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Grief and Bereavement in Compassionate Communities

Who can play a role and how?

Professor Samar Aoun

Perron Institute Research Chair in Palliative Care

Presentation to PHPCI 2022

# what do we know about bereavement as it is lived out in everyday life?

We knew about the **minority** who sought support from professional services but not about the **majority** who did not seek such services.

Therefore we paid **less** attention to the experience and resources the **majority** used to learn to live with their loss.
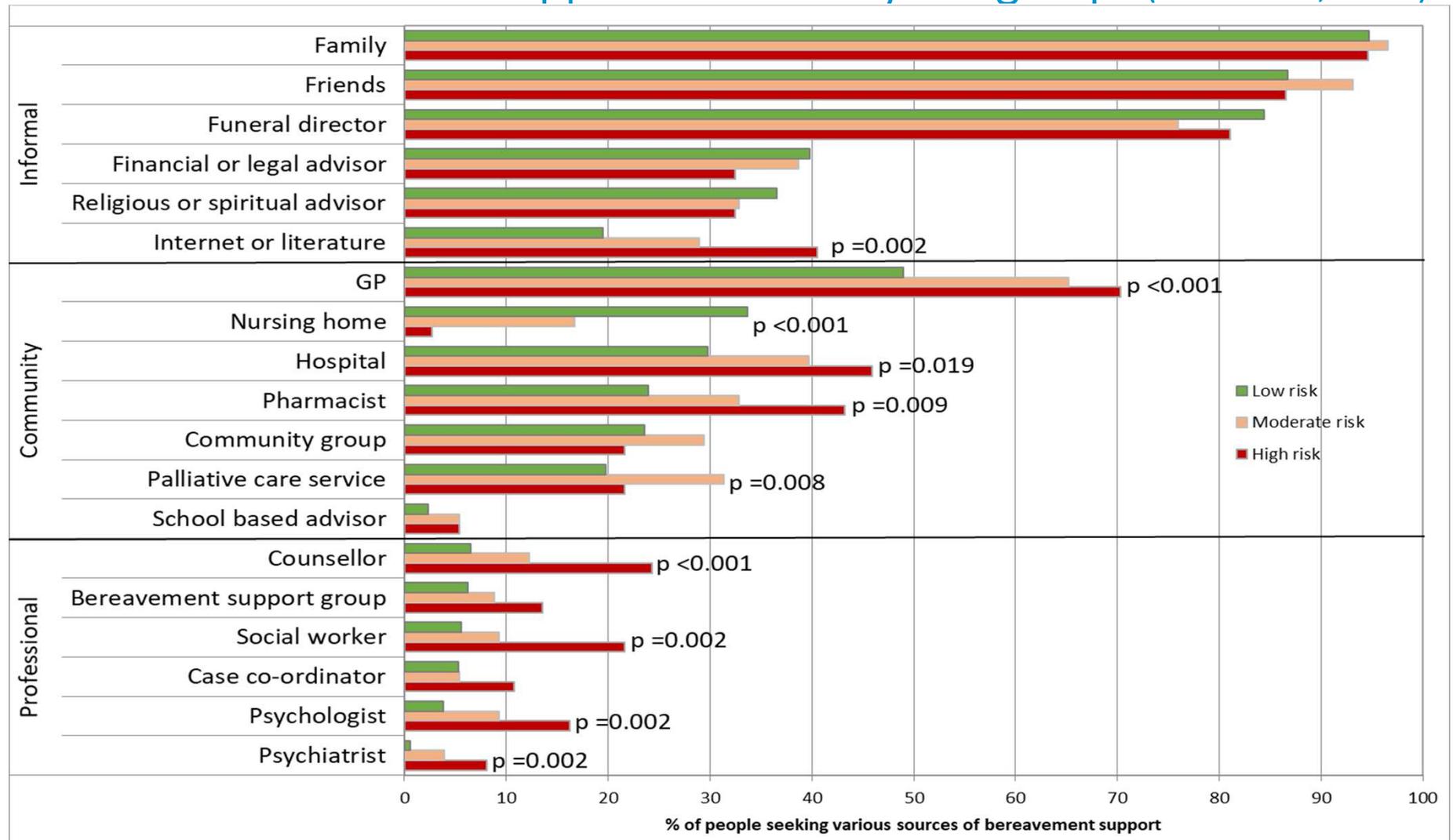
Community assets helping the majority of the bereaved
n=839 (Aoun et al, 2015)
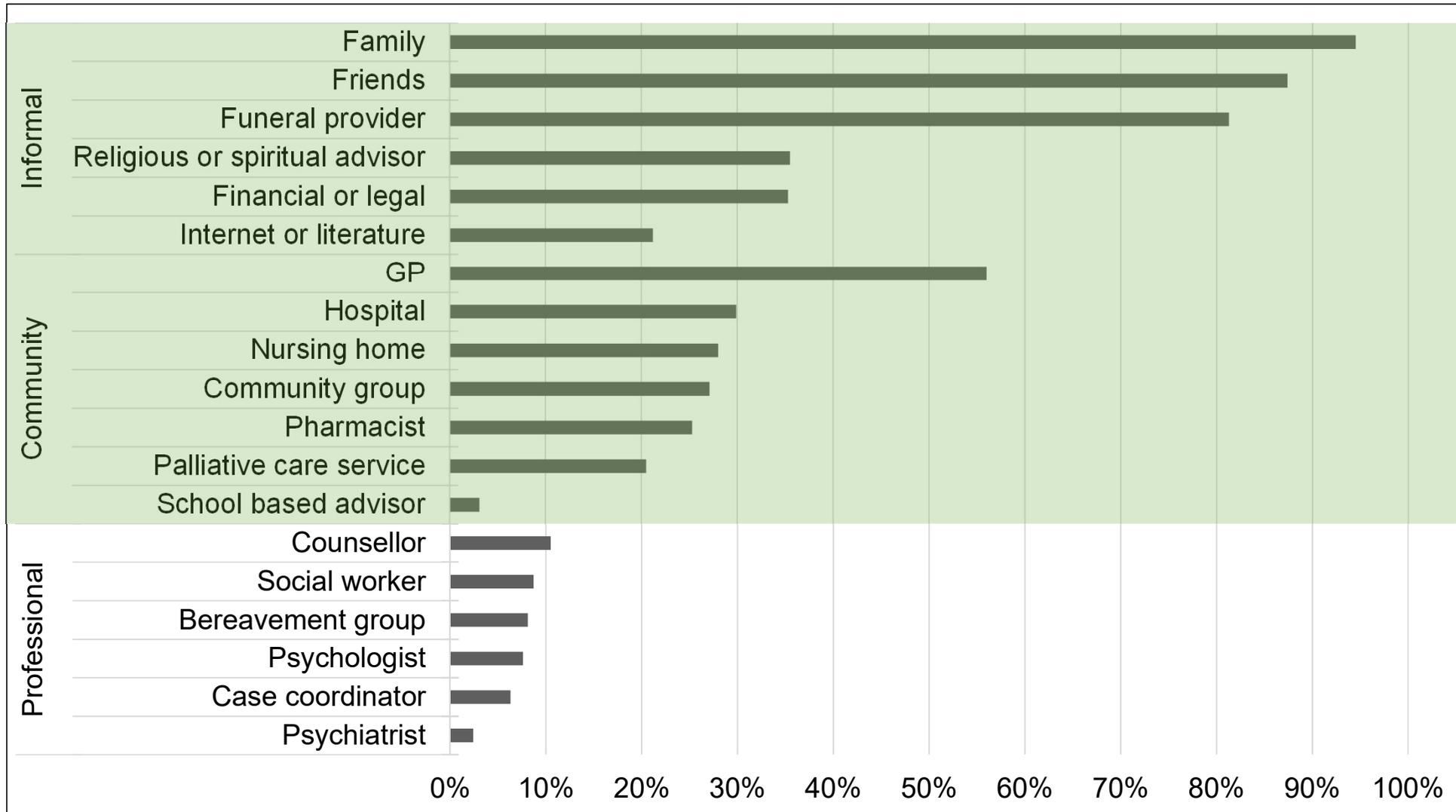
Sources of bereavement support accessed by risk groups (Aoun et al, 2015)

A public health approach to bereavement support services in palliative care

Samar M. Aoun
Western Australian Centre for Cancer and Palliative Care, Curtin Health Innovation Research Institute, Curtin University, Western Australia

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School of Psychology and Speech Pathology, Curtin Health Innovation Research Institute, Curtin University, Western Australia

Moira O'Connor
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Palliative Care Unit, School of Public Health, La Trobe University, Victoria

PLOS | ONE

RESEARCH ARTICLE

Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need

Samar M. Aoun[1]*, Lauren J. Breen[2], Denise A. Howting[1], Bruce Rumbold[3], Beverley McNamara[4], Desley Hegney[5,6]

1 School of Nursing and Midwifery, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia, 2 School of Psychology and Speech Pathology, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia, 3 Palliative Care Unit, Department of Public Health, La Trobe University, Melbourne, Victoria, Australia, 4 School of Occupational Therapy and Social Work, Curtin University, Perth, Western Australia, Australia, 5 Centre for Nursing Research, Sir Charles Gairdner Hospital, Perth, Western Australia, Australia, 6 School of Nursing and Midwifery, University of Southern Queensland, Brisbane, Queensland, Australia

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Abstract

This study identifies and describes the profiles of bereavement risk and support needs of a community sample in Australia and tests the fit of the data with the three-tiered public health model for bereavement support. Family members who were bereaved 6–24 months prior to

Sources of support perceived helpful or unhelpful (Aoun et al, 2018)
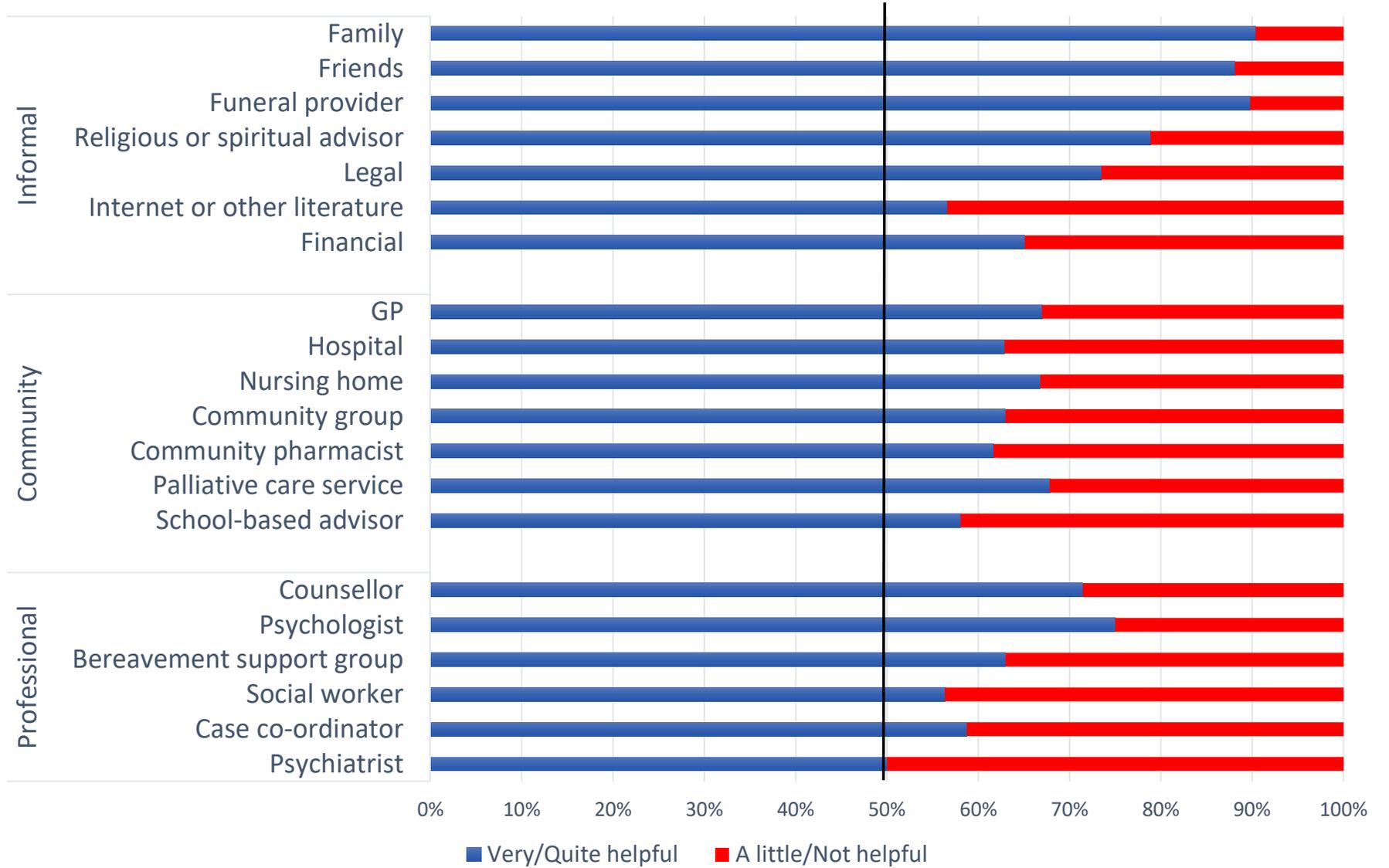
The types of informal social support most valued as helpful (Aoun et al, 2018)

The Social Provisions Scale –SPS:

- Attachment -The emotional and affectionate bonds
- Tangible alliance -The practical assistance
- Social integration -The perceived sense of belonging
- Guidance - advice or information

What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach

Samar M Aoun[1,2] iD, Lauren J Breen[3], Ishta White[3], Bruce Rumbold[1] and Allan Kellehear[4]

Abstract

Aim: To determine who provides bereavement support in the community, what sources are perceived to be the most or least helpful and for what reason, and identify the empirical elements for optimal support in developing any future compassionate communities approach in palliative care.

Design: A population-based cross-sectional investigation of bereavement experiences. Sources of support (informal, community and professional) were categorised according to the Public Health Model of Bereavement Support; most helpful reasons were categorised using the Social Provisions Scale, and least helpful were analysed using inductive content analysis.

Setting and participants: Bereaved people were recruited from databases of funeral providers in Australia via an anonymous postal

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RESEARCH ARTICLE

Matching response to need: What makes social networks fit for providing bereavement support?

Samar M. Aoun iD[1,2]*, Lauren J. Breen[3], Bruce Rumbold[1], Kim M. Christian[3], Anne Same[4], Julian Abel[5]
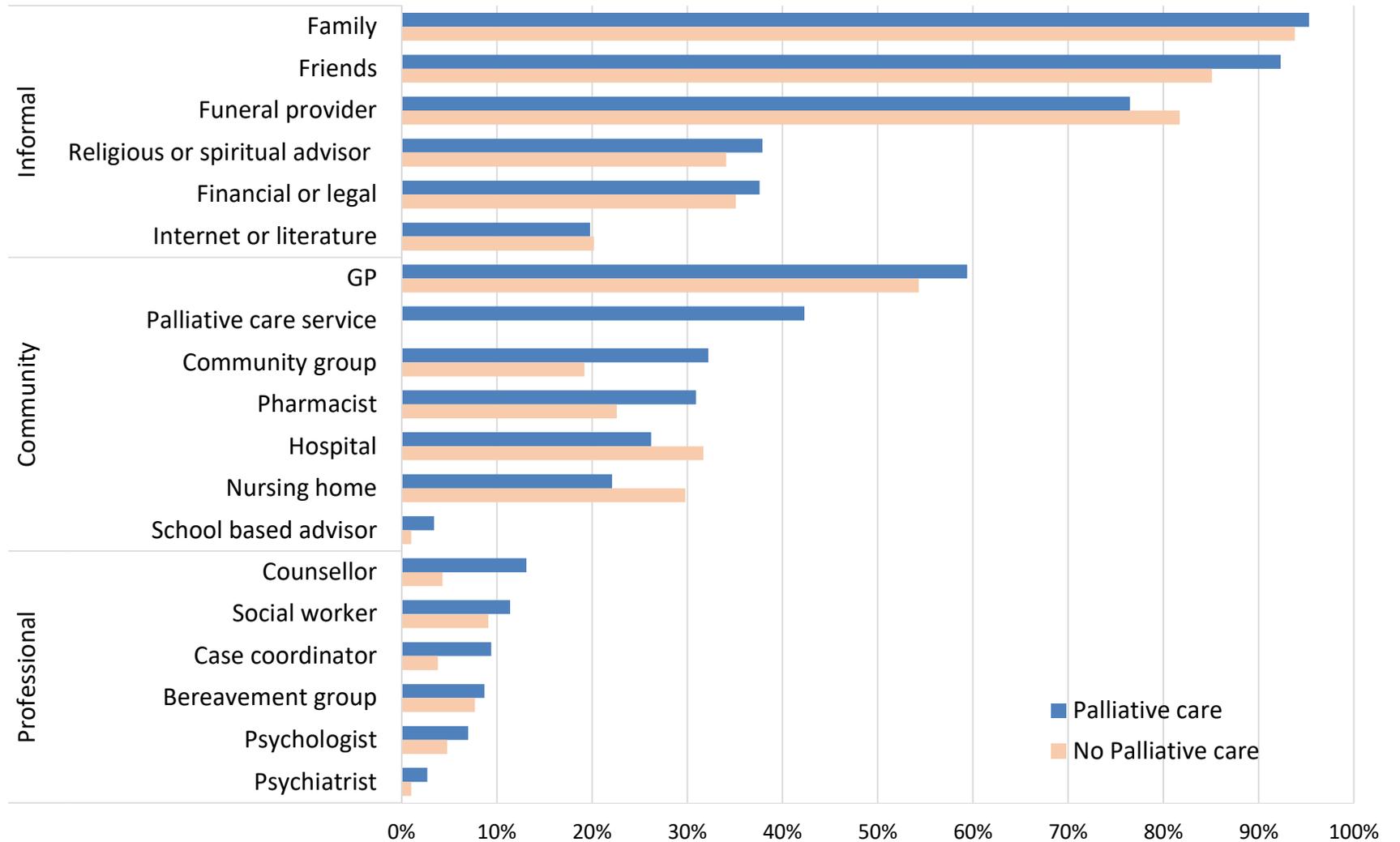
1 Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria, Australia, 2 The Perron Institute for Neurological and Translational Science, Perth, Western Australia, Australia, 3 School of Psychology, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia, 4 School of Occupational Therapy, Social Work and Speech Pathology, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia, 5 Compassionate Communities UK, Honorary Senior Researcher, University of Bradford, Bradford, United Kingdom

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Abstract

The objectives of this study were to explore the goodness of fit between the bereaved peoples' needs and the support offered by their social networks: to ascertain whether this sup-

Sources of support accessed by participants who received Palliative care and those who did not (Aoun et al, 2017)

RESEARCH ARTICLE

Bereavement support for family caregivers: The gap between guidelines and practice in palliative care

Samar M. Aoun[1]*, Bruce Rumbold[2], Denise Howting[1], Amanda Bolleter[3], Lauren J. Breen[4]

1 School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia, 2 Palliative Care Unit, Department of Public Health, La Trobe University, Melbourne, Victoria, Australia, 3 WA Cancer and Palliative Care Network, Health department of WA, Perth, Western Australia, 4 School of Psychology and Speech Pathology, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia

* s.aoun@curtin.edu.au

Abstract

Background

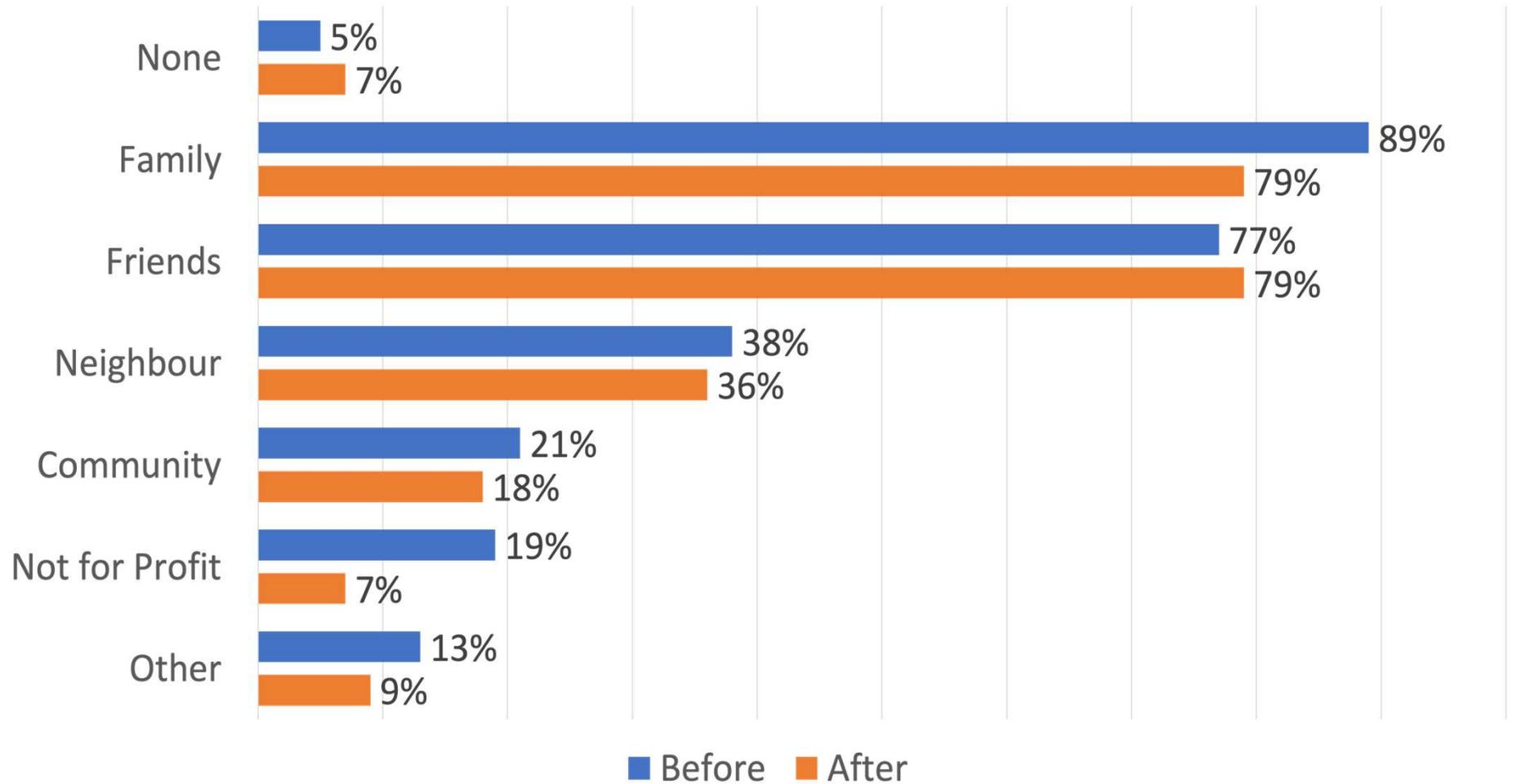Standards for bereavement care propose that support should be matched to risk and need.

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Sources of Informal Support Before and After Death-Consumers with life limiting illnesses in WA (n=353) (Aoun et al, 2021)

Source	Before	After
None	5%	7%
Family	89%	79%
Friends	77%	79%
Neighbour	38%	36%
Community	21%	18%
Not for Profit	19%	7%
Other	13%	9%

■ Before ■ After

Article

Winners and Losers in Palliative Care Service Delivery: Time for a Public Health Approach to Palliative and End of Life Care

Samar M. Aoun [1,2,*] , Robyn Richmond [1], Leanne Jiang [1,2] and Bruce Rumbold [2]

1   Perron Institute for Neurological and Translational Science, Nedlands, WA 6009, Australia; robyn.richmond@perron.uwa.edu.au (R.R.); leanne.jiang@latrobe.edu.au (L.J.)
2   Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, VIC 3086, Australia; b.rumbold@latrobe.edu.au
*   Correspondence: samar.aoun@perron.uwa.edu.au

Abstract: Background: Consumer experience of palliative care has been inconsistently and selectively investigated. Methods: People in Western Australia who had experienced a life limiting illness in the past five years were recruited via social media and care organisations (2020) and invited to complete a cross sectional consumer survey on their experiences of the care they received. Results: 353 bereaved carers, current carers and patients responded. The winners, those who received the best quality

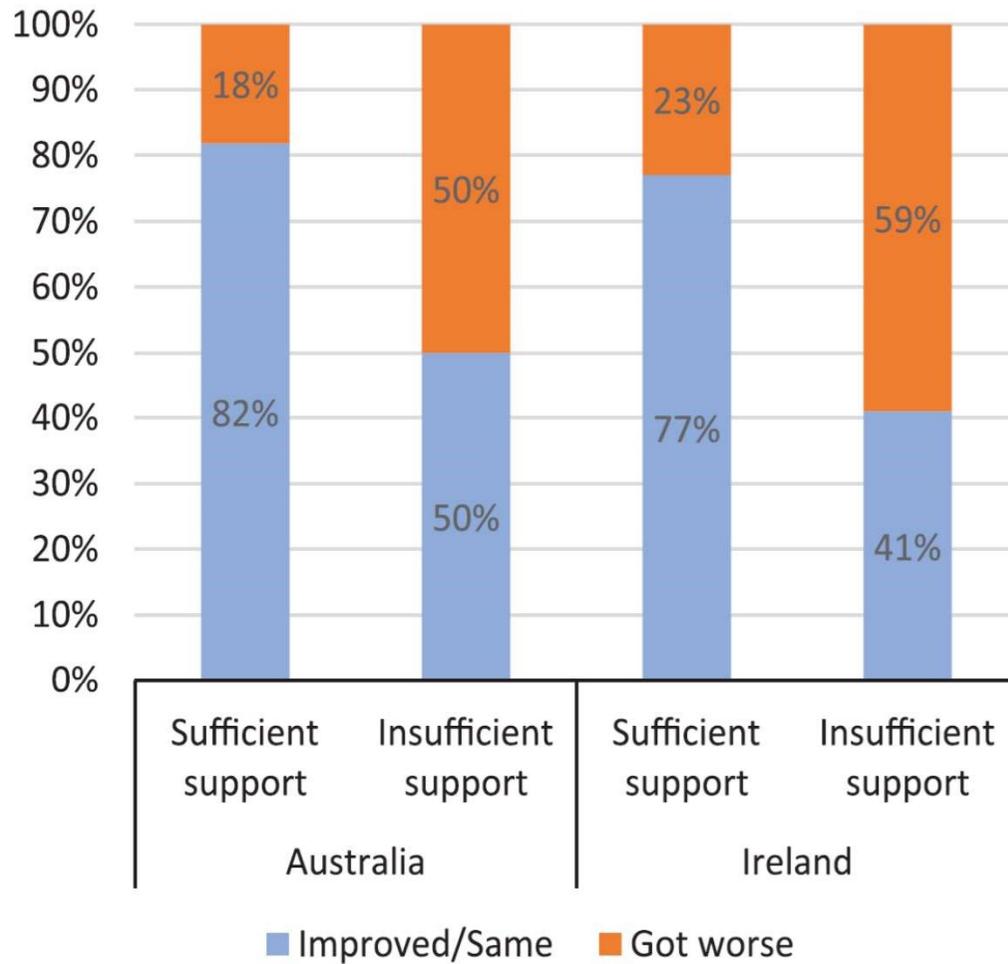# Bereavement support in Australia and Ireland (Aoun et al, 2020)
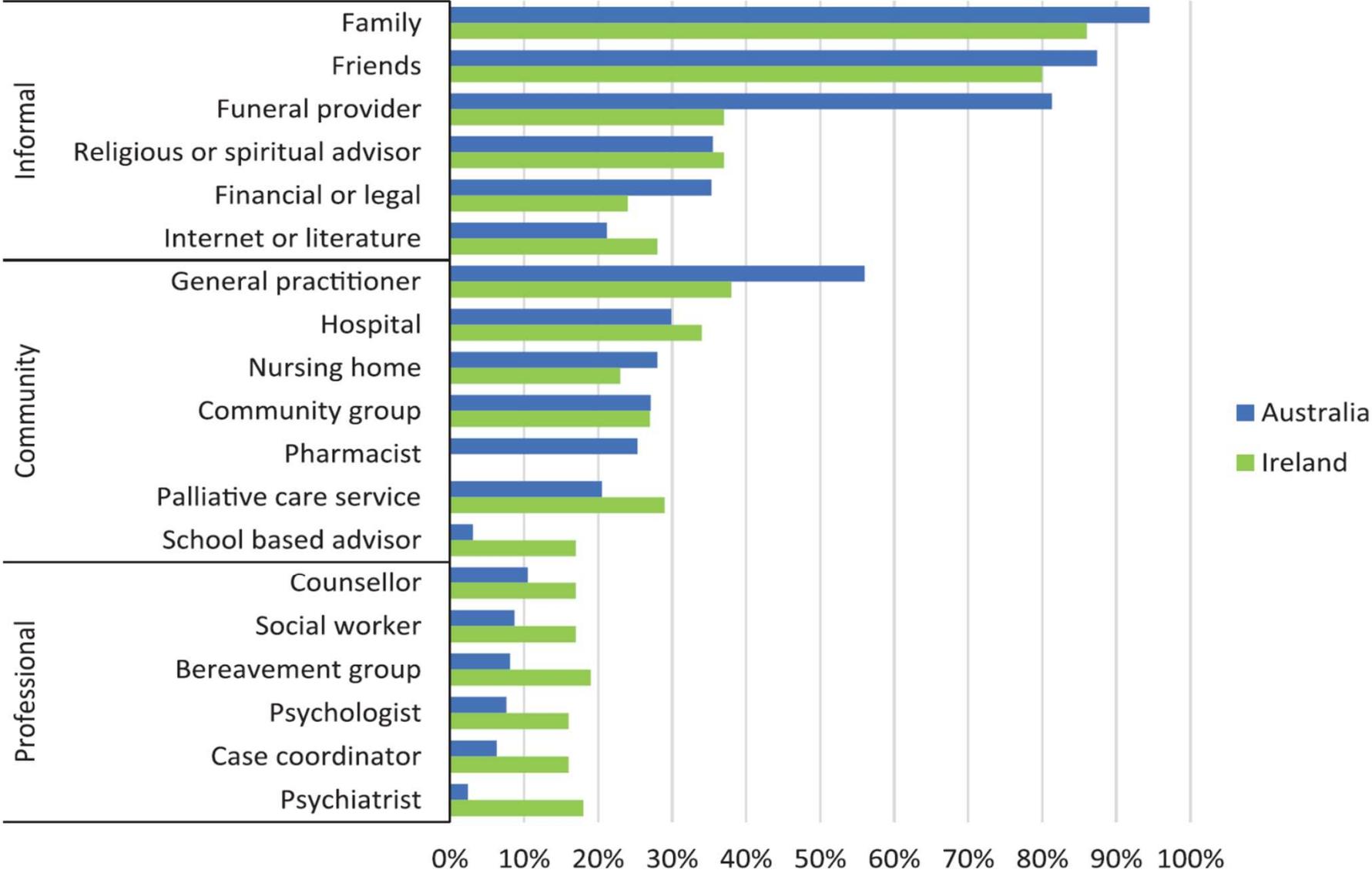
Figure 3. Sufficiency of support in Australia and Ireland.

(a) Physical
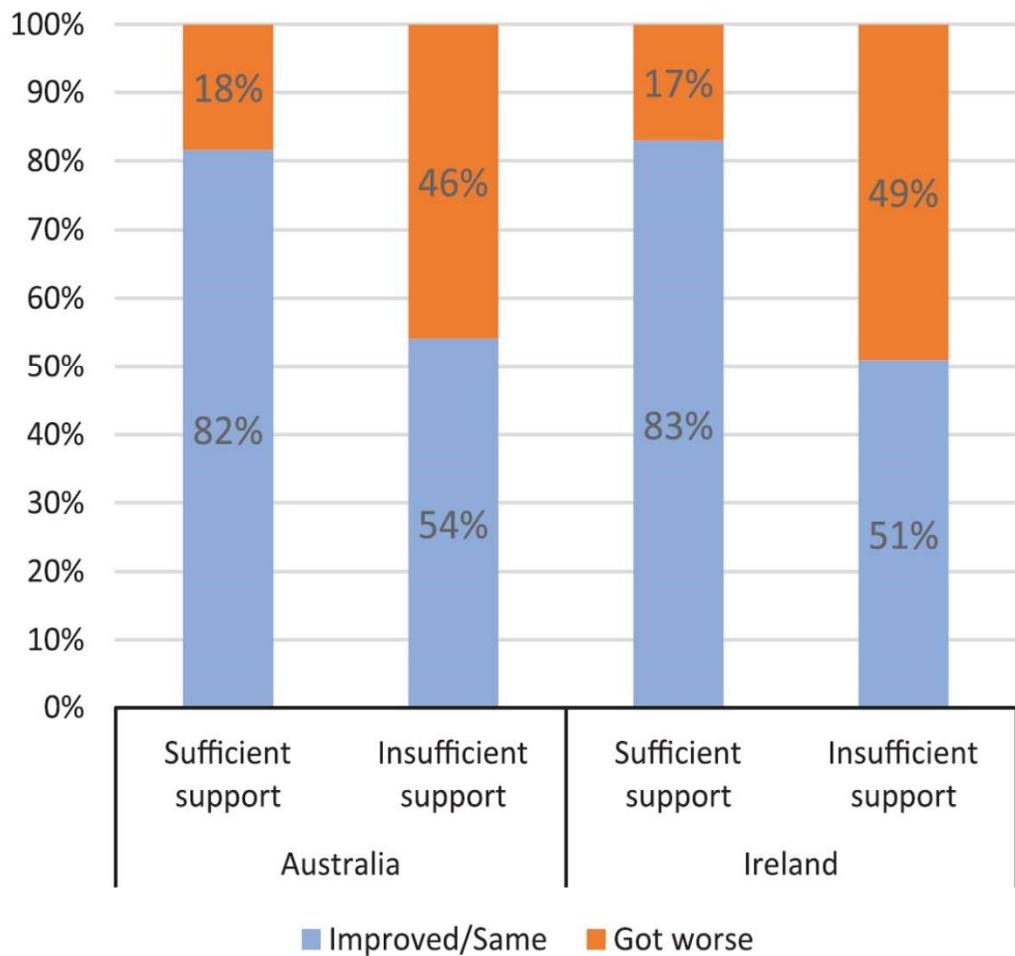
(b) Mental

The impact of bereavement support on wellbeing: a comparative study between Australia and Ireland

Samar M. Aoun [iD], Orla Keegan, Amanda Roberts and Lauren J. Breen [iD]

Abstract

Background: There is a dearth of national and international data on the impact of social support on physical, mental, and financial outcomes following bereavement.

Methods: We draw from two large, population-based studies of bereaved people in Australia and Ireland to compare bereaved people's experience of support. The Australian study used a postal survey targeting clients of six funeral providers and the Irish study used telephone interviews with a random sample of the population.

Results: Across both studies, the vast majority of bereaved people reported relying on informal supporters, particularly family and friends. While sources of professional help were the least used, they had the highest proportions of perceived unhelpfulness. A substantial proportion, 20% to 30% of bereaved people, reported worsening of their physical and mental health and about 30% did not feel their needs were met. Those who did not receive enough support reported the highest deterioration in wellbeing.

Sources of bereavement support accessed by MND family caregivers n=393 (Aoun et, 2021)
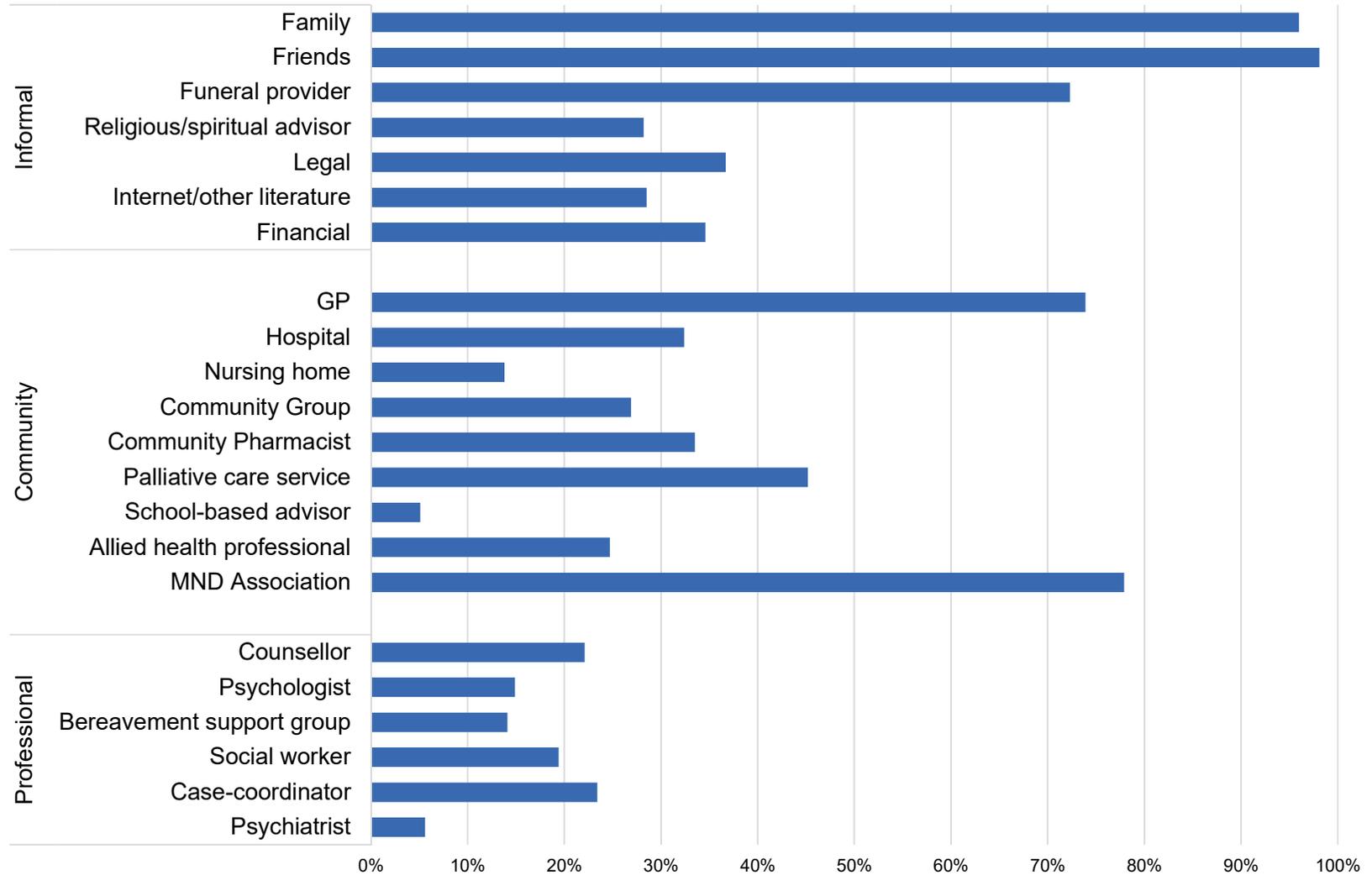
Risk factors for Complicated Grief in MND
(Aoun et al, 2020)

- 8 X more likely if family carer had anxiety

- 18 X more likely if carer had depression

- 4 X more likely with poor family functioning

- A recent bereavement (<12 months)

- 4 X more likely being a spouse/partner of the deceased

- 3 X more likely if deceased is under 60 years of age

- 3 X more likely if they had insufficient support during the disease journey

- 3 X more likely with a shorter period of caring (<1.5 years)

Proportions in the three grief risk groups of the MND bereaved population and the general bereaved population (Aoun et al, 2020)

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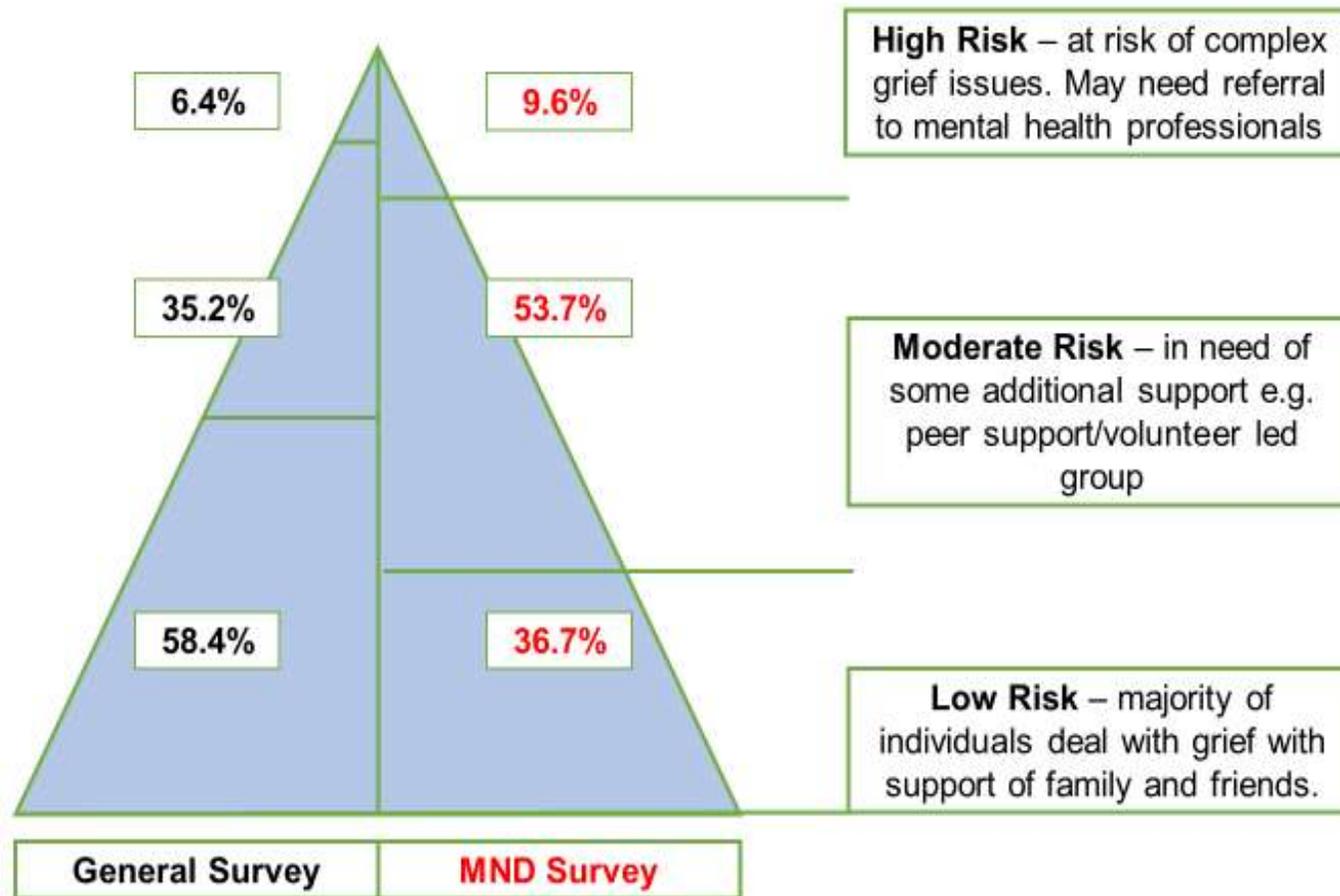
ORIGINAL ARTICLE

Grief, depression, and anxiety in bereaved caregivers of people with motor neurone disease: a population-based national study

SAMAR M AOUN[1,2], DAVID W KISSANE[3,4], PAUL A. CAFARELLA[5,6,7], BRUCE RUMBOLD[1], ANNE HOGDEN[8], LEANNE JIANG[1,2] AND NATASHA BEAR[9]

[1]*Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, VIC, Australia*, [2]*Perron Institute for Neurological and Translational Science, Perth, WA, Australia*, [3]*Palliative Medicine Research, The University of Notre Dame Australia, and The Cunningham Centre for Palliative Care Research, St Vincent's Hospital, Sydney, NSW, Australia*, [4]*Cabrini Psycho-Oncology and Supportive Care Research Unit, Monash University, Melbourne, VIC, Australia*, [5]*Department of Respiratory Medicine, Flinders*

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RESEARCH ARTICLE

Who cares for the bereaved? A national survey of family caregivers of people with motor neurone disease

SAMAR M. AOUN[1,2], PAUL A. CAFARELLA[3,4], BRUCE RUMBOLD[5], GEOFF THOMAS[6], ANNE HOGDEN[7], LEANNE JIANG[1,2], SONIA GREGORY[8] & DAVID W. KISSANE[9,10,11]

[1]*Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Australia*, [2]*Perron Institute for Neurological and Translational Science, Perth, Australia*, [3]*Department of Respiratory Medicine, Flinders Medical Centre, Adelaide, Australia*, [4]*School of Psychology, Faculty of Health and Medical Sciences, University of Adelaide, Australia*, [5]*Public Health Palliative Care Unit, Department of Public Health, School of Psychology and Public Health, La Trobe University, Melbourne, Australia*, [6]*Consumer Advocate Thomas MND Research Group, Adelaide, Australia*, [7]*Australian Institute of Health Service Management, College of Business and Economics, University of Tasmania, Australia*, [8]*Natasha Bear Statistics, Perth, Australia*, [9]*Palliative Medicine Research, The University of Notre Dame Australia, Sydney, Australia*, [10]*The Cunningham Centre for Palliative Care Research, St Vincent's Hospital, Sydney, Australia and* [11]*Cabrini Psycho-Oncology and Supportive Care Research Unit, Monash University, Melbourne, Australia*

Abstract
Background: Although Motor Neurone Disease (MND) caregivers are most challenged physically and psychologically, there is a paucity of population-based research to investigate the impact of bereavement, unmet needs, range of supports,

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Traumatised, angry, abandoned but some empowered: a national survey of experiences of family caregivers bereaved by motor neurone disease

Samar M. Aoun, Kerrie Noonan, Geoff Thomas and Bruce Rumbold

Abstract
Background: There are few illnesses as disruptive as motor neurone disease, a fatal neurodegenerative condition, where diagnosis introduces a clinical narrative of inevitable decline through progressive immobilisation into death. Recent evidence suggests that bereaved motor neurone disease family caregivers are more likely to be at moderate or high risk of complicated grief.
Methods: Qualitative data from an anonymous national survey of bereaved motor neurone disease caregivers ($n = 393$) was examined through thematic analysis to explore the experiences of people who are at low, moderate, and high risk of complicated grief. Up to 40% responded to three open-ended questions: How caregivers viewed their coping strategies; the advice they had for others and what had been positive about their experience.
Results: Ten themes informed the narratives of illness and loss. All three groups shared similar experiences but differed in their capacity to address them. The low-risk group seemed to recognise the uncertainty of life and that meaning needed to be created by them. For the moderate-risk group, while motor neurone disease was a major disruption, they could with support, regroup and plan in different ways. The high-risk group did not have many resources, external or internal. They felt let down when professionals did not have answers and could not see or did not know how to change their ways of responding to this unwanted situation.
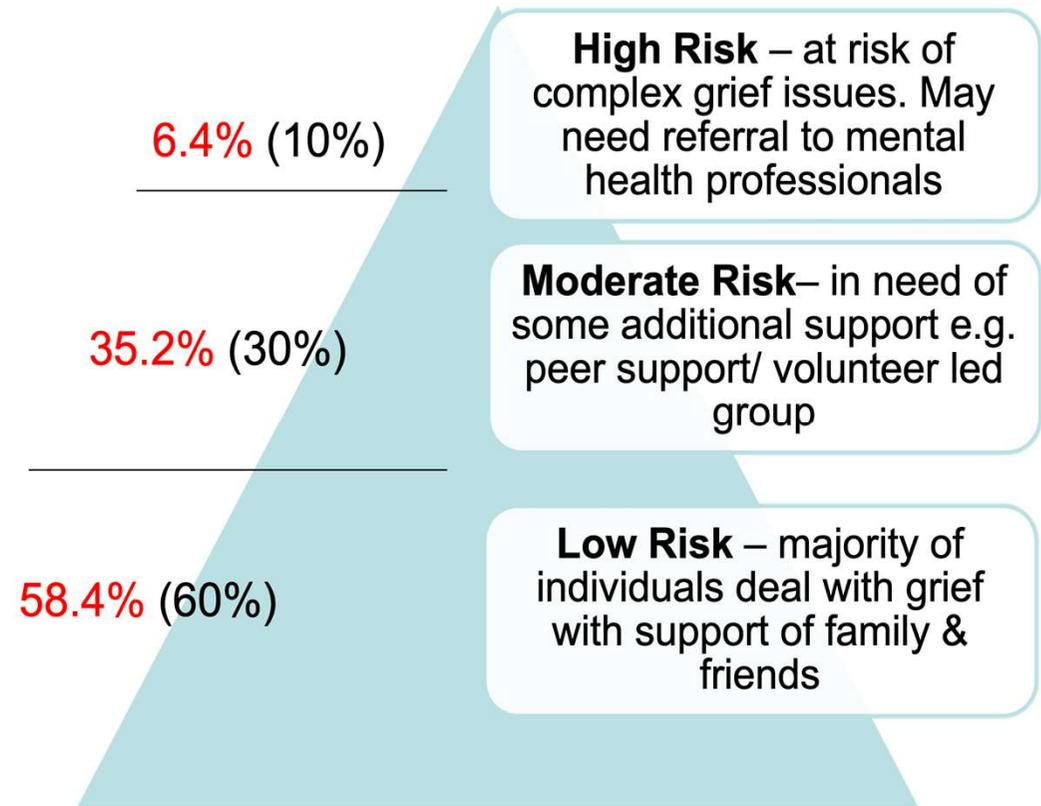**Conclusion:** The differences in these three profiles and their narratives of loss should alert health and community service providers to identify and address the caregivers' support needs early and throughout the caregiving journey. Motor Neurone Disease Associations are involved throughout the illness journey and need to invest in a continuum of care incorporating end-of-life care and bereavement support. Community grief literacy and enhancement of social networks are keys to improved support from families and friends that can enable the focus to be on feelings of empowerment rather than abandonment.

Keywords: bereavement support, compassionate communities, coping, family caregivers, grief literacy, motor neurone disease, social support

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Kerrie Noonan
Public Health Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Bundoora Campus Kingsbury Drive, Melbourne, VIC 3086, Australia

La Trobe University, VIC, Australia
Western Sydney University, NSW, Australia

Geoff Thomas
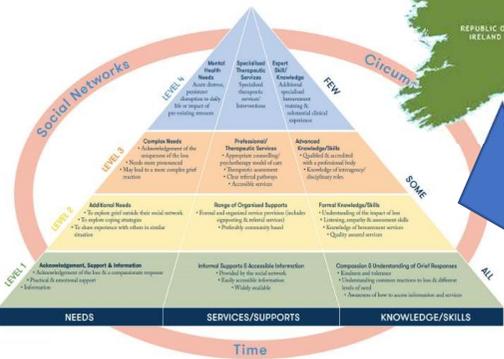Consumer advocate and Thomas MND Research Group, Adelaide, SA, Australia

Public Health Model for Bereavement Support

- Challenged some of this 'received wisdom' in the field.

- Exposed the limitations of clinical services.

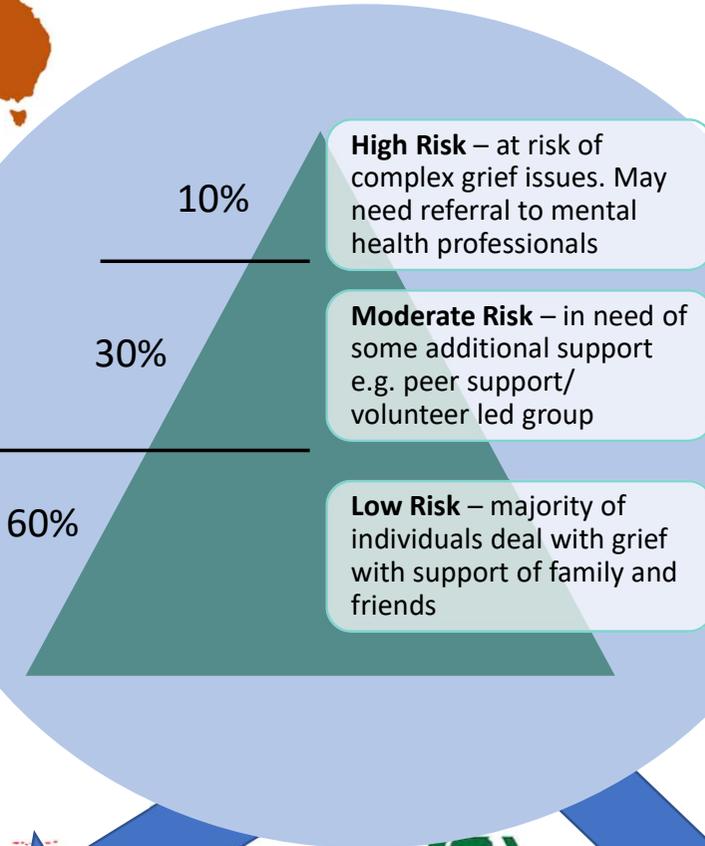- Validated community-based approaches to bereavement support.

6.4% (10%)

High Risk – at risk of complex grief issues. May need referral to mental health professionals

35.2% (30%)

Moderate Risk– in need of some additional support e.g. peer support/ volunteer led group

58.4% (60%)

Low Risk – majority of individuals deal with grief with support of family & friends

The Public Health Model for Bereavement Support-Translation

Palliative Care Australia Standard 6: Grief Support

UK National Bereavement Alliance

10%

High Risk – at risk of complex grief issues. May need referral to mental health professionals

30%

Moderate Risk – in need of some additional support e.g. peer support/ volunteer led group

60%

Low Risk – majority of individuals deal with grief with support of family and friends

From Health practitioners … Thanks so much. I am enjoying your research so much! we've been using it at the service too- That triangle says so much. Cheers.

Irish Hospice Foundation Pyramid of Adult Palliative Care

Bereavement Care Taskforce of the European Association of Palliative Care

Voted best external paper 2018, Cecily Saunders Institute For Palliative Care
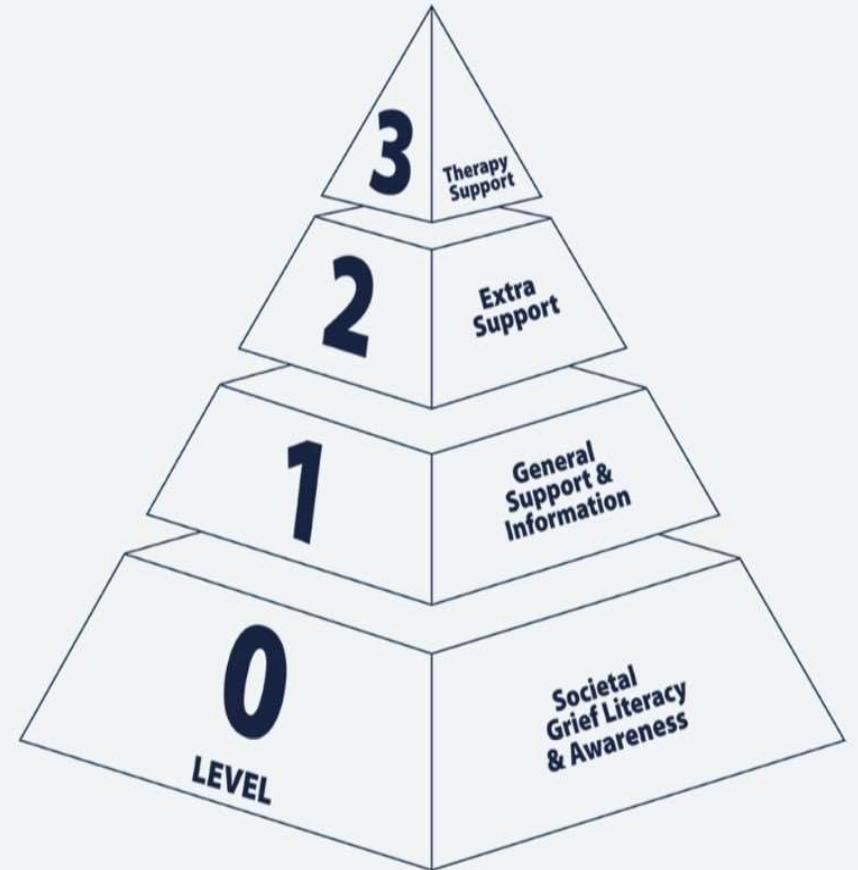
Key Learnings

- The community needs to own its central role in end of life and bereavement care, with formal professionals advising, supporting and contributing as required.

- We need to support the 'everyday assets' in the community who care for the bereaved and who are already involved in the everyday lives of those who were caring and recently bereaved. These assets are family, friends, neighbours, work colleagues and funeral providers to name a few.
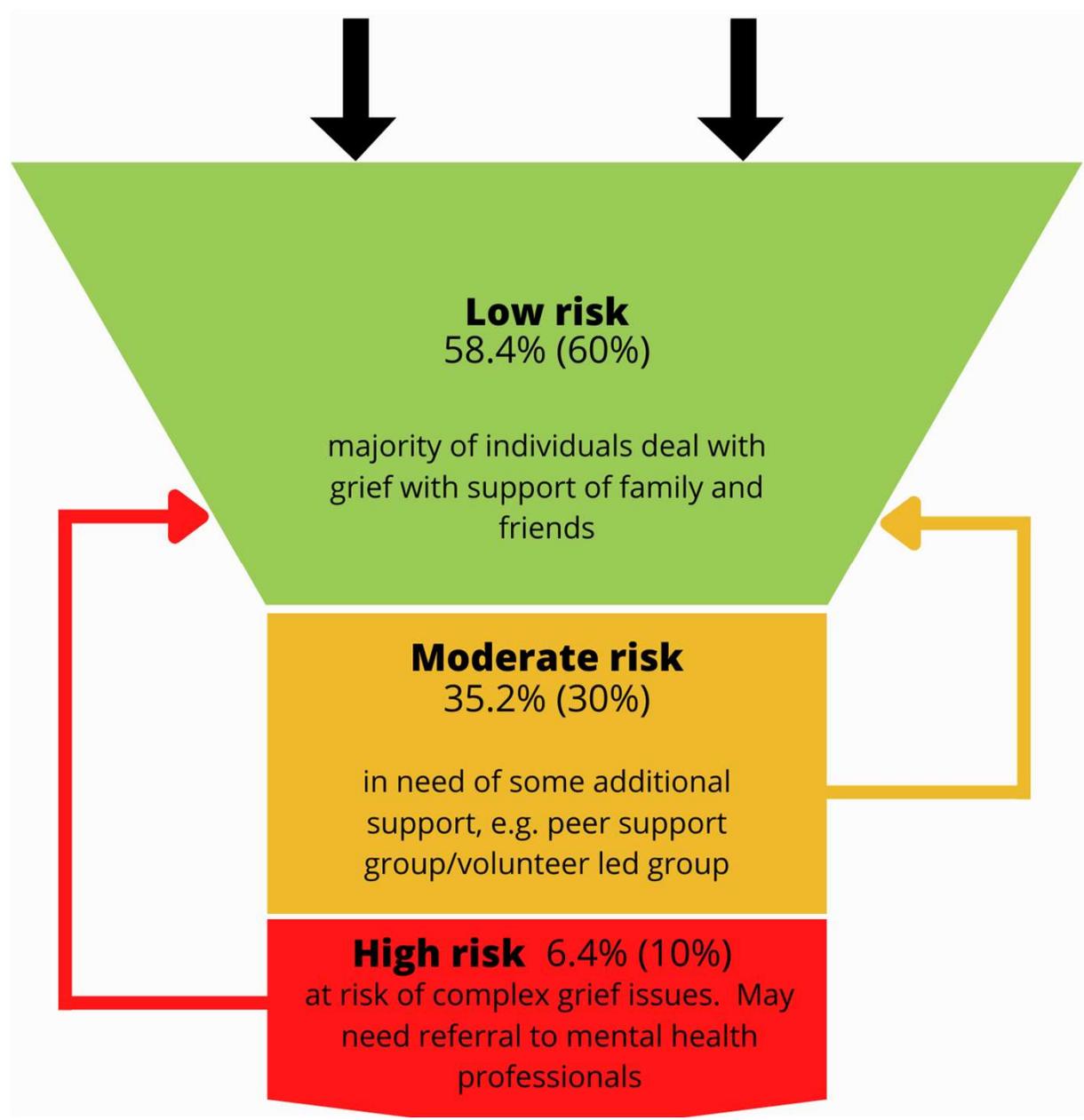
Key Learnings (continued)

- Formal professionals may focus on emotional support, not understanding that emotional support is largely in place, and what clients need is strategic support to help them negotiate their changed world, not merely to adjust their emotions.

- Formal professionals need to remember that they are being consulted not to deal with grief as a separate event, but as one aspect of a tangible, multi-dimensional loss with which that bereaved person has to live.
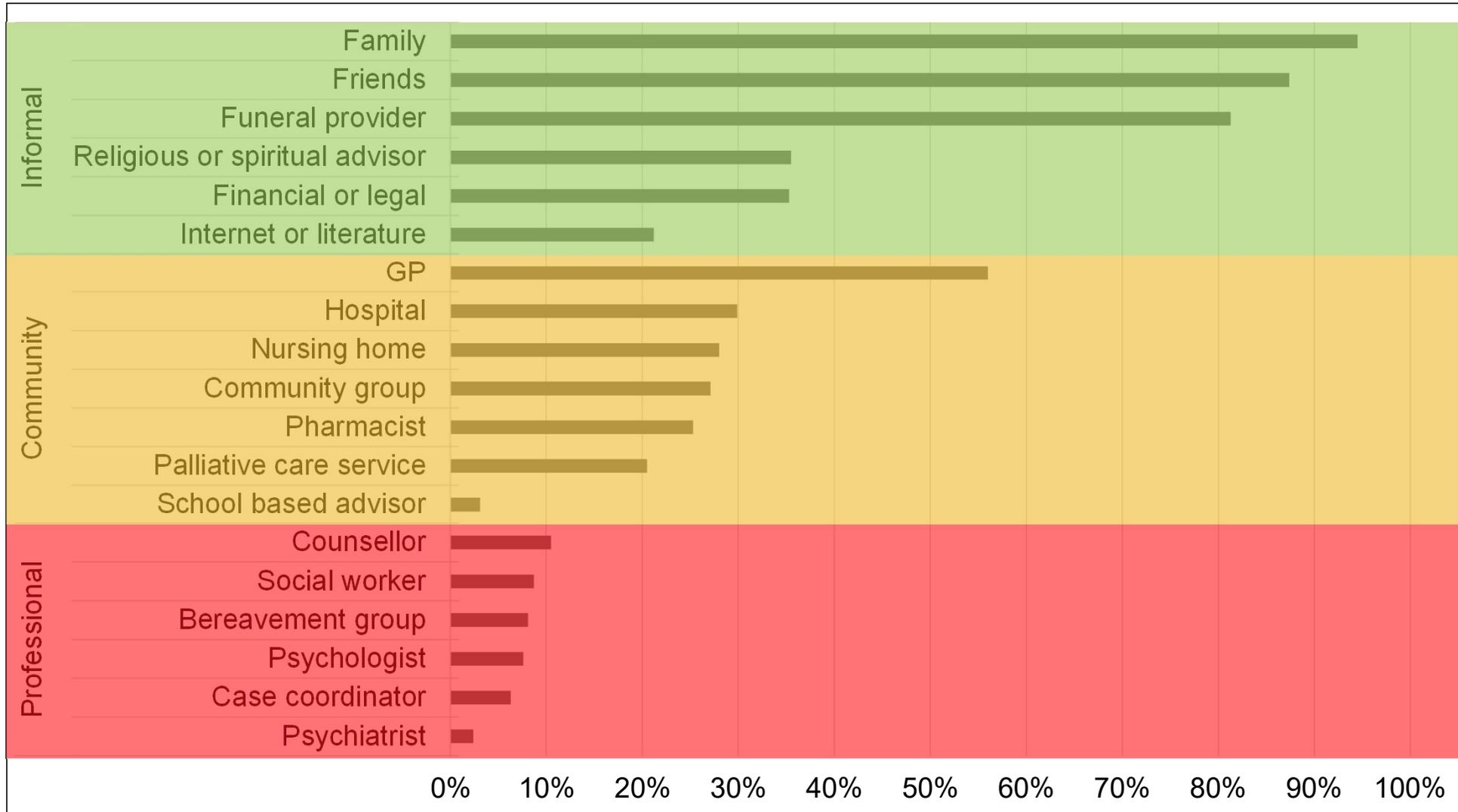
'GROWING AROUND GRIEF'
(LOIS TONKIN, 1996)

WHATSYOURGRIEF.COM

PEOPLE THINK THAT GRIEF

SLOWLY GETS SMALLER

WITH

TIME

IN REALITY, GRIEF STAYS

THE SAME SIZE

BUT SLOWLY LIFE BEGINS

TO GROW BIGGER AROUND IT

Bereavement Support Funnel

Low risk
58.4% (60%)

majority of individuals deal with grief with support of family and friends

Moderate risk
35.2% (30%)

in need of some additional support, e.g. peer support group/volunteer led group

High risk 6.4% (10%)
at risk of complex grief issues. May need referral to mental health professionals

Sources of Bereavement Support Accessed

I think I gave the counsellors a crack at me because I thought I can't be stoic all the time and maybe I could see things differently. But to me a counsellor is supposed to give you tools and ideas on how to deal with things. I never got that in the three people I saw.

Improving social models of bereavement support

- Grief festivals e.g. Day of the Dead, Good Grief Festival, Good Life, Absent Friends Festival, Dying to Know Day……
- Bereavement cafes, Public Living Rooms in hospitals supported by Camerados……

- Information about community sources of bereavement support should be readily available to the community and professionals (GPs, Chemists….)
- Grief and loss policies developed for workplaces, educational institutions, sporting clubs, local government….
  ➢ Compassionate City Charter

Example of Peer Support- A Good Fit

*Yeah this woman,…...she lost her mother this year so we started talking as you do when you lose your mother and so she said to me "would you like to join our group of **Mothers without Mothers?...***
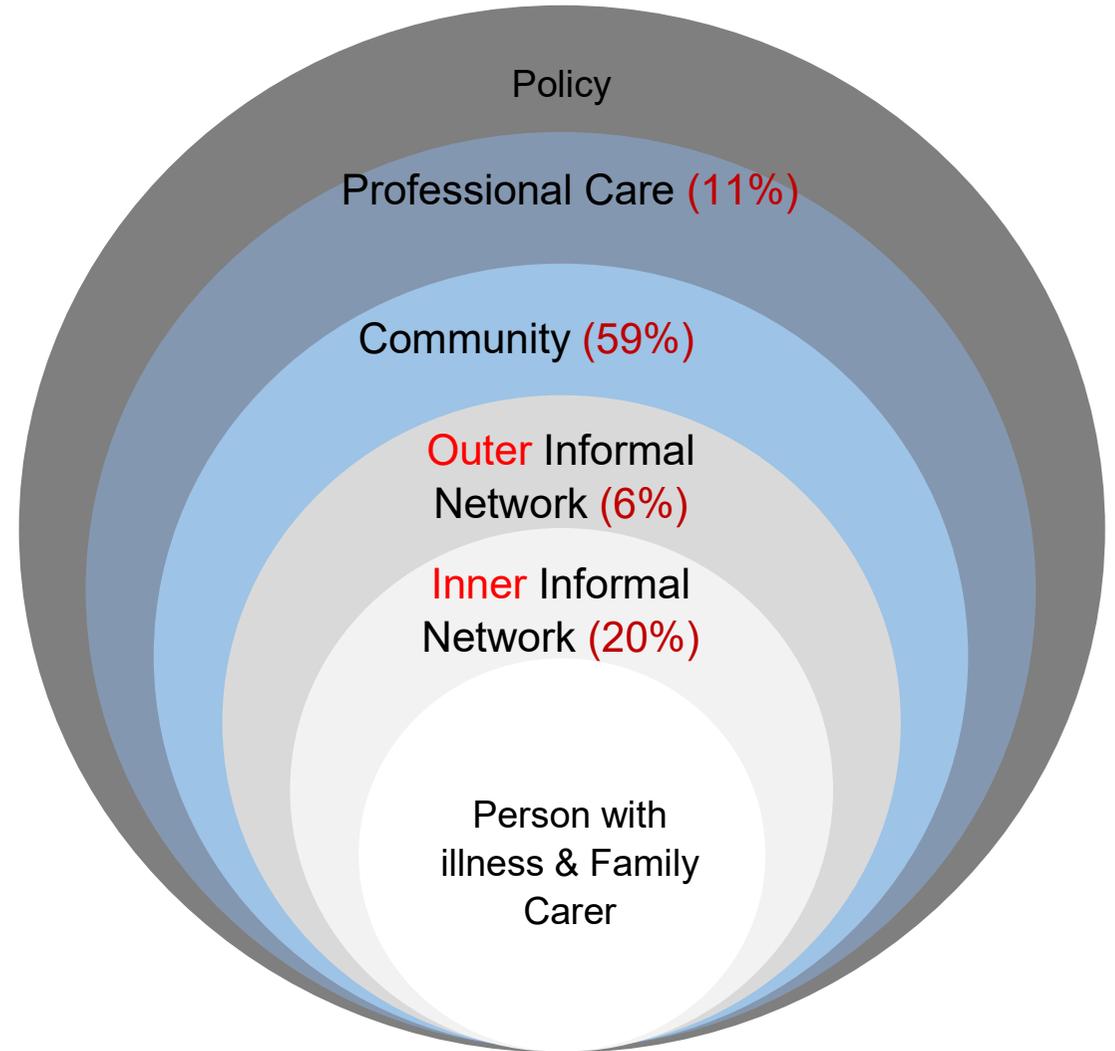
So we go out for lunch on the day of our mother's birthday. Not the day of our mother's passing ...then I got to talk all about my mother and then they told me about their mother.
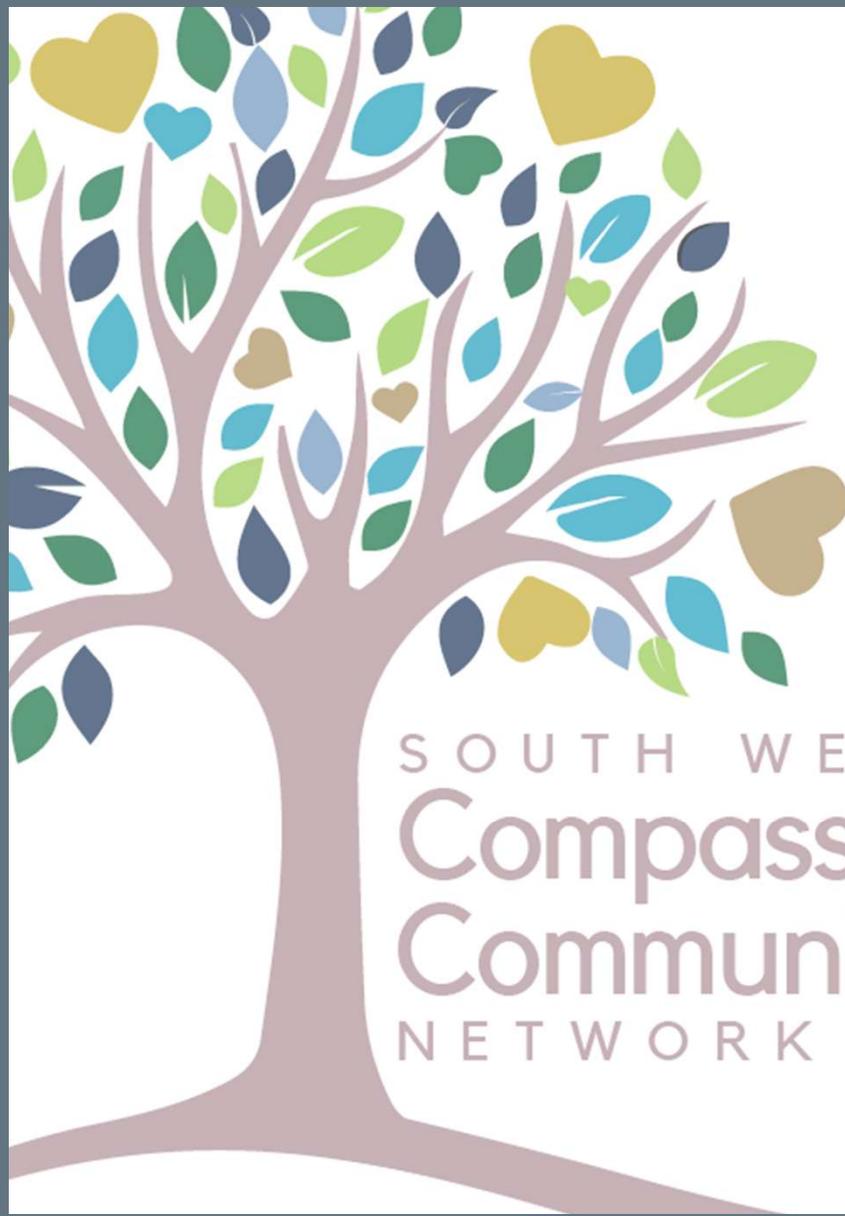
Well this is a fantastic group of friends because we talk about our mother and it's ok to sit there for the whole lunch and talk about your dead mum and no one's going to "oh God can we get off the dead mum subject you know?"

Network Enhancement

Findings from the Compassionate Connectors Program

Naturally Occurring Networks (26% vs Facilitated Networks (59%)

Policy

Professional Care (11%)

Community (59%)

Outer Informal Network (6%)

Inner Informal Network (20%)

Person with illness & Family Carer

Every person, every family and every community knows what to do when someone is caring, dying or grieving.

Palliative care services should invest their efforts principally in developing community capacity for bereavement care rather than seeking to deliver specialized bereavement services (Rumbold & Aoun, 2014; 2015).

Cemeteries, crematoria and the funeral industry have resolved to shape a more contemporary industry and to become more intentional about their social contributions as educators, facilitators and consultants on meaningful, effective and therapeutic rituals for bereaved Australians. (Aoun et al, 2018; Lowe et al 2019, Rumbold et al, 2020).

Not for Profit Organisations can connect both professional and community resources in a way that clinicians alone, or community actors, cannot. (Aoun et al, 2021)- A significant role in person centred care.

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Why and how the work of Motor Neurone Disease Associations matters before and during bereavement: a consumer perspective

Samar M. Aoun iD, Paul A. Cafarella iD, Anne Hogden iD,
Geoff Thomas, Leanne Jiang iD and Robert Edis

Abstract

Background: Studies on the experiences of consumers with Motor Neurone Disease Associations at end of life and bereavement are lacking, and their role and capability within the broader sectors of health and disability are unknown.

Objectives: To ascertain the experiences and views of bereaved motor neurone disease caregivers with Motor Neurone Disease Associations about service gaps and needed improvements before and during bereavement and to propose a model of care that fits with consumer preferences and where Motor Neurone Disease Associations are effective enablers of care.

Methods: A national bereavement survey was facilitated in 2019 by all Motor Neurone Disease

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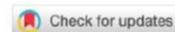## Is there a role for the funeral service provider in bereavement support within the context of compassionate communities?

Samar M. Aoun, Jennifer Lowe, Kim M. Christian & Bruce Rumbold

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Check for updates

Article

Memorialization Practices Are Changing: An Industry Perspective on Improving Service Outcomes for the Bereaved

Jennifer Lowe[1], Bruce Rumbold[1], and Samar M. Aoun[1,2]

Article

The Evolving Landscape: Funerals, Cemeteries, Memorialization, and Bereavement Support

Bruce Rumbold[1], Jennifer Lowe[1] and Samar M. Aoun[1,2]

## Need to build pandemic grief resilient supportive networks

Many of the projections of increased complicated grief because of the pandemic:

- may **over-estimate** the importance of professional support (who is going to fund them?)

- and correspondingly **under-estimate** what family, friends and neighbours can provide

Even during the COVID-19 pandemic, public health strategies like Compassionate Communities retained their value and developed new approaches when face-to-face encounters were minimal and physical means for support were limited.

Somewhat paradoxically, the loss of opportunities to say farewell itself became a different source of **social connection** as people posted their accounts on social media and supported each other in sharing their wishes about what might have been.
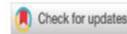
Memorialisation during COVID-19: implications for the bereaved, service providers and policy makers

Jennifer Lowe ID, Bruce Rumbold and Samar M. Aoun

Abstract

Background: The aim of this rapid perspective review is to capture key changes to memorialisation practices resulting from social distancing rules implemented due to the ongoing COVID-19 pandemic.

Method: As published peer-reviewed research pertaining to memorialisation practices during the COVID-19 pandemic is lacking, this rapid review includes academic literature from the pre-COVID-19 period and international media reports during the pandemic.

Findings: Changes to memorialisation practices were under way before COVID-19, as consumer preferences shifted towards secularisation and personalisation of ritual and ceremony. However, several key changes to memorialisation practices connected with body preparation, funerals, cremation, burials and rituals have taken place as a consequence of the

Community opportunities arising from the pandemic

With COVID-19 sharp focus on death, dying, loss and grief:

- Improve **death literacy** - enabling more preparedness and ability to die at home if it is in line with wishes

- Improve **grief literacy** – supporting community understanding, recognition of grief and help-seeking to support the bereaved

Be willing to stand beside the gaping hole
that has opened in your friend's life,
without flinching or turning away.
Your steadiness of presence is
the absolute best thing you can give.

(Megan Devine: Refuge in Grief)

DO THIS NOT THAT

HOW TO HELP A GRIEVING FRIEND

While there is no one perfect way to respond or to support someone you care about, here are some good ground rules.

DON'T	DO INSTEAD TRY
DON'T COMPARE GRIEFS No one else has experienced their grief.	**ASK QUESTIONS** You can connect by showing curiosity about their experience.
DON'T FACT CHECK OR CORRECT Especially in early grief, facts and timelines can be confused.	**RESPECT THEIR EXPERIENCE** It's not important who's "more" correct.
DON'T MINIMIZE Even if you might think their grief is out of proportion to the situation.	**REMEMBER THIS GRIEF IS THEIRS** Grief belongs to the griever. Your opinions are irrelevant.
DON'T GIVE COMPLIMENTS When someone is in pain, they don't need to be reminded how wonderful they are.	**TRUST YOUR FRIEND** All the things you love about the person will help them through this experience.
DON'T BE A CHEERLEADER. When things are dark, it's OK to be dark.	**MIRROR THEIR REALITY** When they say, "This sucks," say, "Yes, it does."
DON'T TALK ABOUT "LATER" Right now, in this present moment, that future is irrelevant.	**STAY IN THE PRESENT MOMENT** Or if the person is talking about the past, join them there.
DON'T EVANGELIZE When something has worked for you, it's tempting to prescribe it for others.	**TRUST THEIR SELF-CARE** They know themselves best. What works for you may not be for them.

Time to give more attention to those supporting 90% of the bereaved
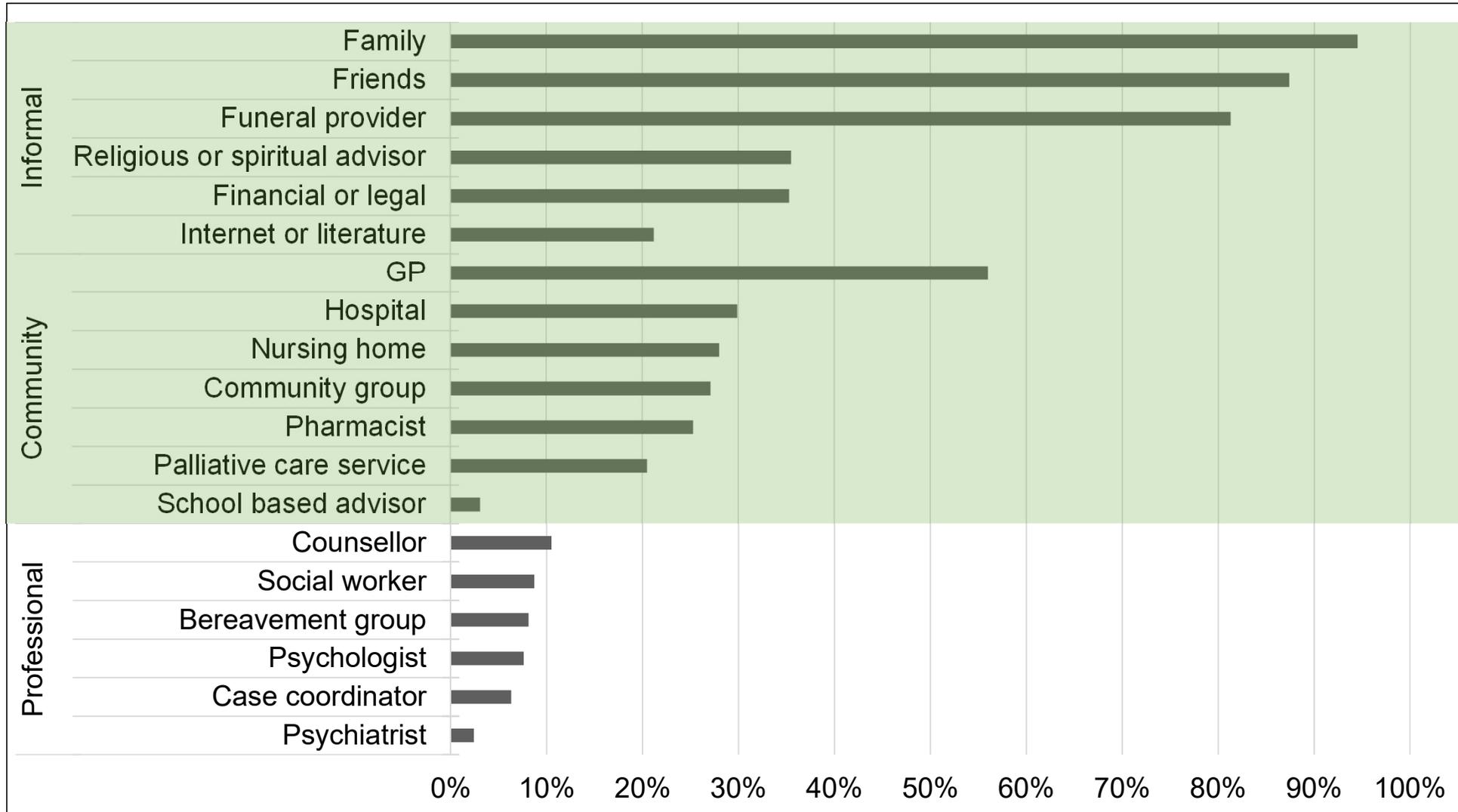
Optimal model of care

Professional services should be aware of, encourage, facilitate and enrich community networks, collaborating with them in mutually understood ways.

This has two advantages:

- The first is that supportive networks are open to everyone while professional bereavement support is available only to a small percentage of those bereaved.

- Secondly, stretched professional services can reserve their care for those most in need.

Informal bereavement support is the "bedrock" with formal services supplementing this support