extend their current reach to include targeted bereavement programs, especially to those experiencing social isolation, and who have, or are at risk of anxiety and depression.

RECOMMENDATIONS

1. All rural palliative care teams require a social worker integrated into the team.
2. Financial distress be valued and addressed equally with physical and emotional distress. Palliative care services need to develop sensitive methods to assess and address these issues, with early intervention to prevent crisis situations in bereavement.
3. HNELHD Palliative and End of life Clinical Stream submit position statement to address Government policy in advocacy for people with life-limiting illness and the criteria for access to personal care packages, especially for people under 65 years. The convoluted processes accessing NDIS and MAC need simplifying for time limited people and their caregivers.

4. Locally: palliative care providers brainstorm to develop strategies to unearth caregiver's true and hidden perspectives on the use of morphine, intervening early to improve understanding and prevent the development of guilt and associated complicated grief.
Nationally: professional palliative care organisations, universities, medical associations and health services need to combine efforts to develop public health strategies to counter the morphine mythical misinformation and potential professional and personal crisis. The palliative care movement and GPs need to ensure it is not seen as a form of euthanasia or secretly performing mercy killings or other such activity.
5. Palliative care be especially vigilant for those more isolated rurally, sensitively working with caregivers to develop plans to guide death in a timely manner. NSW Authorised Adult Palliative Care Plans should also be considered.
6. Rural palliative care services have inbuilt professional support and education for staff who constantly deal with stressed and distressed people, including clinical supervision and debriefing.
7. Palliative care services adopt a HPPC philosophy approach whereby the development of a compassionate community is strategised, inbuilt, and on-going, and opportunity seeking to encourage individuals, groups and organisations to effectively develop the community to respond to the broad range of needs of ill and grieving people. Palliative care volunteers are well positioned to undertake this work.
8. That palliative care volunteer services broaden their scope to response to the needs of the bereaved, irrespective of place of death, especially lonely, socially isolated, anxious and depressed people.
9. That governments and district health services consider the identified rural model of palliative care in planning rural models of palliative care. This model is not idealistic, it is possible and plausible, challenging the death denying cultural norms of the past decades, and forms the bedrock of palliative care practice in the HNELHD Cessnock and Singleton LGA's of the Hunter Valley of NSW.

Strategy for rural palliative care services to address gaps in service delivery:

1. Self-assessment of the palliative care service utilising the Palliative Care Australia's National Standards Assessment Program (NSAP) and the rural model identified in the summary of conclusions above to identify gaps. Ensure management inclusion in process.
2. Ensure that the entire team and some partnership representatives including consumers, allied health professionals and hospital nurses are included in the self-assessment and action plan development to ensure broad input from as many perspectives as possible.
3. Develop an action plan to address the identified gaps. Work with management, NSW Rural Palliative Care Group, LHD committees such as Clinical Streams, consumer advocacy groups and professional palliative care bodies to write up a submission to apply for resources.
4. Utilise the outcomes and recommendations from this study and the identified gaps from the self-assessment process to evidence the need for the rural model of palliative care.

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APPENDIX

- I Medication Safety Project Documents
- II Cessnock Kurri Kurri Singleton Palliative Care 2013 Annual Report
- III Quality Award
- IV Quality Award Application
- V HPPC Framework 1999
- VI Study Population
- VII Participant Information Sheet
- VIII Participant Consent Form
Participant Non-Consent Form
- IX Interview Questions – General
Interview Questions – Aboriginal or Torres Strait Islander
- X UTS Guideline for research which directly or incidentally discloses illegal activity or criminal victimisation.
- XI Sample of Analytic Framework / Coding and Theme Development
- XII Caregiver End of Life Education Guide and Place of Death Plan
NSW Authorised Adult Palliative Care Plan