**Policy Brief**

**November 2017**

**Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients**

**Context to the study**

* Palliative ‘Phase of Illness’ is defined as either ‘stable’, ‘unstable’, ‘deteriorating’, ‘dying’, or ‘deceased’.
* Palliative Phase of Illness is a brief way to describe the acuteness of palliative care needs in advanced illness.
* We don’t know how Phase of Illness relates to symptoms and concerns.

**Summary of findings**

* This study shows that the different Phases of Illness are characterised by differences in function, pain, other physical problems, psycho-spiritual problems and family and carer support needs. Pain is worst in the unstable Phase, family and carer support needs are greatest in the deteriorating Phase and function is worst in the dying Phase.
* Phase of Illness is therefore helpful to understand casemix in palliative care.
* Palliative care teams should be trained in using Phase of Illness and be incentivized to record it routinely across all settings.

**Introduction**

‘Phase of Illness’ is used in advanced illness to describe the distinct stages of an individual’s illness (stable, unstable, deteriorating, dying, and deceased) according to the care needs of the individual, the family and the suitability of the current care plan to address these needs.1 It was originally derived from work on casemix classification within palliative care in Australia and is a major determinant of resource use.2

A recent study across 10 palliative care services in Australia reported fair inter-rater reliability and acceptability.1 But there remains little published evidence on the association of Phase of Illness with other validated measures of clinical needs. In order to address this knowledge-gap, this study aims to

* Describe the distribution of (a) function, (b) pain, (c) other physical problems, (d) psycho-spiritual problems and (e) family and carer support needs, by Phase of Illness;
* Examine, using multinomial logistic regression, associations between these five domains and Phase of Illness.

**Summary of Research**

A secondary analysis was undertaken of individual patient-level data collected as part of routine clinical care between March 2012 and December 2013 from patients attending three palliative care services within the South East of England. These data were collected as part of a pilot data collection following recommendations by the independent Palliative Care Funding Review in England.3,4

All adult patients attending the services over the time period of data collection were eligible for inclusion in this analysis. For

participant, any member of the specialist palliative care team with knowledge of the individual’s clinical status made an assessment of Phase of Illness, along with function (measured by the Australia-modified Karnofsky Performance Scale - AKPS), pain/other physical problems/psycho-spiritual problems/family and carer support needs (the Palliative Care Problem Severity Scale - PCPSS), at entry into the service and at each subsequent change in Phase of Illness.

**Research Findings**

This study, to our knowledge, is the first to examine the association between Phase of Illness and validated measures of palliative care need, including function, pain, other physical problems, psycho-spiritual problems and family and carer support needs.

AKPS and PCPSS items varied significantly by Phase of Illness. Mean function was highest in stable phase (65.9, 95% confidence interval = 63.4–68.3) and lowest in dying phase (16.6, 95% confidence interval = 15.3–17.8). Mean pain was highest in unstable phase (1.43, 95% confidence interval = 1.36–1.51).

Psycho-spiritual problems were not associated with Phase of Illness (*χ*2 = 2.940, *df* = 3, *p* = 0.401). Family and carer support needs were greater in deteriorating phase than unstable phase (odds ratio (deteriorating vs unstable) = 1.23, 95% confidence interval = 1.01–1.49).

The variance in Phase of Illness was not accounted for entirely by AKPS and the selected items on the PCPSS; however, demonstrating that Phase of Illness captures

more than the combination of these measures. These findings underpin the value of Phase of Illness in clinical practice as a measure of overall clinical need, and potentially as a determinant of resource use to meet those needs.

**Policy Recommendations**

Understanding the relationship between Phase of Illness and existing validated measures of need in palliative care is important and valuable. Phase of Illness already forms the basis of the casemix classification in operation in Australia as well as the newly developed casemix classification for specialist palliative care within England, which is currently undergoing evaluation.

1. **Use of routinely collected individual patient-level data**

A considerable strength of the study was the successful use of routinely collected individual patient-level data to answer the research question, an approach that is both economical and facilitates research on a large sample. The analysis of data from a large number of patients, with a range of diagnoses, in a variety of settings, serves furthermore to enhance the generalisability of the study’s findings.

1. **Use of the Palliative care Outcome Scale or Edmonton Symptom Assessment Scale**

Pain, other physical problems, psycho-spiritual problems and family and carer support needs were all measured using the PCPSS. This four 4-point subscales may be limited in scope or sensitivity to capture the full range of problems experienced by this population, which could account for some of the unexplained variation in Phase of Illness in the multivariate analysis. Other instruments, such as the Palliative care Outcome Scale or the Edmonton Symptom Assessment Scale, could be considered in the collection of patient-reported outcomes.

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