Bereavement risk assessment in palliative care: The development of a brief grief measure to screen for carers who may be at risk of complex grief.

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"Developing a Bereavement Risk Assessment Model for Palliative Care in WA: An Action Research Study."

Supervisory team:

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Why? Gap between policy and practice

Ad hoc support to bereaved family carers

Staff intuit carer emotional states

Observational checklists

Blanket bereavement support to all bereaved

Breen, Aoun, O'Connor, & Rumbold, (2014)

Standards & policy based on research

- WHO (2015)
- National Standards Assessment Program

  Palliative Care Australia (2005)
- Victorian Bereavement Standards & guidelines

Hall, Hudson & Boughey (2012)

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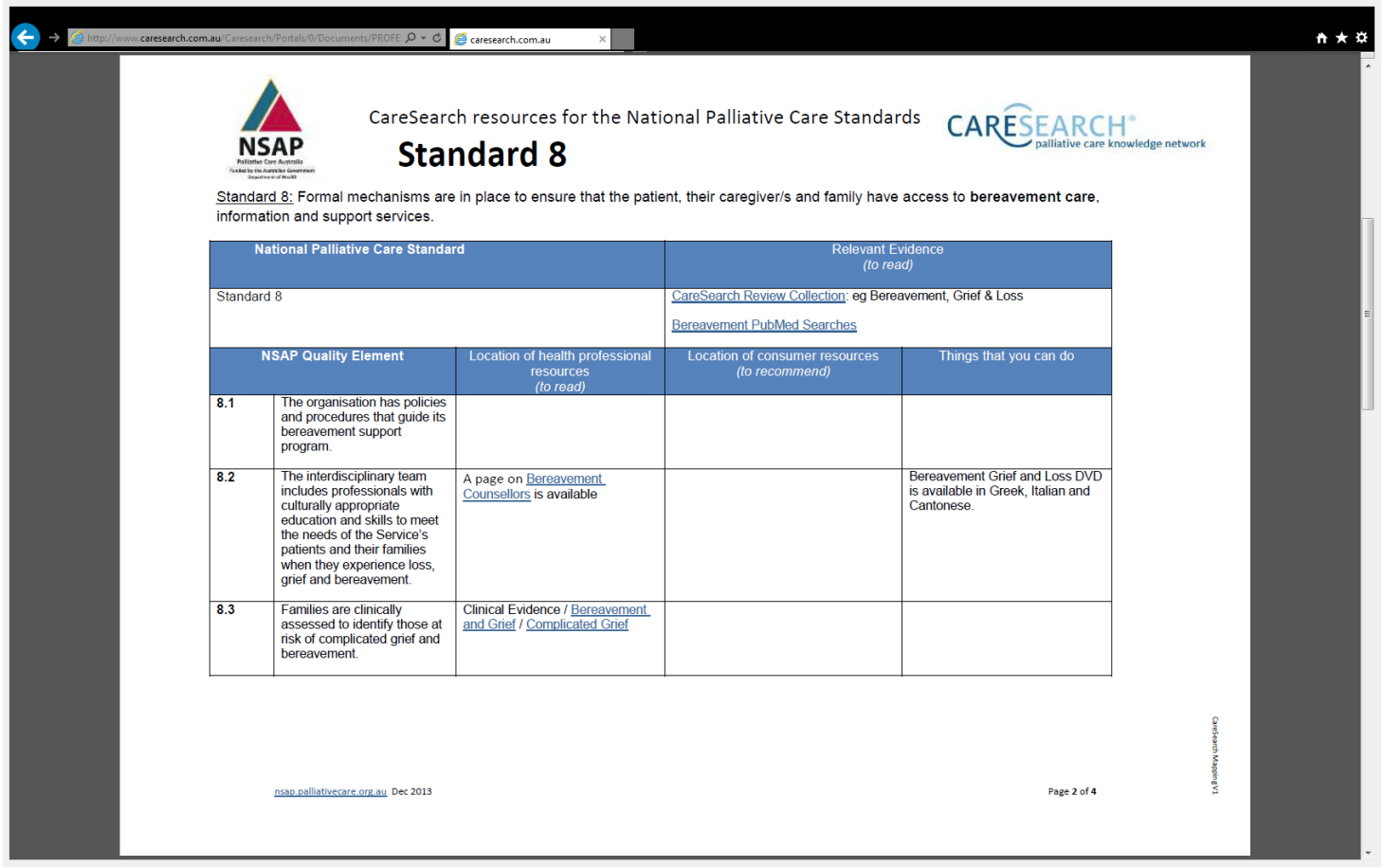
NSAP Standard 8



CareSearch resources for the National Palliative Care Standards

Standard 8

Standard 8: Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to **bereavement care**, information and support services.

National Palliative Care Standard			Relevant Evidence *(to read)*	
Standard 8			CareSearch Review Collection: eg Bereavement, Grief & Loss Bereavement PubMed Searches	
NSAP Quality Element		Location of health professional resources *(to read)*	Location of consumer resources *(to recommend)*	Things that you can do
8.1	The organisation has policies and procedures that guide its bereavement support program.			
8.2	The interdisciplinary team includes professionals with culturally appropriate education and skills to meet the needs of the Service's patients and their families when they experience loss, grief and bereavement.	A page on Bereavement Counsellors is available		Bereavement Grief and Loss DVD is available in Greek, Italian and Cantonese.
8.3	Families are clinically assessed to identify those at risk of complicated grief and bereavement.	Clinical Evidence / Bereavement and Grief / Complicated Grief		

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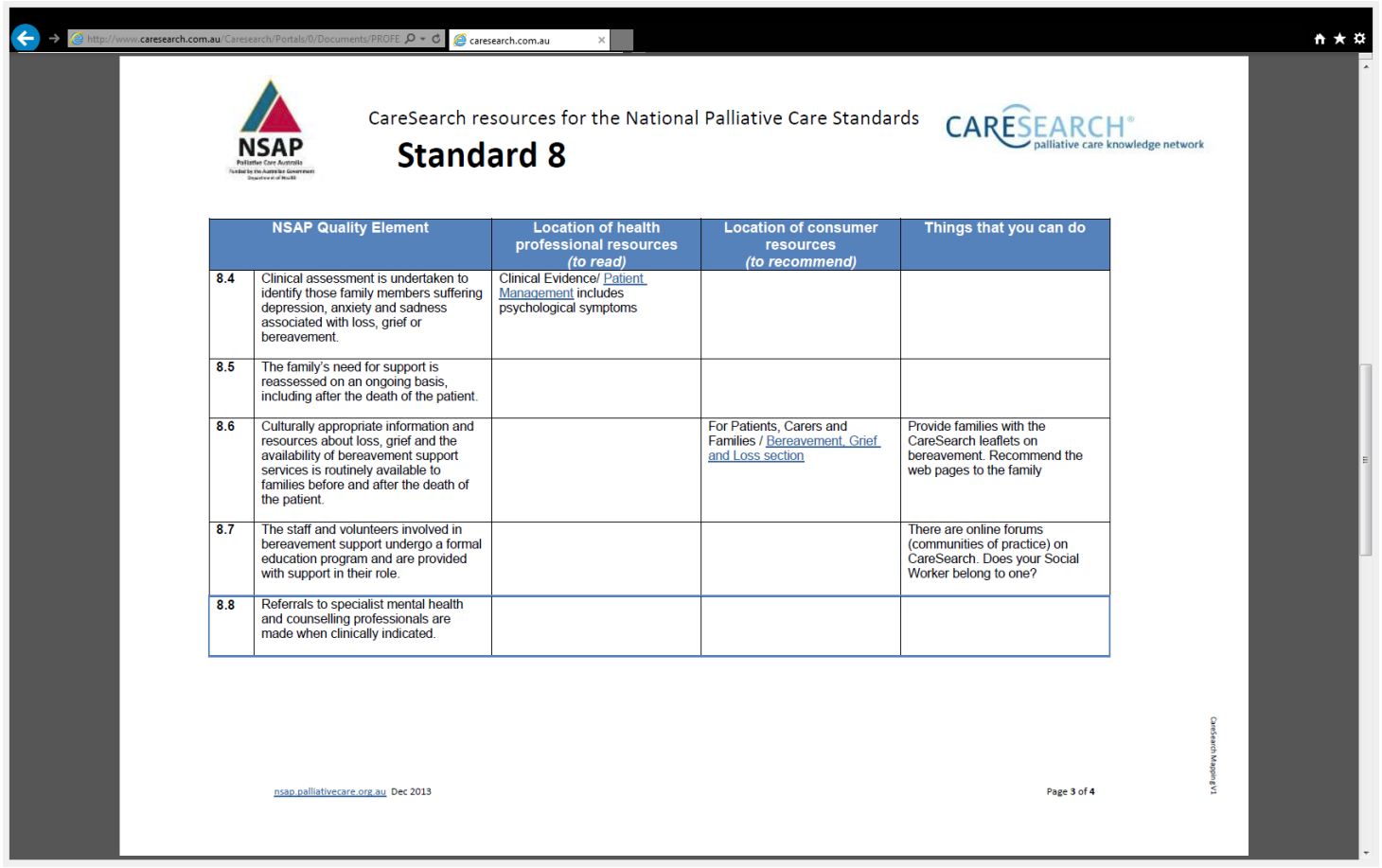
NSAP Standard 8 Cont.



CareSearch resources for the National Palliative Care Standards

Standard 8

	NSAP Quality Element	Location of health professional resources *(to read)*	Location of consumer resources *(to recommend)*	Things that you can do
8.4	Clinical assessment is undertaken to identify those family members suffering depression, anxiety and sadness associated with loss, grief or bereavement.	Clinical Evidence/ Patient Management includes psychological symptoms		
8.5	The family's need for support is reassessed on an ongoing basis, including after the death of the patient.			
8.6	Culturally appropriate information and resources about loss, grief and the availability of bereavement support services is routinely available to families before and after the death of the patient.		For Patients, Carers and Families / Bereavement, Grief and Loss section	Provide families with the CareSearch leaflets on bereavement. Recommend the web pages to the family
8.7	The staff and volunteers involved in bereavement support undergo a formal education program and are provided with support in their role.			There are online forums (communities of practice) on CareSearch. Does your Social Worker belong to one?
8.8	Referrals to specialist mental health and counselling professionals are made when clinically indicated.			

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CareSearch Map Sept V1

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Bereavement support standards for specialist palliative care services (Hall, Hudson, & Boughey, 2012)

- **Standard 4: Screening and assessment.**
- Pre-death: "A comprehensive bio-psychosocial, spiritual & bereavement risk assessment…as soon as possible after client is admitted to the PC service."
- "A structured risk assessment based on a conversational exploration of the risk factors…"
- The assessment "…requires structured documentation, review in team meetings…"
- "The … assessment process begins on intake…continues throughout the PC service's involvement…& beyond…" (p.12)

Bereavement support standards for specialist PC services Cont.

- At-death: “assessment of the level of trauma the family experienced as a result of the death…”
- Post-death: “At 12 weeks after death, a follow-up phone call to all primary carers is undertaken to determine if further assessment/support is required.”
- “At around 6 months following the death: to people identified as being at elevate risk of developing PGD/CG… using a validated tool (e.g.PG-13).”

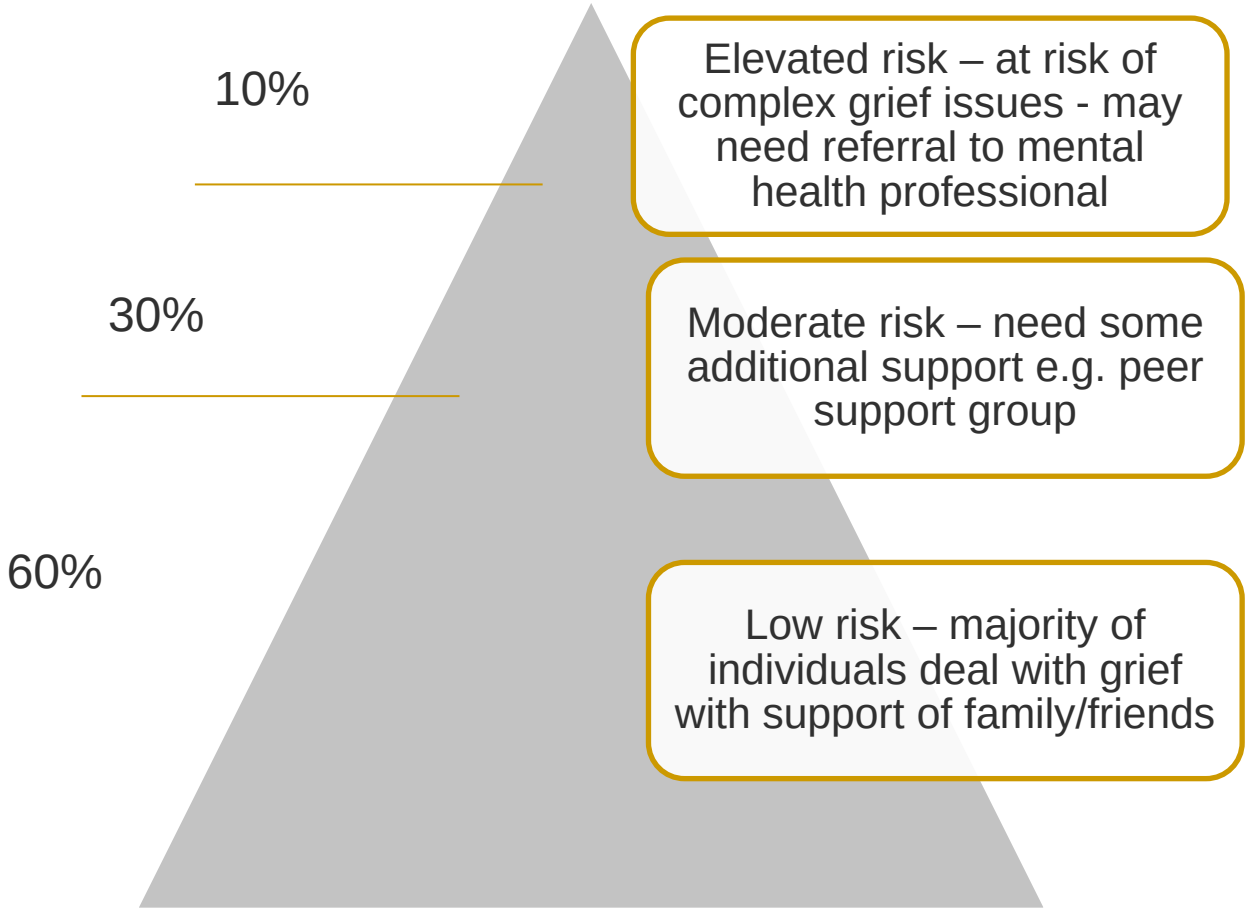
(Hall, Hudson, & Boughey, 2012, p.13)

Aim of this research: To develop a bereavement risk assessment model for PC

- Using **action research** methodology to work collaboratively with palliative care stakeholders (Frogatt & Hockley, 2011)
- Identify existing psychometrically sound grief measures to use in the risk assessment model.
- Congruent with policy and standards and feasible for use in palliative care.
- Using **public health model of bereavement support** as a framework to align bereavement needs with support.

Theory: The Public Health Model

(Aoun, Breen, O'Connor, Rumbold, & Nordstrom, 2012)



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Action cycles one and two

- Scoping review of literature to identify grief measures for use in model (Sealey, Breen, O'Connor, & Aoun, 2015).
- Reference Group of PC health professionals and bereaved former carer (n=9) to develop assessment model.

  - existing measures found unsuitable for use in PC.

  > need to make a new measure

    suitable for PC conditions,

    pre-death (carers in contact with services).

Action cycle three
Development of measure

- Step 1: Review of literature for risk factors and predictors of prolonged and complicated grief.
- Step 2: Construct a pool of items for development of measure.
- Step 3: Advisory panel of grief service providers and bereaved former caregivers (n=8) to guide and inform the measure's development.
- Step 4: Revision of items by academic team.
- Step 5: Pilot of measure at 3 PC services

Step 1- Literature review

- **Aim** – to identify risk factors and predictors of prolonged/complicated grief.
- Risk factor domains (Lobb, Kristjanson, Aoun,Monterosso, Halkett & Davies, 2010)
  - relational and interpersonal factors
  - cognitive risk factors
  - dispositional, resilience and coping factors
  - spiritual/religious, meaning & worldview factors
  - mental health factors
  - environmental, situational, instrumental factors

Step 3 - Advisory Panel

Advisory Panel of bereavement service providers & bereaved former carers (n = 8)

Aim – to develop a new brief grief measure

Method – one on one interviews (iterative process across 4 drafts of the measure)

Participants – 3 Psychologists, 2 Counsellors, 1 Social Worker and 2 bereaved former caregivers (Ages 49 -64 years, M 56.1)

Years of grief and loss counselling experience 4 to 15 years (Median 6 years)

Step 5 – Pilot of measure at 3 PC services

- Consultative team in tertiary teaching hospital,

  Community service (government operated),

  Inpatient palliative care unit (NGO).

Community service closed (recruited 2 caregiver participants).

Inpatient unit did not engage in the assessment process (3 participants recruited).

Consultative team – champion for the measure (14 participants recruited).

Total measures with feedback returned = 19.

Caregiver demographics

N = 19 Ages 30 – 86 (M56.5)
Adult children caregivers 8; Spousal caregivers 4; Parents 3, Sister 1; Granddaughter 1.

	Community	Inpatient	Consultative
Female	2	3	9
Male	0	0	5
Length of PC service contact	6 wks – 2yrs	5 days-8 wks	2 days - 6 wks
Av length of stay this admission	?	4.5 days	2.5days

Time taken to complete measure

Between 5 and 30 minutes,

- average and median = 10 minutes.

English as first language 18 (no formal education 1)

No of Participants	Time taken to complete measure
7	5 minutes
1	7 minutes
1	8 minutes
5	10 minutes
4	15 minutes
1	30 minutes

Action cycle four – Evaluation
Inpatient unit

- “what we use as a gold standard at the moment is really knowing the patients’ families…and us being involved with them as a team, and us collaborating together and identifying…we are all finding the same thing [where] there is an issue.” (physician)
- “Q 16 (I had thoughts of ending my own life) well don’t ask the question unless you’ve got …a procedure or something in place.” (clinical nurse manager)
- “Q9 (I can’t stop thinking about….impending death) well that’s for a busy nurse…you are going to need an hour and a half or two to sort that out.” (clinical nurse manager)

Action cycle four -Evaluation Consultative team

- “with some of our patients they’ve moved very quickly from acute injury to bereavement in a very quick process…it takes them time to catch up with that and they don’t cope very well with that change…we’ve had to be more selective because we don’t want to add to the trauma.”
- “because they’ve [carers] actually not got to the point where they are thinking the patient’s actually going to die.”
- “I’m always very aware that by filling in this form we seem to be taking away the family’s time from the patient.”
- “As we move towards, talking more about advanced care planning…this could be part of that thinking process.”

The measure *may* have promise, but before validation should commence -

- Need for PC community dialogue.
- Staff need education on grief and bereavement, and having appropriate conversations with caregivers, so a variety of assessment is available across service types in the system.
- Triage protocol with networks and pathways to other community bereavement service providers.
- Need for support groups or volunteer led services for the sub-threshold moderate risk category.

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Thank you for your attention

Are there any questions or comments?

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