

Strengths of family carers: Looking after a terminally ill adult under 65 years of age

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ABSTRACT

INTRODUCTION: To learn of a terminal illness is devastating at any age. How much more so when it occurs in early or mid-adulthood, when people are busy with family and career goals. Those facing death when under 65 years of age are a group whose voice is virtually invisible in the palliative caregiving literature. Yet one in every five people die in Aotearoa New Zealand before 65 years of age. For Māori, almost half will die under the age of 65.

METHODS: This qualitative descriptive research involved semi-structured interviews with eight bereaved family carers focusing on the carer's experience of living with their spouse during their final illness.

FINDINGS: Analysis of the research narratives revealed the strengths of love, hope, family, teamwork and resilience in navigating these experiences.

CONCLUSION: In order to support holistic care for those who are receiving palliative care, this research advocates for strength-based assessments to support carers during the illness of their family member. This gives a different lens to the caregiving narrative which has, as its focus, the growth of human potential as well as enabling partnerships between palliative care practitioners and family carers.

KEYWORDS: Family carers; palliative care; under 65; social work; strengths

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This article describes research undertaken as part of the author's palliative care thesis that investigated the strengths that underpin and sustain family carers looking after a terminally ill spouse/ partner/ ex-partner. As a palliative care social worker, there have been times when it seemed that every other week a person under the age of 65 years was referred to the Hospice where I was working for palliative care support. In working alongside this cohort, I became increasingly aware some of their needs were specific to their age and stage of life.

In 2016, McLeod identified that 22% of all deaths in Aotearoa New Zealand between

2000 and 2013 occurred in the under-65 age group. Ministry of Health (2014) data highlight that 48% of Māori die under 65. For these people, there is the immediacy of illness disrupting the plans of their lives, and their hopes and dreams for the present and the future. A new reality has entered their lives and that of their carers, as they work to accommodate news of serious and terminal illness.

This research explored the strengths that underpin and sustain family carers who are looking after a terminally ill spouse aged under 65. The primary focus was on

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bereaved carers who “bear witness” to the experience of their spouse throughout their illness. They were relied upon to be the primary carers who are holding and juggling a multiplicity of information, roles and responsibilities that were once shared between the couple. They are the cheerleaders in times of good news and a source of consolation on the tough days. They have a ringside seat to the inner world of their unwell spouse and all they are going through. At the same time, they are negotiating their own health and wellbeing.

Literature review

In 2018, a literature search was conducted focusing on palliative care and caregiving at the end of life via CINAHL, EBSCOHost, Elsevier Science Direct Journals, ERIC, JSTOR Arts and Sciences, ProQuest Central, PsychINFO, PubMed, SagePub, Springer Standard Collection, Taylor and Francis Social Sciences and Humanities Library, and the Wiley On-Line Library. Key words used included “palliative or end stage”, “psychosocial support”, “under 65”, “social work”, “factors impacting families”, “family distress”, “socioeconomic”, “social impact on caregivers”, “social support”, and “strengths”. The focus was on research published in English, after 2010, unless there was a compelling reason to include research published prior to this date.

Throughout the palliative caregiving literature very little research is age-specific or targeted to those under 65. For those diagnosed with a terminal illness under 65, Ray et al. (2014, p. 472) describes this as a “[s]ocially unacceptable time of life.... A time of life when people in western societies expect to have independent children and be at the peak of their working life, perhaps contemplating retirement.”

Family caregiving in the end-of-life literature is fragmented and contested in terms of

ownership, legitimacy and complexity. The ownership of end-of-life care is debated between those who view it from a biomedical model and those who experience family caregiving (Blum & Sherman, 2010). Much of the literature in end-of-life care is written by professionals yet, implicit within this, is an expectation for family to provide care for an unwell person (Alpass et al., 2017; Rosenberg, 2011). Internationally, this is not always possible or realistic due to issues such as the geographic mobility of families, poverty, unstable housing, immigration concerns, poor physical and/or mental health, and substance abuse. These all impact on the ability of family to care for their terminally ill family member (Alpass et al., 2017; Blum & Sherman, 2010; Gott et al., 2013; Morris et al., 2015; Rosenberg, 2011; Rosenthal Gelman et al., 2014; Williams et al., 2017).

Giesbrecht et al. (2015) identify research devoted to carer burden and vulnerability as inextricably linked to research devoted to resilience. They argued building resilience is an active dynamic process whereby those individuals able to acknowledge the circumstances they are experiencing are better positioned to adapt and find solutions to overcome challenges. Stenberg et al. (2014) advocated the placing of both the unwell person and their carer together at the centre of health and care planning decisions. They argued that giving attention to the positive aspects of family caregiving to identify their strengths encourages peoples coping abilities. The consequences of *not* doing this can result in a deterioration of care provided impacting both the unwell person and their carer. Unson et al. (2016) found that carers most likely to be struggling tend to be those providing care who are young and who may lack additional support.

Alpass et al. (2017) acknowledge whilst informal, family-based care is considered to be an essential component of the health care system and has many benefits, this can come at a cost to the families themselves. Internationally, a number of studies have

taken place focusing on the economic impact of having a terminally ill family member. What they have in common is an acknowledgement that high numbers of women take the role of primary carer. This can impact their employment and social connectivity. By way of example, in Canada, approximately 70% of family carers are 45 years and older; around 25% of carers are over 65 years of age (Stajduhar, 2013). A growing number of carers juggle multiple roles—those of paid employment, and caring for their own families, as well as providing support and care for older family members. As a result, many family carers suffer detrimental effects to their own health as the person they are caring for declines in health (Emanuel et al., 2010; Funk et al., 2010; Keesing et al., 2011; Mendes & Palmer, 2016; Stajduhar, 2013; Stajduhar et al., 2010; Stenberg et al., 2014; Williams et al., 2017).

Within Aotearoa New Zealand, the Te Ārai Research Group at the University of Auckland has published extensively from their research in the field of palliative and end-of-life care. Many of the findings of their research resonate with their international counterparts, as described earlier. Notwithstanding the growing body of literature the group has published, which includes the needs of family carers, some of which have already been referred to (Gott et al., 2013; Williams et al., 2017), their research has yet to specifically focus on the experience of those caring for family members who are under the age of 65 years.

As far back as 2006, family caregiving was identified as an international research priority for end-of-life care (Chai et al., 2013; Funk et al., 2010; Williams et al., 2017). Calls have been made for a different focus on caregiving. Instead of viewing death as a *medically treatable condition*, we could see it as a normal feature of life. Given and Reinhard (2017) argued the benefit of this approach encourages a compassionate response to the social, emotional and spiritual needs of the unwell person and their family.

Focusing research on the positive features of caregiving at the end-of-life gives a more comprehensive and nuanced description as to why people engage in caregiving, and the personal benefits they may gain through the process (Funk et al., 2010). Those who recommend greater exploration of the positive features of family caregiving contend that it is in owning their role as carers, giving meaning to the choices they make, and respecting the cultural and structural dynamics that influence their decisions, that carers can engage in a transformational experience of embracing and harnessing their strengths in navigating this experience (Bowden-Tucker, 2012; Cadell et al., 2011; Given & Reinhard, 2017; Morris et al., 2015).

Method

Ethical consent for the research was given by four separate parties: the regional hospice service to access data; cultural consent was given from a local kaumātua to support Māori participants; consent from the Ngāi Tahu Consultation and Engagement Group, UC; and the University of Canterbury Ethics Committee Ref: HEC 2018/20.

Accessing the database at a regional hospice was undertaken by two independent staff—one to access the database and a second to send letters of invitation to potential participants. This staff member was available to provide support to any participants who might request this. The data search identified 337 people who had died between the ages of 18 and 65 years. From this group, those people who had a spouse/partner/ex-partner as a carer were identified. This refining reduced the number of potential participants to 180 people. The data were refined into two further cohorts: those who died aged between 18 and 54 years of age and those who died between 55 and 64. In order to have an opportunity for equal representation from each cohort, every second person under the age of 55 years and every fourth person between the age of

55–64 years was sent a letter inviting them to participate in the research.

From the postal drop of 60 letters of invitation, 12 replies were received. An information sheet about the research and consent form was sent to them. Within one week, each person was contacted again to confirm their wish to proceed. As everyone did, an appointment time was made to meet and interview them. Most people preferred to be interviewed in their own home, with two being interviewed at a meeting room in the hospice.

Eight bereaved carers were interviewed to explore their experience of caring for a family member with a terminal illness until their death. How they learned to pick up the threads of their life again was also explored. All names are changed to protect their identity. Ethical considerations guiding this research drew from two complementary sources: the feminist ethics of care (Parton, 2003) and ethical approaches to working with those who are bereaved (Bentley & O'Connor, 2015; Sque et al., 2014; Ward & Barnes, 2016).

A critical ethical factor identified by Bentley and O'Connor (2015) and Sque et al. (2014) is the timing of when bereaved carers are invited to participate in research interviews. This research considered only carers who had been bereaved for between 6 months and 5 years to enable time for reflection following the death of their family member. Counselling support was available to all participants following the completion of the interview. One participant made use of this. A kaumātua who worked for an iwi-based health agency was available for cultural support for participants and the researcher.

Data collection was through semi-structured interviews which lasted approximately 60–90 minutes. Some of the questions used included:

“Can you tell me your experience of caring for including the ups and downs and

how you managed them, moving to how your life is now?”

“Where did you get your support from? How did that work?”

“How did your life change as a result of this illness?”

The interviews were recorded and transcribed into narrative text. By analysing the narrative texts into categories of experience, codes were developed to group similar data together. During further reflection and professional supervision, the data continued to be refined. The development of a thematic map helped in clarifying relationship between the codes, categories and broader themes (Braun & Clarke, 2006). The themes constructed were the researcher's interpretation of the experiences shared by the participants. At all times during this process, attention was given to honouring the narratives of the participants who had entrusted the researcher with their experiences.

The role of professional supervision was critical during the data analysis. This process required immersing myself in the data again and again. Each immersion stripped away another level of “professional veneer” and I found myself responding to the details of the narratives at a personal level. In order to attend to my own wellbeing and maintain an ability to respond to and work with the data, professional supervision was a valuable and necessary aid. There were times when the sorrow of loss and grief that the carers recounted touched the sorrow of loss and grief in my own life. Professional supervision enabled me to acknowledge my own grief, and process different aspects of it. Through engaging in this process and reflecting on what was happening, new insights were revealed, and freedom to attend to the details of the research I was analysing ensued. Thomas and Davis (2005) describe this as strength-based supervision in action, where supervisees bring the fullness of themselves

to supervision and reflect on what they notice about the work they are engaged in.

Results

In this research, all of the family carers were married. Six out of eight carers were in their first marriage when their spouse became unwell. Seven of the carers identified as New Zealand European with the eighth being of both Aotearoa New Zealand Māori and European origin. This carer was not connected to her iwi due to early life experiences. Table 1 gives a brief overview of the bereaved carers and their spouses.

All carers had been bereaved for a minimum of 2 years, with half being bereaved for more than 3 years. Each person spoke of what had occurred with their unwell spouse, noting symptoms leading to diagnosis, through to treatment with surgery, chemotherapy and/or radiotherapy. All but one narrative was in relation to a family member with a cancer diagnosis. These stories traversed travelling to other cities for treatment, the complexities of negotiating family communication and existing work commitments while dealing with the ongoing intricacies of medical care. They were stories of love and devotion, and of courage under fire, illuminated with moments of tenderness, humour, and gut-wrenching pain. They were stories of striving to adapt to a new normal as illness continued its relentless march into the lives of men

and women who were not ready for death's intervention. They were stories of accepting that treatment was no longer being effective, of receiving palliative care, of the death of their spouse, and then somehow finding a way to rebuild their lives. Table 2 provides examples of quotes provided by the family carers to illustrate strengths that underpinned and sustained them throughout the duration of their spouse's illness and death.

When identifying the strengths of family carers, Madsen and Gillespie (2014) recommend consideration of the following three areas:

- i) What activities sustain people in their lives?
- ii) What are the intentions, commitments, values, beliefs, hopes and dreams that underpin people's actions? and
- iii) What community connections maintain and sustain people when that operate from their strengths?

Reflection of these questions led to the identification of the strengths of the carers interviewed. These strengths emerged out of the words of the bereaved carers during the research interviews with a particular focus on the question two above. They are love, hope, family, teamwork and resilience.

Early in the interviews, the *love*, care and attention that carers bestowed upon

Table 1. Brief Overview of Research Participants

Name of family carer (pseudonym)	Age at time of spouse's death	Name of spouse (pseudonym)	Age at time of death	Length of time together	Time from diagnosis to death	Time since bereavement at date of interview Years/ months
Penny	54	Jake	58	33 years married	4 years	3 / 7
Sally	55	Luke	64	14 years married	18 months	3 / 5
Kirsten	57	Caleb	46	12 years married	5 years	3
Grace	58	Josh	62	27 years married	8 years	2
Mark	59	Rose	57	37 years married	2 months	2 / 4
Harry	64	Beth	63	40 years married	15 years	3 / 7
Matt	66	Isla	59	37 years married	3 months	3 / 7
George	71	Ruth	63	40 years married	3 years	5

Table 2. Selected Examples of Family Carers' Strengths

Strengths	Representative Quotations from Research Participants
Love	<p><i>I would never have left Caleb. ... I always said he was the love of my life. (Kirsten)</i></p> <p><i>We really just worked together on this ... I found that quite easy to do. I'm a do anything sort of bloke and we'd worked well for 30 years before that so it was just a matter of carrying on. (Harry)</i></p> <p><i>I never thought about walking away. ... I never contemplated not being with Josh ... you just don't do that and I never even thought about it. You can't take any of the suffering away. You can't take anyone's suffering away. All you can do is walk beside them. (Grace)</i></p>
Hope	<p><i>So, the rollercoaster started and through that period we're still fairly optimistic but we would [...] battle this thing. [...] So, we thought we would get through this and we changed; did lots of things to change the way we lived. We changed our diets and we did exercise and we cut down on alcohol and [...] we were particularly positive right through the initial period and little did I know this would go on for fifteen years. (Harry)</i></p> <p><i>It was always a highlight when he says he feels better and he went to work again. (Kirsten)</i></p> <p><i>We do believe in miracles [...] we believe that God does heal and we were praying for his desire for that sort of outcome. So [...] we had hope that the Lord might heal Isla. But we sort of were aware that God doesn't always heal that that the other possibility is quite on the cards as well. So that's how we looked at it. (Matt)</i></p>
Family	<p><i>It was all like bang! Ringing the boys up; jeez, that was horrible. It was the most horrible thing; [...] most worst thing you can do. (Mark)</i></p> <p><i>[Our older son] decided to come home. [...] He moved back home. That winter things really hit the fan. [Jake] struggled and if I didn't have [our son] to support us at home. So, for us it was trying to get him, to keep him well – having the oxygen, keeping the tablets going. It was really hard and working as well. I worked four days a week and had Fridays off. [...] Then [our son] was home during the day to look after him through the other days, just to try and get through. (Penny)</i></p> <p><i>I think we were all pretty proud of how he died and how we managed that, cos it was really hard work, that turning him and all the stuff you would have happening down here [at the hospice] with people that know what they're doing, instead of having people that don't know what they're doing, doing their best. But ... that's how [Luke] would have liked it. ... He would be really proud of us for giving it a go. ... He got the love. ... The kids wrote ... "with loving incompetence; cared for at home with loving incompetence". ... cos we were incompetent cos we're not experienced, trained. ... It's really serious ... moving people, all that turning ... it's huge, huge. (Sally)</i></p>
Teamwork	<p><i>The Hospice was a great institution for people in my situation, no doubt about that. [...] Like, I think that was the longest night I've ever had [...] trying to regulate the pain. (...) It was just unbearable for me. [...] Trying to get through that night and so when that's taken off your hands, I just remember her being wheeled down the path and thinking, "Thank goodness someone's helping her out cos I'd done all I could do." So that was good. (George)</i></p> <p><i>We had people that would come in if I wanted to go out. There would be people looking in. I have to say another source of support was there was just some really faithful friends of Josh's that visited very regularly. [...] It was nice for me because I think [...] it could be enormously difficult if your ill spouse wasn't getting support from anyone except you. [...] I think it's really important that he was getting to see other people and having them visit and that was enormously positive for him. (Grace)</i></p> <p><i>I had [support] from my mates as many boys can do. They were bloody good; [...] they've all kicked in after which is fantastic. But Rose, all Rose's gymmie friends, there was food being dropped off and there [were] people coming to visit. [...] But everyone was very conscious, it was such an intense thing. [...] Everybody was very respectful. But all her friends were really lovely, really nice through that. [...] But it was so intense. [...] There wasn't time to [...] think about anything but looking after Rose. [...] There was nothing else. (Mark)</i></p>

Strengths	Representative Quotations from Research Participants
Resilience	<p><i>I am happy in my own space. I think probably my best thing is to make sure my children, our children are okay. [...] My ambition is to get [my son] through his studies and then I'm free. Then I can go and do some holidays. (Penny)</i></p> <p><i>I'm flatting for the first time in my life. At age 58 I started flatting when Rose died, and I'm still flatting. And the thing is that you really, it's the first time – the first time in my life that I've never been a son or a husband. I'm a father as first and foremost, that's good. [...] So, I'm just me now. And I'm fine with it. I've found out so much about myself that I'm surprised. I'm really surprised. (Mark)</i></p> <p><i>Good and bad things belong together for all people. If it was always good, we wouldn't even know that it was good. (Kirsten)</i></p>

their unwell spouse during their illness was apparent. The descriptor that came to mind again and again was *steadfast love*, demonstrating their constancy in companioning and supporting their loved one throughout the illness. Swinton (2017, p. 285) reminds us:

It is absolutely crucial to remember that love remains love even if its shape shifts and changes. ... Love is more than a feeling; it is a way of being in the world. Sometimes it is hard, willful, intentional, and deeply disappointing. ... But even if we can recognise the way that our love remains real even if it has to adapt to the rhythm of the disease process, we need not feel guilty when our feelings shift, change, and oscillate. Freed in this way, we might just be able to discover new and hopeful ways to love as the old and tested ways move on.

The companion to love is *hope*. Hope holds the promise of outcomes that will satisfy the desires of those who hold it. In the midst of difficulty, hope emerges as a tendril, seeking a pathway of promise. Hope is fluid, adaptive and responsive to the circumstances people find themselves in. It is not fixed in time. It is rooted in the present, forging links with the past and the future. It has threads that connect and reconnect to leverage an ongoing ability to maintain care and caregiving.

Folkman (2010) held the position that hope is essential for people living with serious

ongoing stress. She recognises hope and coping as mutually dependent upon one another. She argued that, as hope traverses the hills and valleys of human experience, it is not static. Feudtner (2014, p. 556) described hope as hardwired into our being as humans:

In every story of hope, there is longing, and within that longing a sense of pain. ... To be a master of hope, one has to be well acquainted with the fear of darkness that hope helps us to surmount, to be comfortable and capable of confronting this darkness directly.

The *family* is a key component of the wellbeing of couples where ill health permeates their lives. They are the immediate group of people couples turn to for support in times of trouble. For all the couples involved in this research, family members nurtured and sustained the couple throughout the illness. The support of families was essential in maintaining the fullness of personhood for both the unwell person and the carer. The myriad of tasks they could assist with was invaluable to the wellbeing of the couple and assisted their ability to manage the ongoing realities of living with an unwell person.

Families also provided opportunities for celebration, as important milestones rolled around. They were active participants and cheerleaders in the accomplishment of 'bucket list' goals, reveling in the opportunity to be together and to share

memories when the endpoint of their family member was unknown. Time together was precious, consciously chosen as a priority.

That was really important. They were all on the journey. We were all on the journey together. (Sally)

For the adult children of the family, the pull to return home to spend time with their parents was vitally important. This could be more difficult when those adult children lived some distance away. There was tension in balancing responsibilities between the needs of parents, study / employment, international travel (for those who lived overseas), and in some cases, their own relationships and / or families.

Throughout the illness of their spouse, an important feature was *teamwork*. This was made up of family, friends and those they met as a consequence of the illness. Through embracing their team, the load carried by the couple was able to be shared allowing others into this intimate circle. Throughout the illness, both husband and wife came to rely on others for knowledge, information, skills and expertise. They learned to assimilate a vast body of information in order to make health decisions. They learned to effectively communicate with health professionals as well as relay key information to family. They learned to adapt to changing environments and an array of people being introduced into their world.

When you're part of a network of a supportive family and some good friends. If you've all that, you can do anything. (Harry)

Throughout the illness, the couples needed to exhibit *resilience*. They did this abundantly, accommodating, adapting and adjusting their lives each step along the way. The research interviews had a dual benefit: for me, as the researcher to obtain narrative data, and for them as the family carers to recall, remember and review their personal experience of caring for their

much-loved spouse. In doing this, with the benefit of distance between the illness and death of their spouse, as well as giving them time to reflect, they brought a freshness to all they had experienced as a carer involved in a complex, interpersonal health-induced drama.

Recounting their stories and seeing them in a new context contributed to carers having a renewed sense of themselves and their role in caring for their loved one during their illness and death. They reflected on their relationships and abilities, and how the love they had for their spouse underpinned and sustained every action. The love shown throughout that important journey had not gone but had changed in form. Each carer built on the foundation of their married life and moved to create a life without the one they had lived with and loved over many years.

Discussion

For couples, caring for an unwell spouse can be all-consuming. It is love with gumboots on, entering new terrain on a regular basis, committed, loving, laughing, honouring, and trusting one another, knowing that decisions made are for the best interests of each other. It is in the tiny gestures: a look, a smile, a whispered "thank you"; it is in the companionship, the quiet moments, the being present, the knowing and being known. It is choosing to look heartbreak in the eye and continuing on, step by step. It is the work of the soul and spirit, the essence of themselves that drives their desire to care for one another.

The data from this research highlighted the strengths of the family carers, including love, hope, family, teamwork and resilience. These strengths do not detract from the physical, emotional and spiritual labour of caring for a much-loved spouse where worry, fear, despair and heartbreak abound. It is through calling on their internal strengths and marshalling the resources available to them

that the carers are able to continue caring for their spouse during some very trying times. By embracing their strengths this allowed the carers the opportunity for self-growth and transformation and thus giving meaning to the care they provided.

People's strengths in and of themselves do not automatically make themselves known. They are often part of the innate makeup of the person making use of them. However, through engaging in the exploration of a carer's strengths and harnessing those strengths, carers are able to find meaning and purpose in their role. This exploration can break open the opportunity to learn and draw on strategies which may not be innate, thus enhancing the carer's ability to continue supporting their family member.

Exploring caregiver strengths is acknowledged as an emerging field of research (Funk et al., 2010). This work gives recognition to those who thrive in a caregiving environment, who may discover new insights to themselves which were previously unknown and to those who wish to offer an alternate narrative to that which focuses on the negative aspects of family caregiving. The transformational process of working from a strengths perspective enables care that is respectful and takes into account the needs of both the unwell person and their carer (Giesbrecht et al., 2015; Unson et al., 2016).

Within this research none of the participants spoke of access to social work during their spouse's illness. Their narratives were primarily focused on the medical and nursing care they received. A key role of palliative care social workers is to help carers identify and access their support networks. Sometimes it can be an accumulation of small matters that hinder the ability of carers to continue providing support and care in the home or community. If family carers are helped to assess, create, support and maintain themselves, they are more likely to operate from a position of strength.

Social work considers the broad social environment of the unwell person and their carer, and works alongside families to help review what is/is not possible. It acknowledges the values, beliefs and cultural considerations that undergird the couple's relationship, and how these guide and influence the decisions that are made. By empowering the unwell person and their carer to make decisions about the ongoing wellbeing of both parties, the environment in the home is better able to be maintained.

The provision of this access to all members of the interprofessional team to enable this to occur is explicit in the Hospice New Zealand Standards for Palliative Care that say:

Initial and ongoing assessments are comprehensive and person-centred, and incorporate the person's physical, psychological, cultural, social and spiritual experiences, needs, preferences and priorities (Hospice New Zealand, 2019, p. 20)

Conclusion

This research focused on the experiences of those whose spouse died prior to the age of 65. It explored the lives of eight bereaved carers who were intimately involved in the experience of their spouse's illness, health care and death. This occurred within the context of an established network of family and social relationships. Their stories give voice to a cohort of people who are largely invisible within the research literature; stories that continue beyond the death of a spouse. It serves as a reminder that, whilst family carers may willingly embrace their role, they also have needs of their own. When these needs are met, they are empowered to operate out of their strengths when caring for the one they have lived with and loved for many years.

Recognition must be given to how the social environment of the unwell person and their carer contribute to the care equation. By giving attention to the support of both parties, it is possible for carers to be sustained in their

role. This research advocates for strength-based assessments to be embraced as palliative care social workers work to provide holistic care to the unwell person and their carer. A strength-based perspective does not leave the harsh realities of caring for an unwell family member unexplored—rather it seeks to validate the lived experience and skills each carer brings to their role.

The strengths that underpin and sustain carers have been identified as love, hope, family, teamwork, resilience and resourcefulness. Palliative care practitioners must recognise such strengths need to be nurtured and supported so that carers can sustain the emotional, physical and spiritual demands of caring for their unwell spouse.

Disclosures and acknowledgements

This research is a snapshot of the experiences of bereaved carers in a couple relationship. It is a stepping-stone into the emerging research on caregiver strengths. It is difficult to make generalisations beyond the experiences of this group as there are many population groups whose voices are not present in the research. Further research into the strengths of caregivers could focus specifically on the experiences of bereaved carers under 55 years of age, the experiences of Māori carers, the experiences of Pacifica carers, the experiences of carers from migrant (CALD) communities, and the experiences of carers in the rainbow (LBGTI) community. While this research has focused on those in a couple relationship, the voices of sibling carers and/or adult children carers of unwell parents, are other potential areas for inquiry. In essence, research into the strengths of family carers of those living with a terminal illness under 65 years of age is a field open for exploration.

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