O3_A2_A_Scientific Evidence

TERMINAL PHASE – MANAGEMENT

Q1	**Is screening for psychological distress in end of life patients and their families efficacious?**
Patients	Patients elderly and/or frail and/or end of life indications in a palliative facility Frail, aged, end of life adults Children in a palliative facility
Intervention	Screening for psychological distress
Comparator	None
Outcome	Psychological outcomes Quality of life
Methodology	Systematic reviews Randomized controlled trials

Indications:
End-of-life patients

Discussions:

Psychological distress is defined as a range of psychiatric disorders that can occur in terminally ill patients and their families, measured using various unidimensional or multidimensional scales (symptom report measures, psychometric screening, assessments of quality of life etc.) [add ref] or psychiatric interviews. As the psychological morbidity can be up to 20%, being higher in metastatic cancer patients, approximately 50% of these issues are undetected [add Parvez].

Distress in families in palliative care is currently conceptualised as a multi-dimensional construct but there appears to be little consensus as to how to capture and measure this construct [add ref Carolan]

Type of measurement	**Sensitivity**	**Specificity**
Single item interviews	54%-100%	67%-74%
VAS	72%	50%
Verbal Mood Rating Scale	80%	43%
Edinburgh depression scale	74%	71%
BEDS	72%	83%
Hospital anxiety and depression scale	74%	71%
General health quastionnaire	Na	Na
Mood evaluation questionnaire	NA	NA
Beck depression inventory short form	79%	75%

[3]

Conclusions:

Currently there is no study comparing psychiatric interview and other diagnostic tools for psychological distress. The unidimensional and multidimensional tools seem to provide a variable sensitivity and specificity for diagnosis.

The evidence base regarding the efficacy of distress

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Q2	**What are the psychological variables related to the end of life? How the psychological variables impact on management of patients?**
Patients	Patients elderly and/or frail and/or end of life indications in a palliative facility Frail, aged, end of life adults Children in a palliative facility
Intervention	behavioral psychological symptom disorders
Comparator	none
Outcome	Efficacy Tolerability Quality of life.
Methodology	Systematic reviews Randomized controlled trials cross-sectional survey

Studies
Systematic review
Cross-sectional survey
Review

Patients
Patients in palliative care
Patients in end of life

Indications
Repeated exposure to the patient’s symptoms may contribute to CG habituation of the psychological distress that they might have initially experienced. Evaluating CGs of patients with a variety of chronic/advanced illnesses who have not yet engaged with formal end-of-life supports would be useful to compare their subjective experience. Another study limitation was the low endorsement rate of CG SI, which resulted in subsequent analyses being limited due to power issues. Low endorsement of CG SI may be attributable in part to the fact that SI was measured in the present study by a single item (i.e., item 9 on the PHQ–9). Although item 9 directly queries the presence of SI, providing face validity, its singularity restricts response variability and may not accurately capture the phenomenology of CG suicidality. For instance, SI is commonly experienced as passive, with fleeting suicidal thoughts (e.g., “What would it be like if I weren’t here?”), and such rather inconspicuous thoughts may not be inferred as SI when an individual responds to PHQ– 9 item 9. Employment of broader suicidality measures that include suicide cognitions (i.e., ideation) and behaviors (Beck et al., 1974), as well as exploration of affective factors known to influence suicidality (e.g., Beck Hopelessness Scale; Wilkinson & Lynn, 2005), would better inform future studies aimed at

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understanding the nature of SI and behavior in this population. CGs' responses to open-ended questions would likely also shed light on this topic, offering support for future research employing qualitative or mixed methods. Furthermore, social desirability and/or concerns about what would happen if SI were endorsed might have prevented CGs who had experienced SI from accurately reporting their experiences, introducing the possibility that greater than 5.3% of our sample had experienced SI. In addition, CG psychiatric history was not assessed, which presents as a limitation to the current study's validity. It is possible that CGs with current or past depressive episodes have a skewed perception of their patient's symptom presentation, which reflects the CG's depressive perspective rather than the patient's symptomatology (1).

The overall contribution of psychosocial variables to the application of interventional therapies for the diagnosis and treatment of pain can be overlooked and ignored, but not denied (2).

Compared with the volume of research examining pain, fatigue, and other physical symptoms during terminal illness, much less attention has been paid to psychological and spiritual issues—a pattern also observed by others Only a few studies address psychological distress and related issues during the last weeks or months of life. In a significant number of these, investigators relied on the reports of surrogates rather than patients (3).

Family caregivers provide extensive help to dying individuals (e.g., Visser et al.,64 Wolff et al.65) in a number of areas, including, for example: domestic chores;20 household tasks and instrumental activities of daily living;7,66,67 personal care and activities of daily living;20,67–69 and medications and symptom management. 7,67 The majority of studies identify caregiver support needs. Some use self-report scales that directly measure various support needs (e.g., Osse et al.70) ormore particular needs (e.g., Kristjanson et al.71 measured needs for night respite). Most often, however, need is inferred from (and conceptually equated with) various subjective and objective indicators of caregiving difficulty, burden, depression, mental and physical illhealth, and, to a lesser extent, barriers to service access, dissatisfaction with formal services, and a lack of informal support. In other words, authors often purport to assess and examine caregiver needs, yet operationalize the concept by relying on these other indicators. Further, not all studies clearly differentiate between patients' needs and family caregivers' needs, describing them as if they were similar. Lastly, the ways in which needs are described in such studies tends to imply that there are common needs for all caregivers, whereas Osse et al.70 for example, note that despite some commonalities, there was considerable diversity in caregivers' individual needs (6).

Various factors that can affect caregiver outcomes were identified in the studies we reviewed, including patient characteristics, disease type, patient health, function and distress, characteristics of caregiving situations (such as setting and intensity of care provided, although findings are mixed), caregiver coping and appraisals, and caregiver characteristics. Findings are not always consistent. As well as the problem of definition, this may be explained in part because different measures, outcomes and patient populations are used. It is also noteworthy that explanations for causal pathways are often lacking. For instance, explanations for age differences are not well explored and are complicated by relationship type (6).

Conclusions

Ignoring these psychosocial variables and their complex interaction does not constitute a solution. The thoughtful practitioner will be mindful of the role of psychosocial variables in so far as they are thought to be relevant in a particular case. Gaps in the research base include insufficient attention to psychological and spiritual issues, the prevalence of psychiatric disorder and the effectiveness of the treatment of such disorders among dying persons, provider and health system variables, social and cultural diversity, and the effects of comorbidity on trajectories of dying.

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Q3	**Can BHS (Beck Hopelessness scale) be used to identify palliative care patients with conception/suicidal behavior?**
Patients	Patients elderly and/or frail and/or end of life indications in a palliative facility Frail, aged, end of life adults
Intervention	beck hopelessness scale
Comparator	none
Outcome	Psychological outcomes
Methodology	Systematic reviews Randomized controlled trials

Studies:
Meta-analysis
Review

Indication:
Palliative care patients

Discussions:
Depression is a major cause of psychological disability, being linked to increased suicidal behaviour. A particular interest is regarding the medically ill, especially the palliative care patients.
Current data show that the Beck Hopelessness Scale is a tool used in predicting suicide and self-harm [add ref mcmillan]. In one meta-analysis suggests a sensitivity of the scale of 0.77 and a specificity of 0.41, adding as a limitation the lack of standard cut-off point to identify a group of patients that would most likely benefit from treatment.

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However, one study that applied the scale to terminally ill patients suggests that it may not accurately assess hopelessness and risk of self-harm at this particular group and an adapted scale may be more applicable. [add ref abbey]
Although the scale is considered a validated screening tool [add ref kocalevent], the study limitation is that it was mainly applied to general population.

Conclusions:

Although BHS can be considered a useful tool in screening for suicidal behaviour in the general psychiatric and non-psychiatric population, it may have some limitations when it comes to palliative care population where, a more adapted scale may be more applicable.
There is not sufficient data to recommend a general utilization of the scale in this particular subgroup of patients.

References

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