

Creating Compassion:
A Grounded Theory Study of Death, Dying, and Bereavement in Primary School
Community Contexts

Submitted by Carla Jane McKerrow Kennedy, M.Ed., Grad. Dip. of Early Literacy
Intervention, B.Ed., B. Arts

A thesis submitted in total fulfilment of the requirements for the degree Doctor of Philosophy.

La Trobe Rural Health School
College of Science, Health and Engineering
La Trobe University
Victoria, Australia

June 2021

TABLE OF CONTENTS

| | |
|--|-----------|
| ABSTRACT | 6 |
| STATEMENT OF AUTHORSHIP | 7 |
| PUBLICATIONS AND AUTHORSHIP | 8 |
| ACKNOWLEDGEMENTS | 9 |
| PRELUDE..... | 10 |
| CHAPTER 1: INTRODUCTION | 11 |
| 1.1 Context of the Study | 11 |
| 1.2 Theoretical Framework..... | 12 |
| 1.3 Problem Statement and Question | 12 |
| 1.4 Aim and Scope of the Study..... | 14 |
| 1.5 Research Design | 14 |
| 1.6 Key Concepts..... | 15 |
| 1.7 Thesis Framework and Structure..... | 16 |
| CHAPTER 2: LITERATURE REVIEW: PERSPECTIVES ON DEATH, DYING, AND BEREAVEMENT AND CONSIDERATIONS FOR SCHOOL COMMUNITIES | 18 |
| 2.1 Theoretical Lenses..... | 18 |
| 2.2 Psychological Theory..... | 18 |
| 2.2.1 Freud..... | 18 |
| 2.2.2 Bowlby | 19 |
| 2.2.3 Stroebe and Schut | 19 |
| 2.2.4 Elisabeth Kubler-Ross..... | 20 |
| 2.2.5 Folkman..... | 20 |
| 2.3 Socio-Cultural Perspectives..... | 21 |
| 2.4 Spirituality Perspectives | 23 |
| 2.5 Death Awareness and Acceptance..... | 24 |
| 2.5.1 Historical and contemporary snapshots of death attitudes | 24 |
| 2.5.2 Exploring fear and anxiety | 25 |
| 2.5.3 Meaning management theory | 26 |
| 2.6 Health Promoting Palliative Care (HPPC)..... | 27 |
| 2.6.1 Considering compassion | 27 |
| 2.6.2 Compassionate cities and empowering communities..... | 29 |
| 2.6.3 Spirituality and storytelling..... | 32 |
| 2.7 School Communities..... | 33 |
| 2.7.1 Death attitudes | 34 |
| 2.7.2 Strategies for changing death attitudes..... | 34 |
| 2.8 Summary | 39 |
| ARTICLE 1: LITERATURE REVIEW ARTICLE: MAKING DEATH, COMPASSION AND PARTNERSHIP 'PART OF LIFE' IN SCHOOL COMMUNITIES | 40 |
| CHAPTER 3: THEORY | 54 |
| 3.1 Social Constructionism..... | 54 |
| 3.1.1 History..... | 54 |
| 3.1.2 Capturing social constructionism | 55 |
| 3.1.3 Language and identity..... | 56 |
| 3.1.4 Social action and power..... | 57 |

| | |
|--|----------------|
| 3.1.5 Socially constructed understandings of power and assumptions in research | 58 |
| 3.1.6 Implications for this study | 58 |
| 3.2 Critical Social Theorists | 60 |
| 3.2.1 Herbert Marcuse..... | 60 |
| 3.2.2 Implications for this study | 61 |
| 3.2.3 Jürgen Habermas..... | 62 |
| 3.2.4 Implications for this study | 64 |
| 3.3 Summary | 65 |
| CHAPTER 4: RESEARCH DESIGN..... | 67 |
| 4.1 Rationale..... | 67 |
| 4.2 Grounded Theory | 67 |
| 4.3 Sampling and Recruitment | 69 |
| 4.4 Data Collection | 70 |
| 4.4.1 Interviewing | 71 |
| 4.5 Analysis | 72 |
| 4.5.1 Coding..... | 72 |
| 4.5.2 Memos and diagramming | 74 |
| 4.6 Theoretical Sampling..... | 75 |
| 4.7 Critical Reflection – Theories, Power and the Researcher..... | 76 |
| 4.7.1 Reflecting-in-action: Schön | 78 |
| 4.7.2 Critical thinking: Brookfield | 79 |
| 4.7.3 Critical reflection: Fook and Gardner | 81 |
| 4.7.4 Implications for this study | 82 |
| 4.8 Measures Promoting Accuracy of Data | 83 |
| 4.9 Summary | 85 |
| ARTICLE 2: METHODOLOGY ARTICLE: RESEARCHING DEATH, DYING AND BEREAVEMENT: TALES OF GROUNDED THEORY, REFLEXIVITY AND COMPASSION..... | 86 |
| CHAPTER 5: FINDINGS | 101 |
| 5.1 Research Design: Specific Information | 101 |
| 5.2 Findings: Shifting Cultural Perspectives and Enacting Strategies..... | 103 |
| 5.3 First Sphere: Challenging Current Cultural Perceptions | 104 |
| 5.3.1 Death as taboo | 105 |
| 5.3.2 Celebratory days..... | 105 |
| 5.4 Second Sphere: Creating a Culture of Support | 107 |
| 5.5 Third Sphere: Creating a Grief Informed Culture..... | 109 |
| 5.5.1 Appealing for grief information | 109 |
| 5.5.2 Information from participants about the school curriculum..... | 110 |
| 5.5.3 Storytelling..... | 111 |
| 5.6 Fourth Sphere: Establishing a Culture of Critical Reflection and Reflexivity | 112 |
| 5.7 Fifth Sphere: Determining a Whole School Plan..... | 114 |
| 5.7.1 Creating a clear communication pathway | 114 |
| 5.7.2 Support for teachers and principals..... | 115 |
| 5.7.3 Considering curriculum and current cultural perceptions | 116 |
| 5.7.4 Considering links between categories | 117 |
| 5.8 Summary | 119 |
| ARTICLE 3: DEATH, DYING AND BEREAVEMENT: CONSIDERING COMPASSION AND EMPOWERMENT | 120 |
| ARTICLE 4: THE ‘INTENTIONAL COMPASSION FRAMEWORK’ FOR SCHOOL COMMUNITIES | 139 |
| CHAPTER 6: RECOMMENDATIONS AND CONCLUSIONS | 151 |
| 6.1 Connecting the Aim with Key Concepts and Understandings | 151 |
| 6.1.1 Lenses..... | 151 |
| 6.1.2 The original aim | 152 |
| 6.1.3 Re-examining power..... | 152 |

| | |
|--|------------|
| 6.1.4 Enacting compassion | 153 |
| 6.2 Significance, Limitations, and Further Research..... | 155 |
| 6.3 Conclusion | 157 |
| APPENDICES | 158 |
| APPENDIX A PROJECT INFORMATION STATEMENT FOR PARENTS, TEACHERS, PRINCIPALS, AND STUDENTS..... | 159 |
| APPENDIX B ETHICS STATEMENT..... | 165 |
| APPENDIX C INITIAL INTERVIEW QUESTIONS..... | 166 |
| APPENDIX D NEW INTERVIEW QUESTIONS..... | 168 |
| APPENDIX E EXAMPLE OF VENN DIAGRAM USED | 169 |
| REFERENCES..... | 170 |

ABSTRACT

As a taboo topic, death cultivates fear and avoidance in rural western education contexts and influences ways of thinking, being, and relating to others who are bereaved in school communities. By using a grounded theory methodology and a social constructionist lens, this study investigated how we can socially and culturally create beneficial and constructive regard for death, dying, and bereavement. This involved an in-depth exploration of students, parents, teachers, and principal's experiences of bereavement through semi-structured interviews.

The participants' insights, knowledge, and advice informed an understanding of how compassion in school communities can be enacted. The overwhelming message from the participants was that positive, proactive, empathetic change was desirable and they were able to identify compassionate ways to achieve this, by serving as an important foundation for social and cultural change. From the findings, a framework for school communities has been developed to guide schools in creating a compassionate culture in light of death, dying, and bereavement.

These findings were examined using a social constructionist, critical, reflexive lens which underscored the need to listen to marginal discourse (participants experiencing bereavement) and unearth assumptions that may have been influenced by existing power structures and dominant discourse in school communities. Policy-based and practical implications for schools, education government departments, and specialist services who have expertise in death, dying, and bereavement are examined. Further research and recommendations are also discussed.

STATEMENT OF AUTHORSHIP

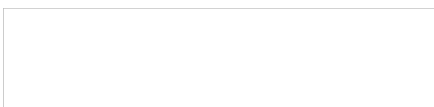
Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

I declare that all research procedures reported in this thesis were approved by the La Trobe University Human Research Ethics Committee in 2017.

The Ethics Committee Approval Number is HEC17-063, and for the Department of Education DET: 2017_003438 and Catholic Education Office CEOM: 0628.

This work was supported by an Australian Government Research Training Program Scholarship.

Carla Kennedy



Date: 25 . 6 . 21

PUBLICATIONS AND AUTHORSHIP

The following table describes the authorship contributions concerning the four published journal articles contained within this thesis. This follows the La Trobe University guidelines.

Publication 1

Kennedy, C. J., Keeffe, M., Gardner, F., & Farrelly, C. (2017). Making death, compassion and partnership 'part of life' in school communities. *Pastoral Care in Education*, 35(2), 111-123. doi:10.1080/02643944.2017.1306873

| | |
|----------------|-----|
| First Author: | 70% |
| Second Author: | 10% |
| Third Author: | 10% |
| Fourth Author: | 10% |

Publication 2

Kennedy, C. J., Gardner, F., & Farrelly, C. (2020). Death, dying and bereavement: considering compassion and empowerment. *Pastoral Care in Education*, 38(2), 138-155. doi:10.1080/02643944.2020.1725905

| | |
|----------------|-----|
| First Author: | 70% |
| Second Author: | 20% |
| Third Author: | 10% |

Publication 3

Kennedy, C. J., & Gardner, F. (2021). Researching death, dying and bereavement: tales of grounded theory, reflexivity and compassion. *Qualitative Research*. doi:10.1177/14687941211000560

| | |
|----------------|-----|
| First Author: | 70% |
| Second Author: | 30% |

Publication 4

Kennedy, C. J., Gardner, F., & Southall, A. (2021). The Intentional Compassion Framework for school communities. *Health Education Journal*, 1-12. doi:10.1177/00178969211006746

| | |
|----------------|-----|
| First Author: | 70% |
| Second Author: | 15% |
| Third Author: | 15% |

ACKNOWLEDGEMENTS

I extend sincere thanks to my supervisors Fiona Gardner, Anne Southall, Cathleen Farrelly, and Mary Keefe who brought a wealth of experience, intellectual rigour, and creative thought to the table. A special thanks to you Fiona for your thoughtful, considered approach from the first to the last chapter.

I wish to acknowledge my friends and family who kept asking about the work, celebrated when works were published, and wanted to discuss the ideas and thoughts of the thesis. Thank you to the participants of the study who entrusted their time and energy to the process and provided much-needed wisdom and advice.

I dedicate this work to my husband Michael Kennedy (1966–2013) whose love, integrity, and wisdom has and will always sustain me and to my daughter, Ailish Jane Kennedy, who brings thoughtfulness, creativity, and joy to our days.

PRELUDE

From Atticus to his daughter Scout

'First of all', he said, if you can learn a simple trick, Scout, you'll get along a lot better with all kinds of folks. You never really understand a person until you consider things from his point of view –

'Sir'?

'- until you climb into his skin and walk around in it'.

(Lee, 1960, p. 35)

Come and Go

... the rhythm of our breathing

Is soul in motion

On an ocean

A drift on endless tide

We listen 'til we lift

Breathe until we drift away ...

(Kennedy, 2006)

1.1 Context of the Study

After completing a Master of Education degree, I began a Doctorate of Education in 2010, pursuing my professional interest in literacy education as a culmination of 15 years of literacy coordination, reading recovery, and classroom teaching in primary schools. Personally, other life events were afoot. My daughter was born and she had only been on the planet for 18 months when my husband died in 2013. This was expected due to chronic illness. A week after my husband's funeral, my father was diagnosed with terminal oesophageal cancer and died 6 months later. My godfather (my father's brother) was buried next to him a month later with lung cancer and my grandfather died of a heart attack before Christmas 2014 was upon us. This is not extraordinary in the world. People lose family members all the time. There are accidents, pandemics, famine, natural disasters, and wars. In my white western world, it was just bad timing.

Considering the overwhelming experience in my family over that period, my Doctorate of Literacy Education was put on hold and slowly paled into insignificance. Instead, I read everything available to me about grief, bereavement, death, and the afterlife. My own newly adopted status as a single white female and mother with a middle class catholic upbringing influenced my perspective but stirred strikingly new questions within me as I observed the reactions of friends, family, and strangers toward me and my daughter as we navigated the painful and strange road of loss and grief. As a white person, who already had an established career and a Masters degree I had access to resources and information that those from other backgrounds might not have. I was aware that as a newly widowed woman I felt marginalised as my power and influence had been lost. Simply, many people in my school and community did not know what to say or do in the short or long term. There was sometimes obvious, sometimes subtle avoidance whether in physical approach or conversation. How to be compassionate in these circumstances seemed a puzzle for many people but for others who had been there before, it came as naturally as breathing.

Also, largely unvoiced from a community perspective, were the positive, enlightening elements of death, dying, and bereavement and the meaning from these experiences. The meaning created from my personal experience continued to elude me until I left the Doctorate behind and began this PhD thesis. Participating in the intellectual rigour, and writing and sharing stories about death, dying, and bereavement continues to imbue my life with meaning. The gift of 'living with death in mind' continues to empower me, and no doubt others, to live with purpose and motivation.

As a teacher, I know how important it is to be a part of a school community where compassion is visible, particularly in times of grief and loss. It reminds me that I am humbly, only human. As a

researcher, I know how vital it is to hear and give value to the authentic voices of community members, for whom death, dying, and bereavement is present. Death can be overwhelming and communicating one's needs may not be easy. In order to normalise death, dying, and bereavement within a community context, it is essential to understand how to create compassionate school communities. It is a privilege to be in the position of finding a way through the crisis and transformation of death, dying, and bereavement — a journey that will ultimately affect us all.

1.2 Theoretical Framework

Part of finding a way was naming the theoretical framework that helped change perceptions of death and dying. Therefore, my chosen ontological position for this study is critical theory and epistemological position, social constructionism. First, critical social theory 'identifies the interrelationships between cultural and social values and expectations and how these are internalized by individuals, often in unhelpful ways as well as emphasizing the value of a social justice approach' (Gardner, 2014, p. 36). This enabled me as a researcher to investigate internalised school community assumptions about death, dying, and bereavement that has led to avoiding or being fearful of these topics and the absence of death, dying, and bereavement learning in the curriculum. From a social justice approach, schools currently respond to experiences of death, dying, and bereavement in ways that marginalise particular perspectives. As a framework, critical social theory encourages investigation of the passive voices existing in school communities and the unearthing of dominant discourses within the school power structure to 'bring truth and political engagement into alignment' (Payne, 1997, p. 118).

A social constructionist critical perspective also enables the examination of social practices (Burr, 2003, p. 13) that are promoted by particular ways of perceiving death, dying, and bereavement. This is a sociological rather than psychological lens, allowing challenge and inquiry of the dominant discourse to take place with the recommendation of alternatives.

Specifically, I argue that theories of social constructionism reveal how particular ways of thinking and behaving are constructed through context, language, and identity. Marcuse (1964, 1970) provides a lens to view inequities, similar to Habermas (1988; 1996) who attends to the uncovering of the dominant culture, power relations, and related discourses. Both social justice and empowerment concepts bind these critical social theorists together which prioritise the inclusion and representation of repressed or marginalised discourses.

1.3 Problem Statement and Question

The problem stems from changing attitudes to death and dying and is demonstrated in the changing attitudes to palliative care. Reflecting on the Middle Ages as an example, death was an intrinsic part of community village life, along with shared religious values that provided support and comfort to the bereaved. People with chronic conditions or those who were dying were generally cared for at home. With modernity and the advent of scientific thinking came the expectation of medical care. Eventually, it led to a hospital or hospice either curing or caring for people until they died. Death became more removed from life and from being part of the inevitable cycle of living and dying. Even in more recent times, attitudes to palliative care have changed. In the 1960s, palliative care was conducted under the more social grassroots, the 'modern hospice movement', where death, dying, and bereavement were more community owned often by religious orders. For example, Cicely Saunders, regarded as the founder of contemporary adult palliative medicine trained at St Joseph's Hospice in Hackney London before continuing to establish St Christopher's Hospice in 1967 (Hain, Heckford, & McCulloch, 2012). However, by the end of the 1990s, it was known as 'palliative care' and had been reintegrated into the mainstream health care system (Rosenberg & Yates, 2010, p. 202). This is a significant example of a more general issue — an overall medicalised morphing of death, dying, and bereavement issues, where community ownership of these very normal life events has largely disappeared. This has profoundly altered and influenced our societal attitudes about death and dying (Rosenberg, Horsfall, Leonard, & Noonan, 2015). As a response and from a health promotion perspective, Kellehear (2016, p. 37) highlights the need to work 'with' communities rather than working 'on' communities by eroding ignorance and fear. The practical implementation and reorientation of Health Promoting Palliative Care Principles (HPPC) in communities is still in its infancy today.

A call to action modelled after the World Health Organizations 1986 Ottawa Charter asserts the need for public health services to form partnerships with communities and in the process '... affirm and enhance community beliefs and practices that make death a part of life' (Becker et al., 2014, pp. 401-402). Potentially, this would bring about extensive and necessary change at local, societal, and global levels (Becker et al., 2014). This then reflects how schools and school communities engage with death, dying, and bereavement and connects to my interest and experience in school communities as a primary school teacher.

Acknowledging the current societal attitudes, the disempowered state of communities to deal with these issues, and the call to action, the critical question became 'how can we create compassionate school communities in light of death, dying, and bereavement?' and prompted further investigation. It is essential to understand how we can socially and culturally enable constructive and inclusive regard for death, dying, and bereavement in school communities, which will allow community

members to discuss these difficult issues. A change of thinking and behaviour is required, where strategies, such as storytelling that ensure the meaning is prioritised, are embedded in the practicalities of school life. Curriculum changes could encourage difficult discussions and normalise the emotions of grief and bereavement, moving one step closer to 'making death ... a part of life' in school communities.

1.4 Aim and Scope of the Study

In order to address my overarching question 'how can we create compassionate schools?' this study aims to explore how we can create compassionate schools that engage constructively with issues of death, dying, and bereavement. This enabled members of school communities to articulate their current and preferred assumptions of death, dying, and bereavement and to suggest strategies based on these understandings to empower their community. Specifically, the exploratory questions of 'what is it like to be a bereaved person in a school community setting' and 'In your school community, what was helpful or unhelpful?' encouraged insights from bereaved persons' perspectives. This provided answers for the non-bereaved members of school communities and in turn, suggested how compassion can be created within school communities.

There are also limitations to this study. These include the limitations of time, number of participants, amount of access to participants, and geographic location. This study has been conducted over 2.5 years in a part-time capacity and 2.5 years in a full-time capacity involving eight primary schools in various townships of central Victoria, Australia. The participants involved in this study included two primary school students, nine parents (among whom, seven were health professionals), three teachers who were also parents in primary schools, and two principals who had been parents and teachers in the past. The schools were all in rural communities.

1.5 Research Design

I chose a qualitative research design that emphasises and focuses on a socially constructed view of reality, where individual experiences and values are explored. Specifically, a qualitative design allows for the examination of beliefs, values, and attitudes of people who have experienced bereavement with an exploration of their interactions within their school community.

A grounded theory methodology provided the opportunity to not only describe the phenomenon of what it is like to be a bereaved person in a school community but also to examine how school communities are helpful or unhelpful when it comes to death, dying, and bereavement experiences. Essentially, the grounded theory focuses on process and specifically on relationship and social structure. As Charmaz (2008b, p. 204) states, 'we can use the processual emphasis in grounded

theory to analyze relationships between human agency and social structure that pose theoretical and practical concerns in social justice studies'. This also allows for the foregrounding of bereaved voices as positioned at the margins in schools, where silence about experiences of death, dying, and bereavement are the norm.

The use of critical reflection as a way of understanding and engaging with emotions, thoughts, and meaning derived from experiences influenced by social context (Gardner, 2014, p. 34) and reflexivity as who we influence, how we understand others, and how we are understood by them (Gardner, 2014, pp. 35-36) formed an essential part of this study, particularly in light of my personal experiences of death, dying, and bereavement. Reflexivity acknowledges the personal and political values that inform the research and the need to explore how the researcher's own history and biography may have influenced or created the research. Charmaz (2008a, p. 403) also considers reflexivity as central to the grounded theory as it enables grounded theorists by definition to prioritise 'improvising their methods and analytic strategies'. What Charmaz (2008a) means is that researchers can take a more nuanced and responsive stance if they can recognise their own influences when working with the research. As a result, analysis is carefully considered from several perspectives, both researcher and participants, and continually calls for scrutiny of assumptions and the research approach.

1.6 Key Concepts

Compassion is a 'virtuous response that seeks to address the suffering and needs of a person through relational understanding and action' (Sinclair et al., 2018, p. 195). In relation to community, compassion means 'hooking the interests of others to our own personal goods' arguing against modern moral theories that denote compassion as 'irrational in human affairs' asserting that 'compassion is above all a certain sort of thought about the well-being of others' (Nussbaum, 1996, p. 28).

Compassionate communities are derived from an earlier set of public health ideas that introduced the concept of 'Healthy Cities' or 'Healthy Communities' and has 'practice roots' in health education (Kellehear, 2013, p. 1072). Compassionate cities/communities is a term encapsulating compassion as an imperative and health as being positively framed even in the presence of loss (Kellehear, 2012). This encapsulates compassion as a holistic idea and implies a concern with the universality of loss. These concepts translate into characteristics such as local health policies recognising compassion as essential and ensuring the offer of a wide variety of supportive experiences, contacts, and communication. These meet the needs of people living with a life-threatening illness and the bereaved (Kellehear, 2012, p. 44).

Health Promoting Palliative Care is a social-based model that is grounded in the promotion of health, employing a palliative care philosophy to inform its mission, values, and strategic direction (Rosenberg, 2011). Essentially, this brings health promotion principles to palliative care and promotes good social, psychological, and spiritual health for carers, people who are dying, and the bereaved.

1.7 Thesis Framework and Structure

The format of this thesis follows a structure that incorporates both chapters and published journal articles. I have begun with this Introduction Chapter that has explicated the context, purpose, direction, and significance of the study. In Chapter 2, the Literature Review using a narrative review methodology (described at the end of this chapter) situates the study in the current literature: how death, dying, and bereavement are conceptualised; the influence of death awareness and attitudes; how compassion is understood and the influence of health-promoting palliative care initiatives and the resulting implications for school communities. Chapter 2 is followed by a published literature review article called 'Making death, compassion and partnership part of life in school communities' (Kennedy, Keeffe, Gardner, & Farrelly, 2017, pp. 138-155).

The Theory in Chapter 3 describes the critical social theories that underpin the implications of this study. In Chapter 4, the Research Design includes the philosophical foundation of the thesis, a discussion and rationale of the research design, particularly grounded theory as the methodology, and an overview of the context and participants and a description of how data was collected and analysed. Critical reflection and reflexivity are also examined. Chapter 4 is followed and accompanied by a published article entitled 'Researching death, dying and bereavement: tales of grounded theory, reflexivity and compassion' (Kennedy & Gardner, 2021, pp. 1-15). This article particularly focuses on the challenge of researching an area that has a personal resonance.

The findings and discussion are then presented in the following manner. First, the Findings are provided in Chapter 5 and this is followed by a published discussion article on the key findings and implications for school communities: 'Death, dying and bereavement: Compassion and empowerment' (Kennedy, Gardner, & Farrelly, 2020). Second, a published article that incorporates the findings and offers a practical approach for schools to follow in the form of a framework is provided. This article is called 'The Intentional compassionate framework for school communities' (Kennedy, Gardner, & Southall, 2021).

Finally, Chapter 6 describes the Recommendations and Conclusions of the study and includes the strengths, limitations, and suggested recommendations for future research.

I will use an active voice instead of writing in the third person throughout the thesis. This explicitly acknowledges my participation and construction of the final formation of the thesis as well as reflecting the subjective nature of this research. This fits with the use of critical social theory, using the lens of social constructionism and the methodology of grounded theory. This openly acknowledges my role in making meaning of and authoring participants' stories and experiences. The following chapter examines literature concerning death, dying, and bereavement conceptualisations, influences, and understandings. This review of the literature was undertaken using a narrative review methodology which Horsley (2019, p. 55) defines as '... an umbrella term for a scholarly summary along with interpretation and critique', this is where selective searching of archive records is expected to support commentary.

CHAPTER 2: LITERATURE REVIEW: PERSPECTIVES ON DEATH, DYING, AND BEREAVEMENT AND CONSIDERATIONS FOR SCHOOL COMMUNITIES

2.1 Theoretical Lenses

The nature of death, dying, and bereavement continues to be shaped by psychological and socio-cultural frameworks. In order to understand conflicting and complementary ideas and variations in perspectives, it is essential to examine the theoretical lenses and their implicit assumptions that are used to conceptualise death, dying, and bereavement.

I will first focus on how death, dying, and particularly bereavement is conceptualised in the broader field, including the influence of key theorists. Second, from a psychosocial and social perspective, I will explore the literature examining how the concept of death influences attitudes and behaviour. Third, research that discusses death and bereavement from a social constructionist perspective with a particular emphasis on 'health promoting palliative care' research, a compassionate approach and critical reflection, will be critically examined. Finally, social constructionist research on death, dying, and bereavement in the primary school community setting will be examined and how death awareness and health promoting palliative care are influential in the primary school community setting will be explored.

2.2 Psychological Theory

2.2.1 Freud

A historical snapshot of various theorists' concepts of grief and bereavement illuminate the diversification of perspectives from a variety of disciplinary backgrounds. Currently, there is more than one theoretical paradigm in bereavement and grief research. Bonanno (2001) explains that over the past half century, the theoretical perspective of working through memories, emotions, and thoughts with the purpose of relinquishing attachment to the deceased has dominated.

This viewpoint has been significantly influenced by Freud's seminal work '*Mourning and Melancholia*' which illustrates his early concept of grief being 'work' (Freud et al., 1900). By definition, Freud refers to mourning as a reaction to the 'loss of a loved person or the loss of an abstraction (Freud et al., 1900, p. 243) noting the similarities between mourning and melancholia, stating that profound mourning is painful and also involves loss of interest in the outside world and a disregard of activity that is not connected with the thoughts of the lost person. Further, Freud et al. (1900, p. 244) explains that 'reality testing has shown that the loved object no longer exists, and it proceeds to demand that all libido shall be withdrawn from its attachments to that object'. In

Freud's view, the process of grief work is carried out over time and involves working through every single memory — 'when the work of mourning is completed the ego becomes free and uninhibited again' (Freud et al., 1900, p. 245).

2.2.2 Bowlby

Bowlby's (1958, 1959) widely acknowledged attachment theory continues to be influential in the study of grief and bereavement. Attachment theory was derived from his studies of children who were taken away from their mother and placed with unfamiliar people. While Freud's definition of mourning was used by other clinicians, Bowlby (1998) was not prepared to define and limit the usage of the word and the overall concept of mourning. Bowlby (1998, p. 17) defined mourning as a 'fairly wide array of psychological processes set in train by the loss of a loved person irrespective of their outcome'. Bowlby (1998) used a psychoanalytic framework but found the forging of new links with cognitive psychology beneficial. This new paradigm illuminated a way of conceptualising one's propensity to make strong bonds with others and explained the various forms of emotional distress that may arise such as anxiety, anger, and depression upon unwilling separation and loss (Bowlby, 1998, p. 39). Bowlby (1998) states that mourning is impressive due to the number and variety of response systems that are engaged in its process and that these processes are sometimes in conflict with one another. This may be characterised by the desire of the bereaved to reunite with their loved one and also anger at their departure or there may be a cry for help and also a rejection of those who offer help (Bowlby, 1998). Mourning is further explained through Bowlby's four phases and can be also viewed as a 'working through' process; the initial phase may last hours to a week where extreme distress or anger may be displayed; a phase of yearning or searching then ensues for few months and sometimes years; a phase of disorganisation and despair is also identified; and finally, a phase of reorganisation (Bowlby, 1998, p. 85).

Stroebe (2002, p. 127) claims that Bowlby's attachment theory, 'rescued the bereavement research field from the limitations of psychoanalysis and the dominance of Freud ...' and credits this theory as the most powerful theoretical force in contemporary bereavement research (with cognitive stress theory and social reconstructionism closing the gap in recent years).

2.2.3 Stroebe and Schut

Stroebe and Schut (1999) developed an extremely comprehensive 'Dual Process Model of Coping with Bereavement' that was born out of a motivation to clarify and understand the differences between adaptive and maladaptive coping in bereavement (Stroebe, 2002, p. 134). Specifically, the model identifies two types of stressors 'loss' and 'restoration oriented' with an integral coping

process of oscillation which sets the model apart from other formulations (Schut, 1999, p. 220). Oscillation describes the dynamic process 'whereby an individual at times confronts and at other times avoids the different tasks of grieving', explaining that there is a need for the individual to take respite from the grieving (Schut, 1999, p. 197). Further to this, they view the essence of adaptive grieving as confronting the reality of the loss where the cognitive process of doing so need not be persistent or not at the expense of attending to other tasks (Schut, 1999). Schut (1999) explains that this sits in contrast with psychoanalytic formulation, which focuses on the damaging effects of denial. Provided the denial is not extreme or persistent, Schut's (1999) model encourages this back and forth process of attending positing that grieving unremittingly may result in severe costs to mental and physical wellbeing.

2.2.4 Elisabeth Kubler-Ross

Elisabeth Kubler-Ross's work resonates with Bowlby's four phases in her widely acclaimed 'Five Stages of Grief': denial, anger, bargaining, depression, and acceptance, generally perceived as a linear sequence of grieving. In her last book, she asserts that the stages, now embedded in community understandings of grief, have been misunderstood over the past three decades. She explains that the five stages are 'tools to help us frame and identify what we may be feeling' and do not exist on a 'linear timeline' (Kübler-Ross & Kessler, 2014, p. 7). Kübler-Ross and Kessler (2014) also emphasise that grief is individual and that there is no typical response to loss. They recognise that the intensity of significant loss is beyond our range of human emotions and also perceive the gift and power in grief and its capacity to heal (Kübler-Ross & Kessler, 2014). The reality is that you will grieve forever. You will not 'get over' the loss of your loved one; you will learn to live with it. You will heal, and you will rebuild yourself around the loss you have suffered (Kübler-Ross & Kessler, 2014, p. 230).

2.2.5 Folkman

According to Genevra, Marshall, Miller, and Center for the Advancement of Health (2004, p. 500), Folkman's (1997) research into cognitive stress theory has influenced research in the role of positive emotions in response to bereavement. Folkman (1997, p. 1207) conducted a longitudinal study of the caregiving partners of men with AIDS and identified the co-occurrence of positive and negative psychological states in the midst of 'profoundly stressful circumstances'. Four types of positive psychological coping states were identified: 'searching for and finding positive meaning; positive re appraisal; problem-focused coping and spiritual beliefs and practices; and infusing ordinary events with positive meaning' (Folkman, 1997, p. 1215). This study highlighted the need to know more

about these positive psychological states in the context of extreme duress in order to understand how people cope with exceptionally difficult times. The importance of finding meaning as a way of coping was emphasised. Interestingly, Folkman (2001) identified that in experiencing a positive psychological state meant that there was 'time out' from the distress of intense emotions. This 'time out' concept is comparable to Stroebe's dynamic process of oscillation where an individual needs to take respite from grieving.

2.3 Socio-Cultural Perspectives

The shift away from interior psychological processes to one that is socially constructed is also evidenced in a social constructionist perspective of mourning. This is in contrast to dominant western conceptions that are more intrapsychic and is enacted in bereaved people seeking meaning from not only a personal position but one involving family and the larger community and cultural spheres (Neimeyer, Klass, & Dennis, 2014). Rosenblatt and Bowman (2013) explain that grief is not a discrete object but discuss its characteristics as being vague, changeable, and diverse from one individual to another. This variability of grief is unique and can depend on particular cultural, historical, and educational backgrounds; therefore, fitting someone's grief into a single model lessens our understanding of the complexity of their grief (Rosenblatt & Bowman, 2013).

From a socio functional perspective of bereavement, Bonanno (2001) challenges the traditional perspective of grief and bereavement as being a process of working through one's memories, thoughts, and emotions. Similar to Folkman's (1997) study highlighting the need to know more about positive psychological states, Bonanno (2001) indicates that there is a general lack of attention to positive emotions in bereavement and if intense negative emotions are experienced and expressed, this will affect the functioning and result in a more severe grief outcome. His research of middle aged recently bereaved individuals and the monitoring of their facial expressions upon describing their lost relationship, at the 6-month mark, showed that sadness and anger were the most common emotions. These were then positively correlated with increased grief ratings at 14 months post loss. Anger was further correlated at the 25-month mark in bereavement. The findings indicate that by lessening the expression of negative emotion in the early months of bereavement, a more successful recovery may then be cultivated (Bonanno, 2001). Bonanno (2001, p. 504) states that the compelling evidence indicates '... That grieving is not solely a negative or distressing experience' and essentially challenges the traditional assumption that positive emotion is insignificant during bereavement.

Bonanno, Papa, and O'Neill (2001) also argue that in bereavement, humans are more resilient than previously thought and do not need professional support to cope with the loss. Bonanno et al.

(2001, p. 193) state that historically, bereavement research has leant towards pathologising what could be considered a normal reaction to loss, and as a result characterise resilience as 'the ability to maintain identity continuity in social identity'. Continued bonds with the deceased and social embeddedness are some of the ways that illustrate this continuity. Further to this, Bonanno et al. (2001) refer to three different non-Western cultures, Japanese, Mexican, and Indian cultures that openly continue bonds with the deceased on a community platform. Bonds with the deceased are facilitated by celebrations, gatherings of family and friends on anniversaries, and special days such as All Saints and All Souls Day in Mexico. This continued relationship is not only a focus on an individual's grief but is an appeal to the community to provide a supportive network for the bereaved (Bonanno et al., 2001). Similarly, Neimeyer et al. (2014) view mourning as an interpretive and communicative activity that focuses on obtaining meaning from the life that was lived, the death that has occurred, and the subsequent change of status of the bereaved in the larger context of the community. Essentially, the survivors 'self-narrative' has been challenged (Neimeyer, 2014, p. 126).

Neimeyer et al. (2014) dismiss the idea that grief is solely a cognitive process and describe making meaning as an interactive meaning making process not an individual psychological phenomenon. Specifically, they argue that the meaning of mourning is found, given voice, is both socially supported and contested, and that it may come in the simple living of our daily lives through our social and spiritual identities in the form of eulogies, elegies, memorial sites on the web, and grief accounts in popular self-help writing (Neimeyer et al., 2014). The implication is that the story of the death itself and our changed relationship to the deceased are shared socially and either adhere to or disobey varying communal rules. Bonanno et al. (2001) idea that there is an appeal to the community to provide a supportive network is questioned by Neimeyer et al. (2014, p. 493) who contest that individuals grieve and continue their bond with the deceased under the 'watchful eyes' of their family, community, and those who exert political and religious control. They claim that society monitors how grief emotions are expressed and how on-going bonds with the dead are managed.

According to Neimeyer et al. (2014, p. 496) then, grieving is an activity that strives to find significance in the death, re-establish a self-narrative, negotiate a 'shared transition' with others, renegotiate and typically preserve a continuing bond with the deceased, retain support in these efforts on a public platform both in oral and/or written traditions and 'conform to or actively resist the dominant cultural narratives' that inform others how to grieve within the dominant social order. They invite us to extend and critique this approach. Similarly, Rosenblatt and Bowman (2013, p. 85) argue for 'critical insecurity' about what it is that people think they know about grief and it's

conceptualisations saying 'that we should be suspicious of what we have been reading, teaching and writing that makes grief seem simple'.

2.4 Spirituality Perspectives

From a social constructionist perspective, the dynamic field of spirituality and its influence on individuals, communities and healthcare is important in conceptualising death, dying, and bereavement. Swinton (2012) acknowledges that spirituality is both structurally measurable and ideographic in its nature referring to a wide range of scientific studies that show the benefits of spirituality (measurable), such as extended life expectancy, lower blood pressure, and increased success in heart transplants. He states that this spirituality refers to the 'concrete elements of religious practice' such as a healthy lifestyle and belonging to a community (Swinton, 2012, p. 100). However, the ideographic nature of spirituality encompasses elements that are not generalisable or replicable, such as love, hope, and meaning. For instance, a person's experience of illness is solely their own experience, being unique in terms of personal meaning and care. 'Spirituality is perceived as a subjective experience that exists both within and outside traditional religious systems' and includes the desire to discover answers to the fundamental questions about the meaning of life, illness, and death, and incorporating elements such as transcendence and a higher power (Swinton, 2012, p. 102).

In terms of individual expression, Burke and Neimeyer (2012, pp. 129-130) make the specific link between loss, spirituality, and health in their term 'spiritual meaning-making' as an inherent aspect of coping after loss. Burke and Neimeyer (2012) refer to studies that show the distress after loss and the subsequent physical health problems that ensue. They suggest that most people are able to accommodate the loss into their lives within a few years but some people struggle with ill health or complicated grief that may last many months, years, or decades. Burke and Neimeyer (2012, p. 129) explain that spiritual meaning making after loss does not come easily but Coleman and Niemeyer's longitudinal study of widows and widowers found that

... those spouses who reported being able to make meaning or sense of the loss - often in spiritual terms - enjoyed an enhanced sense of wellbeing characterized by optimism and a sense of accomplishment over this same period.

Also, Burke and Neimeyer (2012, p. 131) suggest that 'Religious/belief practices can reduce distress in spiritually inclined individuals, and facilitate good decision making, healthy living and altruistic behaviours'.

In terms of community expressions of religion and spirituality, Gardner (2012) states that in Western cultures, religious participation is declining whilst there is an emergence in exploring spirituality.

Gardner (2012, p. 377) notes that new appointments for teaching spirituality are being made and that spiritual direction and support is being provided through spiritual centres ‘... which are emerging to link local congregations with their neighbourhoods and other similar centres nationally and internationally’. Emerging online communities continue to reflect spiritual and religious expression connecting people and providing a sense of meaning in their lives (Gardner, 2012). Swinton (2012) explains that in a health care context, a shared meaning and a common language of spirituality is necessary to enhance our knowledge and practice. Similarly, Gardner (2012, p. 379) states that ‘looking for evidence of spiritual and religious practices requires clarity about the breadth of what is meant by spirituality and an ability to ask about this in a variety of ways’. Also, in relation to healthcare, Burke and Neimeyer (2012) suggest that health care professionals would do well to attend to individual’s spiritual processes, particularly in regard to serious illness or bereavement as this may involve a spiritual crisis. They stipulate that ideally ‘the spiritual nature of the human experience will be given the high priority it deserves’ (Burke & Neimeyer, 2012, p. 131). From a different perspective, Rumbold (2012b, p. 182) acknowledges the limitations of healthcare practice and advises that spiritual care should take place within ‘genuine human encounters’ and cannot be delivered ‘simply as a professional service’. It is with genuine human encounters in mind that death awareness and death acceptance literature are investigated.

2.5 Death Awareness and Acceptance

Next, literature concerning death attitudes, with a particular emphasis on how death awareness and death acceptance influence motivations and behaviour, are examined. This is in order to explore how bereavement/grief care or education may be influenced by concepts of death. In order to do this, a brief historical snapshot is necessary.

2.5.1 Historical and contemporary snapshots of death attitudes

I acknowledge the seminal work of Herman Feifel who was ‘the first psychologist to conduct an empirical study of the death attitudes of older persons’ (Neimeyer, Wittkowski, & Moser, 2004, pp. 311-312).

Death is one of the essential realities of life. Despite this, camouflage and unhealthy avoidance of its inexorableness permeate a good deal of thinking and action in Western culture. (Feifel, 1959, p. 115)

[Further] ... Attitudes toward death can provide us with additional clues in understanding the behaviour of an individual. (Feifel, 1959, p. 128)

There is an increasing volume of work evident in the 1960s and then a following significant amount of death attitudes research in the 1970s. This expansion continued in the 1980s from its origins in North America to increased contributions from researchers in the Middle East, Europe, and Asia (Neimeyer et al., 2004). According to Neimeyer et al. (2004), this correlates with the first widely available instruments that were designed for the assessment of death fear (Collett & Lester, 1969), threat (Krieger, Epting, & Leitner, 1975), and anxiety (Templer, 1970), and a gradual improvement in scientific quality, a validation of assessment tools for measuring of the literature, and the expansion of leading international journals ensued.

2.5.2 Exploring fear and anxiety

In terms of patterns of socialisation, Depaola, Griffin, Young, and Neimeyer (2003) examined the correlation between death anxiety, attitudes toward older adults, and personal anxiety towards one's own aging. Fear of the unknown was specifically highlighted in their review and distinctive anxieties were found in particular subgroups.

Specifically, Depaola et al. (2003, pp. 348-349) in using 'Multidimensional Fear of Death Scale' (MFODS – Fear of the Unknown, Fear of Conscious Death, and Fear of the Body after Death) found that older women scored higher than men. Elderly Caucasian participants had higher levels of death anxiety on the MFODS Fear of the Dying Process subscale when compared with older African American participants, whereas the African American participants had more fear of the unknown, fear of the body after death, and fear of consciousness when dead. In comparison to white participants, they also held more negative attitudes toward other older adults. It is possible that attitudes to older peers may be explained by older people serving as 'visual reminders of an unsettling mortality', representing a closer proximity to death and as a result provoking personal anxieties in regard to aging (Depaola et al., 2003, p. 350). This research emphasises differences between cultural attitudes about death and according to Depaola et al. (2003), this highlights the need for more research in attitudes toward death, specifically in relation to differences in age. With a different emphasis, Neimeyer, Currier, Coleman, Tomer, and Samuel (2011) focus on death attitudes of people and psychological wellbeing of 153 hospice patients. Neimeyer et al. (2011) assert the need to know more about how spiritual, psychological, and social factors shape our attitudes toward life, death, and anticipatory loss, particularly in regard to the increasing research in an End of Life (EOL) context. The results indicated that participants with an 'internalized religious worldview' reported greater 'death acceptance' and less emotional suffering (Neimeyer et al., 2011, p. 792).

Regarding gender and ethnicity, men reported greater death anxiety and avoidance when compared to women. African-American patients indicated more death avoidance than Caucasian participants, internalised religiosity, correlated with death attitudes, reported levels of emotional health, and participants reporting greater concern about the future grappled more with their confrontation of death (Neimeyer et al., 2011). Depaola et al.'s (2003) identification of the need for more research regarding death attitudes, age, race, and gender is supported by Neimeyer et al. (2011) empirical research which provides inconsistent results. However, Neimeyer et al. (2011) suggest that psychosocial or spiritual care providers would be well placed to support the needs of patients, elicit relevant regrets, and identify patient concerns that complicate the goal of a self-determined life in a hospice setting to help the bereaved integrate the death into their own life story in an affirming manner.

An extensive literature review identifies that there is a dearth of empirical literature evaluating death attitudes of children (Neimeyer et al., 2004) which may relate to ethical and practical issues in questioning children. There may be a case for abandoning standardised questions and using drawings of death concepts instead. This non-questionnaire method could be used with children. The phenomenographic method of drawing death concepts has been used by Tamm and Grandqvist (1995) and Yang and Chen (2002) who have also proved it to be beneficial cross-culturally (Neimeyer et al., 2004).

2.5.3 Meaning management theory

From a positive psychology position, Wong (2013) examines death attitudes by focusing on Kubler-Ross's fifth stage of death called 'death acceptance' describing it as 'facing and accepting the reality of death' and uses this as a springboard into the meaning based processes inherent in accepting death (Wong & Tomer, 2011, p. 101). They draw upon recent world events and a 24-hour news coverage to suggest that people are always conscious of the inevitability of death. This can provide an opportunity to remove the taboo of talking about death in psychology and education, and they propose that it is 'high time' for psychologists to focus on death acceptance and for all of us to talk about death in a way that it is liberating and as a result learn to treat each other with increased respect and compassion.

Essentially, Wong's (2013) Meaning-Management Theory (MMT) is situated in existential-humanistic theory and constructivist perspectives like Neimeyer et al. (2014) and also encompasses cognitive-behavioural processes. This is where positively oriented individuals are willing to face the crisis and 'create opportunities for growth', take on difficult tasks, be predominantly determined to achieve their life's mission whatever the risks, where 'the sting of death is swallowed up by our engagement

in a meaningful life' (Wong & Tomer, 2011, p. 103). Essentially, the human quest for an authentic, meaningful, and spiritual life dominates. MMT essentially offers a positive perspective stating that there are four main approaches for meaning making: storytelling, goal striving, social construction, and personal development. Also, from a positive spiritual perspective, Wong and Tomer (2011) suggest that there may be a deepening of spirituality and a renewed dedication to attend to what matters most, ignoring the insignificant aspects of life and devoting oneself to authentic living. Spirituality will also be considered later in terms of health promoting palliative care.

2.6 Health Promoting Palliative Care (HPPC)

To situate death awareness and attitudes in community settings, the following section will critically examine the current social constructionist research with a particular emphasis on a compassionate approach and 'Health Promoting Palliative Care' (HPPC) research.

2.6.1 Considering compassion

Compassion, as a response to others suffering, is evident in the definitions related to health and education. From a health care perspective, Rumbold (2012a) relates compassion to justice, recognising the significance of a person's loss, and their right to having their needs attended to. In restoring compassion to the health care system he 'would see caregivers listening, recognizing, and responding to other's experiences, particularly when these involve fear, anxiety, and suffering' (Rumbold, 2012a, p. 112). Similarly, Sinclair et al. (2018, p. 195) attends to compassion as described by patients who are the receivers of care as 'a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action'.

Aligned with Sinclair et al. (2018), Peterson (2016, p. 2) regards compassion as, 'a cognitive, emotional and volitional response to the suffering of others'. Similarly, in regard to education, he describes compassion as 'an intentional act and practice which requires engagement with and understanding humanity, human fragility and suffering ... which provides structured support for students to grapple with challenging thoughts, feelings and experiences' (Peterson, 2016, p. 118). The empathy implicit in this permeate Nodding's (1984, p. 24) definition. Although not specifically defining compassion, she says that caring involves '... stepping out of one's personal frame of reference into the others. When we care, we consider the other's point of view, his objective needs, and what he expects of us'.

Nussbaum (1996, p. 28) draws upon the philosophical tradition in which compassion links the individual with the community, 'hooking the interests of others to our own personal goods'. She continues by also arguing against modern moral theories that denote compassion as 'irrational in

human affairs' asserting that 'compassion is above all a certain sort of thought about the well-being of others'.

The concept of compassionate cities takes further the links between compassion for individuals and communities. This idea has developed from the field of health promoting palliative care. In recent Australian history, Kellehear (1999) was opposed to the more common and primitive form of palliative care which essentially was the medical and nursing care of the dying person. Palliative care was once conducted under the more social grass roots 'modern hospice movement' formed in the 1960s. By the end of the 1990s, it was known as 'palliative care' and had been reintegrated into the mainstream health care system (Rosenberg & Yates, 2010). The change of palliative care in a more medicalised model has profoundly altered and influenced our societal attitudes about death and dying (Rosenberg et al., 2015). Palliative care was seen as predominantly conducting physical care and as a consequence, there was a devaluing of psychological, social, and spiritual care (Kellehear, 1999). This perspective however may be challenged by recent definitions of palliative care that now centralise psychological, social and spiritual care. The World Health Organisation (2018, p. 3) states that palliative care is defined as relieving the suffering associated with life-threatening illness such as the '... physical, psychological, social and spiritual suffering of patients, and psychological, social and spiritual suffering of family members'.

By drawing upon the fundamental principles of health promotion set down by the World Health Organisations, specifically the Ottawa Charter (1986), Kellehear (1999, pp. 75-76) proposed that health promotion and palliative care should 'enjoy a complementary relationship'. The Healthy Cities projects was developed by the World Health Organization as one way to implement these health promotion principles and in turn, action strategies (Kellehear, 2012).

The work of the Health-Promoting Palliative Care (HPPC) unit at La Trobe University in Melbourne, Australia became an example of this complementary relationship and embodied a more compassionate approach. Kellehear (1999) outlined the main intentions of health-promoting palliative care as follows: to heighten a sense of control and support for the chronically or terminally ill; to provide education and information about health, death and dying; to provide social supports for individuals and the community; and politically, palliative care must encourage a 'reorientation of palliative care services' in order to promote the collaboration of both fields (Kellehear, 1999, p. 77). Once this theoretical grounding was established by Kellehear (1999), further research continued to finely tune the social 'complementary relationship' of Health Promoting Palliative Care (HPPC). However, the practical implementation and reorientation of its principles in communities is still in its infancy today. Rosenberg et al. (2015, p. 32) highlights this point,

The gap between the rhetoric of HPPC and the reality of the experiences of many carers is quite stark. It is not immediately obvious how to move from the current situation to empowered, capable and supported communities working alongside health services to enhance EoLC (End of Life Care).

2.6.2 Compassionate cities and empowering communities

Empowering communities and building capacity is evident in the development of 'Compassionate Cities', an idea derived from the Healthy Cities project (Kellehear, 2012, p. 37). In addition to the definitions provided by Rumbold (2012a), Sinclair et al. (2018), Peterson (2016), Noddings (1984), and Nussbaum (1996), Kellehear (2012) connects the meaning of compassion with loss. Building capacity and creating compassion are relevant to school communities so these ideas and definitions are reviewed in detail.

Compassionate Cities' central concepts encapsulate compassion as an imperative, health being positively framed even in the presence of loss, compassion as a holistic idea and compassion implying a concern with the universality of loss. These concepts meet the needs of people living with life threatening illness and the bereaved (Kellehear, 2012). Kellehear (2012) comprehensively outlines policy implementation and action strategies of Compassionate Cities in order to build capacity in communities. There are also numerous ways of beginning a Compassionate Cities programme and building capacity through community initiatives. For instance, a 'Positive grieving art exhibition' whereby schools or communities are encouraged to give expression to the positive aspects of grieving, such as through dreams of the deceased, personal courage, and spiritual qualities which can all be highlighted in an art exhibition (Kellehear, 2012, p. 141).

Kellehear (2016) states that providing information and giving regular opportunities to discuss and question death, dying, and bereavement assists in building capacity. This works toward a compassionate approach in communities. The following initiatives are examples of this work: McLoughlin et al. (2016) and their descriptions of 'Café Conversations'; Mills and Mills (2016) use of arts and social media, and Noonan, Horsfall, Leonard, and Rosenberg's (2016) explanations of death 'literacy' programmes.

Interestingly, Kellehear (2016) states that current palliative care continues to take a leadership role in support for the dying and bereaved and for the public advocacy of normalising death, dying, and grief; however, he expresses a concern that this public advocacy support should not be confined to solely palliative care but also include the types of strategies that are used in health promotion, such as creating safety workplace policies, wearing a seatbelt, or monitoring ones diet. Therefore, the intent is to be preventative by working towards wellbeing with an inherent focus on potential

difficulties of caregiving, dying, and bereavement. Kellehear (2016, pp. 36-37) emphasises 'that this is not simply a problem for those of us in end of life care, it is a problem for everyone affected by the end of life – and that it absolutely everyone'.

From a practical perspective, Kellehear (2016, p. 37) highlights the need to work 'with' communities rather than working 'on' communities by eroding ignorance and fear. Kellehear and Fook (2010) note that in Australia, palliative care services have been reorienting their approach. Working with communities enables the collective community to define problems and develop solutions. This HPPC approach has now spread internationally (Kellehear, 2016) and community initiatives that use HPPC principles are now increasing locally and internationally (Kellehear, 2013). In alliance with Kellehear, Rosenberg (2011) supports HPPC and describes it as a social based model that is grounded in the promotion of health, employing a palliative care philosophy to inform its mission, values, and strategic direction. Rosenberg (2011) draws specifically on Kellehear's (2013) work, highlighting Compassionate Cities and the need for social change. Dissatisfied with current practice, Rosenberg (2011, p. 16) criticises palliative care services, albeit well intentioned, as paternalistic, stating that they carry a sense of ownership and pose a 'philosophical and structural barrier to a paradigmatic shift towards a more complete understanding of the business of dying'. This is mirrored by Kellehear's concern that public advocacy support should not be confined to only palliative care (Kellehear, 2016). Rosenberg (2011) argues that it is necessary to re-evaluate the business of dying and for the home to be regarded as an appropriate death scene. This may also assist in normalising death in school communities as families experience and communicate about the day-to-day practicalities of caring for a dying person and planning rituals or funerals.

In advocating the HPPC model, Rosenberg (2011, p. 27) understands that death belongs to the community and that this approach normalises 'the conceptualization of dying and the responses of communities to their dying members'. He speculates that this may result in community members establishing a greater readiness for their own dying or caregiving responsibilities. Further to this, Rosenberg (2011, p. 27) acknowledges that this model is one approach to 'normalizing the conceptualization of dying and the responses of communities to their dying members'.

Mills, Rosenberg, and McInerney (2015) investigated community capacity and its implications for HPPC in the Australian Capital Territory and determined that as professional capacity has increased, community capacity has decreased. Mills and Mills (2016, p. 16) state that in 2011, Palliative Care Australia recognised a national priority and stated, 'All Australians must have access to education about dying and death'. Also, Mills et al. (2015) note that the PCA's quality standards explicitly state the importance of community capacity building. They argue that the HPPC practice guidelines that were developed by Kellehear, Rumbold, and Bateman (2003) were too service provision-oriented

and propose that there is a need to develop community-based guidelines in order to build capacity and suggest they be developed in collaborative partnerships between community groups, health services, and public health workers.

Rosenberg et al. (2015) argue that a research focus on informal social networks is necessary. They call for current palliative care practices to reorient themselves towards an actualised health promotion in order to glean a deeper understanding of the role of carers and informal caring networks (Rosenberg et al., 2015). This parallels with Kellehear's earlier proposal that palliative care must encourage a 'reorientation of palliative care services' in order to promote the relationship of both fields (Kellehear, 1999, p. 78). Rosenberg, Mills, and Rumbold (2016, p. 1) emphasise this issue of power stating that health services assume that palliative care is 'the most suitable custodians of the business of dying'. This comment parallels with Rosenberg's idea that palliative care has a sense of ownership (Rosenberg, 2011). For a number of reasons, this is a source of concern. Firstly, it is too expensive to provide support this way; secondly, informal care provided by friends and families differs to professional care; and finally, professional caregivers do not share intimate knowledge of the dying person and their friends and families (Rosenberg et al., 2016). Simply, 'sharing care involves sharing power' and a public health approach to palliative care demands a cultural change where the current holders of expert knowledge need to share this knowledge (Rosenberg et al., 2016, p. 2).

Rumbold and Aoun (2014) in support of Kellehear's (2013) research also call for community capacity building but strongly focus on the area of bereavement. They acknowledge that conceptually comprehensive end-of-life policies and practices for bereavement exist in Kellehear's complete public health approach and the emerging international association for public health and palliative care; however, they state that 'applications to bereavement trail well behind applications to dying' (Rumbold & Aoun, 2014, p. 132). They also suggest that public health strategies and population studies of bereavement are sparse and that the care of bereaved people that palliative care provide has not significantly influenced other health services or support meant for relatives of palliative care clients. They emphasise that palliative care services should attend to building community capacity rather than providing specialised bereavement care of their own partly through having grief portfolios in palliative care teams held by people in education, community development, or health promotion (Rumbold & Aoun, 2014).

Also, with an interesting focus on naming the general community as the 'non bereaved', Kellehear and Fook (2010, p. 21) state the necessity to build a community's capacity for resilience and self-care and also the care of bereaved others. A community understanding of the social and psychological health for people living with a life-threatening illness or bereavement is necessary in a public health

framework, using intervention and preventative thinking. A participatory approach is recommended where palliative care is working alongside schools or workplaces, identifying issues about death, dying, or bereavement. Bereavement care has generally been performed by professionals for and to communities not in partnerships with community organisations (Kellehear & Fook, 2010).

In regard to professional practice, Rumbold and Aoun (2014) emphasise that early professional support to all bereaved people is not effective and it may interrupt the natural course of grieving or interfere with current support networks, possibly resulting in withdrawal of support from family and friends. This criticism is important as bereavement may be perceived as 'needing' professional support and may become self-fulfilling, shaping bereavement as a 'problem to be solved rather than an experience to be engaged' (Rumbold & Aoun, 2014, p. 132).

Fook and Kellehear (2010) also recommend that bereavement care be viewed in the context of prevention and harm reduction for the benefit of the wider community and to focus efforts on the non-bereaved and bereaved, recognising that bereavement experiences will occur for all community members over the course of a lifetime.

In critically examining the ways industrialised societies, such as United States, United Kingdom, Canada, Australia, and Japan support bereaved people, Breen, Aoun, O'Connor, and Rumbold (2014, p. 55) identify the gaps between palliative care policy and practice, stating that 'services struggle to use their limited resources to deliver best practice bereavement care and support'. Similar to Kellehear and Fook (2010), Breen et al. (2014) advocate for a public health approach that represents a partnership model between the health sector and the community. A public health approach would redefine grief, death, and dying as normal human experience and the acknowledgement that communities need some resilience in order to live together with the loss (Breen et al., 2014). Aoun, Breen, Rumbold, and Howting (2014) surveyed people who had been bereaved to ask about their preferences and needs for bereavement support in an innovative pilot study in Western Australia. While there was tentative support for a public health model, they concluded that there is little evidence on experiences of bereavement, particularly for those who don't seek support, thus lacking assistance in guiding development and distribution of bereavement programmes in palliative care, and this includes programmes to develop community capacity.

2.6.3 Spirituality and storytelling

With a different emphasis, Rumbold (2012a) argues that a satisfactory understanding of compassion and dying as a spiritual quest have profound consequences for reforming health systems. He states that palliative care as 'hospice care' in the 1970s understood that in order to care for people it was also necessary to care about them' (Rumbold, 2012a, p. 107). In addition to this, Rumbold (2012a, p.

111) asserts that the 'initial vision of hospice care was to facilitate a spiritual journey', and this quest ideally involved the whole community but like compassion, this may have been weakened by the mainstreaming of palliative care. This corresponds with Kellehear's earlier point that as a consequence to mainstreaming, there was a devaluing of psychological, social, and spiritual care (Kellehear, 1999) but as mentioned is also challenged by recent definitions of palliative care that now centralise psychological, social and spiritual care (World Health Organisation, 2018).

Rumbold (2012a, p. 112) acknowledges that hospice care was a 'crucible of transformation' and understood care as a vocation; he asserts that this gives palliative care the opportunity to reclaim some of its 'historic mission' by acknowledging its place within a public health approach. In practice, this means implementing public health approaches that focus on the development of compassion, exploring the human spirit, promoting scientific research, and developing relevant practice. Further to this, Rumbold, Gardner, and Nolan (2011) state that in order for spiritual care to be effective, reflection and exploration of stories must be encouraged and end of life experiences need to be supported by the community. They suggest that communities may draw upon their own resources, such as cultural resources, relationships, imagination, storytelling, *and* health services, albeit not dominated by medical or religious discourse (Rumbold et al., 2011).

It is important to highlight 'storytelling' at this stage given the frequency 'storytelling' is occurring in the literature. Both storytelling and 'self-narrative' construction have featured throughout this literature review and have been mentioned as an effective strategy to aide bereavement and end of life. To reiterate, Neimeyer et al. (2014, p. 496) refer to grieving as an activity that strives to find significance in the death and re-establish a 'self-narrative'. Further, in regard to bereavement, Neimeyer et al. (2011) note the benefit for the survivor to integrate the death into their own life story. Wong (2013, p. 11) states that narrative construction may 'transform death anxiety into a source of inspiration for authentic living'. Wong (2013) also states that storytelling is one of the four main approaches for meaning making. Rumbold et al. (2011) name storytelling as a community cultural resource. By incorporating both Wong and Neimeyer's ideas, 'transformative storytelling' may be used as a broader term that considers storytelling *and* its variations such as journaling, story writing, story reading, and public speaking that are used to assist people experiencing bereavement to connect others and reduce isolation. This will be discussed further in the concluding remarks.

2.7 School Communities

This section of the literature review will identify specific attitudes and awareness of death, dying, and bereavement in school communities within an Australian context and internationally. The research existing in this field is mostly focused on perspectives from teachers and parents and what

schools need to attend to from a non-bereaved perspective (Engarhos, Talwar, Schleifer, & Renaud, 2013; Galende, 2015; Lane, Rowland, & Beinart, 2014; Mak, 2012; Potts, 2013). Associated strategies or solutions that may be of benefit to bereaved people in communities will be suggested.

2.7.1 Death attitudes

According to Kellehear (2014, p. 221), death is a common source of fear and social avoidance, and that people 'commonly view death education as a morbid affair'. Similarly, Galende's (2015, p. 91) Spanish research found that education professionals in Spain saw death as a topic to be 'constantly banned and avoided' because

1. Teachers believe that death is a subject that doesn't interest children and therefore fear may be generated if it is mentioned;
2. Due to their own fears and attitudes, teachers find it too difficult to address it, even though they acknowledge that it should be addressed;
3. Teachers believe that death worries children and should therefore be dealt with at home with family members.

Similarly, findings from a National Greek study (2002) suggest that most educators consider that they have a role in supporting bereaved students but feel ill-equipped and unprepared to do so (Papadatou, Metallinou, Hatzichristou, & Pavlidi, 2002). Barry and McGovern (2000) states that the highly valued Irish social rituals surrounding death and grief are changing due to a shifting social and economic climate where death is increasingly being addressed clinically, resulting in limited participation for children in rituals, such as wakes in the family home. Similar to Papadatou et al. (2002), Barry and McGovern (2000) found that parents and teachers felt uncomfortable talking to children about death. However, Barry and McGovern (2000) highlights that both teachers and parents expressed a strong desire to discuss death with children before they encountered it.

2.7.2 Strategies for changing death attitudes

Papadatou et al. (2002), Barry and McGovern (2000), Tracey and Holland (2008), Galende (2015), and McGovern and Tracey (2010) all acknowledge that teachers or university student teachers need or want specific training and/or procedures to appropriately respond to situations of death, dying, or bereavement. In some instances, there was a lack of specific training available (Papadatou et al., 2002) (Tracey & Holland, 2008). Owing to this, McGovern and Tracey (2010) recommend Government departments make financial allocations for training and support for teachers, stating that experiences and knowledge need to be shared and best practice adopted internationally. They also suggest that different cultural experiences and multicultural aspects form part of this training.

This is supported by Papadatou et al. (2002, p. 336) who explain that the knowledge and skills gleaned from specialised training 'should be well integrated and make use of the culture's traditional religious practices and community resources which are mobilized in the face of death'.

Rowling (2008) and McGovern and Tracey (2010) strongly recommend policy development in this area. Specifically, McGovern and Tracey (2010) suggest that it may be time to develop bereavement policies and procedures formally in all educational settings. Some positive implementations are cited in Ireland. For instance, Tracey and Holland (2008, p. 262) note the 'Lost for Words' training in Hull (Derry, Ireland) encouraged schools to develop policy and procedure moving from no schools policy to one third of all primary schools and 20% of secondary schools having a policy in place. This affirms the need for schools to have support in developing and formalising policy (Tracey & Holland, 2008). Kellehear (2014) advocates parents, teachers, and students can aid in the development of policy documents and allow for open discussion around the experiences of death, dying, and loss in order to normalise these issues in the school community setting.

In 2011, PCA stated that 'All Australians must have access to education about dying and death' with an ambitious objective and '...That dying, death and the role of palliative care are integrated into the personal development syllabus of all schools and the development of the Australian Curriculum by 2015' (Cited in Mills & Mills, 2016, p. 16). Mills and Mills (2016) suggest that a well-defined, tangible framework of how to accomplish this was perhaps lacking. Addressing this practically, Kellehear (2014) argues for normalising death and loss through death education which can reduce personal and community anxiety, contests fear and ignorance, raises hope, and recreates a social context to insufficient or 'problem focused' images of death, dying, and loss. This is in the context of community engagement where death education is not a didactic approach but one that is participatory and builds on communities skills and wisdom (Kellehear & O'Connor, 2008). For example, the Division of Palliative Care in Newcastle built a partnership with secondary school authorities to develop a death education project which encouraged students to address issues around death as they arose in various subjects. This fostered reflective conversation and reduced reluctance and fear to essentially 'challenge student's perceptions based on media representations of death', and developed student knowledge and comfort levels when talking about these topics (Kellehear & O'Connor, 2008, p. 114).

In the same partnership, a concept called 'Café Conversations' was used to create discussion with teachers about death, dying, and loss in the school setting (Kellehear & O'Connor, 2008). The teachers identified that they did not know what to say to bereaved people, and as a result, they were able to attend practical workshops on grief and bereavement with suggestions about communication (Kellehear & O'Connor, 2008). This school based example resulted in increased

teacher confidence and an ability to discuss death, dying, and bereavement with students; however, there was a need for further resources to assist with student exploration and consideration of death in the future (Kellehear & O'Connor, 2008). Similarly, the need to create and implement educational resources was also noted by Galende (2015). Noonan et al. (2016) and Mills and Mills (2016) also advocate for community engagement as a public health approach. Noonan et al. (2016) contest that unlike the didactic approach of traditional death education, it is about forming workable relationships and partnerships. Mills and Mills (2016, p. 16) also argue for death education in schools and suggest that it be situated in the rapidly growing international field of positive education with 'new and positive narratives'. They suggest that integrating positive education principles and integrating these elements with death education would result in the promotion of compassionate communities.

From a broader perspective, Rowling (2008) also advocates for a holistic public health perspective. Similar to Wong and Tomer (2011), Rowling (2008) explains that trauma and grief now reside in a different landscape with ongoing media coverage of global events, such as terrorism and violence. Rowling (2010) states that experiences of loss are not only private matters and that there is a need for both community recovery and individual and family support. Rowling's (2010) work is particularly innovative as she argues for a holistic approach to loss and grief experiences and a resulting connectedness in school communities by accessing the 'hidden curriculum' or the ethos of the school. For example, the ethos of the school is found in student and staff wellbeing, and within relationships including staff relationships. The health promoting school framework is regarded as a key contributor to whole school approaches (Rowling, 2010).

Practically, Rowling (2008, p. 244) explains that social support comes from organisational practices within the school that provide people with support through periods of grief, such as experiencing 'a connectedness in shared rituals', through special grief support groups at school or for teachers taking informal leave so that 'Grief should be seen as a normal event that can be managed by school communities with outside support ... it should not be pathologized and seen as only the domain of outside experts'. Papadatou et al. (2002) also found that in order to plan suitable interventions that enable childhood adjustment to loss, a team approach is needed between educators, family members, and mental health professionals. Specifically, in terms of practice, both Rowling (2008) and Kellehear (2014) advocate that community sharing or storytelling is a way forward for communities dealing with death, dying, and bereavement.

... It is important to connect individual experiences with the experiences of others, for it is a fact that most people have their own experiences of dying, death, loss or care and that to

swap stories of those experiences with other people is important in reducing a sense of isolation. (Kellehear, 2014, p. 222)

From a school perspective, Rowling (2008, p. 248) contends that where an event has affected many school community members, there is a need to make meaning collectively by 'talking it through and telling their stories'. She also emphasises that 'the voices of young people need to be sought, included and valued' (Rowling, 2010, p. 159). However, '... grief is diverse from individual to individual ...', and as a result, there may be a danger in presuming that 'one size fits all' when it comes to strategy implementation (Rosenblatt & Bowman, 2013, p. 83). For example, young males may need to process and organise their thoughts or take action rather than express their feelings (Rowling, 2008). Rowling (2008) also points out that teachers need to acknowledge the tension between their duty of care to their students and being in control both personally and professionally to ensure there is an '... environment that recognizes and validates their grief and that provides support for it' (Rowling, 2008, p. 247). Kellehear's (2014) idea of sharing stories to reduce isolation is relevant here and may also assist teachers in their grief.

In reflection of the points addressed, Matheson (2013) provides a summary of the steps that schools should take in relation to community grief. Matheson (2013) states that schools need to provide training for teachers and administrators, train facilitators to provide early bereavement support on the school grounds, form partnerships with families and outside professionals to prepare for present and future bereavement, and prepare for long term needs of staff and students. Matheson (2013, pp. 253-254) states that 'Many techniques can be effective and used in multiple contexts that embrace and honour the cultural, spiritual, gender, and familial needs of the group and individual members'.

In this final section, themes, gaps in the literature, suggestions of ways forward, and implications for school communities experiencing death, dying, and bereavement are considered and discussed. As evidenced in this literature review, there is a complex range of perspectives regarding death, dying, and bereavement. However, it is insufficient to rely on purely psychological views as there is a complexity of relationships within communities and the larger existing social environment to consider. The themes expressed are: the acknowledgement that death and bereavement are complex but they are normal experiences; that there is a need for death and bereavement issues to be community owned rather than *only* individually evaluated; attitudes and awareness of death are varied but may provide the motivation to live a meaningful life; and that the larger ideas of spirituality, the positive side of death, dying, and bereavement and transformation cannot be ignored. It is clear that understanding compassion, being compassionate, building capacity in schools, and solidifying death, dying, and bereavement issues in policy is a high priority.

With this study in mind and connecting the idea of compassion as an intention (Peterson, 2016), compassion and ways to restore it (Rumbold, 2012a), linking the individual with the community (Nussbaum, 1996), emphasising relational understanding (Sinclair et al., 2018) and empathy (Noddings, 1984) for the purposes of this study, I am defining compassion as ‘an intention (justice) to understand and empathise with people who are suffering by extending them support in thought, word and action, seeking school community as well as individual change’. This may involve school community members asking people who have been bereaved about how they would like to acknowledge the death within the community and acting on those expressed needs.

The Health Promoting Palliative Care (HPPC) framework resonates and reflects the ideas put forward in the Health Promoting Schools approach advocated by Rowling. This framework offers a specific way forward in school community settings. The literature strategies are provided as examples and some have been used in school settings, but a clear description of what compassion is, what compassionate strategies may involve, and how to implement this overtime in schools, hospitals, or other community settings remain a gap in the literature.

How bereavement is understood and lived out in everyday life is largely an unknown and the literature does not state how specific strategies, such as storytelling, story writing, reading stories, journaling, or public speaking may be already present in the lives of the bereaved. Death attitudes of children are also largely unknown; therefore, it is suggested that children may not have been given a voice as far as death, dying, and bereavement and their story is concerned. There seems to be an identifiable need to explore the positive side of death, dying, and bereavement and to move towards death acceptance in communities as this provides the opportunity for transformation and growth.

Wong’s (2013) Meaning Making Theory (MMT) and Neimeyer et al. (2014) ‘Social Constructionist Model of Grieving’ are particularly relevant to meaning making through narrative construction or storytelling. The genuine struggle of bereavement seems to be acknowledged in the MMT model and the Social Constructionist Model of Grieving. Specifically, MMT acknowledges death anxiety/awareness and views it as a catalyst to a meaningful life. It shows an elegant way through life – with death in mind. The Social Constructionist Model of Grieving (Neimeyer) is also of particular significance here. Kellehear’s practical comment about ‘swapping stories to avoid isolation’ fits well with self-narrative construction and storytelling that reside in this model. The people’s stories that are presented by Neimeyer appropriately acknowledge the pain of loss and subsequent transformational aspects (Neimeyer et al., 2014).

The positive psychology focus that Mills and Mills (2016, p. 16) discuss is also of interest as it provides a tangible way forward in schools and asks for ‘new and positive narratives’ reframing the

reality of death and dying in terms of strength and growth. This also resonates with Mills and Mills (2016, p. 16) term 'flourishing with dying' used as a springboard to develop positive dying curricula.

2.8 Summary

In conclusion, in reviewing the complex nature of death, dying, and bereavement literature and with the intent of further research in school communities, the use of a critical social constructionist theoretical lens is an imperative. It is essential to understand how we can socially and culturally facilitate a positive regard for death, dying, and bereavement in our school communities, which will allow community members to talk about these difficult issues. A change of atmosphere is required where meaning making is embedded and the essence of compassion, spirituality, death acceptance, and transformation is visible; therefore, in the moral pursuit of this ideal and with the practical desire to contribute to future research, my question is: how do we create compassionate schools in light of death, dying, and bereavement? Compassion in terms of my definition, has been influenced by this literature review and refined and clarified by the thoughts and ideas expressed by participants as noted in the following journal article. This article delves specifically into the palliative care literature and school-based research conveying the need for community ownership of death, dying, and bereavement issues in schools. The use of a critical social constructionist lens is argued for (this theory is explored in more detail in Chapter 3) and compassion, partnership, and normalising death are exemplified.

ARTICLE 1: LITERATURE REVIEW ARTICLE: MAKING DEATH, COMPASSION AND PARTNERSHIP 'PART OF LIFE' IN SCHOOL COMMUNITIES



Pastoral Care in Education

An International Journal of Personal, Social and Emotional Development



ISSN: 0264-3944 (Print) 1468-0122 (Online) Journal homepage: <http://www.tandfonline.com/loi/rped20>

Making death, compassion and partnership 'part of life' in school communities

Carla Jane Kennedy, Mary Keeffe, Fiona Gardner & Cathleen Farrelly

To cite this article: Carla Jane Kennedy, Mary Keeffe, Fiona Gardner & Cathleen Farrelly (2017) Making death, compassion and partnership 'part of life' in school communities, *Pastoral Care in Education*, 35:2, 111-123, DOI: [10.1080/02643944.2017.1306873](https://doi.org/10.1080/02643944.2017.1306873)

To link to this article: <http://dx.doi.org/10.1080/02643944.2017.1306873>



Published online: 28 Mar 2017.



[Submit your article to this journal](#)



Article views: 117



[View related articles](#)



[View Crossmark data](#)


Full Terms & Conditions of access and use can be found at
<http://www.tandfonline.com/action/journalInformation?journalCode=rped20>

Download by: [La Trobe University]

Date: 26 June 2017, At: 21:37



Making death, compassion and partnership 'part of life' in school communities

Carla Jane Kennedy , Mary Keeffe, Fiona Gardner and Cathleen Farrelly

School of Education, La Trobe University, Melbourne, Australia

ABSTRACT

Death can be considered a social taboo, a common source of fear and public avoidance. School communities are not immune to this, as the topic of death is constantly avoided. It is vital to understand how we can socially and culturally cultivate a positive regard for death, dying and bereavement in our school communities. Community members need to discuss these difficult issues and use strategies to enhance compassion, connectedness and support. In this literature review we reason that death is specifically not 'part of life' in school communities. Due to the dearth of school community-based literature on this issue and the progressive literature residing in palliative care, we aim to coalesce palliative care and school-based research, evaluate it and highlight compassion and partnership as a way forward for school communities. Essentially, our societal attitudes about death and dying have been profoundly altered and our community ownership of these normal life events has largely disappeared. This is demonstrated for example, by palliative care moving from the social grass roots 'modern hospice movement' formed in the 1960s and being reintegrated into the mainstream health care system by the end of the 1990s, resulting in an overall medicalised morphing of death, dying and bereavement issues. Therefore, we recommend that further research be conducted in how to develop *compassionate* schools to inform us how death may be continually made 'part of life' in school communities, for the benefit of students, teachers and families alike.

ARTICLE HISTORY

Received 26 October 2016
Accepted 5 March 2017

KEYWORDS

School communities;
compassionate schools;
health promoting palliative
care

Introduction

This review of the literature will focus on research that discusses death, dying and bereavement from a social constructivist perspective, which illuminates the ways in which communities and individuals make their own meaning around death, dying and bereavement. As Australian authors, we acknowledge that whilst these

CONTACT Carla Jane Kennedy  18779455@students.latrobe.edu.au

This article was originally published with errors. This version has been corrected. Please see corrigendum (<http://dx.doi.org/10.1080/02643944.2017.1326706>).

© 2017 NAPCE

issues affect all cultures and that attitudes will vary from context to context, this review focuses on western literature and so the ways in which death, dying and bereavement are understood within a western educational context. Understanding 'Health promoting palliative care' and 'school based' research are particularly relevant here. However, ideas about how to manage these issues in community settings are situated within health promoting palliative care. Therefore, ideas from this research are demonstrated here to provide insights and possible ways forward for schools to embrace death, dying and bereavement issues for the benefit of all school community members. In this first section, the palliative care research is critiqued, compassion and community engagement are examined, existing gaps are identified and particular implications for schools are stated.

The business of death and dying

In recent Australian history, Kellehear (1999, p. 75) critiqued what had become the more common, primitive form of palliative care described as the medical and nursing care of the dying person. As it shifted from a social grass roots movement to a more medicalised model, palliative care was seen as predominantly conducting physical care. As a consequence there was a devaluing of psychological, social and spiritual care (Kellehear, 1999, p. 76).

By drawing upon the fundamental principles of health promotion set down by the World Health Organisation, specifically the Ottawa Charter (1986), Kellehear (1999, pp. 75, 76) proposed that health promotion and palliative care should enjoy a complementary relationship. As combined fields, Kellehear (1999) outlined the main intentions of health promoting palliative care (HPPC). These included: to heighten a sense of control and support for the chronically or terminally ill; to provide education and information about health, death and dying; to provide social supports for individuals and the community; and politically, palliative care must encourage a 'reorientation of palliative care services' in order to promote the collaboration of both fields (Kellehear, 1999, p. 77).

Once the theoretical grounding was set down by Kellehear (1999) further research continued to finely tune the social complementary relationship of Health Promoting Palliative Care. However, the practical implementation and re orientation of its principles in communities is still in its infancy today. Rosenberg, Horsfall, Leonard, and Noonan (2015, p. 32) highlight this point,

The gap between the rhetoric of HPPC and the reality of the experiences of many carers is quite stark. It is not immediately obvious how to move from the current situation to empowered, capable and supported communities working alongside health services to enhance EoLC. (End of Life Care)

Rosenberg (2011, p. 20) in alliance with Kellehear, supports HPPC. He describes it as a social-based model that is grounded in the promotion of health, employing a palliative care philosophy to inform its mission, values and strategic direction. Rosenberg (2011, p. 20) draws specifically on Kellehear's (2013) work, highlighting

compassionate communities and the need for social change. In advocating for the HPPC model Rosenberg (2011, p. 27) understands that death belongs to the community. He speculates that this may result in community members establishing a greater readiness for their own dying or caregiving responsibilities. However, dissatisfied with current practice, Rosenberg (2011) criticises palliative care, albeit well intentioned, as paternalistic. He states that palliative care services carry a sense of ownership and pose a 'philosophical and structural barrier to a paradigmatic shift towards a more complete understanding of the business of dying' (Rosenberg, 2011, p. 16).

Rosenberg, Mills, and Rumbold (2016, p. 1) also emphasise this issue of power, stating that health services assume that palliative care are 'the most suitable custodians of the business of dying'. A public health approach to palliative care demands a cultural change where the current possessors of expert knowledge need to share this knowledge to benefit communities (Rosenberg et al., 2016, p. 2). This may shift the community from a current disempowered state to an empowered one. Engaging communities may prove to be one way forward.

How do we engage communities?

Empowering communities and building capacity for the health of whole communities is evident in the development of 'Compassionate Cities', an idea derived from the *Healthy Cities* project (Kellehear, 2012; p. 37). 'The *Healthy Cities* projects were developed by the World Health Organization (WHO) as one way to implement the Ottawa Charter for health promotion (1986)' and in turn, action strategies (Kellehear, 2012; p. 37). The *Compassionate Cities* movement encapsulate compassion as an imperative. Health is positively framed even in the presence of loss, and compassion is a holistic idea that implies a concern with the universality of loss. As the main intentions of HPPC outlined and *Compassionate Cities* reinforces, these concepts better meet the needs of people living with life threatening illness and the bereaved (Kellehear, 2012, p. 44).

Kellehear (2012) comprehensively outlines policy implementation and action strategies of *Compassionate Cities* in order to build capacity. There are also numerous ways of beginning a *Compassionate Cities* programme and building capacity through community initiatives. For instance, a *Positive grieving art exhibition*, whereby schools or communities are encouraged to give expression to the positive aspects of grieving such as through dreams of the deceased, personal courage and spiritual qualities (Kellehear, 2012, p. 141).

Further, Kellehear (2016, pp. 36, 37) acknowledges the benefits of community engagement and endorses the need for more information and exchange of ideas around the topics of death, dying and bereavement. From a practical perspective, Kellehear (2016, p. 37) highlights the need to work 'with' communities enabling the collective community to define problems and to develop solutions. Kellehear and Fook (2010, p. 22) note that in Australia, palliative care services have been

reorienting their approach. Community initiatives that use HPPC principles are now increasing locally and spreading internationally (Kellehear, 2013, p. 1071).

How do we create 'good grief'?

From a sociocultural perspective there is little research on the impact of bereavement on the family and the role of support from family, friends and work colleagues. Much of the literature focuses on grief as an individual, intrapsychic phenomenon (Breen & O'Connor, 2011, pp. 98, 99). Breen and O'Connor (2011, p. 98) interviewed 21 bereaved informants following the death of a family member. Their data clearly illustrated that it was common for familial and social relationships to deteriorate and collapse. This lack of support from social networks was deemed by the bereaved community members as 'particularly hurtful and insensitive' (Breen & O'Connor, 2011, p. 112).

The breakdown of relationships is especially relevant for schools as grief potentially affects not only the bereaved but also friends and families of the bereaved who may belong to the affected school community in the short and long term. This may disrupt the well-being of many school community members at once. Breen and O'Connor (2011) recommend the strengthening of current services to the bereaved and '... the development of improved grief education for service providers, the bereaved and the community' (Breen & O'Connor, 2011, p. 114).

Similarly, Rumbold and Aoun (2014, pp. 131, 132) supporting Kellehear's (2013) research, call for community engagement or capacity building. They acknowledge that conceptually, comprehensive end-of-life policies and practices for bereavement exist in Kellehear's complete public health approach, the emerging international association for public health and palliative care, however, they state that 'applications to bereavement trail well behind applications to dying' (Rumbold & Aoun, 2014, p. 132).

In addition, Rumbold and Aoun (2014, p. 134), strongly advise that grief portfolios in palliative care teams need people with qualifications in education, community development or health promotion, in order to build capacity. This ensures that end-of-life care is community owned with professionals supporting, coaching and advising. They further recommend that end-of-life care use assets-based approach by facilitating 'good grief' (Rumbold & Aoun, 2014, p. 134). This identifies and confirms the assets or strengths people have for caring for themselves and others in bereavement and capitalising on these ... not reinforcing dependence on health services but rather benefitting the community. This is consistent with palliative care philosophy of achieving a 'good death' (Rumbold & Aoun, 2014, p. 134).

With regard to professional practice, Rumbold and Aoun (2014, p. 132) emphasise that early professional support to all bereaved people is not effective. Rumbold and Aoun (2014) explain that this may interrupt the natural course of grieving or interfere with current support networks, possibly resulting in withdrawn support from family and friends. Furthermore, bereavement may be perceived as 'needing'

professional support and may become self-fulfilling, shaping bereavement as a 'problem to be solved rather than an experience to be engaged' (Rumbold & Aoun, 2014, p. 132). This is relevant for the practices of school communities. Currently, many schools offer services to 'solve the issue' associated with a death in a community.

Breen, Aoun, O'Connor, and Rumbold (2014) with a specific focus on bereavement, advocate for a public health approach that represents a model between the health sector and the community (Breen et al., 2014, p. 57). A public health approach would redefine grief, death and dying as normal human experiences and acknowledge that communities need some resilience in order to 'live together with the loss' (Breen et al., 2014, p. 58).

Rumbold and Aoun (2014, p. 131) state that there is little data on how bereavement is lived out in everyday life: we are not well informed about the majority of people who don't seek out support. In addition to this, Aoun, Breen, Rumbold, and Howting (2014, p. 478) state that there is little evidence to assist in guiding development and distribution of bereavement programmes in palliative care and this includes programmes to develop community capacity. This has implications for school communities who also need guidance in responding to bereaved others, developing a bereavement response in either programming or policy and implementing strategies in order to engage communities.

The significance of compassion and spirituality

With a different emphasis, Rumbold (2012, p. 106) argues that a satisfactory understanding of compassion and dying as a spiritual quest have profound consequences for reforming health systems. He states that palliative care as 'hospice care' in the 1970s understood that 'in order to care for people it was also necessary to care about them' (Rumbold, 2012, p. 107). This compassion in care and the way we perceive compassion in terms of current care culture, challenges the behaviours and attitudes of health care practitioners (Rumbold, 2012, p. 108).

Further to this, Rumbold (2012, p. 111) asserts that the 'initial vision of hospice care was to facilitate a spiritual journey'. This quest ideally involved the whole community but as with the practice of compassion, this has also been weakened by the mainstreaming of palliative care. This parallels with Kellehear's earlier point that as a consequence to mainstreaming, there was a devaluing of psychological, social and spiritual care (Kellehear, 1999; p. 76). In regards to spirituality, Rumbold (2012, p. 109) argues that 'When compassionate care was mainstreamed, spiritual care was identified as a component, not as the matrix or the glue, of holistic care. In the process it became disconnected from the whole'. This has resulted in a generic approach to spiritual care. Re-establishing compassion as a central value of health care practice may restore conditions needed for spiritual care.

Compassion is a necessary pre-condition for spiritual care because it recognizes the shared humanity of care giver and care receiver. Spiritual care is an expression of compassion because it attends to the uniqueness of the other. (Rumbold, 2012, p. 111)

This is profoundly relevant for school communities and the caring relationships that exist between community members, especially teachers and students. For community members experiencing death, dying and bereavement, compassion made visible 'would see caregivers listening, recognising, and responding to others experiences, particularly when these involve fear, anxiety and suffering' (Rumbold, 2012, p. 112).

Rumbold, Gardner, and Nolan (2011, p. 145) acknowledge that in order for spiritual care to be effective, reflection and exploration of stories must be encouraged and end of life experiences need to be supported by the community. Communities may draw upon their own resources such as cultural resources, relationships, imagination, storytelling *and* health services ... albeit not dominated by medical or religious discourse (Rumbold et al., 2011, p. 145). This parallels with an earlier point made by Rumbold and Aoun (2014) in confirming and capitalising on the strengths people have in a community for caring for themselves and others in bereavement. This specific exploration of stories and storytelling as a strategy may prove innovative for school communities.

School communities

This next section of the literature review will identify our social attitudes towards death, dying and bereavement, the call for death education, the need for training, policy and partnership and the benefits of a holistic school approach. Storytelling as a strategy will be explicated and ways forward suggested. It is important to keep in mind that school communities largely ignore or avoid any association with death, dying or bereavement issues. Australian schools do respond to critical incidents with short-term solutions, however, they remain, in the long term, disempowered in the face of death.

In 2011, Palliative Care Australia (PCA) stated that 'All Australians must have access to education about dying and death' (cited in Mills & Mills, 2016, p. 16). PCA and set an ambitious objective,

... That dying, death and the role of palliative care are integrated into the personal development syllabus of all schools and the development of the Australian Curriculum by 2015.

Mills and Mills (2016, p. 16) suggest that a well-defined, tangible framework of how to accomplish this was perhaps lacking. This coupled with our social attitudes towards death, dying and bereavement may explain why, in Australia, we are yet to make progress in school community settings.

Why do we fear death at school?

According to Kellehear (2014, p. 221) death is a common source of fear and social avoidance and people 'commonly view death education as a morbid affair'. Similarly, Galende (2015, p. 91) stipulates that death can be considered 'a social and educational taboo', stating that the topic itself is 'constantly banned and avoided'. Based on data collected in the Teacher Training School from the University of the Basque Country (Spain), Galende (2015, pp. 91, 92) states that these social attitudes are also found amongst education professionals who at some stage will have to navigate or simply talk about the topic of death and dying with children.

Galende (2015, p. 92) identifies several reasons why teachers avoid the topic of death. Firstly, teachers believe that death doesn't interest children and therefore mentioning it may generate fear. Secondly, due to their own fears and attitudes, teachers find it too difficult to address it, even though they acknowledge they should. Finally, teachers believe that death worries children and should therefore be dealt with at home (Galende, 2015, p. 92).

Similarly, findings from the National Greek study (2002) suggest that most educators consider that they have a role in supporting bereaved students but feel ill-equipped and unprepared to do so (Papadatou et al., 2002, p. 324). Barry and McGovern (2000, p. 325) state that the highly valued Irish social rituals surrounding death and grief are changing due to a shifting social and economic climate, where death is increasingly being addressed clinically. This has resulted in little participation for children in rituals such as wakes in the family home. Like Papadatou et al. (2002), they found that parents and teachers felt uncomfortable talking to children about death. Barry and McGovern (2000, p. 325) highlight that both teachers and parents expressed a strong desire to discuss death with children before they encountered it.

A call for training and policy

Papadatou et al. (2002), Barry and McGovern (2000), Tracey and Holland (2008), Galende (2015), and McGovern and Tracey (2010) all acknowledge that teachers or university student teachers need or want specific training or procedures to appropriately respond to situations of death, dying or bereavement. In some instances there was a lack of specific training available (Papadatou et al., 2002, p. 326). McGovern and Tracey (2010, p. 250) recommend government departments make financial allocations for training and support of teachers, stating that experiences and knowledge need to be shared and best practice adopted internationally. They also suggest that different cultural experiences and multicultural aspects form part of this training. This is reinforced by Papadatou et al. (2002, p. 336) who explains that the knowledge and skills gleaned from specialized training 'should be well integrated and make use of the culture's traditional religious practices and community resources which are mobilized in the face of death'.

Rowling (2008) and McGovern and Tracey (2010) strongly recommend school policy development in regards to loss. Specifically, McGovern and Tracey (2010, p. 249) suggest that it may be time to develop bereavement policies and procedures formally in all educational settings. Some positive implementations are found in Ireland, for instance Tracey and Holland (2008, p. 262) note the *Lost for Words* training in Hull and Derry encouraged schools to develop policy and procedure around the management and response to death and loss. Initially, schools in this area did not have policies but by 2008, one third of all primary schools and 20% of secondary schools had a policy in place. However, Tracey and Holland (2008, p. 264) note that schools still need support in developing and formalising policy and training staff. Kellehear (2014, p. 223) suggests that parents, teachers and students can aid in the development of policy documents and allow for open discussion around the experiences of death, dying and loss in order to normalise these issues in the school community.

Later, McGovern and Tracey (2010, p. 235) examined how schools in Galway, Republic of Ireland and Derry in the North of Ireland, managed and responded to bereavement. McGovern and Tracey (2010) found that loss was contained in their school policy documents but not formally included in the curriculum. They recommend that students be made aware of bereavement policy and then they would know how to access available support (McGovern & Tracey, 2010, p. 249). These last points bring us to the consideration of death education.

What would death education achieve?

Kellehear (2014, p. 222) in encouraging a normalisation of death and loss, argues for death education as a '... necessary professional responsibility and community action'. By increasing the education level, engaging the community about death and loss '... the level of hysteria and public anxiety' will be reduced (Kellehear, 2014; p. 222). Death education also reduces personal anxiety, contests fear and ignorance, raises hope and recreates a social context to insufficient or 'problem focussed' images of death, dying and loss (Kellehear, 2014, pp. 224–226).

In addition, Kellehear and O'Connor (2008, p. 112) suggest that death education needs to be in the context of community engagement, not adhering to a didactic approach but one that is participatory and builds on a community's skills and wisdom. For example, in Newcastle, New South Wales, Australia, the Division of Palliative Care built a partnership with secondary school authorities, in order to develop a death education programme using HPPC principles. Students were encouraged to address issues around death as they arose in various subjects. This was to encourage reflective conversation and reduce reluctance and fear and to, 'challenge student's perceptions based on media representations of death' (Kellehear & O'Connor, 2008, p. 114). Evaluation of this HPPC project found that students developed knowledge and their comfort levels increased when talking about topics related to death (Kellehear & O'Connor, 2008, p. 114).

A concept called 'Café Conversations' was also used with this school community to create discussion with teachers about death, dying and loss in the school setting (Kellehear & O'Connor, 2008, p. 114). The participating teachers had identified that not knowing what to say to the bereaved was a key issue for them and as a result were able to attend practical workshops on grief and bereavement that included suggestions about communication (Kellehear & O'Connor, 2008, p. 114). Kellehear and O'Connor (2008) noted that teacher confidence and a teacher's ability to discuss death, dying and bereavement with students increased, however, there was a need for further resources to assist with student exploration and consideration of death in the future (Kellehear & O'Connor, 2008, p. 114). Similarly, Galende (2015, p. 91) also noted the need to create and implement educational resources.

Noonan, Horsfall, Leonard, and Rosenberg (2016) and Mills and Mills (2016) in light of death education also advocate for community engagement where workable relationships and partnerships are prioritised. Noonan et al. (2016, p. 32) state that this is where 'community development initiatives are focussed on process and interpersonal relationships'. This emphasis on death education being a community experience also resonates with holistic public health perspectives.

Thinking holistically

In a broader frame, Rowling (2008, p. 241) advocates for a holistic public health perspective explaining that trauma and grief now reside in a different landscape with ongoing media coverage of global events, such as terrorism and violence. Rowling (2010, p. 148) states that experiences of loss are not just private matters and that there is a need for both community recovery and individual and family support.

Rowling (2010) argues for a holistic approach to loss and grief experiences and a resulting connectedness in school communities. A holistic approach means accessing the 'hidden curriculum' or the ethos of the school and can be explained as the unintended curriculum and learning of a school. It is found in school policies that provide emotional well-being of students, a pastoral care system, availability of outside agencies, the belief system and also within relationships (Rowling, 2010, p. 150). This includes staff relationships, staff morale and relationships between the principal and teachers (Rowling, 2010, pp. 151, 152).

The Health Promoting School (HPS) framework provides the conditions for the community to be proactive and take ownership of the health of that community rather than being reactive to grief and loss events as they transpire (Rowling, 2010, p. 150). Grief and loss within this framework requires a focus on ethos, policy, curriculum and partnerships with community. Rowling (2010, p. 148) explains that this public health perspective focuses on the school community and how 'organisational conditions can be created that enhance positive outcomes of connectedness to school as a place for individuals and groups'. Rowling (2008, p. 243) highlights the flawed nature of the individualised approach to intervening with

grieving young people, where young people are seen as having the problem that needs to be fixed. Rowling (2010, p. 148) states,

By concentrating on an individual's experience divorced from its context, we have failed to embed their issues of concern in a social environment ... after the family, this environment involves the school community.

Social support comes from organisational practices within the school, through policy, ethos, curriculum and partnerships that provide people with support through periods of grief such as, experiencing 'a connectedness in shared rituals', through special grief support groups at school or for teachers taking informal leave, where

Grief should be seen as a normal event that can be managed by school communities with outside support ... it should not be pathologised and seen as only the domain of outside experts. (Rowling, 2008, p. 244)

This resonates with Papadatou et al. (2002, p. 336) who also found that a team approach is needed between educators, family members and mental health professionals.

Rowling (2008, p. 248) contends that where an event has affected many school community members there is a need to make meaning collectively by 'talking it through and telling their stories'. In addition, Rowling (2010, p. 159) emphasises that 'the voices of young people need to be sought, included and valued'. Rowling (2008, p. 248) explains that this meaning making engenders a sense of predictability in the 'emotional, physical, social and spiritual world of the school'. Indeed, this idea of sharing stories may also assist teachers in their grief. One consideration however, is that young males may need to process and organise their thoughts or take action rather than express their feelings (Rowling, 2008, p. 246). There may be a danger in presuming that 'one size fits all' when it comes to strategy implementation.

Telling stories at school

It is also important to highlight 'storytelling' at this stage as an effective strategy to aide bereavement and End of life. Rowling (2008) and Kellehear (2014) argue that community sharing or storytelling is a way forward for communities dealing with death, dying and bereavement. Specifically, (Kellehear, 2014, p. 222) states,

... It is important to connect individual experiences with the experiences of others, for it is a fact that most people have their own experiences of dying, death, loss or care and that to swap stories of those experiences with other people is important in reducing a sense of isolation.

Similarly, Rumbold et al. (2011, p. 145) also name storytelling as a community cultural resource.

At this time the literature does not state how specific strategies, such as storytelling or its variations such as story writing, reading stories, journaling or public speaking may be already present in the lives of the bereaved or how they may be used in school communities. The opportunities to use these strategies in school

settings particularly in school assemblies, school newsletters, literacy or literature subjects are endless and it is hoped to explore these further in future research.

Conclusion

There is a complex range of perspectives regarding death, dying and bereavement. They are difficult experiences to grasp but they are normal experiences. In prioritising well-being for all school community members there is a need for these issues to be community owned rather than *only* individually evaluated. Therefore, compassion and partnership are emphasised as ways forward.

The literature identifies the following priorities for improving school communities' capacity to work more effectively with death, dying and bereavement: building partnerships and capacity in schools through community development; solidifying these issues in policy; determining how bereavement is understood and lived out in everyday life; making spirituality and compassion visible and understanding how specific strategies, such as storytelling may be already present in the lives of community members.

With the intent of further research in school communities, the use of a constructivist theoretical lens is an imperative, as this acknowledges the ways in which communities and individuals make meaning around death, dying and bereavement. It is essential to understand how we can socially and culturally create a compassionate, positive and healthy regard for these issues in our communities. Storytelling may indeed prove to be a suitable strategy in facilitating this process.

Creating partnerships between school communities and health promoting palliative care may assist in moving us towards a healthy atmosphere of openness, connectedness and support. However, we are only in the beginning stages of developing *compassionate* school communities. The HPPC and HPS framework have much to offer schools in the development of a model for a way forward, however, what is currently lacking is the training, models, strategies and resources for implementation. Importantly, further research is required to understand how school community members understand death, dying and bereavement within their social networks and how they think compassion and partnership may be made visible, in the worthy pursuit of making death 'part of life' in their school communities.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Carla Jane Kennedy  <http://orcid.org/0000-0003-4504-9951>

References

- Aoun, S. M., Breen, L. J., Rumbold, B., & Howting, D. (2014). Reported experiences of bereavement support in Western Australia: A pilot study. *Australian and New Zealand Journal of Public Health*, 38, 473–479. doi:10.1111/1753-6405.12177
- Barry, M., & McGovern, M. (2000). Death education: Knowledge, attitudes, and perspectives of Irish parents and teachers. *Death Studies*, 24, 325–333. doi:10.1080/074811800200487
- Breen, L. J., Aoun, S. M., O'Connor, M., & Rumbold, B. (2014). Bridging the gaps in palliative care bereavement support: An international perspective. *Death Studies*, 38, 54–61. doi:10.1080/07481187.2012.725451
- Breen, L. J., & O'Connor, M. (2011). Family and social networks after bereavement: Experiences of support, change and isolation. *Journal of Family Therapy*, 33, 98–120. doi:10.1111/j.1467-6427.2010.00495.x
- Galende, N. (2015). Death and its didactics in pre-school and primary school. *Procedia-Social and Behavioral Sciences*, 185, 91–97. doi:10.1016/j.sbspro.2015.03.403
- Kellehear, A. (1999). Health-promoting palliative care: Developing a social model for practice. *Mortality*, 4, 75–82. doi:10.1080/713685967
- Kellehear, A. (2012). *Compassionate cities*. Oxfordshire: Routledge.
- Kellehear, A. (2013). Compassionate communities: End-of-life care as everyone's responsibility. *The Quarterly Journal of Medicine*, 106, 1071–1075. doi:10.1093/qjmed/hct200
- Kellehear, A. (2014). Death education as a public health issue. In J. Stillion & T. Attig (Eds.), *Death, dying and bereavement: Contemporary perspectives institutions and practices* (pp. 221–232). New York, NY: Springer.
- Kellehear, A. (2016). Commentary: Public health approaches to palliative care – The progress so far. *Progress in Palliative Care*, 24, 36–38. doi:10.1080/09699260.2015.1103499
- Kellehear, A., & Fook, J. (2010). Bereavement care for the non-bereaved: A health promotion challenge. *Bereavement Care*, 29, 21–25. doi:10.1080/02682621.2010.522376
- Kellehear, A., & O'Connor, D. (2008). Health-promoting palliative care: A practice example. *Critical Public Health*, 18, 111–115. doi:10.1080/09581590701848960
- McGovern, M., & Tracey, A. (2010). A comparative examination of schools' responses to bereavement and the associated needs of the school community in Galway, West of Ireland and Derry, Northern Ireland. *Pastoral Care in Education*, 28, 235–252. doi:10.1080/02643944.2010.504223
- Mills, S., & Mills, J. (2016). Future directions for community engagement as a public health approach to palliative care in Australia. *Progress in Palliative Care*, 24, 15–18. doi:10.1179/1743291X15Y.0000000012
- Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care*, 24, 31–35. doi:10.1080/09699260.2015.1103498
- Papadatou, D., Metallinou, O., Hatzichristou, C., & Pavlidi, L. (2002). Supporting the bereaved child: Teacher's perceptions and experiences in Greece. *Mortality*, 7, 324–339. doi:10.1080/1357627021000025478
- Rosenberg, J. (2011). Whose business is dying? Death, the home and palliative care. *Cultural Studies Review*, 17, 15–30. doi:10.5130/csr.v17i1.1971
- Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2015). Informal caring networks for people at end of life: Building social capital in Australian communities. *Health Sociology Review*, 24, 29–37. doi:10.1080/14461242.2014.999400
- Rosenberg, J. P., Mills, J., & Rumbold, B. (2016). Putting the 'public' into public health: Community engagement in palliative and end of life care. *Progress in Palliative Care*, 24(1), 1–3. doi:10.1080/09699260.2015.1103500

- Rowling, L. (2008). Linking spirituality, school communities, grief and well-being. *International Journal of Children's Spirituality*, 13, 241–251. doi:10.1080/13644360802236482
- Rowling, L. (2010). Schools and grief: Attending to people and place. In B. Monroe & F. Kraus (Eds.), *Brief interventions with bereaved children* (pp. 147–160). New York, NY: Oxford University Press.
- Rumbold, B. (2012). Compassionate care: Engaging the spirit in care. *Progress in Palliative Care*, 20, 106–113. doi:10.1179/1743291X12Y.0000000005
- Rumbold, B., & Aoun, S. (2014). Bereavement and palliative care: A public health perspective. *Progress in Palliative Care*, 22, 131–135. doi:10.1179/1743291X13Y.0000000079
- Rumbold, B., Gardner, F., & Nolan, I. (2011). Spirituality and community practice. In S. Conway (Ed.), *Governing death and loss: Empowerment, involvement and participation* (pp. 139–147). New York, NY: Oxford University Press.
- Tracey, A., & Holland, J. (2008). A comparative study of the child bereavement and loss responses and needs of schools in Hull, Yorkshire and Derry/Londonderry, Northern Ireland. *Pastoral Care in Education*, 26, 253–266. doi:10.1080/02643940802472197
- World Health Organization. (1986). *The Ottawa charter for health promotion: First international conference on health promotion*, Ottawa, November 21, 1986. Geneva: WHO.

Chapter 3 analyses the critical social theories that relate to this study and argues that they provide a valuable framework for thinking about how we create compassionate schools in light of death, dying, and bereavement. This argument was included in the published article, therefore

- Social constructionism as an overarching theory will be discussed conceptually and within a broad, historic context providing a lens in which to view this study.
- The critical social theorists, Marcuse and Habermas, their broader perspectives, their specific theories that are valuable for this study, and their implications for school communities will be critically examined.

3.1 Social Constructionism

3.1.1 History

According to Burr (2003, p. 12), Nietzsche, Marx, and Kant commonly viewed knowledge partly as ‘a product of human thought rather than grounded in an external reality’. A number of sociologists in the early twentieth century formalised this as the sociology of knowledge, concerned with how sociocultural forces construct knowledge and included concepts such as false consciousness and ideology (Burr, 2003).

These ways of thinking have influenced social constructionism which steers away from modernism or the embodiment of ‘the Enlightenment faith in technological and human progress through the accumulation of legitimate knowledge’, essentially challenging a ‘belief in a knowable world, and with it a knowable self’ (Neimeyer, 1998, p. 136). This also challenges what is perceived as legitimate knowledge. Burr (2015, p. 4) perceives social constructionism as defying scientific progress where ‘psychology is accused of being imperialist toward other cultures’.

Instead, social constructionism embraces postmodernism. Neimeyer (1998, p. 136) eloquently explains that

It is more disquieting, holding out the promise of only a shifting, fragmentary and constructed knowledge, without the bedrock of certainty of firm (logical or empirical) foundations. Even the self is dethroned from a position of agency, freedom and conscious self-determination, vanishing into a proliferation of inconsistent social roles on the interpersonal and cultural stage.

From this paradigm of postmodernism and from the roots of the sociology of knowledge, Berger and Luckmann’s influential book *The Social Constructionism of Reality* (1966) also drew upon Mead’s (1934) work in the discipline of social interactionism (Burr, 2003). The theory of social interactionism

posits that people construct other people's identities and their own, through everyday social interactions. Berger and Luckmann (1967) argued that people form and then continue to see all social phenomena through social practices, with three fundamental processes being responsible for this: internalisation, objectivation, and externalisation (Burr, 2003). According to Berger and Luckmann (1967, p. 79),

... It is important to emphasize that the relationship between man [sic], the producer, and the social world, his product, is and remains a dialectical one ... the product acts upon the producer ... Society is a human product. Society is an objective reality. Man is a social product.

Predominantly, this showed 'how the world can be socially constructed by the social practices of people but at the same time experienced by them as if the nature of their world is pre-given and fixed' (Burr, 2003, p. 13).

Berger and Luckmann's (1967) work has been further developed by other scholars who recognise that knowledge is influenced culturally, socially, historically, and linguistically (Cunliffe, 2008).

3.1.2 Capturing social constructionism

Social constructionism has now developed from a variety of disciplines, spanning research methods such as narrative analysis, ethnography, and discourse analysis (Cunliffe, 2008). This literature assists in understanding social constructionism as a broader concept.

One way of understanding this is by exploring the differing perspectives on postmodernism; in other words, the same basic concept can be perceived very differently depending on your social construction of it. In regard to social sciences, Rosenau (1991, p. 15) emphasises two general definitions representing the alternative ends of the spectrum of postmodern thinking — sceptical and affirmative post-modernism.

Sceptical post-modernism portrays the dark side of the post-modern age and describes it as fragmented, despairing, alienating, and meaningless where 'no social or political project is worthy of commitment' (Rosenau, 1991, p. 15). Through over population, genocide, and environmental devastation, the future shows a continuing decline into chaos.

The affirmative post-modernist position has a more positive, hopeful perspective consenting to positive political action (struggle and resistance). This may encompass the ideas of empowerment and social justice. According to Rosenau (1991, p. 16), 'Most affirmatives seek a philosophical and ontological intellectual practice that is non dogmatic, tentative and non-ideological'. There is a range of moderate to extreme positions lying within both sceptical and affirmative post modernism positions and they are useful for understanding apparent contradictions that exist. Herein lies the

tension of post-modernism as there are values and principles that post modernists operate from; however, there is an acknowledgement that there are many ways to function, not only one way. This resonates with the broader definitions of social constructionism that there are many definitions not only one.

However, Witkin (2011) confirms that despite variations in definitions and meanings, it is possible to draw together some commonalities of social constructionism. Social constructionism is a view of knowledge that is contingent on context – historical, cultural, and social; it is concerned with making meaning particularly through language; it possesses a critical stance toward taken-for-granted knowledge that creates our understanding of reality; it is a view of knowledge as a form of social action and it is a belief that ‘knowledge is sustained by social processes (particularly language)’ (Witkin, 2011, p. 19).

Expressed more boldly, is this personalised view of social constructionism that is still reflective of the commonalities expressed by Witkin (2011).

I call myself a social constructionist. I’m committed to ideas suggesting that much of what we know or think we know is a construction emerging from our unique historic, dialogic, and discursive cultural context. I question the privileged voice of the grand metanarratives of Western social, economic, political, and scientific thought that identifies the Truth – what counts as reality, who is able to define it, and who has access to knowing it. I have contested with vigor the hubris of those claiming the final word on the matter, or those whose stories or interpretations claim to have finally captured events as they truly are. (Besthorn, 2007, p. 169)

Social constructionism may also be viewed in terms of micro and macro orientations (Witkin, 2011). A micro focus emphasises interpersonal contexts, such as families or the teaching staff of a school. A macro focus approach concentrates on broader, historical, cultural, and social factors and may explore how ideas like bereavement are linked to historical and cultural factors.

3.1.3 Language and identity

The role of language in social constructionism is where people create shared ways of understanding through everyday interactions. Our identities and everything we think or talk about is constructed through language and this includes the construction of our personality, attitudes, skill, and temperament (Burr, 2015). These are not psychologically owned but socially constructed. This knowledge and what we know as truth exists between people and is culturally and historically specific. Therefore, what we know as truth also varies cross culturally and historically (Burr, 2015).

From a macro social constructionist perspective, a person's identity is realised by the interweaving of components, such as gender, age, occupation, and class; each constructed by cultural discourse (Burr, 2015). In this process, identities are claimed or resisted and these are contained within various dominant discourses. For instance, Kitzinger (1989, pp. 94-95) claims that discourses that challenge the existing ideology or status quo, such as radical feminist or political lesbian accounts, are discredited or subjugated. As Burr (2015, pp. 127-128) confirms, 'discourses do not interlock neatly with each other ... there are weak points, places where they may be attacked, and points which other discourses pose a real threat; they are implicitly being contested by other discourses'. Constructionists also view language as arbitrary rather than fixed where meanings are contextual. This results in a level of conformity whereby, 'To "make sense" to others, we have no choice but to position ourselves within a symbolic order that precedes us as individuals, that establishes for us a world of socially warranted meanings ...' resulting in meanings remaining open and or contested (Neimeyer, 1998, p. 138).

3.1.4 Social action and power

With the existence of prevailing and dominant discourse, there is the inevitability of analysing and/or contesting power relations within institutions and social organisations. As Burr (2015, p. 5) indicates, the constructions themselves are 'bound up with power relations because they have implications for what it is permissible for different people to do and how they may legitimately treat others'. Similarly, power relations was captured earlier by Besthorn (2007, p. 169) stating '... I question the privileged voice of the grand metanarratives ... what counts as reality, who is able to define it, and who has access to knowing it'. Neimeyer (1998) suggests a critical analytic stance is adopted by constructionists and discourse analysts toward written and spoken texts with the aim of searching for socio-political implications and therefore supporting social change. From a social constructionist or post-modern position, these views are all of equal value and therefore fundamentally operate for social change from a social justice or empowerment perspective. Social constructionists, particularly those coming from a critical perspective, challenge or question the influence of dominant discourses and recommend alternatives (Witkin, 2011). This reflects Burr's (2015) earlier reference to resisting and claiming identities. Burr (2015, p. 141) also draws upon Foucault's proposal that change is possible through opening up marginalised and repressed discourse and that this is a form of 'consciousness-raising'. This implicitly challenges social practices, structures, social relations, and ultimately identities; therefore, resistance should be expected (Burr, 2015). For instance, in schools, the examination of dominant discourse concerning death, dying, and

bereavement offers the possibility of opening up a range of alternative and perhaps more compassionate practices.

This emphasis on social justice and opening up marginalised discourse also aligns with my proposed definition of compassion from the literature review as it focuses on the intention to understand people who are suffering and who may not be in a dominant position. As established, compassion is ‘an intention (justice) to understand and empathize with people who are suffering by extending them support in thought, word and action seeking school community as well as individual change’ (see Chapter 2). Understanding and empathising creates opportunities for ‘consciousness-raising’ and as a by-product, may enable change on social and structural levels.

3.1.5 Socially constructed understandings of power and assumptions in research

Considering the influence of the social world, Charmaz (2006, p. 189) defines social constructionism as a ‘theoretical perspective that assumes that people create social reality(ies) through individual and collective actions ...’ with constructionists studying ‘what people at a particular time and place take as real ...’. In relation to power, objectivity is simply not possible for researchers as assumptions are embedded in our own perspectives informing questions that are and that are not asked (Burr, 2015). Therefore, according to Charmaz (2008a), the researcher needs to acknowledge the integral part they play in the research, viewing the research as a co-construction. This ensures that the research relationship is democratic where the researcher is not implicitly instructed to be more powerful than the participants in the research (Burr, 2015). Social constructionism essentially reconstructs the participant role and their relationship to the researcher (Burr, 2015). In order to make the researcher’s assumptions explicit, there is the need for discussion of power and authority. Specifically, there needs to be an acknowledgement of the researchers personal and political views and also how the researchers own biography may have shaped the research (Burr, 2015).

Moving away from the theoretical perspective of social constructionism and with an emphasis on action and process, Charmaz’s (2006, p. 187) definition of social constructivism specifies that it attends to how realities are made and ‘... assumes that people, including researchers, construct the realities in which they participate’. This is where ‘... constructivists enter the phenomenon, gain multiple views of it and locate it in its web of connections ...’.

3.1.6 Implications for this study

These concepts of social constructionism and constructivism are valuable for this study. From my perspective, death, dying, and bereavement are normal states that will eventually be experienced by everyone. For example, the bereaved or a dying person may be perceived as psychologically

depressed but alternatively, the truth being upheld may be that they are possibly oppressed or isolated by the society in which they reside. Further, it may be a school community who assumes that the issues or difficulties lie with bereaved people or they may simply not understand how to support people in this position. A school's reaction may be to refer students or families to psychologists for support and the community issue of not understanding how to support the bereaved may remain undetected or unresolved.

The dominant discourses of death and dying in schools embedded in the practices of schools and community are worth examining as they open up a range of alternative and perhaps more compassionate practices. Specifically, a psychological discourse of death, dying, and bereavement may prevail in schools upholding truths that deem bereaved people as needing individual psychological help, not a sociological one that may uphold truths that consider social and cultural contingencies such as the way the community is reacting to the bereaved person. This may result in the school continuing to refer bereaved individuals to psychologists and positioning the bereaved as in need of individual assistance rather than acknowledging the sociological perspective and the need for community change.

It is important to identify which voices of death, dying, and bereavement are being heard, what discourse is prevailing or being marginalised, and where resistance or potential for disrupting dominant discourse is apparent. This information may challenge the school as an institution identifying necessary social change or confirm or influence current practices. From a postmodernist perspective, this highlights my interest in social justice and empowerment and an overall political agenda where power is studied rather than the workings of language for its own sake.

It is also evident in the literature review in Chapter 2 that little is known about the lives of people experiencing bereavement and death attitudes of children. It is suggested that children and bereaved others may not have been given a voice as far as death, dying, and bereavement is concerned; therefore, their discourse may be considered marginalised in a school community setting. The dominant discourse may be that students are more resilient or that they don't grieve. These assumptions suppress a bereaved student's voice. As reported in the literature review in Chapter 2, it is known how teachers think and/or feel about talking about death, dying, and bereavement and this suggests that researchers and/or the community are adept at listening to dominant discourse in schools; however, it is essential that researchers and/or the community know how the bereaved think/feel about the reactions of teachers or other school community members. Overall, social constructionism, cultural, social, and historic factors need further deliberation and exploration in regard to an Australian, western primary school community context. Unearthing how

death, dying, and bereavement are understood in school community contexts is vital, particularly if social action or change is needed; marginalised discourse cannot continue to go undetected.

3.2 Critical Social Theorists

Critical social theory highlights connections between cultural and social values, and expectations and how they are often internalised by individuals in undermining ways emphasising a social justice approach (Gardner, 2014). This is underpinned by the complexity of interlinked ideas about power relations, domination, and discourse as outlined by the following theorists. I have chosen to explore these separately as each provides a distinct contribution.

3.2.1 Herbert Marcuse

From a liberatory perspective, Marcuse (1964) views inwardness, privacy, memory, distance, and particularly individual artistic experiences as revolutionary initiates, allowing individuals to liberate themselves from the effects of a dominant culture, its consumerism, and indoctrination. Marcuse (1964, p. 68) states that ‘... The soul contains few secrets and longings which cannot be sensibly discussed, analyzed and polled ...’. Further, Marcuse (1964, p. 19) argues that ‘a comfortable, smooth, reasonable, democratic unfreedom prevails in advanced industrial civilization, a token of technical progress’. He states that independence of thought, self-reliance, and the right to political resistance are being robbed of their critical purpose in a society which is constructed to satisfy the limited, perceived needs of individuals (Marcuse, 1964). Inner freedom is where ‘man [sic] may become and remain “himself”’; however, ‘this private space has been invaded and whittled down by technological reality’ where mass distribution and production claim the whole individual (Marcuse, 1964, p. 25). Marcuse (1964, p. 26) explains that this ‘indoctrination of consumerism becomes a way of life’ and from this persists one dimensional thought and behaviour constantly promoted by politics and mass media where all thought is determined by the available societal material. This indoctrination effectively impedes divergent thinking and limits or obstructs people questioning the system.

Essentially, Marcuse (1964) contests critical theorists and their innate disregard of individual isolation and instead champions inwardness, privacy, memory, and distance as this may allow for divergent thinking and an escape from indoctrination. From Marcuse’s (1964) perspective, memory can provide a type of reverie or space for contemplation, effectively separating oneself from everyday life. This distance according to Marcuse is crucial for developing revolutionary consciousness and is a key to independent critical thought. This concept also applies to Marcuse’s argument regarding aesthetic immersion which may be in itself revolutionary as art opens up new

ways of feeling and sensing; he states that 'art cannot change the world'; however, 'it can contribute to changing the consciousness and drives men and women who could change the world' (Marcuse, 1978, p. 32).

In consideration of democracy, Marcuse (1970) suggests that the only way to make democracy a reality is for participants to be well informed and in full possession of all relevant, authentic information when making deliberations. Marcuse (1970) emphasises that independent thought in an attempt to break with mainstream ideology. He argues that by tolerating a number of truths, the status quo remains unchallenged and instead an objective truth must be determined. This safeguards against dominant discourse prevailing and ensures that insightful or profound ideas are not marginalised. To aide this process, Marcuse (1970, p. 99) advocates for a total immersion '... in a radically different perspective that challenges mainstream ideology' and as a result, free thinking is revived.

According to Brookfield (2005) herein lies an opportunity for educators to work as developers of consciousness, which aligns with Marcuse's desire to escape indoctrination supported by the existing power structure.

3.2.2 Implications for this study

Marcuse (1970) provides fertile ground for this study, particularly in regard to personal introspection and its revolutionary value. This means selecting bereaved members of school communities as participants for the study seems logical as they most likely would be in full possession of authentic information. Importantly, they may also be subjected to regimes of truth; however, in this instance, a death may be providing a break where the participants are already questioning their own reality or truth. Their introspection may be able to offer alternative ways of thinking about death, dying, and bereavement. This may link to the postmodern view that there is a need to acknowledge that there are many ways to operate, not merely one way; this links back to Rosenau's (1991) reference to the spectrum of postmodern thinking.

Further to this, allowing participants time, space, and privacy to record or think about their memories and how they may want to answer questions should also be a priority.

As indicated in the literature review, it is common for bereaved people to experience a breakdown in social relationships (Breen & O'Connor, 2011). Coupled with teachers avoiding the topic of death (Galende, 2015), this creates a situation where the bereaved are marginalised in relation to social contact and discourse. This may also result in a situation where there is an inability or avoidance of sharing experiences of death and bereavement.

Marcuse makes particular reference to the marginalised,

Underneath the conservative popular base is the substratum of the outcasts and outsiders ... they exist outside the democratic process, their life is the most immediate and the most real need for ending intolerable conditions and institutions. Their opposition is revolutionary even if their consciousness is not. (Marcuse, 1964, p. 200)

There is an opportunity for this study to capture the possibly revolutionary or divergent thoughts of bereaved people and their bereavement experience within a school community context. It may be possible to identify and detect dominant and marginalised discourse that exists in the school community about death, dying, and bereavement. This may reveal 'the management and control of consciousness' by the established school power structure.

3.2.3 Jürgen Habermas

As a critical social theorist, Habermas focuses on reclaiming reason. He is particularly focused on communicative learning or communicative action as a democratic process. This pertains to Habermas' ideas of western society where the crises of decline of the public sphere (where people talk about social issues), the threat to civil society, and the invasion of our lifeworld (worldview) results in people being unable to use reason in discussion and determine resolutions (Brookfield, 2005, pp. 220-221). The solutions to these crises lie in human discourse, communicative action, and learning democracy.

Communication and action are central to Habermas's (1992, p. 171) work and are defined by whether or not what people say is understandable or genuine in every word or utterance people make; therefore, an ideal conversation is 'a description of the conditions under which claims to truth and rightness can be discursively redeemed'. Also, the more free-thinking conversation is, the more likely it is to be genuine where reason can emerge. This is a catalyst for creating democracy.

However, with the intrusion and domination of money and power, the life world and public sphere are destabilised and this results in the mass media becoming the mouthpiece, thwarting communication. Habermas (1973, p. 4) emphasises that 'the electronic mass media of today is organized in such a way that it controls the loyalty of a depoliticized population'. This resonates with Marcuse (1964) who refers to the massive indoctrination effort to stop people questioning.

To counteract this effect, Habermas argues that by critically reflecting and developing a moral consciousness that people can distance themselves from the effects of money and power. Habermas (1990, p. 160) explains that moral consciousness occurs when 'the adult rises above the naiveté of everyday life practice'. As mentioned earlier, situations or events like a death or illness may result in this rising above the naiveté of everyday life, where the taken-for-granted thoughts and assumptions of one's individual worldview are thrown into question.

For Habermas, achieving democracy is in reaching agreement, and this ideal situation involves common understanding. Habermas (1979, p. 3) explains that in reaching agreement, people experience 'the intersubjective mutuality of reciprocal understanding, shared knowledge, mutual trust, and accord with one another'. This is essentially a catalyst for social action as Habermas (1984, p. 287) states that it is 'a process of mutually convincing one another in which the actions of participants are coordinated on the basis of motivation by reason'.

What is crucial here in achieving democracy through agreement and action is assessing validity claims. Habermas (1979, p. 3) explains that an 'agreement is based on recognition of the corresponding validity claims of comprehensibility, truth, truthfulness, and rightness'. This is the ability to judge in ordinary conversation whether people can trust what the other is saying. Firstly, Habermas (1973, p. 18) refers to the 'comprehensibility of the utterance' where clarity of the words said are assessed. Secondly, 'the truth of its propositional component' is considered. Thirdly, Habermas (1979, p. 18) explains that 'the correctness and appropriateness of its performatory component' is gauged or whether or not what the person is saying is authentic. Fourthly, according to Habermas (1979, p. 3), 'communicative action can continue undisturbed only as long as participants suppose that the validity claims they reciprocally raise are justified'. If all four of these validity claims can be fulfilled, meaningful, authentic conversation can be achieved.

This legitimacy can also be used to form the basis of democratic process by evaluating conversation or discourse specifically. According to Habermas (1992, p. 260), there are rules where

that (a) all relevant voices are heard, (b) the best of all available arguments, given the present state of our knowledge are accepted, and (c) only the non-coercive coercion of the better argument determines the affirmations and negations of the participants.

Rule (a) reflects ideas expressed by Marcuse in regard to marginalised and dominant discourse, while rule (b) mirrors Marcuse's idea of participants having complete, authentic knowledge.

Habermas also acknowledges that 'language is also a medium of domination and social power ... it serves to legitimate relationships of organized force' (Habermas, 1988, p. 172). He seeks to validate marginalised voices and acknowledges that this 'organized force' threatens civil society but that marginalised groupings 'have the advantage of greater sensitivity in detecting and identifying new problem situations' (Habermas, 1996, p. 381). This is also similar to Marcuse's identification of outsiders and outcasts opposition being revolutionary. Habermas (1975, p. 27) also claims that if society marginalises certain voices, then 'communication between participants is then systematically distorted or blocked'. In response to this, Habermas (1970, p. 7) states that democratic decision making represents 'a consensus arrived at in discussion free from domination', a democracy well worth striving for where all voices are legitimised but no doubt difficult to accomplish.

Further to this, Brookfield (2005) states that Habermas' work also encapsulates two broad forms of learning that has great relevance for critically reflective education – non-reflexive and reflexive learning. Reflexive learning is defined by questioning and challenging everyday assumptions. Habermas (1975, p. 15) states, 'reflexive learning takes place through discourse in which we thematize practical validity claims that have become problematic or have been rendered problematic through institutionalized doubt, and redeem or dismiss them on the basis of arguments'. Opposing this, 'non-reflexive learning takes place in action contexts in which implicitly raised theoretical and practical validity claims are naively taken for granted or rejected without discursive consideration' (Habermas, 1975, p. 15). Simply, non-reflexivity is where validity claims or dominant discourses go unquestioned or unchallenged.

3.2.4 Implications for this study

In reflecting on Habermas' theories, it is noted that reflexive learning is very relevant for this study, particularly in regard to the development of questions for participants. It will be important to encourage reflexive learning in discussions with participants in an attempt to uncover dominant discourses. It is also critical for my own learning as a researcher so my own biases or assumptions are both transparent and continually challenged.

Habermas' ideas in regard to the presence of social power and marginalised discourse, particularly concerning validity claims, are also relevant to this study and to being actively reflexive. His study encourages an exploration of the social power that exists and to ascertain whose voices are being heard. Therefore, a focus on social power within school communities would be beneficial.

Habermas' ideas resonate with Marcuse's preservation of the status quo subverting power. Together, these ideas propose the need to investigate these power relations and how they render some voices invisible.

Habermas and Marcuse are both aligned in their focus upon the central project of understanding and creating the conditions for democracy. Habermas recognises the importance of participants having the best arguments and knowledge available, similar to Marcuse stating the need for participants having full authentic information. This provides good reason for bereaved members of the community to be involved in the study.

Both Habermas and Marcuse aim to release people from consumerism, indoctrination, and the effects of money and power in order to make free decisions. Events such as a death may throw taken-for-granted assumptions into question. Through reflexivity and critical reflection, which will be discussed more specifically in the next chapter, there is the possibility of hearing untainted and non-media influenced conversation from bereaved people while identifying media influenced discourse.

In essence, it allows the possibility of accessing revolutionary thought, as expressed earlier by Marcuse.

The links between social constructionism, the theories espoused by these critical social theorists, and the study at hand continue to illuminate the direction of this study. Specifically, this includes: the practicalities of hearing the voices of the bereaved or grieving school community members; illuminating power that exists in the school setting that contribute to the marginalisation of alternative ways of thinking and being; examining dominant or marginalised discourse and their implications for engendering community compassion; and enabling reflexive learning to resist or disrupt normative and limiting practices. This will continue to assist in answering the question ‘how do we create compassionate schools in light of death, dying, and bereavement’?

3.3 Summary

In this chapter, I have argued that theories of social constructionism reveal how particular ways of thinking and behaving are constructed through context, language, and identity. Schools currently respond to experiences of death, dying, and bereavement in ways that marginalise particular perspectives. Social constructionism, such as postmodernism, can present as value free: seeing a range of perspectives of equal value. Integrating social constructionism with critical social theory provides a lens to view these inequities and to argue for a socially just approach. The ways of uncovering the dominant power relations and the discourses they underpin are offered by Marcuse and Habermas. This strong thread of social justice and empowerment binds these critical social theorists together and prioritises the inclusion and representation of repressed or marginalised discourse.

I have argued that taking a critical social constructionist perspective enables the unearthing of assumptions that are promoted by particular ways of perceiving death, dying, and bereavement. Therefore, this study will be viewed through a critical social constructionist lens, whereby perspectives will be sociological rather than psychological. This allows the challenging and questioning of dominant discourse and the recommendation of alternatives.

The combined theoretical underpinnings of critical social theory and social constructionism also further confirm the relevance of how I have defined compassion in the literature review in Chapter 2 as ‘an intention (justice) to understand and empathize with people who are suffering by extending them support in thought, word and action seeking school community as well as individual change’. In light of these critical perspectives and my definition, this study will focus on the examination of discourse to ensure marginalised and dominant discourse are revealed, the involvement of ‘authentic’ participants, and the understanding and conveying of context.

Firstly, it will be important to identify and analyse the discourse that pertains to death, dying, and bereavement within a school community and determine what may be considered marginal or dominant in order to establish how the school community perceives these issues. This may challenge the school as an institution and identify necessary social change or confirm or influence current practice. To reiterate, this highlights this study's interest in a political/power agenda rather than studying the workings of language; therefore, attention will be paid to how issues of power are expressed in particular ways.

Secondly, in reference to 'full authentic information' and 'accessing revolutionary thought', it will be critical for bereaved community members to be participants in the study because they are the most impacted by the power relations and normalised practices that currently constitute their experiences. Their ideas and thoughts about existing power structures, dominant discourse, and community reactions will form a large focus for the research.

Thirdly, it will also be essential to understand and then convey the context of the school community — its history, culture, mission, and vision as a way of exploring dominant discourse. The individual identities and context of the participants will form a central part of the study. The consideration of a cultural or gendered lens will be critical to unearthing dominant discourses. This study also intends to concentrate on how the bereaved perceive their school community; as a result, context is exceptionally important.

The intention and integrity of this study draws largely on a critical perspective emphasising the ideas of empowerment and social justice. This perspective sits alongside the overarching question, 'how do we create compassionate schools in light of death, dying, and bereavement?' By drawing upon my definition of compassion and this overarching question as a foundation for this study, in the next chapter, I propose a research design that explores the models of critical reflection and reflexivity that can be used to uncover ideologies and assumptions about death, dying, and bereavement. This enables school communities the opportunity to develop a compassionate pedagogy.

This chapter describes and justifies a qualitative research design and methods used to answer the overarching question, ‘how can we create compassionate schools in light of death, dying, and bereavement’? Specifically, this chapter discusses the rationale for the chosen method, sampling, recruitment, data collection, analysis, interpretation of the data, theoretical sampling, the implications of using critical reflection and reflexivity, and measures of promoting accuracy in this study.

4.1 Rationale

The purpose of this study was to propose a framework that explores how to create compassionate schools that are able to engage constructively with issues of death, dying, and bereavement.

Research that emphasises bereaved persons’ perspectives about how school communities react to death, dying, and bereavement is seriously lacking. As stated in Chapter 2, the research existing in this field is predominantly focused on perspectives from teachers and parents and what schools need to attend to from a non-bereaved perspective (Engarhos et al., 2013; Galende, 2015; Lane et al., 2014; Mak, 2012; Potts, 2013). While this information is useful, it is also necessary to gain insight into the perspectives of community members who have experienced bereavement.

According to Denzin and Lincoln (2008, p. 14), qualitative researchers ‘seek answers to questions that stress *how* social experience is created and given meaning’; therefore, a qualitative approach has been chosen for this study. Qualitative researchers emphasise and focus on the socially constructed nature of reality where values are prioritised (Denzin & Lincoln, 2008). This allows the examination of beliefs, values, and attitudes of people who have experienced bereavement and also allows an exploration of their interactions with their school community. Specifically, qualitative research will allow points of view to be captured, rich descriptions of the social world to be garnered, and an examination of the social context of a school community to be considered. This differs from quantitative researchers who would conduct a study based on inferential empirical methods and processes and incorporate the usage of mathematical models and tables (Denzin & Lincoln, 2008).

4.2 Grounded Theory

The grounded theory qualitative research design was first developed in 1967 by sociologists Glasser and Strauss in their publication *The Discovery of Grounded Theory: Strategies for Qualitative Research*. This emerged from their collaboration while researching death and dying in hospitals (Charmaz, 2014). According to Creswell, Hanson, Plano Clark, and Morales (2007) and in contrast to

quantitative research, grounded theorists asserted that theories should be grounded in data from people's actions, interactions, and processes from the field and then a theory is generated from data collected from individuals.

A grounded theory methodology gave me the opportunity in my research to not only describe the phenomenon of what it is like to be a bereaved person in a school community, but also to examine how school communities are helpful or unhelpful when it comes to death, dying, and bereavement. This means I could privilege bereaved voices who are positioned at the margins in schools, where silence about experiences of death, dying, and bereavement are the norm or pathologised (Bonanno et al., 2001). Grounded theory focuses on process and specifically on relationship and social structure. As Charmaz (2008b, p. 204) states, 'we can use the processual emphasis in grounded theory to analyze relationships between human agency and social structure that pose theoretical and practical concerns in social justice studies'. Therefore, this study draws upon grounded theory advocated by Charmaz (2008b, pp. 205-206) who developed it as a social constructionist method. Charmaz (2008b, pp. 205-206) states that she rejects a more positivist framework (Glaser, 1978, 1992) and (Strauss & Corbin, 1998; 1990). After studying both approaches, I chose to use the more flexible, creative approach advocated by Charmaz (2008a, 2008b; 2014) to address the existing social justice issues existing in school communities in regard to power and relationships.

As identified in Chapter 3, the definitions of social constructionism can differ. Writers clearly vary in how they define terms such as this and stress different priorities (Besthorn, 2007; Charmaz, 2006; Neimeyer, 1998). In regard to this research design and broadly defining this concept, Charmaz (2008a) states that a constructionist grounded theory aspires to an interpretative understanding of the phenomenon accounting for context not generalisations. Under this concept of constructionism, Charmaz (2014, p. 14) clarifies her position further, 'strong currents of social constructionism are apparent in constructivist grounded theory' and it is the constructivist position that Charmaz aligns herself with. This is more specific to process, as Charmaz (2014) states that constructivist grounded theory approves of an inductive, comparative, developing, and open-ended approach, emphasising flexibility and treating research as a construction. This is where researchers must acknowledge and examine their own preconceived notions and assumptions that may influence the analysis. This comparative approach as well as acknowledgement and examination of preconceived notions is of benefit to this study, particularly in regard to uncovering assumptions. As such, it is the constructivist grounded theory position that will be subscribed to in this study. This is useful in thinking about working with individuals to understand how they see their experiences in a social context.

Further, Charmaz (2008a, p. 402) advocates relativity and reflexivity making the following assumptions: reality is processual and constructed under specific conditions; the research process surfaces from interaction; the researchers and participants position are considered; and the researcher and participants co-construct the data.

In deciding upon a methodology, I was strongly drawn to phenomenology as this allows the research process to determine the essence of common meaning for individuals who have experienced bereavement (Creswell, 2013). In this study, phenomenology would have described what it is like to live as a bereaved person in a school community; however, this may not have accounted for the ongoing nature or process of grieving across time and the interactions between bereaved and non-bereaved community members. Grounded theory allows the phenomenon to be described and according to Charmaz (2008b, pp. 206-207), it also offers 'a systematic approach to social justice inquiry that fosters integrating subjective experience with social conditions in our analyses' which also means 'taking a critical stance towards actions, organizations and social institutions'. This is beneficial when determining what school communities do to be helpful or unhelpful from a bereaved person's perspective and fits with the theoretical position that I outlined in Chapter 3. Creswell (2013) also notes that phenomenology describes the common experiences of individuals where grounded theory moves beyond a description and attempts to determine a theory for a process/action. In an attempt to answer 'how do we create compassionate schools in light of death, dying, and bereavement?' the answer needs to be about a process or action rather than a described essence. As such, by generating a theory, I am closer to answering the overarching question.

4.3 Sampling and Recruitment

Purposive sampling (Mauk, 2017) was used in this study to establish what it is like to be a person in a school community who has experienced bereavement and to understand what a bereaved person considers helpful or unhelpful in schools. Therefore, it was important that (1) participants have experienced bereavement and (2) that there was a wide representation of different members of the school community in order to glean a diverse range of perspectives and to answer the overarching question. Overall, 23 interviews were conducted with 16 participants. The participants were comprised of two teachers (who were also involved in the school communities as parents), three deputy principals/principals, nine parents, and two students. Interestingly, among the nine parents who participated, seven of them were with health professional backgrounds. This may reflect an interest from the health professions in this subject from a professional perspective and/or personal desire to contribute to the discussion around death, dying, and bereavement. All the participants resided or had resided in a primary school community setting, had been bereaved of a close friend

or a family member (post 6 months and up to 6 years), and could address questions pertaining to their bereaved experience as well as their specific role/membership within their school community. Invitations and notices were sent to principals and teaching staff in four primary schools in central Victoria and notices were displayed in the staffroom. Notices for parents were put into school newsletters. Snowball sampling (Mauk, 2017) was also used as a recruitment method with the parents who were interested in the study by asking whether or not their children may also want to participate in the interviews. In addition, principals, teachers, and conveners of death/bereavement support groups were asked to pass on notices personally to people who fitted the selection criteria and would be motivated to participate, such as in Death Café, suicide support group, and parent/child bereavement support group.

Ethical considerations and strategies to protect the participants' rights and well-being are described in the Project Information Statement (PIS) (Appendix A), ethics statement (Appendix B) approved by the La Trobe University, College of Arts, Social Science and Economics, Human Research Ethics Committee (no. HEC17-063) and the State Government of Victoria Department of Education and Training (DET: 2017_003438) and Catholic Education Office CEOM: 0628 enacted in this study. The Human Research Ethics Committee provided approval prior to the participant selection and data collection. The participants were informed that their participation was voluntary and were provided with contact details if they had any concerns or wished to withdraw their participation at any time. As the data collection was based around the sensitive topic of bereavement, the participants were also informed that if they required support during or after their participation in research interviews, a one-off counselling session was available with Associate Professor Fiona Gardner Head of Social Work at La Trobe University, Bendigo campus. A reminder was given that their doctor could enact a mental health plan if that was required.

4.4 Data Collection

Data was mostly collected through semi-structured interviews and document retrieval, as well as artefacts which were copies of de-identified diaries, journals, social media entries, and emails. After obtaining written consent, I conducted 23 interviews with 16 school community members, including students, teachers, parents, deputy principals, and principals about their experiences of being a bereaved person in a school community and their thoughts and ideas about engaging constructively with death, dying, and bereavement in school communities by using a semi-structured interview style (nine participants had two interviews). Charmaz (2014, p. 56) advocates and defines the type of interview she uses in grounded theory as a 'gently guided, one sided conversation that explores a

person's substantial experience with the research topic' and this depicts a semi-structured approach.

4.1.1 Interviewing

Charmaz (2014) states that grounded theorists' main purpose is to understand what is happening; therefore, in regard to interviewing themes are identified and pursued, ideas are looked for, and focused data is gathered upon returning to the field in order to answer analytical questions. It was essential for me to start with the participants' stories and attempt to 'locate it within a basic social process, which may be implicit' (Charmaz, 2014, p. 87). My understanding of what was happening guided and focused successive interviews. For instance, at the beginning, the following questions were asked in interviews in order to situate the participants' stories:

- a. What were the reactions of parents or students to you at school?
- b. What were some helpful/unhelpful things they did?

After reflecting upon initial participant responses, the questions became more complex, such as the following:

- a. How could the school community act creatively to change their culture so death or bereavement feels a more normal part of life?
- b. How could the school community change its culture so students can respond more creatively to death and bereavement?

Re-interviewing was also required with some participants to further illuminate emerging themes within the data and as a result saturate existing categories (Charmaz, 2014). It was also critical that I was also reflexive about the questions I asked at interviews (Charmaz, 2014) determining whether they work for particular participants or not and when it was appropriate to formulate different questions. For instance, after the first five interviews, it was evident that the participants were pretending to be okay at school even though they admitted to being overwhelmed by the bereavement and subsequent grief. I was able to pursue this idea in the following interviews by not directly asking them about their own pretending behaviour but instead asking them how the culture of pretending might be changed when bereaved at school.

The interviews were digitally audio-recorded and conducted in places negotiated by me and the participants, such as the participants' homes, in the local park, a private room at the University, and local cafés. Each individual interview ceased when all the predetermined questions had been discussed and points had been followed up. The participants were also asked if they would like to provide any personal artefacts concerning their experience of bereavement within a school community context, such as copies of de-identified personal diaries, drawings, journals, online

entries, or emails. Only one participant was able to offer two personal artefacts pertaining to her experience. This included an email to colleagues and a quote relevant to school communities. Data collection from interviews continued until all the categories were saturated. The average length of these interviews was approximately 40–60 minutes with adults and 15–30 minutes with children. In adherence to the ethics committee, all transcripts, recordings of interviews, and artefacts were de-identified and stored securely.

Typically, interviews began with the signing of the consent form and a brief discussion about why the research was being conducted and the participants' role in this. The questions asked were deliberately open-ended, allowing the participants to speak freely and respond to questions how they wished. My focus was to maintain a one-sided conversation as much as possible.

4.5 Analysis

Analysis begins with the collection of data (Corbin & Strauss, 2008). This allows the researcher to identify applicable concepts from the beginning, follow through on ensuing questions, and listen and observe more sensitively. According to Charmaz (2014), the first analytic turn is coding and this requires the researcher to stop and ask questions of the data. This guides subsequent data retrieval. For this study, analysis began after each interview and then categories started to emerge. By the 10th interview and ongoing analysis, it was evident that some categories were reaching a point of saturation, meaning that no new information was emerging in the data (Glaser & Strauss, 1967). Other categories needed to be elaborated. As explained, new questions were developed to further explore these categories. Initial and new questions are provided as examples (Appendix C&D). Through further interviewing, these categories became more robust and as a consequence, refined. By the 23rd interview, all categories were sufficiently saturated. My process of analysis was presented to interested colleagues and I received and acted on feedback when it was required.

4.5.1 Coding

Charmaz (2014) describes two phases of coding, initial and focused coding. Initial coding involves studying fragments of data and developing codes for this data. Coding refers to the categorising of segments of data with a title that assists in summarising the content of each piece. Therefore, initial coding may involve naming each word, line, or segment. This is an interactive process as the grounded theorist interacts repeatedly with participant statements (Charmaz, 2014).

Focused coding follows initial coding and refers to using the most significant and frequently occurring codes to examine and analyse sizeable amounts of data. It involves making decisions 'about which initial codes make the most analytic sense to categorize your data incisively and

completely' (Charmaz, 2014, p. 138). In practice, this means initial codes are studied and assessed. Further, by making comparisons, the validity and conceptual strength of the initial codes are then determined. The codes that have analytic power are then considered as potential categories (Charmaz, 2014).

A third type of coding is axial coding advocated by Corbin and Strauss (2008, p. 198) which is the 'act of relating concepts/categories to each other'. According to Charmaz (2014), this involves specifying the properties and dimensions of a category and results in a reassembling of the data, fractured in initial coding. Charmaz (2014) prefers analytic strategies that are emergent rather than axial coding which involves procedural application or the development of a frame for researchers to apply. Instead, Charmaz (2014) develops sub-categories of a category and shows the links between them as she learns about the experiences the categories represent rather than being restrictive through procedural application. For instance, in the early stages of interviewing, I had developed the broader category 'feeling unsupported' but as I continued interviewing, specific categories emerged of how participants felt unsupported. These became my subcategories and they were clearly linked by the feeling of being unsupported. They included 'feeling avoided or ostracized', 'feeling scrutinised', 'seeing the world move on', and 'sensing a lack of understanding about grief'. Charmaz (2014) does stipulate researchers who would prefer to work with a predetermined structure may benefit from using a frame but for those valuing flexibility and simplicity in their research do not need to do axial coding. In this study, I have chosen to work in a more flexible way; therefore, I did not undertake axial coding. Particularly, in the early stages, I did not want a fixed frame to apply to what the participants were saying. This allowed me to prioritise incoming data from participants and categories were developed straight from coding their words instead of presupposing what following participants in interviews would say.

The next level of coding according to Charmaz (2014) is theoretical coding, which involves following the codes that have been chosen in focused coding in an effort to determine how they may relate to each other and serve as a hypotheses to be amalgamated or formed into a theory. Essentially, the researcher is theorising the data and focused codes, and may assist in telling 'an analytic story that has coherence' (Charmaz, 2014, p. 150). Charmaz (2014) also debates here whether or not the development of theory codes is emergent or a procedural application. Charmaz (2014, p. 155) advises that if one develops theoretical codes that one should, 'let them breathe through the analysis, not be applied to it'. In this study, I remained flexible by prioritising emergent categories and as a result. I allowed the development of theoretical codes. For instance, the codes 'feeling supported' and 'feeling unsupported' became rather dominant within the first five interviews and continued throughout many other interviews. In addition to other similar codes, these codes formed

part of the larger theoretical code 'Creating a culture of support' which assists in answering the overarching question. The Nvivo software package was used to conduct organisation of the data, allowing for the comparing and contrasting of participant comments and to store the data as a whole.

4.5.2 Memos and diagramming

In addition to these types of analyses, ongoing techniques of writing memos and creating and using diagrams are crucial. According to Corbin and Strauss (2008), memos are composed records of analysis and diagrams and serve as a visual device showing relationships between concepts. These are tools for the researcher to use personally not publicly (possibly excepting multiple analysts) and are reflections of analytic thought that need to be captured as soon as they occur (Corbin & Strauss, 2008). Therefore, writing memos may occur during interviews as well as initial re-reading of the transcribed interviews.

Charmaz (2014) discusses memos at length and deems them as informal analytic notes that assist in crystallising questions and directions to be pursued. Effectively, they 'record your path of theory construction'; therefore, researchers should aim to make memos progressively analytic (Charmaz, 2014, pp. 164-165). In this study, memos were written after each interview. At the beginning, the memos were more of a description of information in the interview. For example,

19.10.17 Empowering or managing non bereaved behaviour

In the management of ones 'times ten' emotions, the management of others ... their reactions to you also need some controlling or boundaries purely so you can survive the moment, or the hour or the day. The emotion can be so overwhelming as Mary indicates that it seemed very smart to firstly manage others (non-bereaved) behaviour and secondly manage it from a distance.

As more interviews were conducted, categories started to emerge and comparisons were being made. As a result, the memos became more analytic. For example,

1.5.18 Empowering or managing non-bereaved behaviour

In reflecting, particularly on Jonathon and Mary's account, ... not only are they grieving but they are having to manage the non-bereaved for their own self-protection and community protection. Jonathon is a shield for his children and also ensures that they meet as many friends before school starts to meet awkwardness head on so the kids will be okay once they start school again. In his own words, he finds this taxing. Mary emails the staff before coming into school and this is something she attends to in the midst of shock and grief. She does this because she recognises the need for the staff to know how to behave. The

bereaved aren't just grieving, they are taking charge so reactions between people are organised and controlled to a certain extent so that grief can be managed in a culturally acceptable way.

Charmaz (2014) explains that by using diagramming, researchers are able to visually represent the direction of categories in the analysis and show the relevant connections between them. They can be used at all stages of analysis. In the form of note taking and to sort information, I predominantly used Venn diagrams to show the similarities and differences of categories and to highlight missing information (Appendix E).

4.6 Theoretical Sampling

Corbin and Strauss (2008, p. 143) refer to theoretical sampling of the data as 'a method of data collection based on concepts or themes derived from data'. This is explained further by Charmaz (2014, p. 192) as a process of 'seeking and collecting pertinent data to elaborate and refine categories in your emerging theories'. Theoretical sampling is a continuous strategic, systematic process that begins with data, constructing exploratory ideas about the data, and then investigating these ideas through further empirical inquiry. Theoretical sampling ensures that major categories are full and strong, enabling an understanding of how a process changes and develops (Charmaz, 2014).

Practically, in theoretical sampling, the researcher is led by analysis (Corbin & Strauss, 2008). For instance, in an initial interview, the researcher may come away with insights from the first participant and then use that insight to ask different questions of the second participant in a following interview. After further discoveries or insights are gleaned, further examination of concepts and development of categories occur. The concept of categories may be described as analytic concepts or conceptualisations that are conceived because of patterns or themes emerging from the data. The researcher and the data then operate together in this developmental process of theoretical sampling. It is not too unlike a detective being led by clues — solving the puzzle may lead to different and unexpected pathways in an attempt to build a case or theory. In this study, this occurred during and after conducting the first 5–10 interviews. Categories had been developed from the initial interviews and similar opinions were being put forth by the participants. Questions were then developed to further probe participants' thinking in regard to how they might solve particular issues. Questions were also developed to ascertain how culture may influence the participants' current thinking or behaviour.

Gathering data is halted when the categories are 'saturated' with data. According to Glaser and Strauss (1967), saturation in grounded theory means that no further new data are being found

whereby the researcher can develop further properties of the category. However, Charmaz (2014) challenges this idea arguing that researchers need to be self-critical about saturation by aiming for further analytic development. Asking novel questions may be required, resulting in more complexity in category development. Charmaz (2014) advises that researchers need to be willing to grapple with the data and if puzzled, pursue earlier data, recode it, and establish any new leads. In this study, it was evident that the parents who had a health professional background made comments about teachers that showed that they were able to empathise with teachers and the pressures of their work. There were also several comments made that indicated that these parents wanted teachers to understand them and their bereaved position. It was initially challenging to think of creative ways and questions that I could ask school professionals about empathy or reflexivity without them becoming defensive. Eventually, the idea of asking them to put themselves into the shoes of another person became a strong and respectful way to begin. For example, 'what do you think would help teachers put themselves in to the shoes of bereaved families, be able to see how things might look from their point of view'? This proved to be a very open question that the participants willingly responded to.

4.7 Critical Reflection – Theories, Power and the Researcher

Critical reflection is pertinent to this study, particularly in the collection and analysis stages. Firstly, the broader concepts of critical reflection will be explored. The key concepts are theories underpinning critical reflection, connecting critical reflection to power, critical reflection in regard to grounded theory, and connecting reflexivity with the researcher's personal and political values. Then, specific perspectives from Schön (1983), Brookfield (2003), and Fook and Gardner (2012) will be investigated to identify implications for this study.

In terms of a social constructionist lens and considering thoughts about the well-being of others, the literature concerning critical reflection plays a role in this study as it is concerned with assumptions that people make about themselves and others and how these are influenced by their individual and the broader social context.

The concepts of reflexivity and critical reflection are complex and are largely influenced by the social context in which they are used. D'Cruz, Gillingham, and Melendez (2007, p. 2) suggest, 'such concepts are relatively new to social work and their meanings are still being debated'. However, in her work with Jan Fook, Gardner (2014, p. 35) provides a clear summary of the four key theories that underpin critical reflection and this includes reflexivity. Firstly, *Reflective practice* accentuates the identification of feelings, thoughts, beliefs, and assumptions that influence practice where there is a value placed on practice-based knowledge. Secondly, *Reflexivity* develops an understanding of how

others perceive themselves and each other with the complexity lying in what is brought forward (spiritually, emotionally, physically, etc.) and how this influences perception of others and the self. According to Fook and Gardner (2012, p. 6), reflexivity also plays a critical role and is described as how 'one's self can influence what and how knowledge is made, and can therefore shed light on how specific assumptions we make can arise from our own background and experience' (Fook & Gardner, 2012, p. 6). Thirdly, *Post modernism* contests the modernist notion that people are confined to limited classifications. There is an understanding of the effect of current thinking at a social level and how attitudes and power are embedded in language. Fourthly, *Critical social theory* pinpoints the connections between social, cultural beliefs, and expectations and how these are internalised by individuals (Gardner, 2014). From a critical theory perspective, social justice is prioritised as part of affirming particular values which may or may not be similar to those internalised from prevailing norms.

Daley (2010, p. 69) relates the concepts of critical reflection and reflexivity to 'recognizing and responding to micro practices of power and power relations in the interviewing relationship ...' focusing on emotions, discourse, and women's bodies. Daley (2010, p. 69) explains that 'the practices of reflexivity and critical reflection are aligned in that they both privilege a critical stance towards power, knowledge, and self; however, they are also different from one another'. Zembylas (2014) argues that the emotional aspects of reflexivity offer insights for teacher reflection and cross-examines how emotions are entwined with power relations by using the term, 'critical emotional reflexivity'.

Similarly, Freshwater (2011, pp. 185-186) states

From a *critical standpoint*, reflexivity involves researchers locating themselves within political and social positions ... Critical reflexivity ... calls into question the socio-political structures in which we all find ourselves, and which reflects particularly on the effects of power, oppression and disempowerment ...

The concepts of context, position, and power are clearly a priority in the literature and have significant relevance to school communities, how people interact and react to one another, and the influence of the broader social and cultural field in which they operate in.

In regard to the research design, researcher reflexivity is advocated by Charmaz (2008a, p. 403) who deems it as central to grounded theory as it enables grounded theorists by definition to prioritise 'improvising their methods and analytic strategies'. The 21st century's social constructionist grounded theorists consider the research process itself to be a social construction and acknowledge that researchers position, privilege, and viewpoints affect it (Charmaz, 2008a). Practically, Mills, Bonner, and Francis (2006) explain that in order to move the researcher and participant into a more

equal sharing of power within the relationship, the researcher needs to adopt a more reflexive stance and maintain an open interchange by planning for the time they will spend with the participants. The use of the semi-structured interview approach is appropriate here as the participants may assume more control of the conversation. It may also be beneficial for the researcher to keep a reflective journal so that their own role in the interaction can be carefully considered objectively. By prioritising the equal sharing of power, the researcher and participants in constructivist grounded theory essentially co-construct the data.

Essentially, reflexivity acknowledges the personal and political values that inform the research, such as to explore the ways in which the researcher's own history and biography may have influenced or created the research. My personal experience of bereavement is acknowledged in Chapter 1 and the ways I addressed the influences of my own assumptions will be discussed further in this chapter and in the following published article. Practically, coding of categories and identifying patterns may also be influenced by my own experiences of bereavement. Further, I ensured transparency by being proactively reflexive during analysis by inviting other analysts, specifically, my supervisors to check my coding and offer their opinion on the patterns I was identifying and the categories I was creating. The following frameworks offer insights into how reflective practice and critical social theory play a vital role in this study.

4.7.1 Reflecting-in-action: Schön

The influential book 'The Reflective Practitioner' by Schön (1983) offers a paradigm shift to practitioners or teachers and how they operate at work or school. Schön '... relies heavily on the idea that tacit or implicit knowledge (or assumptions) are embedded in practice. Practice therefore can be improved by making such implicit knowledge explicit, thereby exposing it to scrutiny' (Fook & Gardner, 2012, p. 3).

This is evident in Schön's concepts of 'reflecting-in-action' and 'reflecting-in-practice'. Reflecting-in-action refers to the times where one thinks about what they are doing and adjust their operation in order for it to evolve. Reflecting-in-practice allows the practitioner to make sense of new situations and critique one's understandings. Effectively, this is a thinking back to possibly prepare for other situations that will present themselves in the future (Schön, 1983). Reflecting-in-action and reflecting-in-practice also allows for and encourages reflective conversation where there is an appreciation, action, and re-appreciation. This is where a unique or uncertain situation is understood by attempts to change it and attempts to understand it (Schön, 1983).

Schön (1983) makes particular reference to how this may affect educational bureaucracy. When a teacher thinks and acts not as a technical expert but as a reflective practitioner, the conservative

system in which he or she operates is open to critique. The lesson, the curriculum, school structures, and practices may become unstable or questionable when the teacher begins to really listen and understand the students, parents, and their needs and acts upon those needs. Questions are posed to the students by the teacher in an effort to design lessons and curriculum for the students and may result in present lessons being put aside (Schön, 1983). Reflecting in practice is also relevant to this study when interviewing participants, where a first set of questions asked in a first interview may lead to newly devised questions in the next interview. Similarly, grounded theory is used to analyse/interpret the resulting data and this demands that the researcher be reflective as the study evolves.

A reflective teacher needs to share these new ideas with others, expand his or her own learning, possibly pushing against or disrupting theories of knowledge and the rules and practices of how the school operates. Schön (1983, p. 346) notes that by using reflecting-in-action ‘professionals are more appropriately seen ... as participants in a larger societal conversation; when they play their parts well, they help that conversation to become a more reflective one’.

This reflection-in-action would effectively challenge the rigidity of lesson plans and schedules and defy the idea of isolated classrooms and objective measures of performance. These point to the obvious limits to reflection-in-action as it becomes the central idea of ‘the school as a place for the progressive transmission of measured doses of privileged knowledge’, resulting in the school itself being under scrutiny (Schön, 1983, p. 334). However, a school supportive of reflective teaching becomes a ‘learning system conducive to the continual criticism and restructuring of organizational principles and values’ (Schön, 1983, p. 335). This extrapolates to larger ideas of social reform and the necessary next step of taking action. Schön (1983, p. 141) states that ‘The task of social reform is to empower the relatively powerless – blacks, women, ethnic minority groups, the aged, the disabled, prisoners – to organize for an effective voice in the politics of policy making’.

Reflection-in-action resonates with grounded theory as the researcher, with the participants, co-constructs the data effectively while giving voice to those having experienced bereavement and therefore participating in social reform.

4.7.2 Critical thinking: Brookfield

Brookfield (2003, p. 141) expands on this with his ideas in thinking reflectively in a critical pedagogy frame and states that critical pedagogy

... springs from a deep conviction that society is organized unfairly and that dominant ideology provides a justification for the uncontested reproduction of a capitalist system that should be seen for what it is – as exploitative, racist, classist, sexist, and spiritually

diminishing. Organizing to teach people to realize and oppose this state of affairs is what critical pedagogy is all about.

Largely, Brookfield (2011) is championing critical thinking/pedagogy as transformative, encouraging people to contest or resist dominant ideology and create a genuine democracy. Brookfield (2011) argues that critical thinking is imperative and without it, it is impossible to tell when one is being manipulated. Critical thinking means being alert to the control and influence exerted by organisations that are essentially serving their own or less than just purposes (Brookfield, 2011). Brookfield (2011, p. 1) considers the processes of critical thinking as incorporating the identification of assumptions that inform our thinking and actions, checking the validity and accuracy of these assumptions, viewing our decisions and ideas from several different perspectives and overall, and as a result, taking informed actions. To reiterate, reflexivity acknowledges the personal and political values that inform the research. My own assumptions in regard to death, dying, and bereavement need to be unearthed and transparent for the overall credibility of this study.

Brookfield (2011, pp. 1-3) also classifies three different types of assumptions that are worthy of our attention in research – causal, prescriptive, and paradigmatic. Causal assumptions are those that deal with cause and effect, such as ‘if I do A, then B will happen’ and are generally easier to uncover (Brookfield, 2011). Prescriptive assumptions are generally identified by ‘should’ statements and relate to ideas about what is an appropriate way of thinking or acting. Paradigmatic assumptions refer to one’s worldview and are harder to expose and challenge. They may include our mindsets of a dominant patriarchy or racist attitudes (Brookfield, 2011). These assumptions that originate in dominant discourses that reinforce particular ideologies are particularly difficult to uncover as they are everywhere and appear as common thought. They are learnt from school, from the media and church, and from family relationships.

Unearthing assumptions also mirror Schön’s ideas of understanding, criticising, examining, and scrutinising practices and processes contained in larger establishments and essentially reflects Brookfield’s reference to being attuned to dominant ideology.

In considering our own assumptions, there is the questioning and evaluating of ‘truths’ that are presented. Brookfield (2011) argues that informed action needs to be taken to live and love well, but this action needs to be supported by evidence that is deemed convincing. However, what is found to be convincing or accurate of course may be different from someone else’s point of view; thus, separating critical thinking from power and politics cannot occur, which this leads back to the beginning of Brookfield’s conversation about dominant ideology. Brookfield (2011) clarifies this by noting that assumptions are rarely right or wrong but are contextually appropriate, their accuracy

will depend upon the circumstance or background in place when these assumptions are followed. This informed action also resonates with Schön's incentive to empower minorities. Principally, Brookfield (2003, p. 142) emphasises transformative learning where 'the learner comes to a new understanding of something that causes a fundamental reordering of the paradigmatic assumptions she holds and leads her to live in a fundamentally different way'.

4.7.3 Critical reflection: Fook and Gardner

Fook and Gardner's (2012, pp. 4-6) model of critical reflection focuses much attention on unearthing assumptions. The ideas contained in this model not only include reflective practice, reflexivity, postmodernism, and critical perspectives, but also encompass a range of perspectives including critical spirituality (Gardner, 2011, 2012) and transformative learning (Brookfield, 1995, 2005). In drawing upon Schön's (1983) work, Fook and Gardner (2012) explain reflective practice as focusing on the significance of implicit assumptions and their effect on practice. Reflexivity also plays a vital role and is defined as how 'one's self can influence what and how knowledge is made, and can therefore shed light on how specific assumptions we make can arise from our own background and experience' (Fook & Gardner, 2012, p. 6). Fook and Gardner (2012, p. 6) also highlight the relevance of postmodern understandings as 'the role of language and discourse in creating meanings and interpretations and therefore knowledge and the exercise of power'. This is also reflective of a social constructionist position. Critical perspectives in this model '... emphasize both how individual thinking/behaviours and social arrangements are linked, and therefore how individually held assumptions may emanate from a person's social environment' (Fook & Gardner, 2012, p. 6). This is similar to Schön (1983) and Brookfield, as there is a strong emphasis on uncovering and identifying assumptions, empowering individuals, and encouraging or creating opportunities for action. Practically, Fook and Gardner (2007) explain that the model generally involves small groups of critical reflective learners, although the processes can also be used individually in supervision or in pairs. The first stage of the process is to unsettle assumptions that are embedded in their current practice in a specific experience and the second stage is to focus on how their practice might change as a result of their new awareness after uncovering assumptions. Small facilitated groups allow learning through dialogue, individual reflection, and the expression of multiple perspectives (Fook & Gardner, 2007). This also resonates with Brookfield's appeal for different perspectives. Through this process, both critical reflective questioning and examples of concrete practice experiences are used to assist in unearthing assumptions and to enable conversational depth (Fook & Gardner, 2007). This process allows the opportunity for professional practice to be evaluated, for a change in professional

practice to occur, and the opportunity to learn directly from a professional practice experience (Fook & Gardner, 2007).

4.7.4 Implications for this study

The interconnecting ideas from Fook and Gardner (2012), Brookfield (2003), and Schön (1983) are useful for this study.

Schön's (1983) example of the reflective teacher suggests that there is a need for people who have experienced bereavement to share their ideas and this was evident in the interview process. At times, it was necessary to listen to the participants for a full hour and at times over an hour; such was the participants' motivation to tell their story. Their ideas may push against discourses of knowledge and the rules of how the school operates and suggest the value of challenging school ideology around death, dying, and bereavement.

It is also important to identify school community, participant, and researcher assumptions about death, dying, and bereavement to inform thinking and future actions within a school community context. Gathering data from all these perspectives is vital to ensure validity and accuracy.

Postmodern understandings will also affirm subjective and varied experiences related to bereavement, death, and dying. In this study, teachers, principals, parents, and students were involved and provided good representation of the school community. It would have been beneficial to have more students and more current full-time classroom teachers.

The critical reflection model and process also allow a unique opportunity for researchers to understand their work with participants at a deeper level. In this study, I was able to unearth my own hidden assumptions arising out of my personal background and experience with a supervisor during data collection and analysis. It was also imperative during the data collection and analysis phase to communicate my thoughts and feelings about the issues arising in interviews that may have been reflective of my own grief (see article 2). Fortunately, this was possible in regular meetings with supervisors and provided the necessary transparency.

In addition to this, Burr (2015) refers to the researcher as building in opportunities for the participants to comment on their own and the researcher's accounts. In this study, I was able to offer a second interview to all the participants who asked questions pertaining to their first interview. This allowed the participants to clarify, elucidate, and elaborate on comments from the previous interview as well as change their mind. The newly created questions after theoretical sampling also provided the participants the opportunity to put forward additional comments for final analysis.

This study was able to centre on the stories or experiences of people who had experienced bereavement and this allowed exploration of how these experiences may influence school culture. This was not intended to be a therapeutic process as I wanted people to be critically reflective of their own experiences. The interview process was a narrative interaction where the researcher and participant made meaning together and essentially constructed the knowledge; depth, feeling, and reflexive thought were emphasised in this process (Mills et al., 2006, p. 9).

Considering the importance of reflexivity as a central concept to grounded theory and as a vital component of storytelling, this study prioritised its practical use before, during, and after collection of data and analysis through the use of my own reflective journal and ongoing reflective conversations with my supervisors.

4.8 Measures Promoting Accuracy of Data

In order to ensure that quality findings are derived, Corbin and Strauss (2008) prefer to use the term credibility rather than validity and reliability when discussing qualitative research. Credibility denotes findings that are trustworthy, presenting research that is creative conceptually and grounded in data. Corbin and Strauss (2008, p. 305) criterion for judging the quality of research firstly look at *fit* and ask if the findings resonate with the experiences of the participants in the study and the professionals for whom the research was intended. Secondly, the criterion of *applicability* is considered, asking if the findings offer new insights. The third criterion is *concepts*, stressing the importance of findings being substantial, showing both density and variation.

Specifically, Corbin and Strauss (2008) deem Charmaz's (2006) criteria for evaluating constructionist grounded theory as the most comprehensive as both scientific and creative qualities are attended to. Charmaz (2014) describes these criteria as falling under the categories of credibility, originality, resonance, and usefulness. These also resonate with the criterion described by Corbin and Strauss (2008).

Some of the questions Charmaz (2014, pp. 337-338) asks are as follows:

- Credibility – Has your research attained an intimate understanding with the setting or topic? Have you made methodical comparisons and contrasts between observations and categories? Have you provided enough evidence for your claims to enable your audience to form an independent assessment?
- Originality – Do your categories propose new insights? What is the theoretical and social relevance of the research? How does this work contest, extend or enhance current ideas or practice?

- Resonance – Do the categories show the fullness of the researched experience? Does your research make sense to your participants? Does your analysis convey deeper insights about participant’s experience?
- Usefulness – Does your analysis suggest interpretations that people can use in their everyday life? Do your categories portray any generic developments? If so, have these been scrutinised for any tacit implications? How does your research contribute to knowledge?

According to Charmaz (2014, p. 338), these criteria ‘address the implications and the actions and meanings in the studied phenomenon and help you analyze how it is constructed’. Charmaz (2014) explains that a purposeful, reasoned grounded theory can theorise and express what is meaningful about an area and make a valuable contribution. Its aesthetic and analytic power can create a valuable contribution and may influence wider audiences.

In this study, credibility was achieved by developing an intimate understanding with this topic through intensive interviewing, the constant writing of memos with links to categories, keeping a methodological reflexive insight journal, and having discussions about codes and participants interviews/responses to particular ideas and questions with supervisors on an ongoing basis. My supervisors also read and identified themes in interview data to check for similarity. My observations, categories, and the contrasts and comparisons made between both are well documented in my theoretical sampling and recommendations. The evidence to support my claims are also in my discussion and recommendations and conclusion chapter and my methodological reflective journal. Resonance and originality have been achieved in securing a significant number of quotes from participants that illustrate both the depth of experience and relevant themes. Usefulness of the research is evident through the practical recommendations voiced by the participants and that contribute to the overall proposed framework in Chapter 5. This contributes to education and palliative care research knowledge as well as knowledge needed in school communities.

The original premise or question for the study was to explore how to create compassionate schools that are able to engage constructively with issues of death and dying. The hope was to find ways for school communities to articulate their current and preferred assumptions of death, dying, and bereavement and to build strategies based on these understandings to empower their own community. The exploratory questions were, ‘what is it like to be a bereaved person in a school community setting’ and ‘what was helpful or unhelpful’? Once the answers to these questions were ascertained, theoretical sampling allowed more investigation of the participants’ ideas and thoughts through the development of different questions. As a result, modification to the original design was not needed. Practically, it was thought that I would be able to interview an approximate equal

number of representative groups in the study but this didn't occur. Only two students (with parental consent) wanted to participate in the first interview but not the second and interviewing current full-time classroom teachers was challenging due to their work commitment. As such, only part-time teachers were interviewed.

4.9 Summary

Grounded theory focuses on process, specifically on relationship and social structure, and takes a critical stance towards actions, organisations, and institutions. This fits with the overarching question of 'how do we create compassionate schools in light of death, dying, and bereavement' and more specifically the interview questions that were asked of bereaved community members, 'what is it like to be a bereaved person in a school community' and 'what do you consider helpful or unhelpful in school community settings'?

Intensive interviews and collection of personal written documentation allowed for an in-depth, open ended exploration of these issues. Credibility was established by adhering to the described techniques of data collection, analysis, and critical reflection in conjunction with Charmaz's (2006, 2014) criteria for evaluating constructionist grounded theory, flexibility, and originality. This research design was flexible and ensured that the silent or silenced voices of bereaved school community members were heard.

In listening to the participants' perspectives, various issues emerged in the intricacies of interviewing and analysing. Grounded theory, critical reflection, and reflexivity enabled the examination of my own biography and influence on this study during this process. The following journal article 'Researching death: tales of grounded theory, reflexivity and compassion' depict the insights and difficulties of researching a sensitive topic, how methodology can aide or hinder that process, and how compassion can be extended to researchers.



Standard Article

Researching death, dying and bereavement: tales of grounded theory, reflexivity and compassion

Carla Jane Kennedy^{ID} and Fiona Gardner
La Trobe University, Australia

Q
R

Qualitative Research

1–15

© The Author(s) 2021

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/14687941211000560

journals.sagepub.com/home/qrj



Abstract

Immersing researchers in sensitive and emotive topics such as death, dying and bereavement may result in periods of conflicting logical thoughts and subjective feelings that need to be acknowledged and supported.

The question to be answered in this research was ‘How do we create compassionate schools?’ which led to the interviewing of bereaved school community members in regional areas in Victoria, Australia. As anticipated, Carla, one of the researchers who had experienced recent family deaths was challenged by particular issues arising in interviews and through the transcribing process. Therefore, the purpose of this article is to discuss this complexity, with grounded theory as a conduit, reflexivity and critical reflection as combined tools and compassion as a way forward. We draw upon Carla’s methodological reflective journal and current health literature concerning sensitive topics in qualitative research.

Recommendations of how to support researchers and research teams managing sensitive topics are provided and suggestions of how compassion can be achieved and extended to researchers are offered.

Keywords

sensitive topics, critical reflection, compassion, grounded theory, bereavement, qualitative research

Introduction

Conversations about death, dying and bereavement are sequestered or silenced according to current palliative care and educational literature in western societies (Barry and McGovern, 2000; Galende, 2015; Kellehear, 2014; Papadatou et al., 2002). Therefore, being immersed in this topic, coupled with personal experiences of close bereavement,

Corresponding author:

Carla Jane Kennedy, La Trobe University, Edwards Rd, Flora Hill, Bendigo, VIC 3552, Australia.

Email: Carla.Kennedy@latrobe.edu.au

can become a sensitive experience for researchers as well as the participants. In defining sensitive research, Lee (1993: 4) states that it is 'research that potentially poses a substantial threat to those who are or have been involved in it'. Lee and Renzetti (1990: 511–512) explain that it, 'alerts researchers to their responsibilities to the wider society' and that these topics may involve 'particular kinds of costs' such as guilt or shame. Specifically, they note that the research may also be threatening to the researcher as it may put them in situations that puts their personal security at risk. Similarly, Dickson-Swift et al. (2006) acknowledge that 'undertaking qualitative research on sensitive topics poses particular challenges for both the participants and the researchers'.

To account for this in our research of, 'how do we create compassionate schools?', we chose social constructionist grounded theory as a theoretical framework, particularly for its acknowledgement of the researchers as situated in the process. In terms of methodology, Charmaz (2008a: 402–403) identifies that 21st century social constructionist grounded theorists consider the research process itself to be a social construction, therefore acknowledging that the researcher's social context, position, privilege and viewpoints affect the research. Similarly, Winter and Munn-Giddings (2001: 53) consider that critical reflection has two major dimensions: 'reflexivity' (i.e. *self-questioning*, taking one's own interpretations of events as 'data' to be subject to examination) and 'dialectics' (i.e. focusing on the contradictions, tensions and dilemmas inherent in a situation)".

With this in mind, researchers need to be aware of how the narrative of the story or interview is being co-constructed by the researcher and the participants. Daley (2010: 80) warns that if we do not account for both social context and the researchers' role in the research we may be in danger of producing knowledge about marginalised populations as fixed truths when in fact they are 'fluid narratives that are co constructed by the participants and the researcher within a particular time, place, culture and situation'. Therefore, we argue that the researcher's participation in the process of using a combined critical reflection and reflexivity approach to explore sensitive topics is crucial. This allows the researcher the space to be conscious of their own social context and to engage with their own reactions so these reactions don't hinder the process of analysis and understanding participants' perspectives.

In this research, one on one, semi-structured interviews were conducted with primary school students, parents, teachers and principals from seven schools in regional Victoria, Australia. All participants were members of a primary school community setting at the time of the bereavement and had been bereaved of a close friend or a family member (post six months and up to six years). The participants included students, parents, teachers and principals. In phase one of interviewing there were ten participants, two male and eight female. Ethics approval was granted by La Trobe University and the Education Department in Australia. The potential issue of interviewees becoming distressed was addressed first by making explicit that participation was entirely voluntary, that participants could withdraw at any time and parents giving permission for children to participate. If participants did become distressed the interviewer was to give them information about local counselling services or offer time with the interviewers social work supervisor, who was experienced with counselling. In phase two of interviewing, seven participants from phase one were re-interviewed and then six new participants were interviewed, three male and ten female. Nine of these interviews were with parents who had health or

Table 1. Interviews: phase one.

| Participants | Age | Gender | Occupation | School role | School type |
|--------------|-----|--------|------------------|------------------|-------------|
| Mary | 61 | female | principal | principal | state |
| Jayne | 60 | female | teacher | teacher | catholic |
| Bernadette | 54 | female | principal | principal | catholic |
| Jonathon | 48 | male | health provider | parent | state |
| Halle | 40 | female | health provider | parent | state |
| Maxine | 48 | female | private business | parent | state |
| Lorenzo | 41 | male | teacher | teacher & parent | state |
| Peter | 12 | male | | student | state |
| Abigail | 10 | female | | student | state |
| Bonnie | 38 | female | health provider | parent | state |

Tables 2. Interviews: phase two.

| Participants | Age | Gender | Occupation | School role | School type |
|--------------|-----|--------|------------------|------------------|-------------|
| Mary | 61 | female | principal | principal | state |
| Jayne | 60 | female | teacher | teacher | catholic |
| Bernadette | 54 | female | principal | principal | catholic |
| Jonathon | 48 | male | health provider | parent | state |
| Halle | 40 | female | health provider | parent | state |
| Maxine | 48 | female | private business | parent | state |
| Lorenzo | 41 | male | teacher | teacher & parent | state |
| Meeana | 49 | female | health provider | parent | state |
| Sally | 45 | female | rural business | parent | state |
| Tristan | 42 | male | health provider | parent | state |
| Rachael | 52 | female | health provider | parent | catholic |
| Matilda | 58 | female | teacher | teacher & parent | catholic |
| Nada | 43 | female | health provider | parent | private |

community health provider backgrounds. This may reflect an interest from the health profession in this subject matter or a personal desire to contribute to the discussion around death, dying and bereavement (see Tables 1 and 2). The interview questions explored to participants' experiences of being a bereaved person in a school community, unearthing their assumptions and ideas about engaging constructively with death, dying and bereavement.

The researcher undertook a predominantly listening role in the interview process as Charmaz advocates for a 'gently guided, one sided conversation that explores a person's substantial experience with the research topic' (Charmaz, 2014: 56). Specifically, this allowed the researcher to ask open ended questions, prompt when necessary and follow the participants line of thinking.

In accordance with grounded theory, analysis and interviews ran simultaneously so that as interviews were being conducted, transcribing, coding, categorising and analysis

was occurring. Memos, in the form of reflections and analytic thought, were typed into a methodological reflective journal in the Nvivo program after each interview. Specifically, to encourage a reflexive position from the researcher, thoughts, reactions and awareness of similarities and differences from each interview were recorded including the influence of social context. As Daley (2010: 70) indicates from her research drawing upon constructivist grounded theory method, 'memo writing was foundational to the practices of reflexivity and critical reflection throughout the research process . . .' New questions were also developed as part of the journaling process to further investigate participants' main concerns, ways of thinking and how society and culture may influence the understanding of death, dying and bereavement in a school community.

The research team and theoretical perspectives

The research team comprised three education researchers and a social work researcher working within rural populations. The formulation of the overarching question, 'How do we create compassionate schools in light of death, dying and bereavement?' was developed over a period of team meetings in reference to Kellehear's (2012: 37) concept of 'Compassionate cities'. This finds its origins in the *Healthy cities* project, developed by the World Health Organisation (WHO) as a way to implement the Ottawa charter for health promotion (1986). 'Compassionate cities' encapsulates compassion as an imperative in creating schools that engage well with those experiencing bereavement (Kennedy et al., 2017). This provided the foundation of the research with the coalescing of health promoting palliative care and education literature, with health being positively framed even in the presence of loss. It was important to keep the research questions open and the team agreed to incorporate compassion as an ideal.

In regard to context, one of the education researchers, Carla, who was to conduct the interviews had experienced recent deaths in her family and had worked for many years in primary schools. The interviews took place in regional communities and this resulted in some of the participants in the study being aware of the deaths in Carla's family. This had implications for how the research team might engage with the research and particularly for Carla in engaging with the interviews.

Choosing a world view

The choice was made to use social constructionist grounded theory as a theoretical approach with an emphasis on reflexivity. A constructionist grounded theory aspires to an interpretative understanding of the phenomenon accounting for context rather than generalizations and omitting context (Charmaz, 2008a: 402). As Charmaz (2008b: 204) states 'we can use the processual emphasis in grounded theory to analyse relationships between human agency and social structure that pose theoretical and practical concerns in social justice studies'.

In regard to social justice, Burr (2015: 141) uses a social constructionist perspective and draws upon Foucault's proposal that change is possible through a form of 'consciousness raising' by opening up marginalized and repressed discourse which encourages a reflexive position in considering others thinking and assumptions. The research

team in accordance with social constructionist theory considered the bereaved participants as a potentially marginalised population. The expectation was that the interview process might act as a form of consciousness raising that would implicitly challenge social practices, structures, social relations and ultimately identities.

Considering the researcher

In relation to power, the task of the researcher could also be considered in a critical social constructionist frame. Burr (2015: 172) affirms that objectivity is simply not possible as assumptions from our own experiences and from societal norms are embedded in our own perspectives. The research relationship becomes more democratic when the researcher emphasizes co-production and is not instructed to be more powerful than the participants in the research (Burr, 2015: 174). Charmaz (2014: 14) also emphasises that the research process develops through interaction; the researchers and participants' positions are considered; and the researcher and participants co create the data again using constructivist grounded theory. This was ideal for our study as this allowed the research team to acknowledge and examine their own preconceived notions and assumptions that may influence the analysis.

Reflexivity and critical reflection

The literature suggests understanding, interpreting and participating in reflexivity and critical reflection is complex and is influenced largely by the social context in which we use it. For instance D'Cruz et al. (2007: 2) state 'such concepts are relatively new to social work and their meanings are still being debated' but expand these meanings by identifying participant responses and definitions in their research. On the other hand, Daley (2010: 69) situates the concepts of critical reflection and reflexivity as 'recognising and responding to micropractices of power and power relations in the interviewing relationship . . .' expanding the notion in feminist research and calling for attention to emotions, discourse and women's bodies. Zembylas (2014) argues that the emotional aspects of reflexivity offer insights for teacher reflection and uses the term 'critical emotional reflexivity' cross-examining how emotions are entwined with power relations.

Daley (2010: 69) explains that 'the practices of reflexivity and critical reflection are aligned in that they both privilege a critical stance towards power, knowledge, and self; however, they are also different from one another'. Similarly, Freshwater (2011) states:

From a critical standpoint, reflexivity involves researchers locating themselves within political and social positions . . . critical reflexivity calls into question the socio-political structures in which we all find ourselves, and which reflects particularly on the effects of power, oppression and disempowerment.

This aligns with Zembylas (2014: 219) view that ' . . . teachers and students need to be aware of the technologies of domination and the technologies of the self that construct their ethical selves'. Interestingly, D'Cruz et al. (2007: 14) found that participants (family welfare practitioners) did not engage to a full extent with the concept of power in relation to reflexivity but more with the process of reflection.

In consideration of undertaking this sensitive research and with the emphasis on power, emotions, and Carla's recent experiences of bereavement, we decided it was advantageous to combine the tools of critical reflection and reflexivity for two reasons: First, for our team the unearthing of Carla's thinking and assumptions was critical. Reflexivity ensured Carla's position and emotions were constantly considered so the construction of knowledge between researcher and participant was as transparent as possible. Second, Carla needed to be conscious of being seen as having power as the researcher and to aim to create an equitable space in interviews. Like Freshwater (2011) and Zembylas (2014), Burr (2015: 176–177) states that there needs to be an acknowledgement of the researchers' personal and political views and also how each researcher's own biographies and assumptions, including those related to power and authority, may have shaped the research.

In advocating for a combined reflexivity and critical reflection approach we also decided to use a model of critical reflection drawn from Schön's (1983) reflective practice with much attention on unearthing assumptions combined with an underlying understanding of critical social theory (Fook and Gardner, 2012: 4–6). According to Fook and Gardner (2012: 6), reflexivity also plays a critical role and is described as how 'one's self can influence what and how knowledge is made, and can therefore shed light on how specific assumptions we make can arise from our own background and experience'. Fook and Gardner (2012: 6) also emphasise the significance of postmodern understandings as 'the role of language and discourse in creating meanings and interpretations and therefore knowledge and the exercise of power'. This is also reflective of a social constructionist position. Critical perspectives in this model

... emphasize both how individual thinking/behaviours and social arrangements are linked, and therefore how individually held assumptions may emanate from a person's social environment. (Fook and Gardner, 2012: 6)

Their model is a two-stage process. The first stage of the process is to identify and potentially unsettle assumptions that are embedded in the reflective learners' current practice in a specific experience and what the experience means from them. Next the person explores where they think the 'other' person in this example might be coming from, their assumptions and values and related meaning for them. The person then reviews their reactions and assumptions, understanding more clearly where the 'other' is coming from and may choose to modify their assumptions. The second stage focuses on how their assumptions and/or practice might change or be reaffirmed as a result of their new understanding. Through this process, both critical reflective questioning and examples of tangible practice experiences are used to contribute to the unearthing of assumptions and to allow conversational depth. This process enables professional practice to be evaluated, for a change to occur and the prospect to learn directly from a professional practice experience (Fook and Gardner, 2007: 51). This became useful for our team, in this case, reflecting on research and through conducting a critical reflection session as later described in this article.

Considering complexity

In an effort to describe the critical reflection and reflexivity process used, we now explore the complexity of the research and the sliding of roles, critical reflection and reflexivity as tools, grounded theory as a conduit and compassion as a way forward.

Dickson-Swift et al. (2009a) report that researchers in their study relay ‘a number of emotion-generating situations’, finding that it is not difficult to be drawn into the emotion of the person being interviewed. This was relevant to our study as Carla was interviewing participants who had suffered close, recent bereavement. More specifically, Kumar and Cavallaro (2018: 648) propose four types of emotionally demanding research experiences:

1. Research on sensitive topics or issues (e.g. death)
2. Research comparable to personal trauma previously experienced by the researcher
3. The researcher’s experience of traumatic life events while conducting the study
4. Unexpected events that arise out of the research in what was previously *not* identified as a sensitive issue

According to these types, Carla was researching a sensitive topic (1) and the research was aligned to personal trauma that she had experienced (2). Also Carla experienced an unexpected event in the second year of research where celebratory days such as mother’s, father’s and grandparent’s day approached at her child’s primary school (4).

Carla became conscious that her capacity to have an objective stance as a researcher was challenged by her subjective position as a bereaved parent given her feelings and thoughts were mirrored in many other parents’ experiences and opinions during interviews. The parents were relaying their feelings of disempowerment and isolation when communicating with teachers and other parents about their grief including how some bereaved children were struggling with their grief on the lead up to celebratory days. The following early journal entry illustrates Carla’s reaction at the time:

Possibly the six years absence from teaching has resulted in me forgetting the pressures on teachers and the little time they have. Or maybe parenting and my family bereavement has helped me sort out my priorities. Nevertheless it is easy to feel disempowered by the institution. When a death happens, you feel out of control or on autopilot. Grieving, having to engage daily with people at an institution and trusting them with your child is extremely difficult.

No matter how caring and compassionate the teachers and principals are . . . you (parents) are guaranteed little time and understanding because the institution demands conformity, compliance and controlled time and space . . . but children, parents, teachers and principals are human beings in the midst of grief and loss. I don’t think institutions can hold that space.

Critical reflection and reflexivity had entered many conversations at team meetings and thoughts and feelings about the research were regularly discussed. Assumptions about participants and situations were voiced and questioned. Charmaz (2014: 157) sees the discovery of these pre-conceptions during the research process as fortunate. She states ‘welcome your new awareness. Your analysis will benefit from it’.

Overall, the interviews were going well. The ongoing analysis was an enjoyable process but at times the reading or typing of transcripts after interviewing tapped into Carla's experiences of bereavement.

. . . when I read the transcripts there are some events that I identify with and sometimes grief sneaks in. I explained at the last [research team] meeting that although my own grief presents itself in reflecting upon transcripts, I know it will last a short time and understand the swell and recline of emotion.

Transcriptions are considered emotional labour by Sherry (2013: 282):

During the six years working with this project, the transcription company got to know me and the sensitive nature of my research, and began to assign it to particular transcribers, who they felt were better equipped for the emotional labour of hearing voices and stories of these vulnerable participants.

At one research team meeting, Carla conveyed the challenge of line by line coding in grounded theory (isolating and naming themes) and then trying to bring the codes into categories. Carla was interrogating the data by questioning whether or not it was really what the participant was saying and therefore meaning or if she was creating the code because it reflected her own thoughts about bereavement.

The process of coding requires me to be constantly attentive to my own bereavement experience. I ask are these the principal's (thoughts) or is this me in the analysis? The experience of bereavement is a gift and a curse. The gift is that I have empathy and can offer insights, the curse is that I may taint the data. This is the reason why team meetings are important . . . to look closely and question the codes.

In the meeting one researcher stated that the analysis was about the participants, not Carla. In trying to code as objectively as possible, she was right to say this. Charmaz (2014: 70) also states, 'try to understand the described events, beliefs and feelings from your research participant's point of view, not your own'. However, from a reflexivity and critical reflection perspective, it was important that Carla interrogated her reactions to ensure she was as objective as possible: making conscious assumptions that might have influenced coding. Carla's understanding of bereavement was also useful as a form of insider information. Carla had shared the lived experiences of some of the participants and she was hearing the interview from two perspectives, one as a researcher and the other as a bereaved person. Co-constructing the data took on a more powerful meaning. Carla knew that she couldn't be completely removed from the research as she had brought her own way of being and of experiencing bereavement to the table. It was an intricate and complex process.

This is not an easy research topic as I know that relaying sensitive information is exhausting for the participants . . . and also for me as the researcher.

Sliding of roles

The sliding in and out of roles became evident in the interview process as Carla was unexpectedly challenged when celebratory days like mother's, father's and grandparent's day approached. At the same time she was asking questions of bereaved parents about their experiences. Carla could relate easily to the expressed frustration and sadness that some of the parents were experiencing when anticipating celebratory days. Carla was also asking principals about their thoughts and opinions and was concerned that they would not be able to empathize with bereaved parents in their school communities.

I enjoyed the interview except when the questions of celebratory days came up . . . then part of the interview saw me slipping in and out of researcher and into the bereaved parent role.

This is relevant in thinking about qualitative research as an embodied experience. Dickson-Swift et al. (2009a) state that 'we need to think about how we actually do emotion work and what that might mean'. Specifically, Dickson-Swift et al. (2009b: 68) explain that with this type of 'emotion work' research, the embodied experience can result in an 'outward bodily display that conflicts with their true feelings at the time'. This was evident in Carla's methodological reflective journal:

I asked his [principal] thoughts around celebratory days and dealing with families who had been bereaved . . . as I asked the question and looked up at him, I realized I was also asking him as a parent. I noticed that in the interview when I listened back to the audio . . . my usual hmmmmm hmmmmm interested response had shortened to hmm hmm. I am confident that my body language remained the same and interested but my shortened hmmm response tells me that I was positioned differently . . .

From a social justice perspective, Carla was committed and motivated to give voice to bereaved people especially given their marginalised status. However, applying a reflexive lens to her own assumptions, related to her own and other's experiences of celebratory days made it challenging to be able to listen objectively as some principals presented different views.

It [the interview] has triggered a number of things that I had kept in the back of my mind . . . when I think about this topic my throat constricts.

Through noticing her embodied reaction in this experience, Carla identified one of the reasons why the voices of bereaved people are often marginalised . . . an emotional response (throat constricting) effectively restricts or shuts down conversation for bereaved people and the communication of their needs may never surface. Similarly, Jayne (teacher) reflects on her experience while at work.

Jayne: all I could do was just hold back the tears . . . I just sort of sat there. I wanted to leave but I thought I'll make such a scene . . . I think I probably could've . . . but I thought I'll just sit it out, you know when you just look at the carpet and you just hone in on there. I just thought I wish this would finish . . . I couldn't speak.

Overall, the research in conjunction with a grounded theory methodology was ensuring that the bereaved participants were given time and space to voice their opinions and desires for change in schools. However, Carla remained apprehensive about the second interviews that explored celebratory days further with principals.

Critical reflection and reflexivity as tools

In light of the complexity Carla was experiencing as a researcher and the expressed needs of bereaved parents, the research team engaged in a session of critical reflection and later two meetings to discuss how to conduct upcoming interviews with principals when celebratory day questions needed to be asked. This session was based on the critical reflection model identified above (Fook and Gardner, 2007; Gardner, 2014).

The session of critical reflection involved discussing what both Carla and principals may think about celebratory days. Carla voiced her own assumptions and related these to assumptions of other bereaved parents she had interviewed. Fiona wrote these on a white board so both could see the assumptions. Carla and Fiona checked through each assumption to test whether it was based in fact and then questioned the emotion that sat behind each assumption. A few assumptions proved to be the most impacting. Carla and other bereaved parents had assumed that the power rested with principals alone in determining how celebratory days would play out in schools. There was also the assumption that teachers would not tune in sensitively to children's needs. When Carla and Fiona explored possible assumptions from principals, possibilities included 'principals feel torn between the preferences of traditional nuclear families and those of other families' and 'these celebrations are part of the fabric of the school and some people will be upset if we lost them'. Once these assumptions were brought to the surface and transcripts were reviewed and discussed, there was a realisation that the issue of celebratory days for principals was actually contentious and a work in progress. It was evident that principals and teachers were being influenced by their social context as they were often conflicted about celebratory days themselves and torn between trying to respond to different needs and preferences.

The subsequent research team meetings focused on interviews with principals and how to ask the interview questions. Postponing some interviews was considered. There were very positive moments in those discussions. Carla writes:

Fiona pointed out that as bereaved parents we were coming up against the culture. For future interviews she suggested naming the elephant in the room at the beginning (me being a bereaved parent) and postponing if necessary . . .

Using reflexivity as part of the critical reflection process clarified for Carla the need to postpone some interviews to create distance between herself and the participants' responses about celebratory days and reconsider points of view in the transcripts. Once time had passed she conducted with sustained curiosity and objectivity, perceiving the tussle that principals (and teachers) were having with celebratory days in schools.

Brian [principal] is currently wrestling with the traditional aspects of celebratory days versus the more contemporary perspectives. Clearly, this wrestling with the topic needed to be aired.

Effectively, Carla had moved from the assumption that teachers would not tune into children's needs, to appreciating that teachers would do their best to take into account the needs of all children. Also, Carla moved from the assumption that the power rested with principals alone and that the status quo would be upheld, to acknowledging that principals listen to family's needs, were trying to manage many perspectives and were open to change.

The combined tools of critical reflection and reflexivity had served our research team well and we could see the benefits of using reflexivity with not only other research teams but with bereaved parents, teachers and principals grappling with sensitive issues such as these in their schools.

Grounded theory as a conduit

What I am learning is that grounded theory suits who I am . . . in depth interviewing suits me too but it is certainly an art to master.

Charmaz (2008a: 402) advocates for relativity and reflexivity making the following assumptions: reality is processual and constructed under specific conditions; the research process surfaces from interaction; the researchers and participants position are considered; and the researcher and participants co-construct the data. However, when sensitive research is being conducted how does Charmaz consider the researcher's position? Carla writes:

The gift of grounded theory is that it caters for participants who come in with an agenda or grievance . . . grounded theory sees the researcher following their lead. However, interviewing people is completely varied, surprising, disappointing etc. Grounded theory in its wide-ranging flexibility leaves the door open for any response and reaction. This can be tricky for the interviewer who surrenders control from the outset. Maybe not surrenders . . . but the researcher does not hold the power.

Charmaz (2014, 2016) provides detailed valuable information about considering participants and how to interview carefully. For instance, Charmaz (2014: 70) indicates the do's and don'ts of interviewing and states, 'Do aim to be empathetic and supportive; build trust and be sensitive to the participants' non-verbal responses to you and your questions'. We would argue that the same empathy, support and sensitivity needs to be extended to the researcher researching emotionally demanding or sensitive topics. Specifically, Warr (2004: 584) proposes that researchers 'be prepared for the demands of interviewing' and that opportunities be arranged for debriefing.

Also Charmaz (2016: 46) explains the researcher's struggle to understand the participant in interviews:

Grasping participants' meanings and experiences requires openness and diligence and an awareness of context and culture that we may lack. Many of us study people who have suffered profound distress, disruption, and disappointment. Interpreting their stories requires humility, caring, and attention to silences. (Charmaz, 2016: 47)

Charmaz (2016) rightly acknowledges and advocates for care of the participants but how is care for the researcher accounted for especially when they listen to troubling personal experiences and profound distress? Did critical social constructionism and constructivist grounded theory do enough to prepare us as a team to hold the space of bereavement in research from a professional and personal point of view? From a broad perspective, Sherry (2013: 280) claims that

In failing to acknowledge the human status of the researcher in the same way participants' humanness is considered, there is an implicit assumption that issues surrounding the researcher's experiences does not impact on the research and pose no risk to either the researcher or the outcomes of the research.

We argue that the humanness of the researcher needs to be accounted for in social constructionism and constructivist grounded theory literature especially when in depth interviews and reflexivity constitute the major foci of the methodology. It is essential to use critical reflection and reflexivity when researching sensitive topics as a process that enables the researcher to name their own reactions, but also to see where the reactions of others might be coming from and how all are influenced (though not necessarily in the same way) by the social context.

Compassion and critical reflection as a way forward

In our consideration of our own research question 'How do we create compassionate schools?' a new question emerges, 'How do we create compassionate environments for researchers researching sensitive topics?'

According to Lee and Renzetti (1990) 'if social scientists are not to opt out of research on sensitive topics, they must confront seriously and thoroughly the problems and issues that these topics pose'. Specifically, Dickson-Swift et al. (2009b: 74–75) state the importance of researchers receiving regular formalised supervision when involved in researching sensitive topics and note that post graduate students usually have access to this type of supervision whereas more experienced researchers in universities or large research centres may not. Dickson-Swift et al. (2009b: 74) claim that

. . . the concept of emotion work is undervalued within the university culture . . .

and

If we are to create a space for researchers to explore the emotional nature of the work that they do then we need to ensure that appropriate support is offered, both institutionally and individually.

Similarly, Kumar and Cavallaro (2018: 654) advise that researchers become aware of the associated risks to their own wellbeing when undertaking sensitive or emotionally demanding research and that institutions 'assume greater responsibility for researcher well-being'. They deem individual and institutional responsibility as equally important across academic disciplines advocating for researchers 'connected to their own

emotional responses and their self-care needs during and after the research process' and universities making 'self-care part of the required doctoral curriculum for qualitative researchers, and optional but recommended for all others' (Kumar and Cavallaro, 2018: 655–656).

To foster this approach, we suggest critical reflection and reflexivity enacted in a culture of safety and compassion be embedded from the beginning of the sensitive research to ensure feelings and reactions, thinking and assumptions are unearthed, considered and questioned, prioritising transparency and acknowledging position and context. This means identifying and/or training supervisors to be able to give this support and might well be fostered by having inter-disciplinary supervisory teams, so that one team member has the relevant experience.

What would help from the start is openly identifying the research as sensitive. This requires both the interviewer and other team members to be aware of this possibility and prepared to name it. More specifically, the team needs to develop a shared understanding of reflexivity and critical reflection and how this will be used as part of the research and supervision process. It may be, for example, that a reflective journal should be kept to unearth assumptions or another systematic way of prompting continued discussion about reactions that might undermine the data collection and analysis process.

Specific to our research teams experiences, it is argued that first the research be openly identified as sensitive. Second, an understanding of reflexivity and critical reflection be encouraged and explored and a model of critical reflection and/or reflexivity be decided upon. Third, a reflective journal should be kept to unearth assumptions and lastly continued discussion about potential disconnect or conflicting thoughts and emotions throughout the process, especially in regard to data collection needs to be maintained.

Conclusion

Researching how to create compassionate schools in light of death, dying and bereavement has been an enlightening platform for genuinely listening to and giving voice to bereaved people in school communities. Although Carla as an education researcher knew intellectually that her own grief could surface while researching the topic of death, dying and bereavement, she could not have foreseen what emerged as personally challenging. What was needed was a critically reflective response from team members that encouraged a reflexive understanding of her experience that ideally would be available to all researchers of sensitive topics.

Aligned with the existing literature in the quest for institutional support when researching sensitive topics we advocate that universities and research institutions to acknowledge the *human* qualitative researcher and prioritise and provide structured, formalised self-care strategies and guidelines ideally based on a combined critically reflective and reflexive process for not only the benefit of the researcher but the participants and the integrity of the research process.


Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Carla Jane Kennedy  <https://orcid.org/0000-0003-4504-9951>

References

- Barry M and McGovern M (2000) Death education: knowledge, attitudes, and perspectives of Irish parents and teachers. *Death Studies* 24(4): 325–333. doi: 10.1080/074811800200487
- Burr V (2015) *Social Constructionism*. New York: Routledge.
- Charmaz K (2008a) Constructionism and the grounded theory method. In: Holstein IA and Gubrium JF (eds) *Handbook of Constructionist Research*. New York: The Guildford Press, 397–412.
- Charmaz K (2008b) Grounded theory in the 21st century: applications for advancing social justice studies. In: Denzin NK and Lincoln YS (eds) *Strategies of Qualitative Inquiry*. Thousand Oaks, California: Sage Publications.
- Charmaz K (2014) *Constructing Grounded Theory*. London: Sage Publications.
- Charmaz K (2016) The power of stories and the potential of theorizing for social justice studies. In *Qualitative Inquiry through a Critical Lens*. New York & London: Routledge, 49–64.
- Daley A (2010) Reflections on reflexivity and critical reflection as critical research practices. *Affilia* 25(1): 68–82.
- D'Cruz H, Gillingham P and Melendez S (2007) Reflexivity: a concept and its meanings for practitioners working with children and families. *Critical Social Work* 8(1): 1–18.
- Dickson-Swift V, James EL, Kippen S, et al. (2006) Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research* 16(6): 853–871.
- Dickson-Swift V, James EL, Kippen S, et al. (2009a) Researching sensitive topics: qualitative research as emotion work. *Qualitative Research* 9(1): 61–79.
- Dickson-Swift V, James EL and Liamputtong P (2009b) Undertaking sensitive research in the health and social sciences: managing boundaries, emotions and risks - by Dickson-Swift V, James EL and Liamputtong P. 31(4): 623–624. doi: 10.1111/j.1467-9566.2009.1168_7.x
- Fook J and Gardner F (2007) *Practising Critical Reflection: A Resource Handbook: A Handbook*. UK: McGraw-Hill Education.
- Fook J and Gardner F (eds) (2012) *Critical Reflection in Context: Applications in Health and Social Care*. Oxon: Routledge.
- Freshwater D (2011) Using reflection as a tool for research in G Rolfe, M Jasper and D Freshwater. In *Critical Reflection in Practice: Generating Knowledge for Care*. Houndmills: Palgrave Macmillan, 183–195.
- Galende N (2015) Death and its didactics in pre-school and primary school. *Procedia-Social and Behavioral Sciences* 185: 91–97. doi: 10.1016/j.sbspro.2015.03.403
- Gardner F (2014) *Being Critically Reflective: Engaging in Holistic Practice*. London: Macmillan International Higher Education.
- Kellehear A (2012) *Compassionate Cities*. Oxfordshire: Routledge.
- Kellehear A (2014) Death education as a public health issue. In: Stillion J and Attig T (eds) *Death, Dying and Bereavement: Contemporary Perspectives Institutions and Practices*. New York: Springer Publishing Company, 221–232.

- Kennedy CJ, Keffe M, Gardner F, et al. (2017) Making death, compassion and partnership 'part of life' in school communities. *Pastoral Care in Education* 35(2): 111–123. doi: 10.1080/02643944.2017.1306873
- Kumar S and Cavallaro L (2018) Researcher self-care in emotionally demanding research: a proposed conceptual framework. *Qualitative Health Research* 28(4): 648–658.
- Lee RM (1993) *Doing Research on Sensitive Topics*. London: Sage Publications.
- Lee RM and Renzetti CM (1990) The problems of researching sensitive topics: an overview and introduction. *American Behavioral Scientist* 33(5): 510–528. doi: 10.1177/0002764290033005002
- Papadatou D, Metallinou O, Hatzichristou C, et al. (2002) Supporting the bereaved child: teacher's perceptions and experiences in Greece. *Mortality* 7(3): 324–339. doi: 10.1080/1357627021000025478
- Schön D (1983) *The Reflective Practitioner*. New York: Basic Books.
- Sherry E (2013) The vulnerable researcher: facing the challenges of sensitive research. *Qualitative Research Journal* 13(3): 278–288.
- Warr DJ (2004) Stories in the flesh and voices in the head: reflections on the context and impact of research with disadvantaged populations. 14(4): 578–587. doi: 10.1177/1049732303260449
- Winter R and Munn-Giddings C (2001) *A Handbook for Action Research in Health and Social Care*. London & New York: Psychology Press.
- Zembylas M (2014) The place of emotion in teacher reflection: Elias, Foucault and 'critical emotional reflexivity'. *Power and Education* 6(2): 210–222.

Author biography

Carla Jane Kennedy is a PhD candidate specialising in school community studies. Her PhD research coalesces palliative care and educational research in order to focus on how to make compassion visible in schools experiencing issues of death, dying and bereavement. Carla is particularly interested in social critical perspectives and how institutional power affects students and families in school environments. Carla completed her Masters of Education at the University of Melbourne and this included the study of transnational democratic education at the University of London. Carla has an extensive background in literacy education research and professional experience in schools as a literacy coordinator, reading recovery teacher and class teacher across all primary school year levels.

Fiona Gardner is an Associate Professor and Discipline Lead for Social Work and Social Policy across the four regional campuses of LaTrobe University's Rural Health School in Victoria, Australia. Her research and teaching focuses on the value of critical reflection in organisations for workers across many professional backgrounds and those they work with.

From the spotlight on the researcher, a move is now made back to the participants in the quest to listen to and develop a theory answering, ‘how do we create compassionate schools in light of death, dying and bereavement’? The participants provide valuable information for thinking about how we create compassionate schools. The grounded theory lens advocated by Charmaz (2014) enabled consideration of how school community members are making meaning of death, dying, and bereavement in their social networks. This has affirmed me in giving voice to bereaved school community members, unearthing their assumptions and values and listening to how bereavement is lived out in the social networks of school communities. I was able to co-create an understanding with primary school community members in how they currently engage with these issues, their predominantly marginalised assumptions, and strategies that could empower school communities toward a compassionate approach.

In these findings, I present answers to the following questions: ‘what is it like to be a bereaved person in a school community’, ‘what do you consider helpful or unhelpful in school community settings?’ and further questions that deliberately probe participants thinking and place them in a reflexive position. Simply, collective responses, thoughts, opinions, and advice from participants are formulated into a sphere structure under broad categories, each containing more detailed, specific responses from participants that justify placement in the inherent category.

As the sphere illuminates, the participants suggest that there is a desired cultural and societal shift in relation to how death, dying, and bereavement issues are currently perceived and responded to in primary school communities.

5.1 Research Design: Specific Information

As established in Chapter 4, purposive sampling (Mauk, 2017) was used in this study to establish what it is like to be a person in a school community who has experienced bereavement and to understand what a bereaved person considers helpful or unhelpful in schools. Therefore, it was important that firstly, the participants have experienced a close bereavement and secondly, that there was a wide representation of different members of the school community to glean a diverse range of perspectives.

The area that participants were sampled from was predominantly rural and included students, parents, teachers, and principals. In phase one of interviewing, there were 10 participants (table I). In phase two of interviewing, seven participants from phase one were reinterviewed and then six new participants were interviewed. Nine interviews were conducted with parents who had health or community health provider backgrounds (tables I and II). Occupation was also an indicator of a

varied economic status among the participants. Some teachers were also parents in their school community at the time of the bereavement. All the participants resided or had resided in a primary school community setting, had been bereaved of a close friend or a family member (post 6 months and up to 6 years), and were able to address questions pertaining to their bereavement as well as their specific role/membership within their school community.

An initial finding from a research perspective that is worth mentioning before explaining the findings developed from the participants' contributions is how critical reflection and journaling formed an integral part of the interviewing process. This was particularly helpful when moving from more narrow based questions in initial interviews to more open reflexive questions as my journal entry below indicates.

1.8.18

Some of the questions I have been asking have been too narrow ... now that I am interviewing most people again and that a relationship is already there, asking broader and more reflexive questions are appropriate. By using critical reflection, I am able to ask questions that require teachers or principals to consider others viewpoints ... put themselves into another person's shoes. I'm going to start on a clean page and try to think more reflexively and broadly.

Table I Interviews: phase one

| Participants | Age | Gender | Occupation | School role | School type |
|--------------|-----|--------|---------------------|---------------------|-------------|
| Mary | 61 | Female | Principal | principal | State |
| Jayne | 60 | Female | Teacher | teacher | Catholic |
| Bernadette | 54 | Female | Principal | principal | Catholic |
| Jonathon | 48 | Male | health provider | parent | State |
| Halle | 40 | Female | health provider | parent | State |
| Maxine | 48 | Female | private business | parent | State |
| Lorenzo | 41 | Male | Teacher | teacher & parent | State |
| Peter | 12 | Male | | student | State |
| Abigail | 10 | Female | | student | State |
| Bonnie | 38 | Female | health provider | parent | State |

Tables II Interviews: phase two

| Participants | Age | Gender | Occupation | School role | School type |
|--------------|-----|--------|------------|-------------|-------------|
|--------------|-----|--------|------------|-------------|-------------|

| | | | | | |
|------------|----|--------|---------------------|---------------------|----------|
| Mary | 61 | Female | Principal | principal | State |
| Jayne | 60 | Female | Teacher | teacher | Catholic |
| Bernadette | 54 | Female | principal | principal | Catholic |
| Jonathon | 48 | Male | health provider | parent | State |
| Halle | 40 | Female | health provider | parent | State |
| Maxine | 48 | Female | private business | parent | State |
| Lorenzo | 41 | Male | Teacher | teacher & parent | State |
| Meeana | 49 | Female | health provider | parent | State |
| Sally | 45 | Female | rural business | parent | State |
| Tristan | 42 | Male | health provider | parent | State |
| Rachael | 52 | Female | health provider | parent | Catholic |
| Matilda | 58 | Female | teacher | teacher & parent | Catholic |
| Nada | 43 | Female | health provider | parent | Private |

5.2 Findings: Shifting Cultural Perspectives and Enacting Strategies

The participants indicated desired changes in societal and cultural perspectives and what systematic strategies they wanted embodied by school communities. This is represented in a concentric circle presentation where the four outer spheres focus on societal and cultural change (figure I).

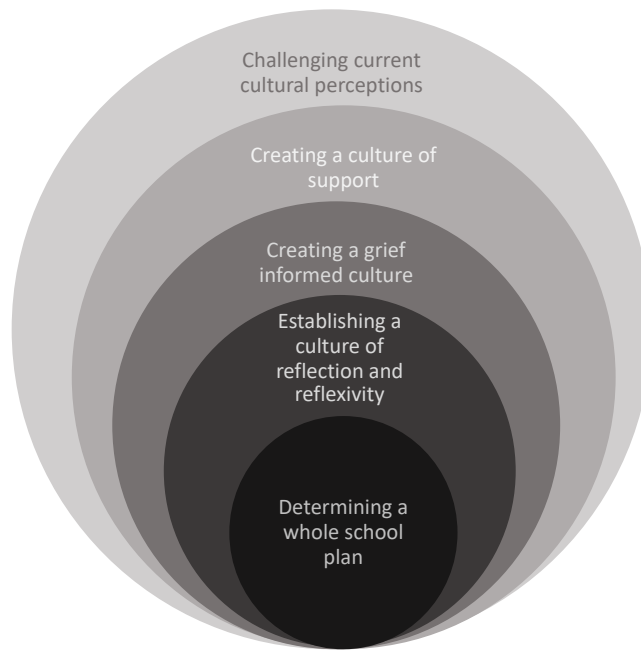


Figure 1

The first outer sphere, 'challenging current cultural perceptions', describes the perceptual change needed when thinking about perceptions of death, dying, and bereavement. The second sphere explains the current support that the bereaved participants received and the type of support they would have preferred. The third sphere represents the participants' desire for a grief informed culture where information about death, dying and bereavement is given to community members. The participants suggest how to create this culture. The fourth sphere elucidates the participants' desire to establish a reflexive and reflective culture in school communities in order to create a compassionate response from schools. At the heart lies the formation of a practical whole school plan that details strategies for school communities in the creation of compassionate schools. More importantly, these theoretical spheres are contained within a whole. The ideas and actions contained within each sphere, in being part of the whole, will at times permeate each other. The spheres represented by lighter shades essentially form the dark centre. For instance, 'challenging current cultural perceptions' and 'establishing a culture of reflection and reflexivity' spheres influence each other and both inform the 'whole school plan' so that school communities understand how to practically develop and establish the changes in cultural thinking and behaving. For the purposes of this chapter, the participant responses will be made explicit under the existing spheres. These will be described and justified by direct quotes from the participants and links between spheres will be made.

5.3 First Sphere: Challenging Current Cultural Perceptions

The participants suggest that a white western culture influences the way people grieve and respond to grieving others. Two subcategories will be explicated here. Firstly, in attitudes about the taboo nature of death, dying, and bereavement and secondly, by celebratory days in school communities such as Mother's and Father's Day.

5.3.1 Death as taboo

According to the participants, death is viewed as a taboo topic and one which is constantly avoided. For example, beginning with the broader culture, Maxine as a white Australian woman observes responses and reactions at a funeral involving First Nations people in the main ceremony and this highlights for her the challenge to white western ways of thinking. Maxine describes a clash of cultures where she is struck by the inability of white people to express their grief openly.

Maxine: The Aboriginal people are screaming and wailing next to you. The coffin's right in front of you ... there are 300 people standing around in the dirt and the dust and the rain, with grief all over them. I just could not believe that all the white people could not cry in public, that the white people could not physically get involved with what was going on in front of them.

The participants also draw a link between the taboo nature of sex education and death.

Halle: I keep going back to puberty stuff because that's where my mind is, but I got this really awesome book from someone who's written a book about a young girl who's about to get her first period. She runs and talks to her grandma, then runs through the village and sees all these people from different cultures. They talk about how they celebrated menarche, their first period. It's a lovely book, so something like that around death, I guess.

As indicated in these quotes, there is a desire to change current perceptions. As such, death, dying, and bereavement are normalised instead of avoided. The following quote from Nada pinpoints the tension in the present school culture and communicates her ideals:

Nada: I am curious about this place of this tension, I feel like it's a tension between and we, we have touched on it, avoiding difficult conversations versus having difficult conversations. Or not even, avoiding difficult feelings, versus learning how to deal with difficult feelings ... what I wouldn't like to see... is that we create a school culture where we end up avoiding having difficult experiences. I'd rather see a school culture develop where the teachers and the whole culture of the school have the capacity to bring up difficult subjects.

5.3.2 Celebratory days

In the second subcategory, there is a wrestling of ideas about the western idea of celebratory days, such as Father's, Mother's and Grandparent's Day, and how they are managed. Some people prefer to still celebrate these as they currently do; others desire inclusivity reflecting the changing structures of families. Perspectives range from having celebratory days to not having them at all. Jonathon reflects on what Mother's Day is like for his family since the death of his wife.

Jonathon: I think the challenge around Mother's and Father's Day and things like that when you've had a parent that's died or a parent that you don't have, is a big challenge for schools around how they manage that. I think the challenge with Mother's Day or generally is that it's heavily promoted and my kids always get tetchy around that time and we have discussions about it ... for schools it's much better to say ... you know 'Carers Day' or to kind of work in a way that says 'how to celebrate the people that care for us' would be a much better framework ...

Lorenzo, whose daughter has died, offers this perspective on considering inclusivity on celebratory days.

Lorenzo: The key behind it is to actually you know bring up and talk about what it is to be part of a family... not doing colouring activities that's based upon you know a coloured in rose picture for your mother or a coloured in hammer picture for your dad. You know it's more complicated than that. Families are different ... what your family looks like, it might not be what anybody else's family in your classroom looks like and it might be great for them to hear ... you live with your granddad and your dad because you know both of their partners have passed away or you live with two mothers and because you know you've got gay parents. I think that those opportunities are too valuable to pass up.

Carla: Yes

Lorenzo: And it kills bigotry and it kills racism and it kills homophobia and all that stuff if you're exposed to those things as a young person. If you're sheltered from it and you live in a homogenous, you know sanitised world, then it's easy to see the other as being very different. Whereas, if it's in your face and it's there, then it's really hard to foster those opinions that aren't very helpful.

Jayne (teacher) also reconsiders these days for bereaved families.

Jayne: I guess it's about reaching out and being aware of different peoples' situations. Even today (Father's Day), it's a tricky time. How we publicise that, invitations, it can so easily slip off the tongue. It's Father's Day or something ... no, it's just a day that we acknowledge someone special in our lives. I think it's being mindful. It's raising a flag and saying let's broaden that so it's not a reminder I'm different. Yes, it's a reality you may have lost a

parent. We know that, but it's another stab in the heart about that person's absence. I think we need to be very sensitive to that.

Interestingly, the participants suggest that current cultural perceptions and how to engage with bereavement is challenged by the practical reality of family structural change. The nuance is that the participants still wanted to affirm the values of motherhood and fatherhood, but were simultaneously open to change and were able to offer alternatives to the current practice.

5.4 Second Sphere: Creating a Culture of Support

The second category 'creating a culture of support', overlaps with the first category 'challenging cultural perceptions'. Specifically, the participants' responses were contradictory in regard to the support received by the school community. Some participants felt well supported by their school community, while others did not. This may be related to cultural perceptions of death, dying, and bereavement being considered abnormal as opposed to normal. After the death of a student, Maxine reflects on the support offered from her first school community and described it as 'phenomenal'.

Maxine: ... Lots of hugs from everybody, from teachers and everything. Lots of letters written to us saying this is what's going to happen, this is how you can get involved, everybody's welcome, everybody's invited. Lots of advice around our children, how they might react. Yeah, and I think for me my son, he talked about it a lot, and I would lie in bed with him at night, and he would tell me about what Kade was up to, and they all did these most beautiful pictures and paintings. And he had Kade flying with animals I think in the picture. And I remember going to the school hall where assembly was and him showing it to me. And it was there all year.

Maxine continues in the interview and compares this supportive community response to her current school where this level of support is not evident. Bonnie too, after her son's death, tells a different story where initial support is identified but not sustained.

Bonnie: I didn't feel supported or understood really by the teachers, the principal, or the parents. I think it was mainly because of the parents that I didn't want to hang around. I just didn't want to have those conversations ... it could have been I withdrew and they didn't really know ... I didn't feel like I had to be the person to approach people. I felt like it was kind of their job.

The participants' responses also suggest that a parent/teacher divide exists — in who receives what type of school community support and in what amount. Parents were satisfied with the support from friends within their school community but generally dissatisfied with the lack of

communication and support over time from the general school community and school professionals. This was juxtaposed with teachers and principals who felt largely an abundance of support and communication when they were bereaved. After her experience of bereavement, Halle (parent and health provider) illuminates the lack of support she felt.

Halle: I think they're very focused on what's going on in the classroom and what they see in the classroom ... but I didn't feel like I could reach out and just sort of say I'd really like to keep checking in with you, or anything like that. But I guess that would've ... looking back on it now, that would've been really useful.

Carla: Checking in with the teacher about your daughter Olivia, that's what you mean?

Yeah, or even just about the whole thing. You know, Olivia is part of my family, so it's, we're a unit, and so having the teacher check in to see how the whole thing's going, not just Olivia, but you know, how my journey might be impacting on her, I guess. Yeah, that would've been helpful.

In contrast, Lorenzo's reflections as a teacher and a parent, whose daughter had died is provided below.

Lorenzo: They made cards and they made pictures, and they made a book for Frances. Everyone in the school wrote a page for this book and they put this book together. It was beautiful. It was amazing. My time back there at the start was really supportive and I felt really understood and supported and the school went out of their way to help me and to help everyone in their own grief in that process. In that regard they were great. It was amazing just to see and feel all that support from the school and the community around the school.

Parent participants explained the type and amount of support they needed from the school community which is also reflected in 'the whole school plan'. There was a strong desire expressed by parent participants to be given the time, space, support, privacy as needed, and understanding after a death, particularly in regard to their children's needs. As indicated by Halle and Bonnie, parents also wanted to be reached out to, particularly when grief was disabling and also followed up on over the short and long term. Although infrequent, when this type of support occurred, parent participants were particularly overcome with gratitude. The participants also wanted an acknowledgment of the death/deceased person over time. Many participants wanted to be asked what they needed and not have people make assumptions. Jayne (teacher) explains this.

Carla: How do you know what to do when the anniversary comes?

Jayne: Because we ask the person ... because we go to the source and we say this is maybe the fourth anniversary or the fifth anniversary, how would you like that to be? I think there

is a huge caution Carla around assumption ... that we assume that is what the person wants ... no ...

The participants particularly valued ways of acknowledging the death in the school community through ritual, ceremony, and providing routine for bereaved children including communal grieving in school communities. Allowing the school community to express their grief creatively was highlighted by parents and teachers alike and is also linked with 'challenging cultural perceptions' and 'determining a whole school plan'. Creative expression included creating art pieces, allowing time for reflective writing, dedicating a room or memorial to the deceased where one could go to sit and reflect, and exploring practical topics that include death like life cycles, dead bodies, and the natural world. Effective counselling was also valued by the participants and is illustrated by Peter, a current secondary school student.

There is a counsellor at my high school but in the primary school there wasn't anyone that was a bit bad because I think that all schools should probably have a counsellor or someone that you can talk to and they actually have two counsellors in my school now and it's a good idea.

According to most participants, the 'Seasons for growth' programme (a small group programme for children experiencing grief, loss, and bereavement) was viewed positively in the ways it supported grieving students in school communities over the short and long term. However, one parent decided not to access the programme for her children due to her concerns with confidentiality in a small town.

5.5 Third Sphere: Creating a Grief Informed Culture

Broadly and in regard to being grief informed, the participants' responses revealed three subcategories. Firstly, there was an appeal for school communities to have more information and advice about bereavement and grief. Secondly, the participants were able to provide information about their own grief and bereavement that may assist school communities in creating a grief informed culture. Thirdly, the participants spoke about storytelling as a way of providing information. I referred to this as transformative story telling in Chapter 2 as encompassing the telling of one's story in a variety of forms as well as reading stories to connect people who have been bereaved with the community.

5.5.1 Appealing for grief information to educate school communities

The following quotes from Jonathon illustrates the desire for more information about grief and bereavement:

Jonathon: ... the school could give out some information around loss and grief so they (parents) can become more aware ... I also think information to parents around stability for kids is really important.

... the trauma training that Berry Street does in terms of some of the stuff I've seen has actually created a new language around trying to understand what children are up to. It would be nice to have something similar around loss and grief or emotion, something that actually brings in a different language with which to understand children's behaviour and then say what can we do differently. They talk about trauma informed schools where teachers are now acting differently ... if there was a similar ilk programme that helped teachers be aware of loss and grief not just loss and grief that's bereavement focused but loss and grief that is more broadly focused, then I think that becomes important.

5.5.2 Grief information from participants about the school curriculum

The participants' bereavement experiences allow us to reflect on what schools may need to understand in terms of grief informed culture. This also links to 'determining a whole school plan' and 'creating a culture of support' spheres.

Lorenzo: I'm not an expert. I don't have all the answers. I think the principal's probably really important. Just for it to be okay to have grief and just for it to be okay to talk about death and when people die and to normalise that experience a bit more. It would be much more helpful if people say, 'I'm feeling really sad about something' and let them talk about it. Let them feel it. It's okay to feel crap. You don't need to be soothed and comforted at all moments. Sometimes you just need to be able to feel crap. You just need to be able to do it. If people want to make it better, then they're not actually listening to you. They're just scared of it. And I don't think that's very helpful ... to be scared of grief.

Further to this, Jonathon (parent and health provider) and Jayne's (teacher) responses suggest that grief responses are overwhelming, individual, and diverse. Grief is not fixable and it can be triggered and reawakened in the short and long term. This is valuable information for schools in their response to bereaved families.

Jonathon: ... even though the kids may not be demonstrating grief in the classroom it's because they are covering it up ... it doesn't mean that within the short term that things are now all fine but that stuff still rolls ... that every developmental stage the grief will reawaken in a different way. You know? That at different points it be re awakened in terms of what people say and do and therefore the kids do need a bit of that kind of support.

Jayne: It might be anniversaries or it might be reminders about peoples' absences. When you've got 400 children, you can't be on all of that, but I can as the principal say to a teacher, 'I'll let you know that August is a really hard time for this family. Despite the fact that it happened 8 years ago, August for this family is really hard. They go away for three days. They acknowledge the death'. Just raising peoples' awareness. As those three children in the school now, just making those teachers aware. I guess it's about reaching out and being aware of different peoples' situations.

Further, the participants described their management of grief and emotions when at school, whether they were at work as a teacher or principal or whether they were taking their children to school that morning and facing the school community. As a principal, Mary was challenged by the intensity of her emotions after the suicide of her sister. This links to 'challenging cultural perceptions' when considering this idea of needing to endure in the face of grief.

Mary: It was very hard to manage those emotions. It was very tiring to manage those emotions and I suppose in the management of those I wasn't present and therefore all I just kept thinking was am I losing my mind, you know because suddenly someone would come in and say I just told you that 15 minutes ago and I'd think they didn't. I had no recollection at all and that's a scary feeling. It's like people go through with Alzheimer's. It's like I should know that. I should know that that just happened and I didn't. And then I'd think am I really fit to be doing this? That questioning of myself was not very nice.

Similarly, Maeena (parent and health provider) provides an interesting perspective that informs us about grief and links into the 'challenging current cultural perceptions' category.

Maeena: In Australia we just, we shy away from anything emotional. You know it's always, you know, 'Doing it hard, but I'm going to be right' you know 'Just, just push on through'. 'Just pull your socks up and you'll, you'll be right mate'. You know we don't admit to vulnerability or high emotion or distress. We push it down into our toes and I think schools will avoid that like the plague.

5.5.3 Storytelling

Another aspect of creating a grief informed culture was through the act of transformative storytelling and listening to other's stories about death, dying, and bereavement. The storytelling that the participants engaged in while being interviewed was largely a positive experience for them. As recommended from a grounded theory methodology, there was very limited talking on my part as the interviewer. The first 10 interviews for adult participants was at its shortest 43 minutes with most participants being closer to an hour or over. The two student interviews were shorter. The

participants were motivated and enjoyed contributing to the process, became emotional at times, commented on a liking for the questions (particularly in the second phase), and were looking forward to reading about participant responses.

Storytelling was also mentioned by the participants in regard to using story books as a way into conversations about death and bereavement; also as a way to create shared understandings for children in classrooms and to normalise bereavement or grief experiences. This also links to the 'determining a whole school plan' category. In Nada's interview, she emphasizes the benefits of storytelling.

Nada: ... a personal account is really helpful ... I don't know if a bereaved parent has the capacity to write a letter and go 'Hey, this is what's going on for me ...'. 'I just want to, can I just let you know that you know some days I can't get out of bed, some days I'm so overwhelmed, I, you know I'm a zombie and you know I forget to the pack the lunch and I forget ...', 'And you know it comes in waves and, and yes it's been 6 months and some days I'm fine, some days I'm not'. I can see with grief that we can be really sensitive in the fortnight after and then you know a month after some people are sensitive and then 6 months after, very few people have that memory and the bereaved person is still in that time where they're either in the ocean or they're getting knocked by waves ...

Nada is able to perceive the ongoing nature of grief here and empathise with grieving others.

Similarly, the following category relates to reflexivity and critical reflection, and how people in the school community can step into the shoes of bereaved people.

5.6 Fourth Sphere: Establishing a Culture of Critical Reflection and Reflexivity

Broadly, the ideas underlying critical reflection and reflexivity were important to the participants, particularly the importance of school communities being aware of their own experiences and related assumptions about death and grief and how these might influence reactions to others. The participants suggest that teachers and principals value and prioritise beneficial training in emotional literacy. In addition to this, training for teachers particularly in empathy, loss, and grief is desired by the participants.

There was also a desire from the participants, including parents and teachers, to connect children's behaviour at school with grief and bereavement. Interestingly, some parents went a step further and advocated teachers to be in touch with their own experiences of grief and related assumptions to draw upon this when working with children. As indicated by a number of participants, this may lead to teachers having conversations and sharing stories about their own vulnerabilities. This may normalise the feelings of grief and bereavement for children; as such, death and the deceased are

viewed positively. When I asked Maeena and Tristan (parents and health providers) about how teachers could put themselves into the shoes of bereaved individuals or families, they responded as follows:

Maeena: I don't know. I mean surely, they've experienced their own grief and loss in some ways. You know, whether it's a loss of a parent or sibling. I guess teachers aren't asked to reflect on their own grief and loss and how to incorporate that as a health professional, we're often asked to reflect about what we bring into the dynamic or what our own personal experience ... you know ... contributes. And I do a lot of self-disclosure, not massive, but just little bits, like 'Oh when I was a kid, I found dah, dah, dah, dah' and I think that there's a lot to be said for that.

Tristan: I think any training or support around emotional awareness is going to help teachers and also being able to process and work through their own grief and loss could possibly help them as well to talking with others who have lost ...or been bereaved. So you know it's harder to support someone like a teacher, a student or a parent when you haven't processed your own needs around your own grief ... but you know that's, that's a long journey that doesn't happen overnight. But at least, yeah if it's got avenues, support groups, men's groups, women's groups, other community groups that support you ... for your own counselling. I guess more teachers that are more emotionally resilient ... they're going to make better supports for others.

A number of participants also mentioned the benefits of 'circle time' (social relationships and awareness programme) for student and staff wellbeing and this process was viewed positively. This also connects with the next category 'determining a whole school plan' where mental health strategies for school communities are examined. Bernadette (principal) explains the wellbeing focus at her school.

Bernadette: It comes from your general relationship with children and how secure and safe they feel at school and the rapport the teacher has with them and the way they conduct the classroom. It's through the relationship. We have circle time every day. We have their safety plans. They know if we talk about feelings and life and death through RE (Religious Education), and we talk about different things you can do when you're feeling this way or that way ... that's all part of our wellbeing, work on our behaviour, self-regulation work, Berry Street work. They are used to it from prep ... hearing that it's normal to feel angry. It's normal to feel sad. It's normal, but they don't last all the time. You can feel all those things in one day or an hour. When you're feeling challenged by a feeling or what are the things we can do to assist you.

5.7 Fifth Sphere: Determining a Whole School Plan

Four categories emerged from the participants' interview responses and analysis and related to determining a whole school plan. Firstly, creating a clear communication pathway; secondly, supporting teachers and principals; thirdly, considering curriculum and current cultural perceptions; and lastly, linking categories.

5.7.1 Creating a clear communication pathway

Th participants suggested that a clear communication pathway is needed between families and school staff both in a short and long term capacity for families experiencing bereavement. Specifically, the participants would have liked schools to be proactive in reaching out to provide time and space, to listen and understand, and to check in and follow up in the short and long term.

Matilda (parent and teacher) states the following:

Matilda: I'd need them to sort of report back to me about how my child is going. I'd need that to be structured in, not just at the end of the day at the door. Some sort of regular little check-in with me as the parent to report back and about how my child is travelling. And just things that they might've observed. I'd like that be structured because otherwise ... I would feel like I was imposing on the classroom teacher too at the end of the day ... you know I'd like it to be that it was a formal sort of locked in arrangement with the class teacher and principal maybe or the wellbeing coordinator ...

Carla: So, follow-ups scheduled in?

Matilda: Schedule, that's the word I'm looking for ... even if it's re-scheduled a couple of times but 'this is our weekly ...' and then might be 'This is our monthly' ... or 'this is our ...', whatever it is scheduled appointment to see how you're travelling and how you think your child is travelling. Extra things that you need to tell us about what we can watch out for or ways that you think we can support you and your child. So those sort of things need to be in a written sort of format. Then it doesn't get lost ... is something really formal and that I could rely on that is going to be there ... and that I knew that I had the teacher and the principal's attention for the duration of the, whatever it is, the half hour chat. I wouldn't like to feel that I was imposing on them or that I was asking a favour. I'd want to feel that that was a natural and accepted part of what is done to support a member of our community.

Matilda suggests a recorded ongoing scheduled appointment with teachers. Policy is also given attention by the participants. Maxine (parent) suggests policy in keeping abreast of a changing culture.

Maxine: Well, I mean it's really around, it's about a policy position. I mean we're shifting culturally from sweeping everything under the carpet and being stoic ... to being more overt and acknowledging.

5.7.2 Support for teachers and principals

The participants acknowledged that teachers are under a great deal of pressure in schools. Some parents were reticent when communicating their family's needs for bereavement support as they recognised the intensity of a teacher's role. The participants suggest that classroom teachers, largely due to time and pressure, are unable to meet the family's grief needs on their own and that a dedicated person such as a wellbeing teacher/school counsellor/principal would need to fulfil this role. There were varying opinions on how this could work practically. Jayne's (teacher) thoughts are as follows:

Jayne: ...we've had a recent bereavement in our school in the last couple of weeks, so this is pretty fresh in my head, of a parent. I think it's definitely essential to have somebody that can ... not wear a family outreach hat but somebody is tagged to the leadership role who can be the contact person. It can't be just the classroom teacher. It needs to be above and beyond that. Having that person that can tap into that family ... however we can reach out to that family is something I really feel is absolutely critical. Not just at the point but ongoing down the track, in the weeks and months. To be able to have a voice for that child, for that family within the school ... I think is really critical.

Also, the principals and teachers were specific in regard to how to support staff. To begin with, Mary contrasts how mental health is addressed in mainstream school culture with special education school culture.

Mary: Teachers have 5 mental-health days a year ... that is really scorned upon if teachers are using those in mainstream. We insisted everyone take those 5 days a year. That was really important and we would celebrate if somebody came back and said, 'Oh, my God, I've had a massage, and then I went for a swim, and that's what I did yesterday'. We would all go, 'Yeah! That's fabulous, good for you'. When I was in the mainstream and you had a day off, you almost had to be on death's door or you were letting the whole team down somehow. Great pressure on you. So these attitudes made a very big difference, and those attitudes, unfortunately, come from leadership and whole school policy and approach. There isn't enough in mainstream in your performance planning as teachers, even in your time allocated for staff meetings and things. There's not enough mental-health time.

With links to the ‘challenging current cultural perceptions’ category, Mary recognises the need for attitudinal and policy initiatives or change. Support is needed from management bodies such as the Department of Education or Catholic Education when dealing with issues of death, dying, and bereavement. The participants suggested the following:

- a shadow person to be provided when a principal was bereaved to serve as a buffer from work demands
- time off for bereaved staff without the pressure of returning to work
- reaching out to staff and an acknowledgement of the death
- checking in with and following up on bereaved staff over time
- sending support people into schools who are past principals or people who have experienced and are knowledgeable about grief and bereavement

5.7.3 Considering curriculum and current cultural perceptions

Principals and teachers particularly spoke about the need to provide authentic support by word or action for children, to normalise children’s grief reactions, and to be aware of the danger and stigma when reminding people in school communities about loss on celebratory days. The participants saw the value in providing rituals and normalising grief responses when grief came upon students unexpectedly. The other commonalities expressed by principals and teachers were to

- listen to bereaved people
- ask them what they need
- acknowledge the diversity of families and their individual stories
- prioritise authentic relationships with families
- consult families about celebratory days
- use family and friend connections within the school to support bereaved families
- visit bereaved families and offer practical support
- normalise varying grief responses

The participants felt grateful when sound leadership was provided after a death in the community and welcomed ritual for the community and routine for the students. Authentic, strong relationships between families and teachers/principals were also considered to be a priority for schools. The participants suggested that conversations about death or its inclusion in the curriculum was desirable. The participants were asked ‘how can schools act creatively to change their culture, so death or bereavement feels more like a normal part of life at school’?

Jayne (teacher): I think story is a really powerful way. I think it’s very beneficial to prepare children for a bereavement. We know death is a part of life as birth is. We do that before a

child then has to deal with that. We talk about funerals. We talk about perhaps burial. We talk about what all that can mean.

Carla: How does that come into the curriculum?

Jayne: For me, it fits really nicely with social and emotional learning. When we were doing a unit of work with some five/sixes on sadness and grief... 'let's think of a time when you might experience it ... or you might imagine it and let's have some shared story and some shared understanding about that'. Not waiting until you've got the grief right there and bereavement right there ... that you start to talk about that.

Jayne's thoughts about preparing children for bereavement with conversation is also reiterated by Rachael (parent and health provider) when talking to her daughter about her own mortality.

Rachael: ... she said to me one day for example, she said to me, 'Mum are you going to die'? she said this about a year ago. And I said 'Darling, I'll promise that I'm not going to die if you can promise you're not going to die'. I said 'You know we're all going to die, all living things die, anything that's alive dies. Trees, grass, birds, people, grandma's, aunties, uncles, parents, children, we all die. But we all, we all have a different number and some, some of us our numbers are a bit lower and some of our numbers are a bit higher and so you get that ticket and when that number is up, it's up. You can do as much as you like, but you know, you can improve your lifestyle I guess to be healthier. I said, 'Can you promise me that you're not going to die young'? And she went 'Ooh...' she thought about it for a while and she said, 'No, I can't promise you mum'. And I said, 'There you go, I can't promise either'.

Differently, Nada (parent and health provider) incorporates the natural world as a way of discussing birth and death with children.

Nada: ... I'm a big fan of, you know working with or learning about and observing the natural world. So schools that have pets, I think is a really great thing. Any bush walks, like schools that just incorporate walks in nature, because you're going to come across, you're going to come across death ...and birth. And nests and birds falling out of nests. So I would say more contact with the natural world and I would also say a strong focus on cycles. Like seasonal cycles because all of them are death aren't they, on some level ... this is passing and now we're moving onto this next season.

5.7.4 Considering links between categories

Overall, there was a desire from the participants for teachers to be open and communicative about death, dying, and bereavement and the deceased in a developmentally, empathetic way. In some

cases, the participants said that this was dependent on the teachers' experiences and expertise. The participants also wanted safety and an offering of choice and options for bereaved children while at school.

These participants' responses provide a challenge to not only school community members but to senior education management as well in their support of principals and teachers. The participants also suggest training for teachers that should focus on loss and grief, empathy, emotional awareness, critical reflection, and reflexivity. The importance of discussing death, dying, and bereavement openly was highlighted alongside other specific ways of making death part of the curriculum. The attendance to policy in regard to changing perceptions of death, dying, and bereavement in communities is suggested.

In considering the 'challenging current cultural perceptions' category and the way this can be enacted in a whole school plan, the participants suggest that this would require the school community to learn about other cultures and how they deal with death, dying, and bereavement. This may shine a light on current western ways of thinking.

In thinking about 'challenging current cultural perceptions' within a whole school plan, the participants suggest that currently, principals and teachers are uncertain about how to handle celebratory days and that discussion, consideration, and determination of how to manage celebratory days is required. This would be in light of grief triggers and a shifting societal perspective, inclusivity, and diversity.

In reflecting on 'creating a culture of support' in a whole school plan, the commonalities communicated by the participants were to acknowledge the death and understand the deep impact of bereavement. This also includes the space and time for ceremony and ritual. Further, the participants expressed the desire to listen to bereaved people, offer them time and space which may include privately reaching out and asking what is needed without making assumptions about what people need. To provide short and long-term support including practical support, such as time away from work, providing meals, picking up and dropping off children, and scheduled meetings; also to provide access to professional services such as counselling, training, and mutual support groups.

In regard to 'creating a grief informed culture' and 'determining a whole school plan', the participants suggest that it would be beneficial to provide advice and information to the community about bereavement and grief. The advice from bereaved participants in this study is also critical information for schools. Specifically, acknowledge, listen to people's stories, be aware of grief reminders and anniversaries, reach out to bereaved individuals, understand the overwhelming and consuming nature of bereavement, ask them what they need, and talk about the deceased.

In 'establishing a culture of critical reflection and reflexivity' for a whole school plan, offer training in emotional awareness, critical reflection and reflexivity, empathy, grief and loss, and the Berry street programme currently run in schools for teachers and principals. Offer 'circle time' for staff and students.

5.8 Summary

Essentially, the findings have provided a voice to bereaved individuals who offer ways to make compassion visible in schools in times of death, dying, and bereavement. It is hoped that their experiences and suggestions foster thinking and empower decision making in school communities to generate a more compassionate culture.

Two published articles will now follow. The first is the discussion of the findings that combines the literature review with the theory chapter. It uses a critical social constructionist and grounded theory lens, and examines the findings from this chapter, arguing that school community members' experiences be discussed and practical strategies be considered in the pursuit of compassion. Please note that this article reports that 23 participants were interviewed. This is incorrect as there were 16 participants some of whom were reinterviewed, totalling overall 23 interviews. The second published article draws upon the findings chapter and discussion article and explicates a foundationally strong framework essential for creating compassion in school communities.

ARTICLE 3: DEATH, DYING AND BEREAVEMENT: CONSIDERING COMPASSION AND EMPOWERMENT



Pastoral Care in Education

An International Journal of Personal, Social and Emotional Development



ISSN: 0264-3944 (Print) 1468-0122 (Online) Journal homepage: <https://www.tandfonline.com/loi/rped20>

Death, dying and bereavement: considering compassion and empowerment

Carla Jane Kennedy, Fiona Gardner & Cathleen Farrelly

To cite this article: Carla Jane Kennedy, Fiona Gardner & Cathleen Farrelly (2020): Death, dying and bereavement: considering compassion and empowerment, *Pastoral Care in Education*, DOI: [10.1080/02643944.2020.1725905](https://doi.org/10.1080/02643944.2020.1725905)

To link to this article: <https://doi.org/10.1080/02643944.2020.1725905>



Published online: 07 Feb 2020.



Submit your article to this journal [↗](#)



Article views: 70



View related articles [↗](#)



View Crossmark data [↗](#)

Full Terms & Conditions of access and use can be found at
<https://www.tandfonline.com/action/journalInformation?journalCode=rped20>

ARTICLE



Death, dying and bereavement: considering compassion and empowerment

Carla Jane Kennedy, Fiona Gardner and Cathleen Farrelly

Education Department, La Trobe University, Melbourne, Australia

ABSTRACT

How to create compassionate schools able to engage constructively with death, dying and bereavement in a rural Western educational context was the focus of this research. Grounded theory and a social constructionist lens were used to gain an in-depth exploration of people's experiences of bereavement, death and dying in the context of their school community. Reflexivity combined with critical social theory deepened participants' reflections on how their perceptions are influenced by their social and specific school experience and how they and others may influence these in turn. Twenty-three participants including principals, teachers, parents and students were interviewed. All participants resided in a primary school community setting at the time of the bereavement and had been bereaved of a close friend or a family member (post six months and up to six years). Interviews were semi-structured and included questions about the participants' experiences, unearthing their assumptions and ideas about engaging constructively with death, dying and bereavement. In accordance with grounded theory, analysis and interviews ran simultaneously so that as interviews were being conducted, analysis was occurring, and categories were emerging. New questions were prepared to further investigate participants' main concerns, ways of thinking and how society and culture may influence the understanding of death, dying and bereavement in a school community. Finally, we argue that school communities need to explicitly discuss community members' experiences and preferences for changes in attitudes as well as practical strategies. Empowered schools could then actively navigate the taboo nature of death, dying and bereavement.

ARTICLE HISTORY

Received 14 May 2019
Accepted 22 January 2020

KEYWORDS

Compassion; bereavement;
death; grounded theory;
school community

Introduction

According to palliative care and educational literature in western societies, any explicitness about death, dying and bereavement is silenced or sequestered (Barry & McGovern, 2000; Galende, 2015; Kellehear, 2014; Papadatou, Metallinou, Hatzichristou, & Pavlidi, 2002). Simply, death instigates fear and social avoidance and people 'commonly view death education as a morbid

CONTACT Carla Jane Kennedy  Carla.Kennedy@latrobe.edu.au

© 2020 NAPCE

affair' (Kellehear, 2014, p. 221). Palliative care, for example, has moved from a social grass roots movement in the 1960s where death and dying were predominantly owned by the community to one that is now more medicalized, resulting in a devaluing of psychological, social and spiritual care (Kellehear, 1999, p. 76). Therefore, Kellehear (1999, pp. 75–76) draws upon the principles of health promotion set down by the World Health Organisation, Ottawa charter (1986) proposing that palliative care and health promotion form a complementary relationship in order to socially and culturally positively regard death, dying and bereavement. However, the practical implementation of these principles in communities is still in its infancy today (Rosenberg, Horsfall, Leonard, & Noonan, 2015, p. 32). This forms the theoretical underpinnings of our research.

Grounded theory as a research method which seeks to understand these issues from the perspective of those experiencing them is complemented here by critical theory, reflexivity and social constructionism. Once chosen for this study, these lenses encourage the exploration of not only the historical context determining the foundations of this research but the participants' current social contexts and how these are influenced by relevant history. Participant responses indicate how their daily lives were affected by death, dying and bereavement in the context of their culture, society and specifically school communities.

We present the findings through three key areas that answer, 'How do we create compassionate schools?' and then we argue the validity and the necessity of these for school communities. Firstly, in this research compassion is understood by (1) *examining school and related community culture* through a social constructionist lens, reflexivity and critical theory. This complexities of power are examined given the school is viewed as an institution. Marginalized perspectives of people who are bereaved are explored, through unearthing societal and cultural assumptions. Secondly, we identify how *compassion could be created* by school communities acknowledging and responding to the marginalized perspectives of bereaved participants (2). The participants' advice and concerns are discussed under the following categories: a call for support (2.1), a need for information (2.2), what participants want to change (2.3) and where to from here? (2.4). Thirdly, we explore how compassion could be created by *considering new partnerships* (3). Recommendations are then discussed and offered for future research.

Examining culture

In using grounded theory and social constructionism, the research is situated within a societal and cultural context. Creswell, Hanson, Plano Clark, and Morales (2007, p. 249) explain that grounded theorists assert that theories should be grounded in data from people's actions, interactions and processes from the field. Next, a theory is generated from data collected from individuals. We chose to emphasize process, relationship and social structure as Charmaz

(2008b, p. 204) highlights 'we can use the processual emphasis in grounded theory to analyse relationships between human agency and social structure that pose theoretical and practical concerns in social justice studies'.

According to Charmaz (2014), the main purpose for grounded theorists is to understand what is happening. Therefore, it was essential to begin with each participant's story and attempt to 'locate it within a basic social process, which may be implicit' (Charmaz, 2014, p. 87). We then identified and pursued themes, gathered focused data and returned to the field to answer analytical questions (Charmaz, 2014, pp. 85–86).

A social constructionist lens also takes a socio-cultural perspective rather than a psychological perspective which focuses more on bereaved individuals as having a problem that needs to be fixed. As Rowling (2005, p. 160) states

By concentrating on an individual's experience divorced from its context, we have failed to embed their issues of concern in a social environment ... after the family, this environment involves the school community.

A social constructionist lens combined with critical theory also ensured a contextual view of knowledge being dependent on historical, cultural and social context and a way of critically analyzing existing attitudes and values. In drawing upon critical theory, we have taken a critical analytic stance toward the status quo. This creates our understanding of the reality of those having contact with schools after bereavement, with the intent of searching for sociopolitical implications and therefore supporting socially just change (Neimeyer, 1998, p. 139).

For compassion to be created in a school community it is vital to understand the processes and interactions happening within that community. This study focuses on the culture that the participants live in and experience, their school, their community and their everyday interactions. Charmaz (2008a, p. 402) assumes that reality is processual and constructed under specific conditions that the research process surfaces from interaction and that the researchers and participants position are considered. Charmaz (2014, p. 14) also states that 'strong currents of social constructionism are apparent in constructivist grounded theory'. This theory is an inductive, comparative, developing and open-ended approach, emphasizing flexibility and treating research as a construction (Charmaz, 2014, pp. 12–13).

Power and marginalized perspectives

In taking 'a critical stance towards actions, organizations and social institutions' (Charmaz, 2008b, pp. 206–207) we consider power through discourses that exist within the school community context, as this influences our understanding of the participants' thoughts, concerns and advice. The constructions themselves are 'bound up with power relations because they have implications for what it is

permissible for different people to do and how they may legitimately treat others' (Burr, 2015, p. 5).

As indicated in our literature review (Kennedy, Keffe, Gardner, & Farrelly, 2017) it is common for the bereaved to experience a breakdown in social relationships (Breen & O'Connor, 2011, p. 98). Coupled with teachers avoiding the topic of death (Galende, 2015, p. 92) this creates a situation where the bereaved are marginalized in relation to social contact and discourse. There is an avoidance of sharing experiences of death, dying and bereavement.

Maeena (parent and health care provider): it's such a complex, emotionally loaded discussion ... that schools shy away from it because in Australia we just, we shy away from ... you know it's always, "Doing it hard, but I'm going to be right" you know "Just, just push on through." "Just pull your socks up and you'll be right mate." ... we don't admit to vulnerability or high emotion or distress. We push it down into our toes and I think schools will avoid that (discussion), like the plague.

Peter (student): they mostly avoided me. I think they were just ... they didn't know what to say so ...

Habermas (1975, p. 27) who primarily writes about higher education, claims that if society marginalizes certain voices then 'communication between participants is then systematically distorted or blocked'. Participants' voices were marginalized and communication blocked when they were unable to express their needs due to the overwhelming nature of their grief.

Halle (parent and health provider): You're just ... you know you're just getting by day by day, and it's a success to get the kids to school, let alone anything else. I guess you're not really able to see what would be helpful for you or what would be useful. You're just going with the flow as best you can, I guess.

Later in the interview, Halle is able to offer advice and strategies to schools but in the initial time of her bereavement, she could not offer suggestions and was marginalized because of her grief. Power was also evident in school communities when participants named a parent teacher divide. When teachers and principals were bereaved, they predominantly felt well supported by their community but most parents did not.

In regard to cultural influence and what people are permitted to do, this description provides an example of cultural assumptions clashing. Maxine who as a white woman has lived and worked in First nations communities is struck by the inability of white people to express their grief openly.

The Aboriginal people are screaming and wailing next to you. The coffin's right in front of you ... there are 300 people standing around in the dirt and the dust and the rain, with grief all over them. I just could not believe that all the white people could not cry in public, that the white people could not physically get involved with what was going on in front of them.

This quote not only reflects the taboo nature of death in a white western culture but also unearths cultural assumptions that impact on school communities. For example, if we assume that bereaved people who are visibly upset want to be taken to a private place in the school to grieve this may lead to further isolation from the community. This illustrates the power that exists in these interactions and how society monitors how grief emotions are expressed and how ongoing bonds with the dead are managed (Neimeyer, Klass, & Dennis, 2014).

By examining how other cultures manage death, dying and bereavement we have the opportunity to learn more about our own cultural or societal assumptions. This is a chance to consider, reflect upon and question our own processes and practices. Lorenzo (parent and teacher) says

I think I like the idea of that Mexican Day of the Dead, where you go and sit in the cemetery, talk to your dead people. I like that. That's bringing those people back into your life. Whoever you've lost in your life is in you. They live in you, in your heart, and your memories and live in your flesh.

In considering cultural or societal assumptions as rooted in practice, Schön (1983)

... relies heavily on the idea that tacit or implicit knowledge (or assumptions) are embedded in practice. Practice therefore can be improved by making such implicit knowledge explicit, thereby exposing it to scrutiny. (Fook & Gardner, 2012, p. 3)

This is evident in Schön's concepts of 'reflecting-in-action' and 'reflecting-in-practice'. Reflecting-in-action refers to the times we think about what we are doing and adjust our operation in order for it to evolve. Reflecting-in-practice allows the practitioner to make sense of new situations and critique one's understandings. Reflecting-in-action and reflecting-in-practice also allows for and encourages reflective conversation by where there is an appreciation, action and re-appreciation. This is where a unique or uncertain situation is understood by attempts to change it and attempts to understand it (Schön, 1983, p. 132).

For example, there may be implicit assumptions in school communities about continuing current forms of celebratory days such as Mother's Day, Father's Day and Grandparents day. However, Jonathon (parent and health provider) offers a different perspective after the death of his wife ...

I think the challenge around Mother's and Father's Day when you've had a parent that's died or a parent that you don't have, is a big challenge for schools around how they manage that. I think the challenge with Mother's day or generally is that it's heavily promoted and my kids always get tetchy around that time and we have discussions about it ... for schools it's much better to say ... you know 'Carers Day' or to kind of work in a way that says 'how to celebrate the people that care for us' would be a much better framework ...

Jonathon's ideas may push against or disrupt theories of knowledge and the current rules and practices of how the school and community manage celebratory days. The opportunity is there for school communities to take a critical

stance, unearth assumptions and explore different ways of thinking or perceiving current processes. Brookfield (2011, p. 1) considers this process of critical thinking as incorporating: the identification of assumptions that inform our thinking and actions; checking the validity and accuracy of these assumptions; viewing our decisions and ideas from several different perspectives and overall and as a result, taking informed actions. Being informed is a critical part of this process. From a different perspective, Lorenzo (parent and teacher) states

The key behind it is to actually you know bring up and talk about what it is to be part of a family ... not doing colouring activities that's based upon you know a coloured in rose picture for your mother or a coloured in hammer picture for your dad. You know it's more complicated than that. Families are different ... what your family looks like, it might not be what anybody else's family in your classroom looks like and it might be great for them to hear ... you live with your granddad and your dad because you know both of their partners have passed away or you live with two mothers and because you know you've got gay parents. I think that those opportunities are too valuable to pass up.

This quote may also disrupt theories of knowledge and challenge current practice. Given these different perspectives from participants, school communities might need to consider what celebratory days mean for all community members including bereaved individuals. Brookfield (2003, p. 142) emphasizes this as transformative learning where

the learner comes to a new understanding of something that causes a fundamental reordering of the paradigmatic assumptions she holds and leads her to live in a fundamentally different way.

Considering, family as a flexible and changing entity may disrupt previously held assumptions by school community members. We argue that this critically reflexive way of thinking about death, dying and bereavement issues in schools will lead to rethinking of current processes and possible change to current practice. We challenge school community members to firstly consider the preferred assumptions of participants in this study for themselves, and then to secondly build strategies to empower their communities. Schön (1983, p. 141) states that

The task of social reform is to empower the relatively powerless – blacks, women, ethnic minority groups, the aged, the disabled, prisoners – to organize for an effective voice in the politics of policy making.

Creating compassion

Compassion is created by listening to the voices of marginalized bereaved participants. In this study, we included students, parents, teachers and principals from primary school communities who had experienced a close bereavement. Their current and preferred assumptions, sometimes nuanced, are drawn from interview data and are discussed under the following categories:

a call for support, a need for information, what participants want to change and where to from here? Rosenblatt and Bowman (2013, p. 83) explain that grief is not a discrete object and that its characteristics are vague, changeable and diverse from individual to individual. Grief is unique and can depend on particular cultural, historical and educational backgrounds and therefore fitting someone's grief into a model lessens our understanding of their grief (Rosenblatt & Bowman, 2013, p. 83). Clearly, one size does not fit all when it comes to supporting individual experiences of bereavement and grief. However, by situating this study in a school context, bereaved participants offer similar or common thoughts and their combined ideas form an overall perspective.

A call for information

Participants in the study named the particular types of support that they needed. Commonly participants wanted to be listened to, offered time, space, privacy and ongoing support and for people to understand the deep impact of bereavement. Practical support such as providing meals, taking children to and from school and having time off work were also desired. Participant needs that challenged existing culture of how to respond to a bereaved person were largely unexpressed to the school community. For example, participants wanted to be reached out to or asked what they needed and not have people make assumptions. In reflection of the time after his wife died, Jonathon's (parent and health provider) experience illustrates how people may assume what is required in times of bereavement.

Jonathon: we had the highest concentration of soups and casseroles in Dennidown for quite some time and people were very good, they needed to do something but I didn't want them to cook for me because trying to feed my kids other food it was a real challenge for me. They really wanted the food that we would normally cook ... the kids were a bit adverse to change ...

Also, in regard to ongoing support, participants wanted both short and long-term support and a clear communication pathway between families and school professionals.

Specifically, parent and parents who were also teachers did not want their children to be seen as different. Instead, they wanted death, dying and bereavement to be normalized. Parents wanted consideration and options for their children on celebratory days and the school to be proactive by providing a clear communication pathway between families, teachers and principals.

Students wanted to be treated normally and the death to be acknowledged. They valued options and choice in regard to going to safe places at school. Students also wanted: a rethinking of celebratory days; options in regard to activities and an available counsellor at school.

In regard to feeling safe teachers and principals wanted to provide options for bereaved children in regard to feeling safe. They wanted more experienced and qualified support from head office and a shadow person to be provided to be a buffer from work demands when bereaved. They valued having time off work, with no pressure to return to work. They wanted to have their work pressures acknowledged and mental health attended to by schools supporting time off for mental health days and offering professional development with a mental health focus.

Generally, participants valued rituals, ceremonies and routine. Rowling (2008, p. 244) reinforces that social support comes from organisational practices within the school that provide people with support through periods of grief such as, experiencing 'a connectedness in shared rituals', through special grief support groups at school or for teachers taking informal leave.

Parent participants' first priority was the wellbeing of their children and teachers first priority were the children in the classroom. However, what was acknowledged but not attended to in a practical sense was the teachers understanding that the families/parent's wellbeing was linked with the child's wellbeing at school.

Halle: You know, Olivia is part of my family, so we're a unit and so having the teacher check in to see how the whole thing's going, not just Olivia, but you know, how my journey might be impacting on her, I guess. Yeah, that would've been helpful.

This also highlights the inability of teachers to attend to family's needs due to workplace pressures. Teachers and principals explained the need for a dedicated person in the school that could support families whether it be through a psychologist/social worker/counsellor/wellbeing coordinator or principal. Participants also valued grief programs, an emotional awareness focus in schools, community support groups and counselling support both in and out of schools.

A need for information

In regards to death, dying and bereavement, Kellehear (2016) states that providing information and giving regular opportunities to discuss and question assists in building capacity. Jayne's (teacher) comments illustrate this point.

Carla: If you were a bereaved parent what might you need or want from the class teacher, the principal or parents?

Jayne: I guess depending on what information I already knew ... but I'd want to know a bit about developmentally perhaps how children might think, about how they might process information, depending on how old the child was.

The need for regular opportunities to discuss issues was reflected in this quote from Matilda (parent and teacher) when asked about what support she would like from teachers

Matilda: I'd need them to sort of report back to me about how my child is going ... I'd like that to be structured because otherwise ... I would feel like I was imposing on the classroom teacher too at the end of the day ... you know I'd like it to be that it was a formal sort of locked in arrangement with the class teacher and principal maybe or the wellbeing coordinator ... extra things that you need to tell us about what we can watch out for or ways that you think we can support you and your child.

So those sort of things need to be in a written sort of format. I wouldn't like to feel that I was imposing on them or that I was asking a favour. I'd want to feel that that was a natural and accepted part of what is done to support a member of our community.

Participants also acknowledged the need for teachers to have grief information and training. Papadatou et al. (2002), Barry and McGovern (2000), Tracey and Holland (2008), Galende (2015), and McGovern and Tracey (2010) state that teachers or university student teachers need or want specific training or procedures to appropriately respond to situations of death, dying or bereavement. They also suggest that different cultural experiences and multicultural aspects should form part of this training. Papadatou et al. (2002, p. 336) affirm that knowledge and skills gleaned from specialized training, 'should be well integrated and make use of the culture's traditional religious practices and community resources which are mobilized in the face of death'.

What participants want to change

In total there were fifteen parents or parents interviewed. Some of these parents were teachers. Interestingly, of this fifteen, nine of the interviewees were with parents who were health providers. This may reflect an interest from the health profession in death, dying and bereavement or a personal desire to contribute to the discussion around these issues.

Participants' responses focused on how grief was experienced. They described the overwhelming nature of grief and the inability to function properly or efficiently when in grief. Adult participants largely pretended that everything was okay and worked hard to conceal emotions.

Rachael (parent and health provider): I prefer to talk about it in intimate terms with certain people only. The rest of the time, it's "Oh no, we're fine." When really, we're not that great, but we don't really want to talk about it.

Participants acknowledged that for children grief reoccurs at different developmental stages. Grief may be triggered at school and children may cover grief up at school. Participants wanted teachers to be sensitive to grief reminders for children and to be mindful on celebratory days such as Mother's and Father's Day.

A number of participants who were parents and health providers explained that in order to support bereaved children, teachers need to be in touch with

their own grief, express their vulnerabilities and have support around their own experiences. Participants spoke about the need to acknowledge emotion from staff and students in a safe way. Some programs or processes were able to provide support for students in this way such as circle time (social relationships and awareness program), the 'Berry street' program (positive education program about trauma), and the 'Seasons for growth' program (education program for children experiencing loss). However, programs or training for teachers in regard to their own journey of grief and ways to express emotion safely were unaccounted for practically in the school system. Teacher reflection and reflexivity support would play an active role here. One participant suggested teachers access support groups and counselling.

Rowling (2008, p. 246) recognizes this duality where teachers are pulled between their duty of care to their students and being in control both personally and professionally (wanting to hide emotion) but then also the teacher as a human ... affected by the grief. She states that 'Teachers need an environment that recognises and validates their grief and that provides support for it' (Rowling, 2008, p. 247).

Participants also wanted death, dying and bereavement normalized and talked about before children were confronted by it. In support of this Barry and McGovern (2000, p. 325) highlight that both teachers and parents expressed a strong desire to discuss death with children before they encountered it. Participants explained the value of being honest with children, learning about death through the coming and going of the seasons, nature and pet ownership. Participants also valued their relationship to the deceased and wanted to maintain that relationship. Memories of the deceased were valued and participants wanted the deceased person to be talked about. Neimeyer et al. (2014, p. 496) state that grieving is an activity that strives to find significance in the death, re-establish a self-narrative, negotiate a 'shared transition' with others, renegotiate and typically preserve a continuing bond with the deceased.

Rachael (parent and health provider): ... if they maybe ask the kids, in a happy, joyful way, "Oh what was your mum like?", "Oh she was funny or she was really cheeky or you know she was really outspoken". I think it's really important. There was one little girl who lost her mum when she was only eighteen months old and I would often say to her, "Your mum used to wear lots of different coloured hats" and I would say all these little things and "Oh did she?" because she obviously couldn't remember her because it sort of embeds in their brain, it gives them a bit of identity. That yes ... acknowledgement that person has died but it's okay to talk about them occasionally. We don't have to sit around moping all day but just to acknowledge them. Asking nice questions about the parent, "I hear your dad was very good at music" or you know ...

Participants were able to suggest ways of incorporating death, dying and bereavement into the curriculum and support death conversation through open dialogue, storytelling, prayer times, sharing books with children about these issues incidentally, in newsletters and classrooms. Some participants were

concerned about teacher's willingness to do this and in some cases, participants recognized that this may depend on teachers' level of expertise and experience.

Kellehear (2014, pp. 224–226) encourages a normalization of death and loss explaining that death education reduces personal and community anxiety, contests fear and ignorance, raises hope and recreates a social context to insufficient or 'problem focused' images of death, dying and loss. This is in the context of community engagement where death education is not a didactic approach but one that is participatory and builds on communities skills and wisdom (Kellehear & O'Connor, 2008, p. 112).

Developing authentic relationships with families was also advocated by participants and death education certainly aides this process in terms of sharing stories. Rowling (2008) and Kellehear (2014) advocate that community sharing or storytelling is a way forward for communities dealing with death, dying and bereavement. In regards to bereavement, Neimeyer, Currier, Coleman, Tomer, and Samuel (2011, pp. 796–797) note the benefit of the survivor to integrate the death into their own life story.

Participants also expressed the value of a creative 'hands on' response to death, dying and bereavement in school communities where the school community is invited to participate. This may include children responding artistically or being involved in the funeral proceedings and acknowledging the death through ritual and ceremony.

Lorenzo (parent): After we built it (coffin) we had a day where all the kids got to come and paint it. They had a go and they were really sombre and with it for an hour, hour and a half max. Then they lost interest, and they went off and played. Then all the parents were there. It turned into this big thing. It was amazing.

Creative ideas like these essentially foster compassion and assist in building a supportive community. Ideas of responding positively and creatively in order to normalize death in communities are advocated by Kellehear (2012, p. 141) who suggests holding a 'Positive grieving art exhibition' whereby schools or communities are encouraged to give expression to the positive aspects of grieving such as through dreams of the deceased, personal courage and spiritual qualities.

In regard to support, participants suggested that a clear communication pathway is needed between families and school staff both in a short and long-term capacity for families experiencing bereavement. Participants wanted schools to be proactive in reaching out, providing time and space, listening and understanding and checking in and following up in the short and long term. The principal's leadership was deemed important and their follow up of family's needs. Ongoing scheduled appointments with teachers were suggested and an appointed person in the school to give the time to bereaved families. A multidisciplinary team approach was suggested where health professionals such as psychologists or social workers have an active role in supporting families

and staff. Papadatou et al. (2002, p. 336) found that suitable interventions that enable childhood adjustment to loss and a team approach is needed between educators, family members and mental health professionals.

Where to from here?

Reflection and reflexivity

Current programs and processes such as circle time, Berry Street program and Season's for growth program are valuable to participants. One participant, Mary (principal) brought our attention to a process called 'Reflective Circles' for staff wellbeing created from Fook and Gardner's (2007) model of critical reflection. This would be beneficial for teachers and the school community. It allows the opportunity to explore issues such as celebratory days, how we respond to grief in our culture and the parent teacher divide.

Fook and Gardner (2012, p. 4–6) draw on the work of Schön to develop a model of critical reflection which focuses on unearthing assumptions. This model includes ideas of reflective practice and reflexivity but also includes a variety of perspectives including transformative learning (Brookfield, 2005) and critical spirituality (Gardner, 2011, 2012). Practically, Fook and Gardner (2007, p. 44) explain that the model generally involves small groups of critical reflective learners, although the processes can also be used individually in supervision or in pairs. The first stage of the process is to unsettle assumptions that are embedded in their current practice in a specific experience. The second stage is to focus on how their practice might change as a result of their new awareness after uncovering assumptions. Small facilitated groups allow learning through dialogue, individual reflection and the expression of multiple perspectives (Fook & Gardner, 2007, pp. 44–45).

Participants support a more reflexive/reflective type of training for teachers.

Tristan (parent and health provider): I think any training or support around emotional awareness is going to help teachers and also being able to process and work through their own grief and loss could possibly help them as well to talking with others who have lost ... or been bereaved.

Maena (parent and health provider): I mean surely, they've (teachers) experienced their own grief and loss in some ways. You know, whether it's a loss of a parent or sibling. I guess teachers aren't asked to reflect on their own grief and loss and how to incorporate that as a health professional, we're often asked to reflect about what we bring into the dynamic or what our own personal experience ... you know ... contributes. And I do a lot of self-disclosure, not massive, but just little bits, like "Oh when I was a kid, I found dah, dah, dah, dah" and I think that there's a lot to be said for that.

Death education

In reflection of participant's responses, it would seem prudent to move away from a didactic approach to death education in schools. This would be where

death is not a separate entity to be taught to children but an integrated topic. Conversation, storytelling and other cultural perspectives of death, dying and bereavement can then be accessed through the primary school art, literacy, science, environmental, LOTE (Languages other than English), health and religious education curriculum. Nada (parent and health provider) states

I'm a big fan of, you know working with or learning about and observing the natural world. So schools that have pets, I think is a really great thing. Guinea pigs and chickens. Any bush walks, like schools that just incorporate walks in nature, because you're going to come across death and birth and nests and birds falling out of nests. So I would say more contact with the natural world and I would also say a strong focus on cycles ... seasonal cycles, because all of them are death aren't they, on some level. They're all in a sense "Okay this is passing and now we're moving onto this next season".

Halle (parent and health provider): I know I'm taking the word creative literally here, but there's no reason why they couldn't explore death in art and look at -- I know it's a bit morbid, but look at dead bodies, out of interest and curiosity. Then I guess a lot of the schools will have food gardens and chickens, so there's an opportunity there for kids to be learning about the cycle of life. I think they sort of have the tools and resources there. It's just about the teachers reaching out and using what's there in front of them to casually bring those lessons in.

Mills and Mills (2016, p. 16) also argue for death education in schools and suggest that it be situated in the international field of positive education. They argue that there needs to be 'new and positive narratives' in the area of death education (Mills & Mills, 2016, p. 16). We would argue that although this does provide an avenue it would depend on funding and access to the positive education program. Accessing current curriculum would therefore be more practical and assured.

Developing a clear communication pathway

The line of communication between parents and school professionals needs to be clear. According to participants, schools need to be proactive in their communication with families. Grieving people generally feel overwhelmed both in the short and long term. This diagram suggests a pathway for schools to take so bereaved families are supported within a school community structure.

Policy

Rowling (2008) and McGovern and Tracey (2010) strongly recommend policy development. Specifically, McGovern and Tracey (2010, p. 249) suggest that it may be time to develop bereavement policies and procedures formally in all educational settings. Tracey and Holland (2008, p. 264) also note that schools need support in developing and formalising policy.

The most practical and efficient way to create a clear communication pathway for bereaved families is to ensure conversations occur in the curriculum. Committing to a process such as reflective circles for school communities would

be helpful as well as including death, dying and bereavement information and strategies in current student wellbeing policies. Kellehear (2014, p. 223) suggests that parents, teachers and students can assist in the development of policy documents as this allows open discussion around the topics and experiences of death, dying and loss. This normalizes death, dying and bereavement in the school community setting.

Considering new partnerships

This article has set about explaining how school communities can become more compassionate in response to death, dying and bereavement issues. School communities need support to do this. In Australia, the present-day holders of death, dying and bereavement knowledge and experience are Palliative Care Australia (PCA), and it would be desirable to have their knowledge accessible to schools. However, participants did not name or discuss PCA as a support agency in their community and there are no formal partnerships between schools and PCA. Rosenberg, Mills, and Rumbold (2016, p. 2) state that a public health approach to palliative care demands a cultural change where the current possessors of expert knowledge need to share this knowledge. Interestingly, Mills, Rosenberg, and McInerney (2015, p. 221) state that Palliative Care Australia (2005) acknowledges a priority area which says 'All Australians must have access to education about dying and death' and that the PCA's quality standards explicitly state the importance of community capacity building (Cited in Mills et al., 2015, p. 227). PCA also set an ambitious goal

... That dying, death and the role of palliative care are integrated into the personal development syllabus of all schools and the development of the Australian Curriculum by 2015 (Cited in Mills & Mills, 2016, p. 16).

Practically, Mills and Mills (2016, p. 16) suggest that a well-defined, tangible framework of how to accomplish this was perhaps lacking. In addition to this Rosenberg et al. (2015) argue that a research focus on informal social networks is necessary. They call for current palliative care practices to reorient themselves towards an actualised health promotion in order to glean a deeper understanding of the role of carers and informal caring networks (Rosenberg et al., 2015, p. 35).

This study has focused on those informal social networks and provides valuable information for the PCA. PCA have an opportunity to now move towards primary school communities and offer schools information, support and guidance. Practically, PCA by working with principals, school counsellors and student well-being coordinators can supply schools with: resources; grief information; provide professional development for teaching staff; assist in policy development and provide information for families through information evenings at schools and through school newsletters. Celebratory days such as

Halloween, All Souls day or Easter may be opportunities for PCA to harness a positive energy to inform school communities about ongoing relationships with the deceased and celebrating memories of the deceased.

Partnership is noted by Rumbold and Aoun (2014, p. 134) who strongly advise that grief portfolios in palliative care teams should be held by people in education, community development or health promotion. They recommend a participatory approach where palliative care is working alongside schools or workplaces, identifying issues about death, dying or bereavement. More broadly and from a practical perspective, Kellehear (2016, p. 37) highlights the need to work 'with' communities rather than working 'on' communities, by eroding ignorance and fear. Kellehear and Fook (2010, p. 22) note that in Australia palliative care services have been reorienting their approach. However, Kellehear (2016) endorses the need for more information and exchange of ideas around the topics of death, dying and bereavement. This study enables the collective community in partnership with PCA to define problems and to develop solutions.

Recommendations

In relation to responding to community bereavement, Matheson (2013) states that schools need to provide training for teachers and administrators, train facilitators to provide early bereavement support on the school grounds, form partnerships with families and outside professionals to prepare for present and future bereavement and prepare for long-term needs of staff and students.

We would recommend that management bodies overseeing schools invest in reflective circles training and provide trainers to work with school communities under the banner of health and socio-emotional curriculum. Connected to this, universities especially education faculties need to invest in teaching critical reflection and reflexivity to student teachers.

Schools need to invest time in normalizing death, dying and bereavement through policy development with their school communities. Policy needs to include: communication with bereaved families (Figure 1); including death, dying and bereavement conversations in the curriculum and providing access to professional development, e.g., reflective circles for staff. This is supported by Rowling (2005, pp. 163–164) who argues for a holistic approach to loss and grief experiences and a resulting connectedness in school communities. A holistic approach means accessing the 'hidden curriculum' or the ethos of the school. The hidden curriculum is found in school policies that provide emotional well-being of students, a pastoral care system, availability of outside agencies, the belief system and also within relationships.

Given its knowledge and expertise, PCA as an external agency and is well positioned to provide both short and long-term support to school communities. Local palliative care bodies need to partner with schools by approaching

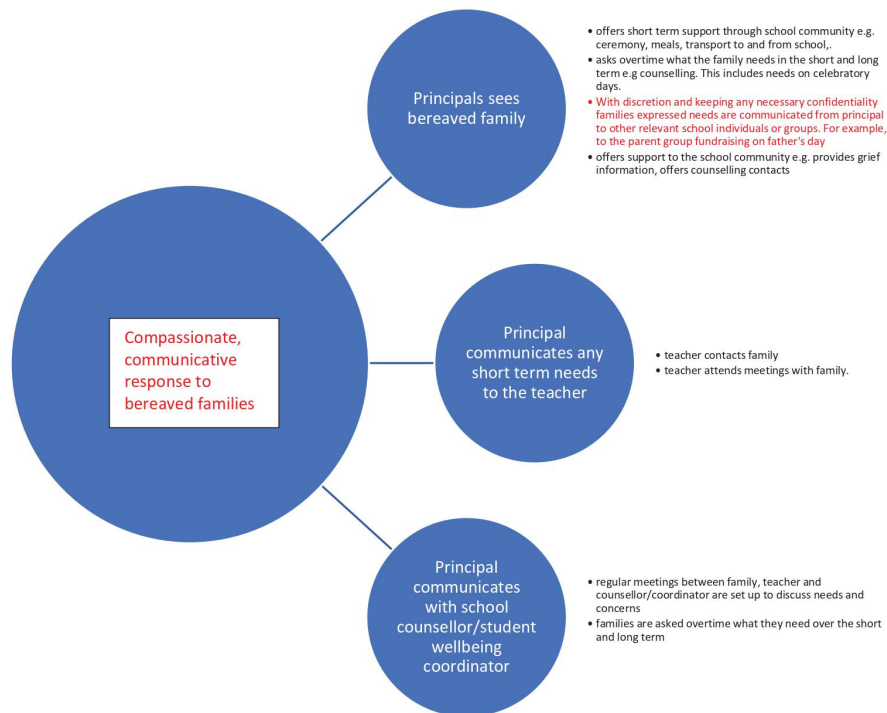


Figure 1. Communication pathway.

principals and school counsellors/wellbeing coordinators and making schools aware of the information and support they can offer.

In terms of future research, we also consider the limitations. The teachers that we interviewed were holders of leadership positions, part-time or working as casual relief teachers. It would have been valuable to have perspectives from current full-time classroom teachers to understand the ongoing relationships they have with bereaved families, the pressures of their workload when factoring in family support and understanding what support full-time teachers need when bereaved. Also, there were only two students who were interviewed, possibly due to the sensitive nature of the topic. More student perspectives may have provided more robust information about experiences of bereavement in the classroom and in the playground, experiences of celebratory days and what support they would have liked from the school community.

In this article we have presented our findings by giving voice to bereaved school community members. We have discussed the influences of society, culture and how our assumptions influence the way we think about death, dying and bereavement through the lenses of grounded theory and social constructionism. We have discussed valid and necessary techniques that are likely to prove empathetic and effective and provide avenues for school

community support through social networks, procedure, structure and training. It is time for school leadership and PCA to take up the gauntlet and form partnership on behalf of all bereaved families and bereaved families to come. To listen, to understand, to connect and to essentially be present and compassionate when death, dying and bereavement are in our midst.

Disclosure statement

No potential conflict of interest was reported by the author.

References

- Barry, M., & McGovern, M. (2000). Death education: Knowledge, attitudes, and perspectives of Irish parents and teachers. *Death Studies*, 24(4), 325–333.
- Breen, L. J., & O'Connor, M. (2011). Family and social networks after bereavement: Experiences of support, change and isolation. *Journal of Family Therapy*, 33(1), 98–120.
- Brookfield, S. (2003). Putting the critical back into critical pedagogy: A commentary on the path of dissent. *Journal of Transformative Education*, 1(2), 141–149.
- Brookfield, S. (2005). *The power of critical theory for adult learning and teaching*. New York: Open University Press.
- Brookfield, S. D. (2011). *Teaching for critical thinking: Tools and techniques to help students question their assumptions*. San Francisco, CA: John Wiley & Sons.
- Burr, V. (2015). *Social constructionism*. London: Routledge.
- Charmaz, K. (2008a). Constructionism and the grounded theory method. In I. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397–412). New York: The Guildford Press.
- Charmaz, K. (2008b). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 203–242). London: Sage.
- Charmaz, K. (2014). *Constructing grounded theory*. London: Sage.
- Creswell, J. W., Hanson, W. E., Plano Clark, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist*, 35(2), 236–264.
- Fook, J., & Gardner, F. (2007). *Practising critical reflection: A resource : A handbook: Handbook*. Maidenhead: McGraw-Hill Education (UK).
- Fook, J., & Gardner, F. (2012). *Critical reflection in context: Applications in health and social care*. London: Routledge.
- Galende, N. (2015). Death and its didactics in Pre-school and primary school. *Procedia-Social and Behavioral Sciences*, 185, 91–97.
- Gardner, F. (2011). *Critical spirituality*. Farnham: Ashgate.
- Habermas, J. (1975). *Legitimation Crisis*. Boston: Beacon Press.
- Kellehear, A. (1999). Health-promoting palliative care: Developing a social model for practice. *Mortality*, 4(1), 75–82.
- Kellehear, A. (2012). *Compassionate cities*. Oxfordshire: Routledge.
- Kellehear, A. (2014). Death education as a public health issue. In J. Stillion & T. Attig (Eds.), *Death, dying and bereavement: Contemporary perspectives institutions and practices* (pp. 221–232). New York: Springer Publishing Company.
- Kellehear, A. (2016). Commentary: Public health approaches to palliative care–The progress so far. *Progress in Palliative Care*, 24(1), 36–38.

- Kellehear, A., & Fook, J. (2010). Bereavement care for the non-bereaved: A health promotion challenge. *Bereavement Care*, 29(3), 21–25.
- Kellehear, A., & O'Connor, D. (2008). Health-promoting palliative care: A practice example. *Critical Public Health*, 18(1), 111–115.
- Kennedy, C. J., Keefe, M., Gardner, F., & Farrelly, C. (2017). Making death, compassion and partnership 'part of life' in school communities. *Pastoral Care in Education*, 35(2), 111–123.
- Matheson, J. (2013). Assessment and intervention in the family and larger systems. In D. K. Meagher & D. E. Balk (Eds.), *Handbook of Thanatology*. New York: Routledge.
- McGovern, M., & Tracey, A. (2010). A comparative examination of schools' responses to bereavement and the associated needs of the school community in Galway, West of Ireland and Derry, Northern Ireland. *Pastoral Care in Education*, 28(3), 235–252.
- Mills, J., Rosenberg, J. P., & McInerney, F. (2015). Building community capacity for end of life: An investigation of community capacity and its implications for health-promoting palliative care in the Australian capital territory. *Critical Public Health*, 25(2), 218–230.
- Mills, S., & Mills, J. (2016). Future directions for community engagement as a public health approach to palliative care in Australia. *Progress in Palliative Care*, 24(1), 15–18.
- Neimeyer, R. A. (1998). Social constructionism in the counselling context. *Counselling Psychology Quarterly*, 11(2), 135–149.
- Neimeyer, R. A., Currier, J. M., Coleman, R., Tomer, A., & Samuel, E. (2011). Confronting suffering and death at the end of life: The impact of religiosity, psychosocial factors, and life regret among hospice patients. *Death Studies*, 35(9), 777–800.
- Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies*, 38(8), 485–498.
- Papadatou, D., Metallinou, O., Hatzichristou, C., & Pavlidis, L. (2002). Supporting the bereaved child: Teacher's perceptions and experiences in Greece. *Mortality*, 7(3), 324–339.
- Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2015). Informal caring networks for people at end of life: Building social capital in Australian communities. *Health Sociology Review*, 24(1), 29–37.
- Rosenberg, J. P., Mills, J., & Rumbold, B. (2016). Putting the 'public' into public health: Community engagement in palliative and end of life care. *Progress in Palliative Care*, 24(1), 1–3.
- Rosenblatt, P., & Bowman, T. (2013). Alternative approaches to conceptualizing grief: A conversation. *Bereavement Care*, 32(2), 82–85.
- Rowling, L. (2005). Loss and grief in school. In B. Monroe & F. Kraus (Eds.), *Brief interventions with bereaved children* (pp. 159–172). USA: Oxford University Press.
- Rowling, L. (2008). Linking spirituality, school communities, grief and well-being. *International Journal of Children's Spirituality*, 13(3), 241–251.
- Rumbold, B., & Aoun, S. (2014). Bereavement and palliative care: A public health perspective. *Progress in Palliative Care*, 22(3), 131–135.
- Schön, D. (1983). *The reflective practitioner*. New York: Basic Books.
- Tracey, A., & Holland, J. (2008). A comparative study of the child bereavement and loss responses and needs of schools in Hull, Yorkshire and Derry/ Londonderry, Northern Ireland. *Pastoral Care in Education*, 26(4), 253–266.
- Witkin, S. (2011). *Social construction and social work practice: Interpretations and innovations*. New York: Columbia University Press.



Original Article

HEJ

The Intentional Compassion Framework for school communities

Health Education Journal

1–12

© The Author(s) 2021

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/00178969211006746

journals.sagepub.com/home/hej



Carla J Kennedy^a , Fiona Gardner^a
and Anne Southall^b

^aSchool of Public Health, La Trobe University, Bendigo, VIC, Australia

^bSchool of Education, La Trobe University, Melbourne, VIC, Australia

Abstract

Objective: This article offers a framework to guide schools in developing a compassionate culture. Using a social constructionist/critical perspective, five spheres of work are identified to help schools achieve this goal. Framing death, dying and bereavement from a health promoting perspective, they involve challenging current cultural perceptions, creating a culture of support, creating a grief-informed culture, establishing a culture of reflection and reflexivity, and developing a whole school plan.

Setting: Eight rural primary school communities in central Victoria, Australia.

Method: Constructivist grounded theory with interviews and analysis occurring concurrently, allowing categories to develop alongside new questions to explore participants' thinking and priorities.

Results: Participants' insights, knowledge and priorities fostered understanding and led to the five strategies for change that underpin this framework.

Conclusion: Study participants' desire for a societal, cultural shift in how to understand death, dying and bereavement issues in school communities serves as an important foundation for change.

Keywords

Compassion, critical theory, education, grief, health promotion, social constructionism

Corresponding author:

Carla J Kennedy, School of Public Health, La Trobe University, Edwards Road, Flora Hill, 3552, Bendigo, VIC 3552, Australia.

Email: carla.kennedy@latrobe.edu.au

Introduction

In Western societies, attitudes towards death, dying and bereavement are typically characterised by avoidance and fear (Kellehear, 2014). However, this dominant perspective is now challenged by experience in other cultures and by new waves of thinking. To normalise death, dying and bereavement in school communities, we developed a framework for more compassionate schools arising from research participants' responses.

The framework offered is underpinned by the theoretical perspectives provided by critical theory and social constructionism and therefore focuses on context, power in schools, and dominant and marginalised discourses. It is informed by and builds on literature from educational and palliative care research, with a particular emphasis on health promoting palliative care which offers a progressive way to address the normalisation of death, dying and bereavement.

Grounded theory was utilised to analyse data from in-depth interviews with school students, parents and staff. This aimed to bring the experience of grieving families' feelings, thoughts and opinions to the fore for the benefit of other community members. The foundations of the framework reflect wisdom in our midst, engaging with the experiences, thoughts and opinions of participants who know bereavement and have experienced it while being part of a school community.

Literature review

Galende (2015: 91) has argued that death can be considered 'a social and educational taboo' stating that the topic itself is 'constantly banned and avoided'. In regard to school communities, findings from a national study in Greece suggest that the majority of educators want to support bereaved students but feel ill-equipped and unprepared to do so (Papadatou et al., 2002: 324). Similarly, Barry and McGovern (2000: 325) found that teachers and parents feel uncomfortable conversing with children about death. Suggestions on how best to manage the taboos of death, dying and bereavement in community settings can be found within health promoting palliative care literature. Mills and Mills (2016: 16), for example, quote Palliative Care Australia (PCA) as advocating

. . . That dying, death and the role of palliative care are integrated into the personal development syllabus of all schools and the development of the Australian Curriculum by 2015.

However, a well-defined, tangible framework for how to accomplish this is lacking.

The work of organisations such as PCA aims to provide an inclusive strategy for bereavement support in many communities (Aoun et al., 2014) and may inform our understanding when thinking about these issues in school. Kellehear's (1999) notion of 'compassionate cities' is also significant, emphasising the need to empower communities and build capacity to promote compassion. In the school community literature, Rowling (2008: 244) suggests that,

Grief should be seen as a normal event that can be managed by school communities with outside support . . . it should not be pathologised and seen as only the domain of outside experts.

Rowling (2010) argues that a Health Promoting Schools Framework has much to offer in this respect in that it promotes ownership over community health generally rather than being reactive to grief and loss events as they occur. Finally, based on work creating a partnership between a hospice and two schools, Paul (2016: 15–16) advocates for capacity building including health promotion, community ownership, education and support.

Using this and related literature as a springboard, the framework provided here offers a way forward for schools seeking to integrate death, dying and bereavement more fully into their work.

This study offers an understanding of how school community members, who have experienced bereavement, perceive death, dying and bereavement within their social networks. Their narratives provide the basis for a framework which identifies how compassion can be made more visible in school communities.

Prioritising context

Our concern here is to advance a socio-cultural understanding of grief and bereavement which avoids an individualised, psychological perspective and embeds death, dying and bereavement issues in their social context. Rowling (2008) emphasises the erroneous nature of an individualised approach when intervening with young people who are grieving, presuming they have a ‘problem’ that needs to be fixed:

By concentrating on an individual’s experience divorced from its context, we have failed to embed their issues of concern in a social environment . . . after the family, this environment involves the school community (Rowling, 2010: 148).

Instead, we combine a social constructionist lens with critical theory to offer a contextual understanding of how school community members make meaning of death, dying and bereavement within their social networks. This lens brings to the fore an understanding of historical, cultural and social factors, and meaning making through language. Through their work, social constructionist researchers seek to question the influence of dominant discourses and recommend alternatives in recognition of the fact that ‘knowledge is sustained by social processes (particularly language)’ (Witkin, 2011: 19). This way of seeing things encourages reflexive learning and the challenging of everyday assumptions. As researchers, the importance of questioning our own assumptions while conducting research cannot be underestimated (Habermas, 1975).

Fook and Gardner (2012) see critical reflective practice as focusing on implicit assumptions and their effects on practice. Reflexivity involves thinking carefully about how ‘one’s self can influence what and how knowledge is made’. By so doing it can ‘shed light on how specific assumptions we make can arise from our own background and experience’ (Fook and Gardner, 2012: 6). Understanding and using critical reflection and reflexivity is valuable both for researchers and for those responding to people who are bereaved in school communities.

In developing the framework offered here, we draw on grounded theory to illuminate the voices listened to in school communities and shed light on who the decision makers are. As Charmaz (2008: 204) states, ‘we can use the processual emphasis in grounded theory to analyse relationships between human agency and social structure that pose theoretical and practical concerns in social justice studies’. Grounded theory holds the potential to give voice to bereaved school community members, revealing their assumptions and values, listening to how bereavement is experienced in school social networks and identifying strategies for how compassion can be made more visible.

Understanding compassion

Charmaz’s (2008) thoughts concerning social justice resonate with Rumbold’s (2012) work relating compassion to justice. By restoring compassion to the health care system, Rumbold (2012: 112) states, we ‘would see caregivers listening, recognizing, and responding to other’s experiences, particularly when these involve fear, anxiety, and suffering’. Such an approach is advocated for by Sinclair et al. (2018) who argue that compassion is better articulated by patients who are the recipients of care rather than by theoretical writing. Collectively, patients see compassion as – ‘a virtuous

response that seeks to address the suffering and needs of a person through relational understanding and action' (Sinclair et al., 2018: 195).

From an educational perspective, Schubert and He (2020) state that, 'compassion is the thoughtful feeling that begets caring actions' through an 'empathic concern for others'. Similarly, Nussbaum (1996: 28) explains that in the philosophical tradition, compassion links the individual with the community, arguing against modern moral theories that regard compassion as 'irrational in human affairs' and stating that 'compassion is above all a certain sort of thought about the well-being of others'.

Informed by such understandings, the perspectives of participants in this study and the theoretical underpinnings of critical theory and social constructionism, we define compassion as 'a justice-based intention to understand and empathise with people who are suffering by extending them support in thought, word and action'. The proposed Intentional Compassion Framework which we offer will be discussed first in terms of the research design used to develop it, and second through a description of the framework itself and each sphere, its links to other spheres and implications for school communities.

Research design

According to Creswell et al. (2007), grounded theorists assert that theory should be grounded in data from people's actions, interactions and processes in the field. Therefore, in developing this framework, the questions asked in interviews were deliberately in-depth and open ended, allowing participants who had been bereaved to speak freely about their experience and express their thoughts about how best to create compassionate schools.

Purposive sampling was used to ensure the representation of different members of the school community and to access a range of perspectives.

Once ethical approval for the study had been granted by La Trobe University, invitations were sent to principals, teaching staff and parents in four primary schools in central Victoria and the study was also advertised through community groups. Students were recruited through parents who were willing to participate in the study. Overall, community members from eight regional schools agreed to participate in the study. Interviews took place in two stages.

In the first phase of interviews, 10 participants were involved. In phase 2, seven participants from phase 1 were re-interviewed and six new participants were interviewed (Tables 1 and 2). The names of participants have been anonymised. All participants belonged to or had belonged to a

Table 1. Interviews: Phase 1.

| Participants | Age (years) | Gender | Occupation | School role | School type |
|--------------|-------------|--------|------------------|--------------------|-------------|
| Mary | 61 | Female | School principal | Principal | State |
| Jayne | 60 | Female | Teacher | Teacher | Catholic |
| Bernadette | 54 | Female | School principal | Principal | Catholic |
| Jonathon | 48 | Male | Health provider | Parent | State |
| Halle | 40 | Female | Health provider | Parent | State |
| Maxine | 48 | Female | Private business | Parent | State |
| Lorenzo | 41 | Male | Teacher | Teacher and parent | State |
| Peter | 12 | Male | | Student | State |
| Abigail | 10 | Female | | Student | State |
| Bonnie | 38 | Female | Health provider | Parent | State |

Table 2. Interviews: Phase 2.

| Participants | Age (years) | Gender | Occupation | School role | School type |
|--------------|-------------|--------|------------------|--------------------|-------------|
| Mary | 61 | Female | School principal | Principal | State |
| Jayne | 60 | Female | Teacher | Teacher | Catholic |
| Bernadette | 54 | Female | School principal | Principal | Catholic |
| Jonathon | 48 | Male | Health provider | Parent | State |
| Halle | 40 | Female | Health provider | Parent | State |
| Maxine | 48 | Female | Private business | Parent | State |
| Lorenzo | 41 | Male | Teacher | Teacher and parent | State |
| Meeana | 49 | Female | Health provider | Parent | State |
| Sally | 45 | Female | Rural business | Parent | State |
| Tristan | 42 | Male | Health provider | Parent | State |
| Rachael | 52 | Female | Health provider | Parent | Catholic |
| Matilda | 58 | Female | Teacher | Teacher and parent | Catholic |
| Nada | 43 | Female | Health provider | Parent | Private |

primary school community setting in a professional or community capacity; all had been bereaved of a close friend or a family member (between 6 months and 6 years previously); and all were happy to answer questions pertaining to their bereavement as well as their specific role/membership within their school community.

Analysis began after each interview and categories began to develop through initial and grounded theory theoretical coding. By the 10th interview and ongoing analysis, it was evident that some categories were reaching a point of saturation. Other categories needed further exploration, so new questions were developed for inclusion in the second phase of interviews. Through further interviewing in this second phase of work, saturated categories became stronger and undeveloped categories became more clearly defined. These categories were then further developed to ultimately form the spheres within the framework. Each sphere is therefore a broad category, encompassing the thoughts, priorities and approaches suggested by participants.

The Intentional Compassion Framework

To create more compassionate schools in regard to death, dying and bereavement, participants wanted change in societal and cultural perspectives and systematic change in school communities. The framework and its key elements are best represented by a series of concentric circles where the four outer spheres focus on societal and cultural change (Figure 1).

The first outer sphere, ‘challenging current cultural perceptions’ describes the change in perceptions needed when thinking about death, dying and bereavement in school communities. The second sphere describes the type of support bereaved participants would have preferred to have received within their school communities. The third sphere addresses how best to create a grief-informed culture. The fourth sphere describes participants’ desire to establish a reflexive and reflective culture in school communities, in order to support a compassionate response from schools. At the heart of the framework is the creation of a practical whole school plan that details the strategies to be adopted to create a compassionate school.

Importantly, each theoretical sphere is part of a larger whole. By being part of a bigger whole, the ideas and practices within each sphere interact with one another. The spheres represented by lighter shades interact to form the dark centre. For instance, ‘challenging current cultural perceptions’ and ‘establishing a culture of reflection and reflexivity’ interact with one another. Both

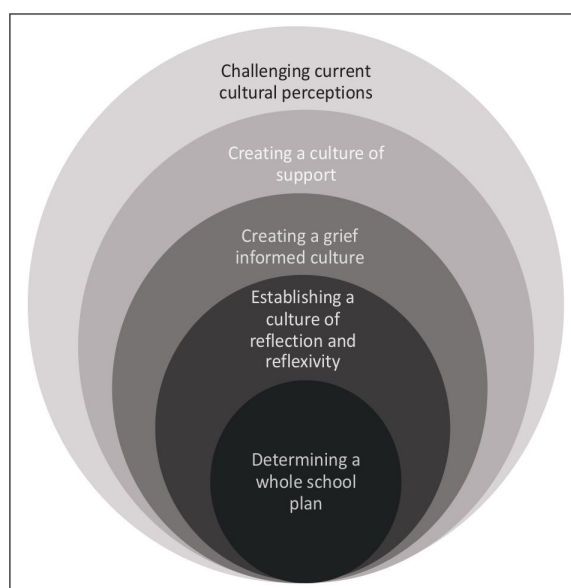


Figure 1. Intentional Compassion Framework.

together inform the whole school plan. That way, school communities better understand how to develop and establish change in cultural thinking and behaviour.

Sphere 1: Challenging current cultural perceptions

Participants acknowledged that White Western culture strongly influences the way we grieve and respond to grieving others. People make assumptions about how to respond to death, dying and bereavement in school communities that derive from the broader culture. However, according to participants, many of these assumptions, and by implication the broader culture itself, need to be challenged. Assumptions about bereavement also interact with other assumptions about culture, family structure and the availability of family members.

One example of this described by participants concerns how schools engage with Mother's and Father's days. These days are frequently celebrated in school communities in ways that marginalise the perspectives of people who have experienced bereavement or whose family structure differs from that of a nuclear family. While participants had different views about how to manage this, Lorenzo (parent and teacher, aged 41 years, bereaved parent), whose daughter had died, provided an often shared perspective:

The key behind it (celebratory days) is to actually, you know, bring up and talk about what it is to be part of a family . . . not doing colouring activities that're based upon a coloured in rose picture for your mother or a coloured in hammer picture for your dad. You know, it's more complicated than that. Families are different . . . what your family looks like, it might not be what anybody else's family in your classroom looks like and it might be great for them to hear . . . you live with your granddad and your dad because, you know, both of their partners have passed away or you live with two mothers and because you know you've got gay parents. I think that those opportunities are too valuable to pass up. And it kills bigotry and it kills racism and it kills homophobia and all that stuff if you're exposed to those things as a young person.

If you're sheltered from it and you live in a homogenous, you know sanitised world, then it's easy to see the other as being very different. Whereas, if it's in your face and it's there, then it's really hard to foster those opinions that aren't very helpful.

Lorenzo's comments suggest that school communities need to engage critically with conventional White Western ways of thinking and behaving. Death, dying and bereavement topics can be included in cultural or language studies using cultural resources such as story books or non-fiction. Inviting families from a variety of cultural backgrounds to talk about their experiences of, and responses to, death, dying and bereavement could help normalise differences. Participants also suggested presenting cross-cultural practices or responses to death, dying and bereavement in school communications with families. This might include the provision of information on relevant days or occasions such as Mother's or Father's Day, or Halloween.

Schools could actively discuss with staff, parents and students the diverse range of family structures that exist, the relevance of these days in a changing culture and what might be appropriate for celebratory days. Listening more closely to marginalised voices including same-sex parents, bereaved parents, single parents and grandparents as carers, and eliciting their thoughts and opinions could lead to reconsidering how best to celebrate or acknowledge these days. Some schools will need policy development to ensure all family types are considered in such decision-making.

Sphere 2: Creating a culture of support

This second sphere recognises that different people need different responses at different times. Some participants interviewed felt well supported by their school community, others did not. For instance, parents were satisfied with support from friends within their school community but generally dissatisfied with the lack of communication and support received from the school community more generally and school professionals in particular. Their views contrasted with those of teachers, teachers (who were also parents within school communities), and principals who largely felt an abundance of support and communication when they were bereaved. In conversation, Halle (parent and health provider, age 40 years, bereaved daughter) stated the following:

I think they're (classroom teacher) very focused on what's going on in the classroom . . . but I didn't feel like I could reach out and say I'd really like to keep checking in with you. But I guess that would've . . . looking back on it now, that would've been really useful.

Int. checking in with the teacher about your daughter Olivia, that's what you mean?

Yeah, Olivia is part of my family, so it's, we're a unit, and so having the teacher check in to see how the whole thing's going, not just Olivia, but you know, how my journey might be impacting on her. Yeah, that would've been helpful.

Parent participants described the type and amount of support they needed. This included time, space, support, privacy if needed and understanding following a death, particularly with respect to their own and their children's needs. Although infrequent, when teachers did offer support, parent participants were overcome with gratitude. Many participants, parents, teachers and principals wanted to be asked what they needed and not have people make assumptions. Overall, participants wanted assumption-making challenged so that dominant discourses did not prevail.

For schools, this means creating the time and space for acknowledgement of death and the deceased person, showing proactive support and having clear communication pathways as outlined in the fifth sphere below.

Sphere 3: Creating a grief informed culture

School communities need to question who holds information or power to achieve a more equitable state of affairs constituted by an 'intersubjective mutuality of reciprocal understanding, shared knowledge, mutual trust, and accord with one another' (Habermas, 1975: 3). Put simply, sharing knowledge is a way of sharing power. In this study, many participants reported experiencing marginalisation, with their knowledge of loss and bereavement being seen as less valuable than that of specialist teachers: and so had '... the advantage of greater sensitivity in detecting and identifying new problem situations' (Habermas, 1996: 381). Jonathon's (parent and health care provider, age 48 years, bereaved spouse) thoughts shed insight into this greater sensitivity:

... even though the kids may not be demonstrating grief in the classroom, it's because they are covering it up ... it doesn't mean that within the short term that things are now all fine but that stuff still rolls ... that every developmental stage the grief will reawaken in a different way. That at different points it be re-awakened in terms of what people say and do and therefore the kids do need support.

... the school could give out some information around loss and grief so they (parents) can become more aware ... I also think information to parents around stability for kids is really important.

Schools can create a grief-informed culture by providing time and space to engage in conversation about grief and ensuring that information about grief is accessible and made available to all families. Principals and staff need to commit to relevant training and then share what they learned with parents and families.

Sphere 4: Establishing a culture of reflection and reflexivity

Critical reflection and reflexivity were important to participants. They wanted teachers to be reflective in identifying learning and assumptions from their own past experience of loss and grief so as to disrupt the influence of dominant ways of thinking. Teachers being in touch with their own grief might lead to conversations about their own vulnerabilities and so normalise feelings of grief and bereavement for children so that death and the deceased are viewed positively. When Tristan (parent and health provider, age 42 years, bereaved spouse) was asked about how teachers could put themselves in the shoes of bereaved individuals or families, he responded,

I think any training or support around emotional awareness is going to help teachers, and also being able to process and work through their own grief and loss could possibly help them as well, [when] talking with others who have lost ... or [have been] been bereaved. So, you know it's harder to support someone like a teacher, a student or a parent when you haven't processed your own needs around your own grief ... but that's a long journey ... I guess more teachers that are more emotionally resilient ... they're going to make better supports for others.

To develop such empathy and awareness, it is valuable for principals and staff to commit to accessing training in emotional awareness, grief and bereavement, together with training in critical reflection and reflexivity.

Sphere 5: Developing a whole school plan

Three sub-categories emerged under this broad theme: creating a clear communication pathway between school professionals and families; supporting teachers and principals; and considering current cultural perspectives and developing curriculum. Together, these lay the foundations for a whole school plan for schools to implement.

Creating a clear communication pathway. Participants suggested a clear communication pathway was needed between families and school staff, both short and longer term. Schools can be proactive in reaching out and communicating with families to support them by providing time and space to listen, understand, check in and follow up over time. This type of communication and support was encapsulated by Matilda (parent and teacher, age 58 years, bereaved parent) who said the following:

I'd need them to report back to me about how my child is going. I'd need that to be structured in, not just at the end of the day at the door. I'd like that be structured because otherwise . . . I would feel like I was imposing on the classroom teacher too at the end of the day . . . you know I'd like it to be a formal locked in arrangement with the class teacher and principal or wellbeing coordinator . . .

Int: So, follow-ups scheduled in?

Schedule, that's the word I'm looking for . . . even if it's re-scheduled a couple of times but 'this is our weekly . . .' and then might be 'This is our monthly' . . . or 'this is our . . .', whatever it is scheduled appointment to see how you're travelling and how you think your child is travelling. Extra things that you need to tell us about what we can watch out for or ways that you think we can support you and your child. So, those sort of things need to be in a written sort of format. Then it doesn't get lost . . . is something really formal and that I could rely on that is going to be there . . . I'd want to feel that that was a natural and accepted part of what is done to support a member of our community.

Ensuring openness to hearing those who are bereaved contributes to change in dominant discourses about death, dying and bereavement. A clear communication pathway would enable participants who are currently marginalised to be listened to and heard. Kennedy et al.'s (2020: 16) compassionate communication model (Figure 2) may be helpful in this respect.

Supporting teachers and principals. Participants acknowledged that teachers are frequently under pressure so parents may be reticent to voice their family's need for bereavement support. Given this, parents, teachers and principals recommended that a wellbeing coordinator or school counsellor be employed, or for principals to have such a responsibility recognised as part of their role. Principals and teachers also had suggestions about how to support staff. Mary (principal, age 61 years, bereaved sibling and daughter) who had worked in both mainstream and special education contrasted the way in which mental health issues were addressed in both settings.

Teachers [working in special education] have five mental-health days a year . . . that is really scorned upon if teachers are using those in mainstream. We insisted everyone take those five days a year. That was really important and we would celebrate if somebody came back and said, 'Oh, my God, I've had a massage, and then I went for a swim, and that's what I did yesterday!' We would all go, 'Yeah! That's fabulous, good for you'. When I was in the mainstream and you had a day off, you almost had to be on death's door, or you were letting the whole team down. Those attitudes, unfortunately, come from leadership and whole school policy. There's not enough mental-health time.

This perspective challenges the culture and understanding of mental health that exists in many mainstream schools. Clearly, support is needed from management when dealing with issues of death, dying and bereavement. Possible strategies could include providing flexible or extended leave for bereaved staff, having a shadow person be provided when a principal or deputy principal has been bereaved and ensuring ongoing communication with affected parties over time.

Considering current cultural perspectives and developing curriculum. Principals and teachers spoke about the value of support to children who have been bereaved. This should seek to normalise

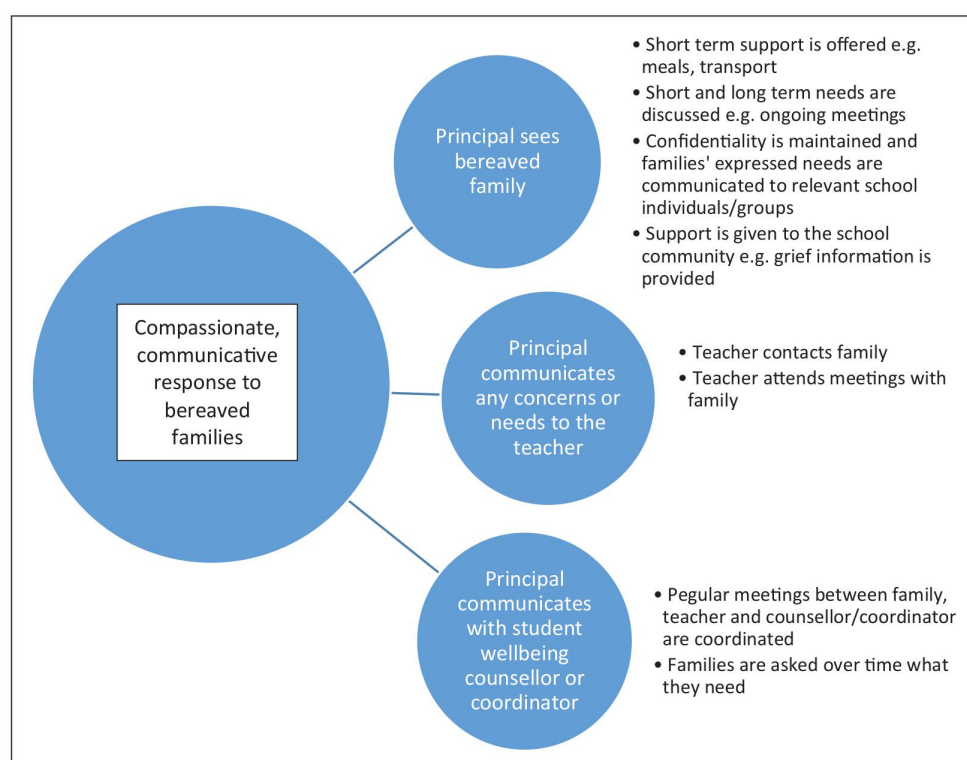


Figure 2. Compassionate communication model.

Source: Kennedy et al. (2020: 16).

children's grief reactions that show awareness of the danger, stigma and marginalisation that may heighten feelings of grief and loss before, during and after celebratory days. To normalise death, dying and bereavement in schools, participants who were principals and teachers suggested relationship building through active listening and visiting, acknowledging family diversity, consultation over celebratory days and normalising grief responses.

Participants suggested that conversation about death, dying and bereavement be more fully included in the curriculum so children were prepared for the grief and bereavement that would occur during their lives. Rachael's (parent and health provider, age 54 years, bereaved daughter) response to her daughter provides one example of an open and receptive conversation:

. . . she said to me, 'Mum are you going to die?' And I said, 'Darling, I'll promise that I'm not going to die if you can promise you're not going to die'. I said, 'You know we're all going to die, all living things die, anything that's alive dies. Trees, grass, birds, people, grandma's, aunties, uncles, parents, children, we all die. But we all have a different number and some of us our numbers are a bit lower and some of our numbers are a bit higher and so you get that ticket and when that number is up, it's up. You can do as much as you like, but you know, you can improve your lifestyle I guess to be healthier'. I said, 'Can you promise me that you're not going to die young?' And she went 'Ooh . . .' she thought about it for a while and she said, 'No, I can't promise you mum'. And I said, 'There you go, I can't promise either'.

Schools therefore need to be proactive when it comes to death, dying and bereavement. They can do this by encouraging conversation about these issues and engaging openly with them in the curriculum as a natural part of life, not a taboo topic, and ideally before a close bereavement is experienced in children's lives. The literacy, science, art, religious education, socio-emotional and environmental/sustainability curricula are obvious choices when considering where these conversations might take place.

Importantly, curriculum development needs to be supported by groups beyond the school community with specialist understanding of and experience working on death, dying and bereavement; shared knowledge is shared power. In Australia, these might include PCA and the Australian Centre for Grief and Bereavement. Schools need to partner with these bodies to ensure information and support is well managed and delivered appropriately in the school context.

Conclusion

Overall, participants prioritised the following kinds of support they wanted to receive from compassionate schools: being listened to and understood; being asked what their needs were; having the death of a loved one acknowledged; being offered practical support; and having bereavement and varying grieving responses normalised.

There was also a desire from participants for the school community to be more open and communicative about death, dying and bereavement and the deceased in an empathetic way, allowing open conversation to be a part of the curriculum and providing advice and information to the wider community.

With regard to open communication, participants asked that school communities more fully acknowledge death, listen to people's stories, be aware of the need for grief reminders and anniversaries, reach out to bereaved individuals, understand the overwhelming and often consuming nature of bereavement and ask people what they need to talk about in reference to death, dying and the deceased. In support of this, training in emotional awareness, critical reflection and reflexivity, empathy, grief and loss may be beneficial.

The framework offered here challenges current ways of being and thinking with respect to how to respond to death, dying and bereavement issues in school communities. It questions how we think and behave towards others. Its adoption and use should enable participants who are currently marginalised to be heard and communicated with, and it describes how compassion might be made visible in times of death, dying and bereavement, and extended to others.

In the face of possible resistance, the Intentional Compassion Framework gives voice to people who are bereaved and exist on the margins of many school communities. The experiences and suggestions that make up the framework encourage new ways of thinking, challenging schools and other educational institutions to make bold decisions to change a current culture of fear and develop policies that guarantee a more compassionate response.

Voices for change can easily be drowned out by the everyday busyness of school life, by the competing demands of parenting and work, and by the noise in our heads of all the things we need to attend to. Then suddenly, and perhaps when we least expect it, we are confronted by a life taken. It is at that moment that our humanity is touched, our response to others is brought into sharp relief and we are left with ourselves and the compassion we may now know how to offer.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

ORCID iD

Carla J Kennedy  <https://orcid.org/0000-0003-4504-9951>

References

- Aoun SM, Breen LJ, Rumbold B, et al. (2014) Reported experiences of bereavement support in Western Australia: A pilot study. *Australian and New Zealand Journal of Public Health* 38: 473–479.
- Barry M and McGovern M (2000) Death education: Knowledge, attitudes, and perspectives of Irish parents and teachers. *Death Studies* 24: 325–333.
- Charmaz K (2008) Grounded theory in the 21st century: Applications for advancing social justice studies. In: Denzin NK and Lincoln YS (eds) *Strategies of Qualitative Inquiry*. Thousand Oaks, CA: SAGE, pp. 203–241.
- Creswell JW, Hanson WE, Plano Clark VL, et al. (2007) Qualitative research designs: Selection and implementation. *The Counseling Psychologist* 35: 236–264.
- Fook J and Gardner F (2012) *Critical Reflection in Context: Applications in Health and Social Care*. Oxford: Routledge.
- Galende N (2015) Death and its didactics in pre-school and primary school. *Procedia-Social and Behavioral Sciences* 185: 91–97.
- Habermas J (1975) *Legitimation Crisis*. Boston, MA: Beacon Press.
- Habermas J (1996) *Between Facts and Norms: Contributions to a Discourse Theory of Democracy*. Cambridge, MA: MIT Press.
- Kellehear A (1999) Health-promoting palliative care: Developing a social model for practice. *Mortality* 4: 75–82.
- Kellehear A (2014) Death education as a public health issue. In: Stillion J and Attig T (eds) *Death, Dying and Bereavement: Contemporary Perspectives Institutions and Practices*. New York: Springer, pp. 221–232.
- Kennedy CJ, Gardner F and Farrelly C (2020) Death, dying and bereavement: Considering compassion and empowerment. *Pastoral Care in Education* 38: 138–155.
- Mills S and Mills J (2016) Future directions for community engagement as a public health approach to palliative care in Australia. *Progress in Palliative Care* 24: 15–18.
- Nussbaum M (1996) Compassion: The basic social emotion. *Social Philosophy and Policy* 13: 27–58.
- Papadatou D, Metallinou O, Hatzichristou C, et al. (2002) Supporting the bereaved child: Teacher's perceptions and experiences in Greece. *Mortality* 7: 324–339.
- Paul S (2016) Working with communities to develop resilience in end of life and bereavement care: Hospices, schools and health promoting palliative care. *Journal of Social Work Practice* 30: 187–201.
- Rowling L (2008) Linking spirituality, school communities, grief and well-being. *International Journal of Children's Spirituality* 13: 241–251.
- Rowling L (2010) Schools and grief: Attending to people and place. In: Monroe B and Kraus F (eds) *Brief Interventions with Bereaved Children*. New York: Oxford University Press, pp. 147–160.
- Rumbold B (2012) Compassionate care: Engaging the spirit in care. *Progress in Palliative Care* 20: 106–113.
- Schubert WH and He MF (2020) *Practicing Care and Compassion*. Oxford Research Encyclopedia of Education. Oxford: Oxford University Press.
- Sinclair S, Hack TF, Raffin-Bouchal S, et al. (2018) What are healthcare providers' understandings and experiences of compassion? The Healthcare Compassion model: A grounded theory study of healthcare providers in Canada. *BMJ Open* 8: e019701.
- Witkin S (2011) *Social Construction and Social Work Practice: Interpretations and Innovations*. New York: Columbia University Press.

6.1 Connecting the Aim with Key Concepts and Understandings

What is understood from this study that was not known at the beginning? What has been learned from the people who volunteered their thoughts, advice, and opinions on the subject of death, dying, and bereavement in schools? And where to from here? To reflect and answer these questions, it's important to (1) reiterate the lenses used, (2) revisit the original aim, (3) re-examine how power informs understanding, and (4) illuminate how compassion can be achieved in both an individual and community frame. Lastly, limitations and further research are discussed.

6.1.1 Lenses

Using a critical social constructionist lens has meant that I have been committed to challenging or questioning dominant discourses, including the influence of power evident in dominant discourse in school communities. This study challenges current ways of being within school communities when responding to the otherwise taboo topic of death, dying, and bereavement. The implications for challenging current ways of thinking and being means offering alternatives to current practice. A critical theoretical lens ensured that I took a critical stance towards taken-for-granted knowledge or assumptions – my own and the participants who were involved. A critical theoretical lens is situated here with a social constructionist view of knowledge that is dependent on context – historical, cultural, and social and concerned with making meaning. It takes a critical stance toward taken-for-granted knowledge that creates our understanding of reality; it is a view of knowledge as a form of social action and also according to Witkin (2011, p. 19), a belief that 'knowledge is sustained by social processes (particularly language)'. In interviews with the participants, this meant being aware of marginal and dominant discourse including indoctrination of media influenced conversation. For instance, if the participants referred to 'closure' and wanting to achieve 'closure', then as the interviewer, it was important for me to understand what the participant meant personally and in their own context rather than rely on outside influences to assume or determine meaning for the participant.

A reflexive lens also enabled me to uncover dominant discourse and assumptions within school communities. Practically, this meant the exploration of the participants' ideas and thoughts in interviews by following leads and developing reflexive questions that unearthed these assumptions. My personal views and biography had the potential to shape the research. As such, from the beginning, my perspectives and experiences have been declared, and the participation in critical reflection and journaling have formed an integral part of the interview and reflection process. A

grounded theory lens also complemented this approach enabling the examination of social actions and interactions of school community members, illuminating the influences of dominant discourse. Therefore, the recommendations that will be offered uphold the marginal voices of the participants. The compassion definition used in this study also provided a lens to look through with a focus on individual and community change. This definition and the exploration of how the participants understood compassion from interviews prioritises both a proactive response and empathy. Compassion was defined as ‘an intention (justice) to understand and empathise with people who are suffering by extending them support in thought, word and action, seeking school community as well as individual change’. The participants reflected critical understandings of how they and others in the school community had internalised social norms about how to be compassionate during/after bereavement and this underscored the need to change these assumptions.

6.1.2 The original aim

The original aim of the study was to explore how to create compassionate schools that can engage constructively with issues of death, dying, and bereavement. The exploratory questions were ‘what is it like to be a bereaved person in a school community setting’ and ‘in your school community, what was helpful or unhelpful’?

Due to the lenses used in the study, it became obvious that people who had been bereaved in school communities were in a marginalised position: a minority of people who had experienced the death of a family member. This status meant that they had a greater sensitivity to problems (Habermas, 1996) that this generated for them in the school’s community. The participants were in possession of authentic information about death, dying and bereavement from their lived experiences. The participants reflections on the interview questions enabled them to rise above what Habermas (1990) would refer to as the naiveté of everyday life and offer what Marcuse (1978) calls divergent or revolutionary thought to the study. Therefore, when asking about how compassion can be created in schools, the participants in this study offered school communities wisdom from experience.

6.1.3 Re-examining power

The lenses used in this study serve as justification for identifying power in school communities. Therefore, an exploration of social power and how some voices were silenced were explored. As identified in Galende’s (2015) research, teachers in this study were reluctant to talk about death which became part of the ‘hidden curriculum’ of the school (Rowling, 2010). It was also evident from

the participants' responses how being emotional is sequestered and the appropriate public behaviour of behaving non-emotionally is prioritised.

The use of power through marginalised or dominant discourse became obvious in various ways. Firstly, how bereaved voices are silenced. For instance, at times, the participants felt that they were being avoided and not reached out to or asked what they needed. Secondly, how being emotional is less acceptable with participants trying desperately to keep emotions in check. For example, Mary explained that 'It was very hard to manage those emotions. It was very tiring to manage those emotions and I suppose in the management of those I wasn't present and therefore all I just kept thinking was am I losing my mind ...'. Thirdly, how professionals in schools may hold power that they are unaware of, such as professionals being the keepers of grief information, making decisions about celebratory days without asking bereaved parents or children about their thoughts or opinions, or by offering different amounts of bereavement support to community members depending upon their role in the school. This was described in Chapter 5 as the 'parent teacher divide' where the participants had identified existing power structures that resulted in teachers feeling more supported than parents during times of grief and bereavement.

6.1.4 Enacting compassion

Schools can be an intellectual and emotional investment for families and the demands upon teachers and principals are varied and constant. This study asks that social and cultural change occurs in the form of compassion as the pressures and emotions that exist in schools and for families are acknowledged. Compassion can foster school communities that intentionally engage in caring ways with students and families affected by loss and grief (Peterson, 2016; Sinclair et al., 2018). From this research, the definition of compassion described an intention (justice) to understand and empathise with people who are suffering by extending them support in thought, word, and action seeking school community as well as individual change.

Critical reflection has enabled the exploration of power and exposed a social justice imperative to engender compassion. By listening to the marginalised voices of the participants, an understanding has been reached of how death, dying, and bereavement was experienced and understood in school communities and how to implement social action or change. The specific opinions and advice garnered from the participants clearly demonstrates how to create compassion in school communities on both an individual and community level.

6.1.4.1 Individual change

Considering the taboo nature of death, dying, and bereavement in white western societies, individual change is required for subsequent whole community change. This was evident in the

findings chapter where the participants relay the importance of having conversations about death, dying, and bereavement. These conversations may be challenging to initiate broadly unless individuals take the initiative first. However, the participants clearly expressed the desire to be reached out to. Individual school community members need to proactively approach others who are experiencing bereavement and offer support. The participants suggest that the individual listens to the person experiencing bereavement, allow them to tell their story, and to ask them what they need presently and over time without making assumptions. Connecting with the definition of compassion in this study, the responsibility carried out by individuals begins to effect change in communities.

There was also a desire from the participants for teachers and principals to be mindful, individually acknowledge the diversity of families, prioritise authentic relationships with families, consult families about celebratory days, and visit families experiencing bereavement and offer support. The participants also wanted teachers to be aware of their own personal grief journey and access appropriate training which may in turn help normalise and positively influence the experience of grief for children. Initiating conversations with children in classrooms about death, dying, and bereavement may also have this normalising, positive effect. These suggestions for individual change may subsequently affect community change.

All these changes necessitate a more critically reflective attitude in school communities; an awareness of how people's own assumptions about death, dying, and bereavement are internalised from the broader social structure. The link between individual and community change may be achievable by understanding how these attitudes need to change at both individual and community levels. Providing systemic training that encourages reflective practice in school communities could encourage more capacity for compassion related to death and dying.

6.1.4.2 Community change

The participants were able to offer advice for the broader school community. They wanted schools to create opportunities that encouraged death conversations and conversations about family diversity regarding celebratory days. Conversations about death, dying, and bereavement are easily initiated by using transformative story telling as mentioned in the literature review and in the findings, encompassing strategies such as telling one's own story and reading stories to encourage conversation. Effectively, this breaks down the fear and avoidance of death, dying, and bereavement and disrupts the status quo by thinking about the diversity of families. Further, disruptive to the status quo is for teachers to commit to the learning of how other cultures respond to death, dying, and bereavement as this would illuminate how the western culture currently responds to these

issues and supports school communities in becoming aware of their own assumptions and biases in the area of death, dying, and bereavement.

The participants highlighted the importance of receiving information about grief or having access to training and participating in open dialogue in school communities. They wanted schools to be more proactive in reaching out and ensuring clearer communication channels between principals, teachers, and families. The clear communication pathway (Kennedy et al., 2021) provides an effective way to do this in schools. Other ways to do this are by providing grief information to school communities and encouraging ritual and ceremony in acknowledging deaths in the community. The participants also suggested expressing grief creatively and exploring topics around death, dying, and bereavement in the curriculum through various subject areas such as life cycles and seasons in science. Having more information was also suggested for teachers and principals in accessing relevant professional development or training.

Compassion can be enacted by individuals and communities as a whole to support social and cultural change in an ongoing capacity and benefit school community members over time. This research confirms McGovern and Tracey's (2010) and Rowling's (2008) views that these changes must be written in school policy as well as policy existing in overseeing bodies, such as in Australia, the Department of Education and Catholic Education Office. Such bodies are also able to offer support to school communities above what principals can offer. For example, they could actively encourage teachers to feel justified in taking mental health days or providing schools with expert education/grief personnel over time in situations of death and bereavement or financially supporting schools by providing a dedicated, qualified person to the task of supporting families such as a social worker, psychologist, or counsellor. Overseeing bodies also need to finance ongoing training and professional development in critical reflection, reflexivity, emotional awareness, and empathy for teachers and continue valuable ongoing programmes like 'Seasons for Growth'. Partnerships between education departments and specialist services that have a sound knowledge base and high level of expertise in grief, death, dying, and bereavement would ensure that schools receive current, relevant, and reliable support. For example, this could be a partnership created between school communities and their local palliative care service or perhaps, education government departments partnering with Palliative Care Australia.

6.2 Significance, Limitations, and Further Research

A number of benefits result from exploring how to create compassionate schools that are able to engage constructively with issues of death and dying.

Firstly, the key recommendations may be transferrable to other educational contexts. There is relevance to other school or kindergarten settings grappling with these issues. As a result, curriculum and policy may be further informed. The information gained in this study is also relevant to universities that influence how teachers respond to children and families within their school communities with implications for training for teachers and the work undertaken in schools.

Secondly, this study is beneficial for other primary school communities. Families or staff experiencing death, dying, or bereavement in the future may be able to depend on and access support from their school community informed by these understandings. Fear and ignorance surrounding the issues of death, dying, and bereavement may dissipate enabling a normalised view to prevail and prevent people experiencing bereavement from feeling or becoming isolated. This change in societal attitudes may also reverberate into the wider community allowing non-bereaved people a certain comfort level when interacting with bereaved people. This will influence the curriculum in how conversations and topics of death are conducted and influence the review and or development of resources for schools.

Thirdly, the information gained in this study will have strong theoretical relevance in the fields of health and education and practical relevance for schools and public health services, particularly, in regard to public health services offering grief and bereavement support to community members and partnering with schools.

Overall, this study will have significance for schools, particularly white Western community settings, nationally and internationally as it offers new perspectives and ways of thinking about and responding to ongoing death, dying, and bereavement issues in communities in the short and long term.

For further research about school communities and death, dying, and bereavement, I acknowledge this study's limitations and offer the following advice. The first limitation was that only two interviews with students were conducted; therefore, this study represented a disproportionate number when compared to participating parents and school professionals. This is a common issue in research related to death and dying (Neimeyer et al., 2004) but remains an issue that needs to be addressed. It is suggested that student's voices be prioritised in further research by interviewing more students who have experienced bereavement and wish to describe their experiences in relation to classroom and playground social interactions and relationships. For instance, understanding students' perspectives, thoughts, and advice and other possible changes they would like to see in schools would strengthen future considerations and recommendations.

The second limitation was that there was a lack of current full-time classroom teachers participating in the study. Most of the teachers whom I interviewed currently worked in a part-time or casual

relief teaching capacity and had in the past experienced full-time teaching loads. It would be valuable to understand the current full-time teachers' perspectives in regard to how teachers interact and support families on a regular ongoing basis as this may differ from part-time staff experiences. Full-time teachers may also offer different perspectives on how they can/cannot meet student and family needs and how death, dying, and bereavement may be integrated into the curriculum which they attend to on a daily basis.

Third, this was a study in rural school communities and while the literature does not suggest that different results are likely in urban communities, this is another limitation of the study that provides opportunities for further research.

6.3 Conclusion

Essentially, this study challenges the current societal and cultural perspectives of death, dying, and bereavement in predominantly white western school communities. Disrupting the status quo is now essential, questioning and uncovering assumptions and long held processes and routines in schools need review and ongoing discussion by school communities and professionals. This is not necessarily an easy task as assumptions are embedded in the policies and practices of school communities. Processes such as critical reflection and reflexivity with their established efficacy in unearthing taken for granted beliefs can be powerful conduits for changing school community culture. If we continue to ignore these processes as a way forward, we risk the perpetuation of fear, avoidance, and misunderstandings. Opportunities for compassion and much needed change will lay dormant.

It is in the revealing of marginalised perspectives of people who have experienced bereavement that we are justified in calling for new ways of seeing, thinking, and being. It is time for the taboo nature of death, dying, and bereavement to recede and compassion to be embodied individually and collectively in school communities.

APPENDICES

| | |
|------------|---|
| Appendix A | Project information statement for parents, teachers, principals, and students |
| Appendix B | Ethics statement |
| Appendix C | Initial interview questions |
| Appendix D | New interview questions |
| Appendix E | Example of Venn diagram used |

APPENDIX A PROJECT INFORMATION STATEMENT FOR PARENTS, TEACHERS, PRINCIPALS,
AND STUDENTS



School of Education

PARTICIPANT INFORMATION STATEMENT: PARENTS/TEACHERS/PRINCIPALS

Project Title: Creating Compassionate Schools

Approval No's.: La Trobe Human Ethics: HEC17- 063, CEOM: 0628, DET:
2017_003438

Project researchers:

| | | | |
|--|---|---|--|
| Associate Prof. Mary Keefe Faculty of Education, La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Ph: (03) 54447753 Email: M.Keefe@latrobe.edu.au | Prof. Fiona Gardner Faculty of Social Work La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Ph: (03) 5444 7875 Email: F.Gardner@latrobe.edu.au | Dr. Cathleen Farrelly Faculty of Education La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Ph: (03) 5455 7252 Email: C.Farrelly@latrobe.edu.au | Ms. Carla Kennedy Faculty of Education, La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Email: kennedy.c@students.latrobe.edu.au |
|--|---|---|--|

We would like to invite you to participate in the Creating Compassionate Schools research project, which aims at assisting school communities in managing situations of death, dying, and bereavement. Your participation in this research project is voluntary.

Researcher: My name is Carla Kennedy and I am currently a PhD candidate in the Faculty of Education at La Trobe University, Bendigo Campus. My principal supervisor is Associate Professor Mary Keefe and her contact details are shown above.

Purpose: The specific purpose of this research is to explore what it is like to be a person experiencing bereavement in a school community and to understand from that person's perspective, what barriers may exist in schools and school communities when it comes to supporting bereaved people.

Participant description: To participate, you will have been bereaved for at least 6 months and no longer than 6 years. You will be a member of or were a member of a primary school community at the time you were experiencing bereavement of a close friend or family member. Your school community would have been aware of your loss.

What will you do: If you choose to be involved in this study, you will be invited to participate in an interview of approximately 60 minutes which will be digitally audio-recorded to explore your experience of bereavement in your school community and your opinions regarding barriers or enablers that may exist in schools communities when supporting bereaved individuals. If you have a diary, journal, online social media entries/email, or artwork about your experience and would be willing to provide me permission to copy or photograph them for use in my research, it would be appreciated if you could bring them along to the interview. The time and location of the interview will be at your convenience and negotiated with me. A follow-up interview with me of the same duration may be requested at a later time.

Benefits to you as a participant: While the outcomes of this study may not have immediate benefit to you, it is hoped that this research will provide primary schools with information and support to improve their response to members of their school communities experiencing bereavement. In addition, you may find that the opportunity to speak about your experiences within the school community context is personally satisfying.

What are the possible risks or discomforts in participating in this project: For confidentiality purposes, your name and school will not be identified in any part of the research. Considering the sensitive nature of this research, you may experience some feelings of sadness either during or after the interview(s). To assist you with this, a one-off counselling session can be provided with a trained counsellor at La Trobe University, Bendigo Campus.

What happens to the data collected: To ensure that the data collected during this project remains completely confidential, digital audio-recorded interviews, related transcripts, meeting notes, interview notes, and any copied documents or artifacts such as your artwork, journals, diaries, emails, or social media entries, will be de-identified and given a codes/pseudonym instead of your name. All the codes are stored separately from the data collected. The original audio recordings, transcriptions, copies of documents, or artifacts are stored with password protection on a computer and any hard copies are locked in the principal supervisor's offices at the La Trobe University, Bendigo Room 3.12. They are then deleted 5 years after any publications that arise from this project. Data collected from this research project will be used in a PhD thesis and may be used in conference presentations, recorded performances, research reports, journal articles, and book publications. You or your school will not be identified in any publications as codes/pseudonyms will be used for all the participants and

schools. You will be able to contact me and request the digital link to my thesis once it has been assessed.

What do you do if you want to withdraw from the project: If you decide to take part and later change your mind, you can at any time withdraw from this project. We would like you to allow us to use the information you have provided until that time but if you do not want us to have this data, you can say so and the data will be immediately destroyed up until 4 weeks after your last interview. There are no disadvantages or adverse consequences to withdrawing from the project. If you choose to withdraw from this project, you will not be asked to participate any further. A withdrawal form is attached.

Approval of this project: This study has been approved by the College of Arts, Social Science and Commerce, Human Research Ethics Committee at La Trobe University and by the Melbourne and Sandhurst Catholic Education offices. If you have any questions regarding this project, please contact any of the researchers listed above. If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086 (P: 03 9479 1443, E: humanethics@latrobe.edu.au).

Thank you for your interest in this study.

Carla Kennedy

PARTICIPANT INFORMATION STATEMENT: STUDENTS

Project Title: Creating Compassionate Schools

Approval No's.: La Trobe Human Ethics: HEC17- 063, CEOM: 0628, DET: 2017_003438

Project researchers:

| | | | |
|--|---|--|---|
| Associate Prof. Mary Keffe Faculty of Education, La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Ph: (03) 54447753 Email: M.Keffe@latrobe.edu.au | Prof. Fiona Gardner Faculty of Social Work La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Ph: (03) 5444 7875 Email: F.Gardner@latrobe.edu.au | Dr. Cathleen Farrelly Faculty of Education La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Ph: (03) 5455 7252 Email: C.Farrelly@latrobe.edu.au | Ms. Carla Kennedy Faculty of Education, La Trobe University, Bendigo P.O. Box 199, Bendigo VIC 3552 Email: kennedy.c@students.latrobe.edu.au |
|--|---|--|---|

We would like to invite you to participate in the Creating Compassionate Schools research project, which aims at assisting school communities in managing situations of death, dying, and bereavement. Your participation in this research project is voluntary.

Researcher: My name is Carla Kennedy and I am currently a PhD candidate in the Faculty of Education at La Trobe University, Bendigo Campus. My principal supervisor is Associate Professor Mary Keffe and her contact details are shown above.

Purpose: We want to understand what it is like to be a person experiencing grief at school after a loved one has died and to understand how schools are helpful or unhelpful when that happens. This means your information will help schools get better at supporting people who have had someone close to them die.

What will you do: You will participate in up to two interviews that will take approximately 30 minutes each and I will ask you questions about your experience at school. The interview will be digitally audio-

recorded. If you have a diary, journal, online social media entries, emails, or artwork about your experience and would be willing to provide me with a copy for my research, it would be appreciated if you could bring them along to the interview. The time and location of the interview will be worked out with your parents/guardians and me.

What type of questions will I ask you: What can you tell me or remember about your experiences at school in the days, weeks, or months after your loved one died? How did your friends react to you? How did the teachers or principal react to you? How did you want them to react to you? Who helped or supported you? What were some helpful or unhelpful things that they did? What did you want them to do? What else could they have done? What can you tell me about special celebration days at school now that the person has died? What is it like at school now with your friends and teachers since your loved one has died? What were some positive things that happened at school since the death of your loved one? Are there other questions you wished I had asked you?

Benefits to you as a participant: While the outcomes of this study may not have immediate benefit to you, it is hoped that the outcomes of this research will provide primary schools with information and support to improve their response to members of their school communities experiencing grief. In the meantime, you may find that the opportunity to speak about your experiences is personally satisfying.

What are the possible risks or discomforts in participating in this project: You may experience some feelings of sadness either during or after the interview(s). To assist you with this, a one-off counselling session can be provided with a trained counsellor at La Trobe University, Bendigo Campus.

What happens to the data collected: To ensure that the data collected during this project remains completely confidential, digital audio-recorded interviews, related transcripts, meeting notes, interview notes, and any copied documents or artefacts such as your artwork, journals, diaries, emails, or social media entries will be de-identified and given a code/pseudonym instead of your name. All the codes are stored separately from the data collected. The original audio recordings, transcriptions, copies of documents, or artefacts are stored with password protection on a computer and any hard copies are locked in the principal supervisor's offices at La Trobe University, Bendigo Room 3.12. They are then deleted 5 years after any publications that arise from this project. Data collected from this research project will be used in a PhD thesis and may be used in conference presentations, recorded performances, research reports, journal articles, and book publications. You or your school will not be identified in any publications as codes/pseudonyms will be used for all the participants and schools. You will be able to contact me and request the digital link to my thesis once it has been assessed.

What do you do if you want to withdraw from the project: If you decide to take part and later change your mind, you can at any time withdraw from this project. We would like you to allow us to use the

information you have provided until that time but if you do not want us to have this data, you can say so and the data will be immediately destroyed up until 4 weeks after your last interview. There are no disadvantages or adverse consequences to withdrawing from the project. If you choose to withdraw from this project, you will not be asked to participate any further. A withdrawal form is attached.

Approval of this project: This study has been approved by the College of Arts, Social Science and Commerce, Human Research Ethics Committee at La Trobe University and by the Melbourne and Sandhurst Catholic Education offices. If you have any questions regarding this project, please contact any of the researchers listed above. If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact the Senior Human Ethics Officer, Ethics and Integrity, Research Office, La Trobe University, Victoria, 3086 (P: 03 9479 1443, E: humanethics@latrobe.edu.au).

Thank you for your interest in this study.

Carla Kennedy

APPENDIX B ETHICS STATEMENT

Dear Researcher,

Please find attached information regarding your application for ethical review of research involving human participants at La Trobe University.

Application ID: HEC17-063

Application Status/Committee: Finalised - Approved

Project Title: Creating Compassionate Schools.

Chief Investigator: Mary Keeffe

Other Investigators: Cathleen Farrelly, Carla Jane McKerrow Kennedy

To access the application online, log in to ResearchMaster: <http://rmenet.latrobe.edu.au>

NOTE: This email is not a confirmation of submission. Please check the 'Status' of the application in ResearchMaster.

If you have any further questions, please contact the:

UHEC at humanethics@latrobe.edu.au

SHE College Human Ethics Sub-Committee at chesc.she@latrobe.edu.au

ASSC College Human Ethics Sub-Committee at chesc.assc@latrobe.edu.au

APPENDIX C INITIAL INTERVIEW QUESTIONS

Age _____

Gender ☐ Female ☐ Male

Primary School ☐ State ☐ Catholic

Status ☐ Student ☐ Parent ☐ Teacher ☐ Principal

Contact phone number _____

What was your relationship to the person who died? _____

How long have you been bereaved for? _____

Now, I would like to ask you questions about your experiences.

1. Upon returning to the school community

- a. When you returned to the school community for the first time (taking children to school, school event) after your loss, what problems or issues did you face in those first few weeks or months?
- b. What forms of support did you receive?
- c. Who helped/supported you and how did they do this?
- d. What issues did your children face? What forms of support did they receive? Was it helpful/unhelpful? Why?

2. Reactions of parents/students

- a. What were the reactions of parents or students to you at school?
- b. What were some helpful/unhelpful things they did?
- c. How did you react to them? (Prompt: feelings, behaviours, interactions)
- d. What did you actually want others to do or say?
- e. Was there anything else that could have helped?
- f. What were the reactions of other parents or students to your child/children? What was helpful or unhelpful? How did your children react to others?

3. Reactions of teachers/principal

- a. What were the reactions of teachers or principals to you at school?
- b. What were some helpful/unhelpful things they did?
- c. How did you react to them? (Prompt: feelings, behaviours, interaction)
- d. What did you actually want them to do or say?
- e. Was there anything else that could have helped?
- f. Were there any other supports in the school community that we haven't talked about?
- g. What were the reactions of teachers or the principal to your child/children? What was helpful or unhelpful? How did your children react to the teachers or principal?

4. Giving advice

- a. What would your advice be for people experiencing bereavement in a school community? (Prompt: other parents experiencing bereavement, your children's teachers experiencing bereavement)
- b. What would you like the teachers or principal to know about this experience?
- c. What would you like other parents to know about this experience?
- d. What would you advise about the lead up to special celebratory days at school like Mother's Day, Father's Day, Grandparents Day, and Graduation?
- e. What are/were the grief programmes in your primary school? What was helpful or unhelpful about them? (Prompt: Season's programme)
- f. Can you describe how the school participated in your family's grief? (prompt: funeral/assembly/newsletter). Can you describe how this was helpful or unhelpful?

5. Beliefs

- a. What are your (spiritual) beliefs about bereavement and death?
- b. What do you think teachers and/or principals believe about bereavement?
- c. What do you think other parents believe about bereavement?
- d. Have your beliefs (spiritual) changed since your loved one died? How? Why?

6. Current times

- a. What is it like to be in your school community now?
- b. What are some positive things that have come out of your experience of these difficult times?
- c. Are there other questions you wished I had asked you?
- d. Do you have any copied documents or artefacts for the research, such as emails, social media entries, diaries, journals, and/or artwork?
- e. Before we finish, is there any other information you would like to add?

APPENDIX D NEW INTERVIEW QUESTIONS

1. Cultural change

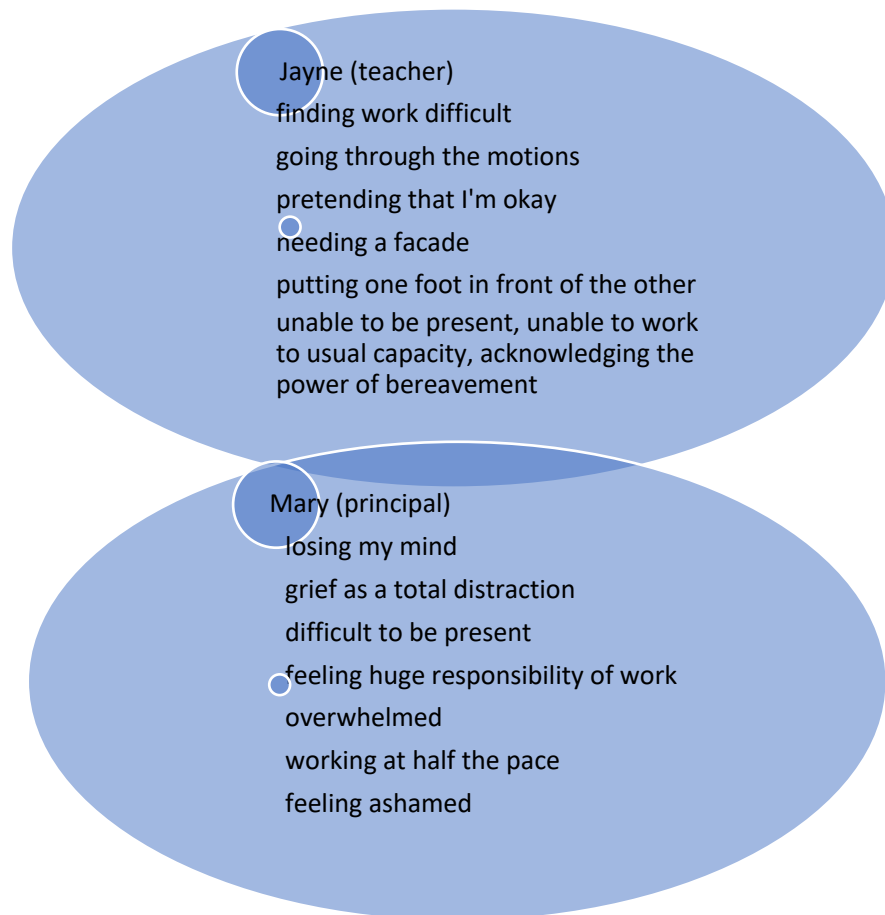
- a. How could the school community act creatively to change their culture so death or bereavement feels a more normal part of life?
 - b. How could the school community change its culture so students can respond more creatively to death and bereavement?
 - c. How could the school community change its culture so students, parents, or teachers are able to talk more about death and tell stories about their experiences?
 - d. How could the school community change its culture so students, parents, teachers, and principals are more open about their grief and are not pretending to be okay most of the time?
 - e. What do you think or feel about teachers/principals discussing death in classrooms or assemblies with parents and students? What are the advantages or disadvantages that might come from this?
 - f. Are there any events or opportunities that you can think of which could be created at school that would enable the community to become more aware of different cultures and their understandings of death, dying, and bereavement?
-

2. Reflexive questions

- a. If you were a parent whose spouse had died and you had a child at school, what might you need or want from the class teacher? The principal? Other parents?
- b. If you were a school parent of a child who died, what might you need or want from the class teacher? The principal? Other parents?
- c. If you were a student in your school and your mother had died, what would you think or feel about an approaching Mother's Day? What would you need or want from the class teacher? From your principal? Other parents?
- d. Some people have said that mothers or fathers or grandparent's day should be called 'Carers'/family day. What are your thoughts or feelings about this?
- e. What do you think would help teachers put themselves in to the shoes of bereaved families, be able to see how things might look from their point of view?
- f. Are there other questions you wished I had asked you?
- g. Before we finish, is there any other information you would like to add?

APPENDIX E EXAMPLE OF VENN DIAGRAM USED

Venn diagram used in analysis: Repressing Emotions in early bereavement. 6.12.17



Intersecting ideas: Feeling challenged by work and being present.

REFERENCES

- Aoun, S. M., Breen, L. J., Rumbold, B., & Howting, D. (2014). Reported experiences of bereavement support in Western Australia: A pilot study. *Australian and New Zealand Journal of Public Health, 38*(5), 473-479. doi:10.1111/1753-6405.12177
- Barry, M., & McGovern, M. (2000). Death education: Knowledge, attitudes, and perspectives of Irish parents and teachers. *Death Studies, 24*(4), 325-333. doi:10.1080/074811800200487
- Becker, C., Clark, E., Despelder, L. A., Dawes, J., Ellershaw, J., Howarth, G., . . . O'Connor, P. (2014). A call to action: an IWG charter for a public health approach to dying, death, and loss. *OMEGA-Journal of Death and Dying, 69*(4), 401-420. doi:10.2190/OM.69.4.d
- Berger, P. L., & Luckmann, T. (1967). *The social construction of reality: A treatise in the sociology of knowledge*. New York: Anchor Books.
- Besthorn, F. (2007). En-Voicing the World. In S. Witkin & D. Saleeby (Eds.), *Social Work Dialogues: transforming the canon in inquiry, practice, and education* (pp. 167-202). Alexandria, VA.: Council on Social Work Education.
- Bonanno, G. A. (2001). Grief and emotion: A social-functional perspective. In *Handbook of bereavement research: Consequences, coping, and care*. (pp. 493-515). Washington, DC, US: American Psychological Association. doi:10.1037/10436-021
- Bonanno, G. A., Papa, A., & O'Neill, K. (2001). Loss and human resilience. *Applied and Preventive Psychology, 10*(3), 193-206. doi:10.1016/S0962-1849(01)80014-7
- Bowlby, J. (1958). *The nature of the child's tie to his mother*. Richmond, Surrey: E.H. Baker & Co.
- Bowlby, J. (1959). *Separation anxiety*. [London]: Tavistock Clinic.
- Bowlby, J. (1998). *Loss: Sadness and depression*. Random House.
- Breen, L. J., Aoun, S. M., O'Connor, M., & Rumbold, B. (2014). Bridging the gaps in palliative care bereavement support: An international perspective. *Death Studies, 38*(1), 54-61. doi:10.1080/07481187.2012.725451
- Breen, L. J., & O'Connor, M. (2011). Family and social networks after bereavement: Experiences of support, change and isolation. *Journal of Family Therapy, 33*(1), 98-120. doi:10.1111/j.1467-6427.2010.00495.x
- Brookfield, S. (2003). Putting the critical back into critical pedagogy: A commentary on the path of dissent. *Journal of Transformative Education, 1*(2), 141-149. doi:10.1177/1541344603254148
- Brookfield, S. (2005). *The Power of Critical Theory for Adult Learning and Teaching*. New York: Open University Press.
- Brookfield, S. D. (2011). *Teaching for critical thinking: Tools and techniques to help students question their assumptions*. San Francisco, CA: John Wiley & Sons.
- Burke, L., & Neimeyer, R. A. (2012). Meaning Making. In M. Cobb, C. M. Puchalski & B. D. Rumbold (Eds.), *Oxford Textbook of Spirituality in Healthcare*: Oxford, England : Oxford University Press.
- Burr, V. (2003). *Social constructionism (2nd edition)*: London: Routledge.
- Burr, V. (2015). *Social constructionism (3rd edition)*. New York: Routledge.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis. (Introducing Qualitative Methods Series)*. London: Sage Publications.

- Charmaz, K. (2008a). Constructionism and the grounded theory method. In I. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397-412). New York: The Guildford Press.
- Charmaz, K. (2008b). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (pp. 203-241). Thousand Oaks, California: Sage.
- Charmaz, K. (2014). *Constructing grounded theory*. London: Sage.
- Collett, L.-J., & Lester, D. (1969). The fear of death and the fear of dying. *The Journal of Psychology*, 72(2), 179-181. doi:10.1080/00223980.1969.10543496
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research*. Thousand Oaks, CA: Sage Publications.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*: Sage publications.
- Creswell, J. W., Hanson, W. E., Plano Clark, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The Counseling Psychologist*, 35(2), 236-264. doi:10.1177/0011000006287390
- Cunliffe, A. L. (2008). Orientations to social constructionism: Relationally responsive social constructionism and its implications for knowledge and learning. *Management Learning*, 39(2), 123-139. doi:10.1177/1350507607087578
- D'Cruz, H., Gillingham, P., & Melendez, S. (2007). Reflexivity: A concept and its meanings for practitioners working with children and families. *Critical Social Work*, 8(1), 1-18. doi:10.1093/bjsw/bcl001
- Daley, A. (2010). Reflections on reflexivity and critical reflection as critical research practices. *Affilia*, 25(1), 68-82. doi:10.1177/0886109909354981
- Denzin, N. K., & Lincoln, Y. S. (2008). *Strategies of qualitative inquiry (3rd edition)* (Vol. 2). Los Angeles: Sage.
- Depaola, S. J., Griffin, M., Young, J. R., & Neimeyer, R. A. (2003). Death anxiety and attitudes toward the elderly among older adults: The Role of gender and ethnicity. *Death Studies*, 27(4), 335-354. doi:10.1080/07481180302904
- Engarhos, P., Talwar, V., Schleifer, M., & Renaud, S.-J. (2013). Teachers' Attitudes and Experiences Regarding Death Education in the Classroom. *Alberta Journal of Educational Research*, 59(1), 126-128.
- Feifel, H. (1959). Attitudes toward death in some normal and mentally ill populations. In H. Feifel (Ed.), *The meaning of death* (pp. 114-130). New York: McGraw Hill.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine*, 45(8), 1207-1221. doi:10.1016/S0277-9536(97)00040-3
- Folkman, S. (2001). Revised coping theory and the process of bereavement. In *Handbook of bereavement research: Consequences, coping, and care*. (pp. 563-584). Washington, DC, US: American Psychological Association. doi:10.1037/10436-024
- Fook, J., & Gardner, F. (2007). *Practising critical reflection: A resource handbook*: McGraw-Hill Education (UK).
- Fook, J., & Gardner, F. (Eds.). (2012). *Critical reflection in context: Applications in health and social care*. London: Routledge.
- Fook, J., & Kellehear, A. (2010). Using critical reflection to support health promotion goals in palliative care. *Journal of palliative care*, 26(4), 295. doi:10.1177/082585971002600406

- Freshwater, D. (2011). Using reflection as a tool for research in G. Rolfe, M. Jasper and D. Freshwater. In *Critical reflection in practice: Generating knowledge for care* (pp. 183-195). Houndmills: Palgrave Macmillan.
- Freud, S., Strachey, J., Freud, A., Rothgeb, C. L., Richards, A., & Scientific Literature, C. (1900). *The standard edition of the complete psychological works of Sigmund Freud*. London: Hogarth Press.
- Galende, N. (2015). Death and its Didactics in Pre-School and Primary School. *Procedia-Social and Behavioral Sciences*, 185, 91-97. doi:10.1016/j.sbspro.2015.03.403
- Gardner, F. (2012). Spiritual experience, practice and community. In M. Cobb, C. M. Puchalski & B. Rumbold (Eds.), *Oxford Textbook of Spirituality in Healthcare*. Oxford, UK: Oxford University Press. doi:10.1093/med/9780199571390.003.0051
- Gardner, F. (2014). *Being critically reflective: Engaging in holistic practice*. London: Macmillan International Higher Education.
- Genevro, J. L., Marshall, T., Miller, T., & Center for the Advancement of Health. (2004). Report on bereavement and grief research. *Death Studies*, 28(6), 491-575. doi:10.1080/07481180490461188
- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. (1992). *Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press.
- Glaser, G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Publishing Company.
- Habermas, J. (1970). *Toward a Rational Society*. Boston: Beacon Press.
- Habermas, J. (1973). *Theory and Practice*. Boston: Beacon Press.
- Habermas, J. (1975). *Legitimation Crisis*. Boston: Beacon Press.
- Habermas, J. (1979). *Communication and the Evolution of Society*. Boston, MA: Beacon Press.
- Habermas, J. (1984). *The Theory of Communicative Action, Vol. 1, Reason and the Rationalization of Society*. Boston: Beacon.
- Habermas, J. (1988). *On the Logic of the Social Sciences (Shierry Weber Nicholse and Jerry A. Stark, Trans.)*. Cambridge, MA: MIT Press.
- Habermas, J. (1990). *Moral consciousness and communicative action*. Cambridge, MA: MIT Press.
- Habermas, J. (1992). *Autonomy and solidarity: interviews with Jürgen Habermas*. London: Verso.
- Habermas, J. (1996). *Between facts and norms: Contributions to a discourse theory of democracy*. Cambridge, MA: MIT Press.
- Hain, R., Heckford, E., & McCulloch, R. (2012). Paediatric palliative medicine in the UK: past, present, future. *Archives of disease in childhood*, 97(4), 381-384. doi:10.1136/archdischild-2011-300432
- Horsley, T. (2019). Tips for Improving the Writing and Reporting Quality of Systematic, Scoping, and Narrative Reviews. 39(1), 54-57. doi:10.1097/ceh.0000000000000241
- Kellehear, A. (1999). Health-promoting palliative care: Developing a social model for practice. *Mortality*, 4(1), 75-82. doi:10.1080/713685967
- Kellehear, A. (2012). *Compassionate cities*. Oxfordshire: Routledge.
- Kellehear, A. (2013). Compassionate communities: End-of-life care as everyone's responsibility. *QJM: An International Journal of Medicine*, (106), 1071-1075. doi:10.1093/qjmed/hct200

- Kellehear, A. (2014). Death education as a public health issue. In J. Stillion & T. Attig (Eds.), *Death, dying and bereavement: Contemporary perspectives institutions and practices* (pp. 221-232). New York: Springer Publishing Company.
- Kellehear, A. (2016). Commentary: Public health approaches to palliative care—The progress so far. *Progress in Palliative Care*, 24(1), 36-38. doi:10.1080/09699260.2015.1103499
- Kellehear, A., & Fook, J. (2010). Bereavement care for the non-bereaved: A health promotion challenge. *Bereavement Care*, 29(3), 21-25. doi:10.1080/02682621.2010.522376
- Kellehear, A., & O'Connor, D. (2008). Health-promoting palliative care: A practice example. *Critical Public Health*, 18(1), 111-115. doi:10.1080/09581590701848960
- Kennedy, C. J., & Gardner, F. (2021). Researching death, dying and bereavement: tales of grounded theory, reflexivity and compassion. *Qualitative Research*, 1-15. doi:10.1177/14687941211000560
- Kennedy, C. J., Gardner, F., & Farrelly, C. (2020). Death, dying and bereavement: considering compassion and empowerment. *Pastoral Care in Education*, 38(2), 138-155. doi:10.1080/02643944.2020.1725905
- Kennedy, C. J., Gardner, F., & Southall, A. (2021). The Intentional Compassion Framework for school communities. *Health Education Journal*, 1-12. doi:10.1177/00178969211006746
- Kennedy, C. J., Keeffe, M., Gardner, F., & Farrelly, C. (2017). Making death, compassion and partnership 'part of life' in school communities. *Pastoral Care in Education*, 35(2), 111-123. doi:10.1080/02643944.2017.1306873
- Kennedy, M. (2006). *Come and Go Seed*. Castlemaine, Victoria: Quartz Hill Music.
- Kitzinger, C. (1989). The Discursive Construction of Identities. In J. E. Shotter & K. J. Gergen (Eds.), *Texts of Identity*. London: Sage Publications, Inc.
- Krieger, S. R., Epting, F. R., & Leitner, L. M. (1975). Personal constructs, threat and attitudes toward death. *OMEGA-Journal of Death and Dying*, 5(4), 299-310. doi:10.2190/WCDW-PNPQ-OERV-RNM7
- Kübler-Ross, E., & Kessler, D. (2014). *On grief and grieving: Finding the meaning of grief through the five stages of loss*. London: Simon and Schuster.
- Lane, N., Rowland, A., & Beinart, H. (2014). "No Rights or Wrongs, No Magic Solutions": Teachers' Responses to Bereaved Adolescent Students. *Death Studies*, 38(10), 654-661. doi:10.1080/07481187.2013.840018
- Lee, H. (1960). *To kill a mockingbird*. Great Britain: William Heinemann.
- Mak, M. H. (2012). Quality insights of university teachers on dying, death, and death education. *Omega (United States)*, 66(2), 173-194. doi:10.2190/OM.66.2.e
- Marcuse, H. (1964). *One dimensional man: The ideology of industrial society*. Great Britain: Routledge and Kegan Paul.
- Marcuse, H. (1970). *Five lectures*: Beacon Press.
- Marcuse, H. (1978). *The aesthetic dimension: Toward a critique of Marxist aesthetics*. Boston: Beacon Press.
- Matheson, J. (2013). Assessment and intervention in the family and larger systems. In D. K. Meagher & D. E. Balk (Eds.), *Handbook of Thanatology*. New York: Routledge.
- Mauk, K. L. (2017). Qualitative designs: Using words to provide evidence. *Evidence-based practice for nurses: Appraisal application of research*, 221-254.
- McGovern, M., & Tracey, A. (2010). A comparative examination of schools' responses to bereavement and the associated needs of the school community in Galway, West of

- Ireland and Derry, Northern Ireland. *Pastoral Care in Education*, 28(3), 235-252. doi:10.1080/02643944.2010.504223
- McLoughlin, K., McGilloway, S., Lloyd, R., O'Connor, M., Rhatigan, J., Shanahan, M., . . . Keevey, A. (2016). Walls, wisdom, worries, and wishes: Engaging communities in discussion about death, dying, loss, and care using Café Conversation. *Progress in Palliative Care*, 24(1), 9-14.
- Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, 12(1), 8-13. doi:10.1111/j.1440-172X.2006.00543.x
- Mills, J., Rosenberg, J. P., & McInerney, F. (2015). Building community capacity for end of life: an investigation of community capacity and its implications for health-promoting palliative care in the Australian Capital Territory. *Critical Public Health*, 25(2), 218-230 213p. doi:10.1080/09581596.2014.945396
- Mills, S., & Mills, J. (2016). Future directions for community engagement as a public health approach to palliative care in Australia. *Progress in Palliative Care*, 24(1), 15-18. doi:10.1179/1743291X15Y.0000000012
- Neimeyer, R. A. (1998). Social constructionism in the counselling context. *Counselling Psychology Quarterly*, 11(2), 135-149. doi:10.1080/09515079808254050
- Neimeyer, R. A. (2014). The changing face of grief: Contemporary directions in theory, research, and practice. *Progress in Palliative Care*, 22(3), 125-130. doi:10.1179/1743291x13y.0000000075
- Neimeyer, R. A., Currier, J. M., Coleman, R., Tomer, A., & Samuel, E. (2011). Confronting suffering and death at the end of life: The impact of religiosity, psychosocial factors, and life regret among hospice patients. *Death Studies*, 35(9), 777-800. doi:10.1080/07481187.2011.583200
- Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death studies*, 38(8), 485-498. doi:10.1080/07481187.2014.913454
- Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death studies*, 28(4), 309-340. doi:10.1080/07481180490432324
- Noddings, N. (1984). *Caring. A feminine approach to ethics and moral education* (Vol. 177, pp. 27). Berkeley and Los Angeles: University of California Press.
- Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care*, 24(1), 31-35. doi:10.1080/09699260.2015.1103498
- Nussbaum, M. (1996). Compassion: The basic social emotion. *Social Philosophy and Policy*, 13(1), 27-58. doi:10.1017/s0265052500001515
- Papadatou, D., Metallinou, O., Hatzichristou, C., & Pavlidi, L. (2002). Supporting the bereaved child: Teacher's perceptions and experiences in Greece. *Mortality*, 7(3), 324-339. doi:10.1080/1357627021000025478
- Payne, M. (Ed.). (1997). *A Dictionary of Cultural and Critical Theory*. Malden, Massachusetts: Blackwell.
- Peterson, A. (2016). *Compassion and education: Cultivating compassionate children, schools and communities*. [London, England]: Palgrave Macmillan.
- Potts, S. (2013). Least said, soonest mended?: Responses of primary school teachers to the perceived support needs of bereaved children. *Journal of Early Childhood Research*, 11(2), 95-107. doi:10.1177/1476718x12466201

- Rosenau, P. M. (1991). *Post-modernism and the social sciences: Insights, inroads, and intrusions*: Princeton University Press.
- Rosenberg, J. (2011). Whose business is dying? Death, the home and palliative care. *Cultural Studies Review*, 17(1), 15-30. doi:10.5130/csr.v17i1.1971
- Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2015). Informal caring networks for people at end of life: Building social capital in Australian communities. *Health Sociology Review*, 24(1), 29-37. doi:10.1080/14461242.2014.999400
- Rosenberg, J. P., Mills, J., & Rumbold, B. (2016). Putting the 'public' into public health: Community engagement in palliative and end of life care. *Progress in Palliative Care*, 24(1), 1-3. doi:10.1080/09699260.2015.1103500
- Rosenberg, J. P., & Yates, P. M. (2010). Health promotion in palliative care: the case for conceptual congruence. *Critical Public Health*, 20(2), 201-210. doi:10.1080/09581590902897394
- Rosenblatt, P., & Bowman, T. (2013). Alternative approaches to conceptualizing grief: A conversation. *Bereavement Care*, 32(2), 82-85. doi:10.1080/02682621.2013.812826
- Rowling, L. (2008). Linking spirituality, school communities, grief and well-being. *International Journal of Children's Spirituality*, 13(3), 241-251. doi:10.1080/13644360802236482
- Rowling, L. (2010). Schools and grief: Attending to people and place. In B. Monroe & F. Kraus (Eds.), *Brief interventions with bereaved children* (2nd ed., pp. 147-160). New York: Oxford University Press.
- Rumbold, B. (2012a). Compassionate care: Engaging the spirit in care. *Progress in Palliative Care*, 20(2), 106-113. doi: 10.1179/1743291X12Y.0000000005
- Rumbold, B. (2012b). Models of spiritual care. In M. Cobb, C. Puchalski & B. Rumbold (Eds.), *Oxford textbook of spirituality in healthcare*. Oxford: Oxford University Press.
- Rumbold, B., & Aoun, S. (2014). Bereavement and palliative care: A public health perspective. *Progress in Palliative Care*, 22(3), 131-135. doi:10.1179/1743291X13Y.00000000079
- Rumbold, B., Gardner, F., & Nolan, I. (2011). Spirituality and community practice. In S. Conway (Ed.), *Governing death and loss: empowerment, involvement and participation* (pp. 139-147). New York: Oxford University Press.
- Schön, D. (1983). *The reflective practitioner*: New York: Basic Books.
- Schut, M. S., Henk. (1999). The dual process model of coping with bereavement: Rationale and description. *Death studies*, 23(3), 197-224. doi:10.1080/074811899201046
- Sinclair, S., Hack, T. F., Raffin-Bouchal, S., McClement, S., Stajduhar, K., Singh, P., . . . Chochinov, H. M. (2018). What are healthcare providers' understandings and experiences of compassion? The healthcare compassion model: a grounded theory study of healthcare providers in Canada. *BJM Open*, 8(3). doi:10.1136/bmjopen-2017-019701
- Strauss, A., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA: Sage Publications, Inc.
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, Calif: Sage Publications.
- Stroebe, M. S. (2002). Paving the way: From early attachment theory to contemporary bereavement research. *Mortality*, 7(2), 127-138. doi:10.1080/13576270220136267
- Swinton, J. (2012). Healthcare spirituality: a question of knowledge. In M. Cobb, C. M. Puchalski & B. Rumbold (Eds.), *Oxford Textbook of Spirituality in Healthcare*. Oxford,

- UNITED KINGDOM: Oxford University Press.
doi:10.1093/med/9780199571390.003.0015
- Templer, D. I. (1970). The construction and validation of a death anxiety scale. *The Journal of General Psychology*, 82(2), 165-177. doi:10.1080/00221309.1970.9920634
- Tracey, A., & Holland, J. (2008). A comparative study of the child bereavement and loss responses and needs of schools in Hull, Yorkshire and Derry/Londonderry, Northern Ireland. *Pastoral Care in Education*, 26(4), 253-266.
doi:10.1080/02643940802472197
- Witkin, S. (2011). *Social construction and social work practice: Interpretations and innovations*. New York: Columbia University Press.
- Wong, P. T., & Tomer, A. (2011). Beyond terror and denial: The positive psychology of death acceptance. *Death Studies*, 35(2), 99-106. doi:10.1080/07481187.2011.535377
- Wong, P. T. P. (2013). Meaning management theory and death acceptance. In G. T. Eliason, P. T. P. Wong, A. Tomer & G. Eliason (Eds.), *Existential and spiritual issues in death attitudes* (pp. 65-87). London: Taylor and Francis. Retrieved from
<https://ebookcentral-proquest-com.ez.library.latrobe.edu.au/lib/latrobe/reader.action?docID=1099176>
- World Health Organisation. (2018). *Why Palliative care is an essential function of primary health care* (No. WHO/HIS/SDS/2018.39). doi:
<https://www.who.int/publications/i/item/WHO-HIS-SDS-2018.39>
- Zembylas, M. (2014). The place of emotion in teacher reflection: Elias, Foucault and 'critical emotional reflexivity'. *Power and Education*, 6(2), 210-222.
doi:10.2304/power.2014.6.2.210