Feedback on the draft Clinical Guidance for Responding to Suffering in Adults with Cancer

General comments

Australian College of Nursing (ACN) presents the following general comments on the draft Clinical Guidance for Responding to Suffering in Adults with Cancer (the Clinical Guidance).

1) ACN notes that there is relatively little discussion of physical suffering in the Clinical Guidance. Physical conditions such as serious physical debilitation and severe physical discomfort due to a wide range of reasons cause people to suffer independently from any mental or psychosocial response to their physical experience. Physical suffering is of great interest to nurses because the nursing profession is one of the main custodians of expertise of how to alleviate physical suffering and restore physical comfort. ACN acknowledges that the physical elements of suffering are touched on to some extent in the Clinical Guidance. However, ACN believes that clinicians would benefit from a more in-depth treatment of the many ways physical suffering can be experienced by people with cancer. Alternatively, the ‘Background’ section could note that physical suffering is not the focus of the Clinical Guidance and direct readers to other sources of information.

2) While the working group included a wide range of relevant professional and consumer representatives, ACN notes that no male consumer representative was included. Men with cancer may experience suffering differently from women, and as such it would be useful to encourage male consumers to provide feedback on the Clinical Guidance.

3) The Clinical Guidance would be particularly useful if Cancer Australia could make available on its website some of the assessment and intervention tools reviewed in the document where such publication does not contravene copyright. This would enable clinicians to quickly review the available tools, select the most appropriate tool and access it within minutes.

4) It would be useful for ‘WG consensus’ to appear in the tables of the Practice Points throughout the document, to reiterate that Practice Points which are not referenced were produced by working group consensus.

5) A number of ACN members who reviewed the draft Clinical Guidance suggested that the guidance could give greater prominence to the roles of interpreters and multicultural liaison officers.

6) The document should reflect the need for a much greater emphasis on understanding suffering from different cultural perspectives.

Comments on specific aspects of the Clinical Guidance

ACN presents the following comments on specific sections of the Clinical Guidance:

Referral flowchart

The following comments refer to Figure 1: Referral flowchart for responding to suffering in cancer patients on page 6.

- Cancer and Palliative Care Nurse Specialists often co-ordinate the care of people with cancer, including the...
services of psychologists, dieticians, physiotherapists, etc. As a result, ACN believes it would be appropriate for ‘Cancer and/or Palliative Care Nurse Specialist’ to appear at the top of both lists in the “Promptly refer to specialised service...” box.

- Mental Health Liaison Nurses should also be listed in the “Promptly refer to specialised service...” box.
- In the “Promptly refer to specialised...” box, “interpreter” could be included.
- The wording “Monitor suffering and psychological concerns at regular intervals” does not provide clinicians with guidance on the changes in a patient’s condition (physical, mental or social) that should trigger re-assessment.
- “Hopelessness” could be included in the “Factors indicative of high risk” box.
- No definition of “intense distress” is provided. One ACN member who reviewed the Clinical Guidance suggested that the National Comprehensive Cancer Network’s (NCCN) Distress Thermometer may be a useful tool for gauging distress. The Distress Thermometer is available on the NCCN’s website: http://www.nccn.org/patients/resources/life_with_cancer/distress.aspx

Summary of evidence

1. The importance of responding to suffering

Benefits for patients and families, p. 9

- Some of the benefits listed in this paragraph are not direct benefits for patients and families. Rather, they are benefits for the health service or the wider health system. For example, reducing the need for service provision, reducing the costs of hospital stays and increasing the efficiency of resource utilization are not primarily benefits for patients or families. These benefits could be included in a separate paragraph titled ‘Benefits for health services and the health system’ (or similar).

2. Identifying suffering

Articulating suffering, p.12-13

- The list of indicators of suffering could include “desire to die” statements.
- This section could remind clinicians that the ways in which people articulate suffering may vary according to their cultural and linguistic background, and that utilising appropriate interpreter services may assist people to express their suffering. Further, health care professionals should ensure that they have a good understanding of the approach other cultures take to dying and suffering so they can respond appropriately and with understanding.

3. Responding to suffering

Timing of assessment, p. 17

- This section could note that a person’s suffering should be reassessed when life or family circumstances change. Examples of changes in life or family circumstances may include when a person stops working or when a relationship breaks down or a relative dies.

Further reading, p. 27

- ACN suggests the following reference as useful further reading on communicating with people with cancer: Kissane, D. W., Bultz, B. B, Butow, P. M. and Finlay, I. G. 2011 Handbook of Communication in Oncology and Palliative Care (Oxford University Press, UK).

4. Care coordination, referral and interventions

Referral options, p. 30

- Referral to a multicultural or Aboriginal liaison officer could be discussed further in this section
Areas of further research

Additional areas for further research could include:

- The relationship between depression and suffering.
- Identifying and responding to unrealistic expectations and denial.
- The meaning of requests for physician-assisted suicide or euthanasia and best-practice responses to these requests from clinicians.
- Barriers and enablers of effective communication with people experiencing suffering.
- The relationship between psychological resilience and suffering.

Glossary

Appendix 1 – Measures of suffering and its various analogues

*Measures of suffering, p. 44*

- The acronym for the Mini-Suffering State Examination is MSSE, not MMSE.
- It would be useful for Appendix 1 to summarise measures of suffering in a table so that clinicians can easily gain an overview of the various measures. The table columns could include:
  - The name and acronym of the tool
  - What the tool measures (suffering, distress, quality of life, etc.)
  - Whether the tool has been validated in people with cancer
  - Advantages and disadvantages of the tool.

Appendix 2 – Other interventions

*Other interventions, p. 73:*

- Other cancer centres which provide alternative interventions include:
  - The Olivia Newton-John Cancer and Wellness Centre, which offers therapies including music therapy, oncology massage, mindfulness meditation and acupuncture.
  - The Westmead Breast Cancer, which offers yoga.