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Palliative care phase: inter-rater reliability and acceptability in a national study

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Abstract

Background: The concept of palliative care consisting of five distinct, clinically meaningful, phases (stable, unstable, deteriorating, terminal and bereavement) was developed in Australia about 20 years ago and is used routinely for communicating clinical status, care planning, quality improvement and funding.

Aim: To test the reliability and acceptability of revised definitions of Palliative Care Phase.

Design: Multi-centre cross-sectional study involving pairs of clinicians independently rating patients according to revised definitions of Palliative Care Phase.

Setting/participants: Clinicians from 10 Australian palliative care services, including 9 inpatient units and 1 mixed inpatient/community-based service.

Results: A total of 102 nursing and medical clinicians participated, undertaking 595 paired assessments of 410 patients, of which 90.7% occurred within 2 h. Clinicians rated 54.8% of patients in the stable phase, 15.8% in the unstable phase, 20.8% in the deteriorating phase and 8.7% in the terminal phase. Overall agreement between clinicians' rating of Palliative Care Phase was substantial ($\kappa = 0.67$; 95% confidence interval = 0.61-0.70). A moderate level of inter-rater reliability was apparent across all participating sites. The results indicated that Palliative Care Phase was an acceptable measure, with no significant difficulties assigning patients to a Palliative Care Phase and a good fit between assessment of phase and the definition of that phase. The most difficult phase to distinguish from other phases was the deteriorating phase.

Conclusion: Policy makers, funders and clinicians can be confident that Palliative Care Phase is a reliable and acceptable measure that can be used for care planning, quality improvement and funding purposes.

Keywords

care, palliative, phase, study, reliability, acceptability, national, inter, rater

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and a good fit between assessment of phase and the definition of that phase. The most difficult phase to distinguish from other phases was the deteriorating phase.

Conclusions

Policy makers, funders and clinicians can be confident that Palliative Care Phase is a reliable and acceptable measure that can be used for care planning, quality improvement and funding purposes.

Key words

Episode of care, needs assessment, palliative care, reproducibility of results, patient acuity

What is already known about this topic

- The concept of palliative care consisting of distinct, clinically meaningful, phases was developed in Australia about 20 years ago and is widely used for communication of clinical status, care planning, quality improvement and funding.
- Only one previous study regarding the inter-rater reliability of Palliative Care Phases has been conducted.

What this paper adds

- The study demonstrated a substantial level of inter-rater reliability when two clinicians assessed the same patient for Palliative Care Phase at approximately the same time.
- The results indicate that there were no significant difficulties assigning patients to one of the four phases and a good fit between assessment of phase and the definition of phase.
- The most difficult phase to distinguish from other phases was the deteriorating phase.

Implications for practice, theory or policy

- Palliative Care Phase is a reliable and acceptable measure which can be used with confidence to facilitate clinical communication, improve quality of care and fund services.

Introduction

The Palliative Care Outcomes Collaboration (PCOC) was established in 2005 to support continuous improvement in palliative care with a combination of routine clinical outcome measurement, periodic surveys and benchmarking.¹ Since then, PCOC has collected data on clinical outcomes from palliative care services across Australia using standardised clinical assessment tools. One of those tools, Palliative Care Phase (PC Phase),^{2,3} is the subject of this study.

In 1993, the Australian Association for Hospice and Palliative Care held a 2-day national workshop for palliative care clinicians which resulted in the development of a draft casemix classification for palliative care.³ The classification described five distinct, clinically meaningful, phases of palliative care – stable phase, acute phase, deteriorating phase, terminal phase and a post-death bereavement phase – based on four palliative care principles:

- In palliative care, the patient and carers are the unit of care.
- In palliative care, the focus is on the patient's needs, goals and priorities rather than the disease.
- Palliative care patients have 'episodes of care' that include acute changes in condition.
- Such 'episodes' must be applicable in community and inpatient settings, and reflect the resource implications of the care provided.⁴

An episode of care is a period of contact between a patient and a palliative care service occurring in one setting e.g. inpatient unit, patient's home. Given the unpredictable trajectory of many life limiting conditions, PC Phases do not necessarily represent a linear progression of disease; patients can move between phases in any direction. It was

proposed that the acute, stable and deteriorating phases could be determined by the presence or absence of three variables: problem-related variables, variables related to activities of daily living and variables related to the level of carer support. It was also proposed that in the terminal phase the level of carer support was likely to be the only variable 'to cause significant variation in a clinical and resource sense'.^{3,p2}

The classification system was tested in 1994,³ resulting in revisions to the initial definitions of the five phases to clarify the intention of the original concepts and make the definitions easier to use.² The inter-rater reliability of the revised definitions was tested two years later resulting in a level of agreement of 0.736 and an associated kappa statistic of 0.52.²

Further refinement led to replacement of the term 'acute' with 'unstable', resulting in the nomenclature that has been used to this day: stable, unstable, deteriorating, terminal, bereavement.² These definitions were used in the development of the Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) casemix classification, with PC Phase providing the foundation for developing classes for both inpatient and ambulatory palliative care.^{5,6}

Extensive consultation took place with palliative care providers in 2011 to revise the definitions of the PC Phases in response to clinician concerns that the existing definitions were not always clear. This resulted in the development of revised definitions based on how phases both start and end, whereas the previous definitions were based solely on how phases began. The revised definitions are now part of the PCOC education program and a toolkit including the revised definitions is available on the PCOC website. The revised definitions are included in Appendix 1.

These revised definitions prompted the need to test their reliability, which is the primary aim of this study. The secondary aim is to test the acceptability of the revised definitions, by seeking feedback on ease of use and the 'fit' between the PC Phase assigned to a patient and the definition of that phase.

Methods

The study involved a convenience sample of ten palliative care services in two states of Australia, of which nine were inpatient services and one a mixed inpatient/community-based service. Nine of the services had been collecting data on PC Phase for over five years. The services ranged from small rural services to large metropolitan services. Data collection took place from March to June 2013.

Study coordinators at each site invited clinicians to participate, provided instructions to participating clinicians and managed on-site data collection. Study coordinators maintained a list of participating clinicians and a Clinician ID, unique to each clinician, for the purposes of the study. Clinicians with little or no knowledge of the patients were excluded (e.g. returning from a period of extended leave). Participants were requested to provide a small amount of demographic information: job title, profession, length of clinical experience and any training in use of the tools.

The study involved two clinicians independently assessing each patient according to the revised definitions of each PC Phase, with a maximum of two hours between the two assessments used as a guide to those participating in the study. It was left to the discretion of each service as to how this was organised. Participants were requested not to discuss their assessments with each other. Data were collected on specified days, at least one week apart (to ensure that a range of different patients were assessed), with a data collection form used to collect data on:

- a) The assessment of the patient according to the PC Phase.
- b) How well the assessment ‘fitted’ the needs of the patient (on a 5-point scale from 0-4)
- c) The ease of assigning a PC Phase to the patient (on a 5-point scale from 0-4).

The scales for degree of ‘fit’ and ease of assignment, with minor modification, were based on scales used in a previous study to test the reliability of case types in sub-acute care.⁷ Four of the five PC Phases were tested in the study. The bereavement phase, which is used after the patient has died, was excluded.

Completed assessments were collected from the study site by the research team. Data were entered into an Access database and uploaded into SAS 9.2 and Excel for analysis. The medical record number for each patient was used to link the assessment data (collected as part of this study) with demographic data routinely collected and provided to PCOC every six months by the study sites.

At the conclusion of data collection, participating clinicians were invited to a meeting in their place of work to thank them for their participation and give them an opportunity to make additional comments regarding assessment of phase. The meetings were recorded by the taking of notes.

The study sample size was calculated to be 400 patient assessments in order to test the reliability of the PC Phase. This was based on an expected level of agreement (using the Kappa statistic) of 0.75, with a 95% confidence interval from 0.675 to 0.825. This calculation assumed (1) an expected agreement between raters of 0.825; (2) the probability of raters observing each of the four PC phases based on the most recent PCOC data at the time the study was conducted (0.39, 0.26, 0.28 and 0.07 for the stable, unstable, deteriorating and terminal phases respectively).

The Kappa statistic (k) was used to determine the significance of the level of agreement between clinicians. The kappa co-efficient of agreement is the ratio of the proportion of times that the clinicians agreed on the PC Phase (corrected for chance agreement) to the proportion of times that the clinicians could agree (corrected for chance agreement).

The Kappa coefficient is based on a measurement scale ranging from +1 (perfect agreement) to -1 (complete disagreement), with zero indicating a level of agreement that would be expected by chance. The interpretation of the results for the kappa coefficient is based on the work of Landis and Koch.⁸

The research was approved by the University of Wollongong/Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee (reference no. HE12/484). Consent by staff was implied by completing the data collection forms.

Results

Patient characteristics

The 595 matched assessments relate to 410 patients who were assessed during the study period. All assessments took place in inpatient units, except for eight assessments undertaken in the community. The one community-based service participating in the study found it difficult to identify situations where patients could be assessed in accordance with the study protocol (i.e. by two clinicians at approximately the same time).

PCOC was able to retrieve demographic data for 281(69%) patients by linking to information stored in PCOC's National Longitudinal database. Two sites would not allow medical record numbers to be recorded on the assessment forms, thus reducing the ability to link with data in the national database. As seen in Table 1, the study

sample was representative of Australian palliative care patients as reported by the Palliative Care Outcomes Collaboration in terms of age, gender, diagnosis and preferred language spoken at home.⁹

Table 1. Patient characteristics.

		Study		PCOC
		n	%	total (%)
Age Group (years)	< 25	0	0	0.4
	25-54	35	13	11.1
	55-64	36	13	15.8
	65-74	69	25	25.5
	75-84	71	26	27.4
	85+	66	24	19.8
	Total	277	100	100
Gender	Male	147	52	54
	Female	134	48	46
	Total	281	100	100
Diagnosis	Malignant	248	88	80.2
	Non-malignant	30	11	18.5
	Not reported	3	1	1.3
	Total	281	100	100
Preferred Language	English	248	89	85
	Other	30	11	15
	Total	278	100	100

Clinician demographics

Of the 102 participating clinicians, 77 (75%) provided information regarding their position title, profession, clinical experience and education in use of the tools. Of those who responded, 70 (91%) were nurses and 7 (9%) were doctors (registrars and specialists). Fifty-five nurses identified as a registered nurse. PCOC does not routinely collect data on the discipline of those completing patient assessments but the high proportion of nursing staff is consistent with the most recent profile of the Australian palliative care workforce. Based on full-time equivalents, the ratio of nursing staff to medical staff working in palliative care across Australia is approximately 9.5:1.¹⁰ Participants had extensive clinical experience, including considerable experience in palliative care, with 55% reporting more than 15 years in clinical practice overall and 23% reporting more than 15 years in palliative care. Similar numbers of clinicians had attended a PCOC education workshop as those who received on the job training (Table 2). Forty-two clinicians (55%) reported having received both formal and on-the-job training.

Table 2. Clinician demographics.

Experience	All clinical experience		Palliative care experience	
	n	%	n	%
Less than 5 years	19	25	33	43
5-9 years	9	12	19	25
10-14 years	6	8	6	8
15 years or more	42	55	18	23
Not reported	1	1	1	1
Total	77	100	77	100
Training in use of the PCOC tools				
	Education program		On-the-job training	
	n	%	n	%
Less than 3 months ago	9	12	14	18
3-12 months ago	20	26	23	30
More than 12 months ago	23	30	17	22
Time of training not reported	2	3	4	5
No training	22	29	16	21
Not reported	1	1	3	4
Total	77	100	77	100

Inter-rater reliability

There was a perfect match for 472 (79.3%) of the 595 patients and a mismatch in the ratings for 123 patients (Table 3). The most mismatches were for stable/unstable,

stable/deteriorating and unstable/deteriorating combinations, with these three types of mismatch accounting for 89% of all mismatches. The time interval between the two assessments was generally within the 2-hour time frame of the study protocol (Table 3) with 90.7% of paired assessments occurring within two hours of each other and 99.6% within four hours. The time between ratings did not have a statistically significant effect on rater agreement when investigated using a logistic regression model and a significance level of 0.05.

Table 3. Characteristics of ratings by two clinicians.

	Rating 1	Rating 2	n	%	Median time between ratings (minutes)
Matched ratings	Stable	Stable	283	47.6	53.5
	Unstable	Unstable	58	9.7	27.5
	Deteriorating	Deteriorating	86	14.5	30.0
	Terminal	Terminal	45	7.6	52.5
Mismatched ratings	Stable	Unstable	45	7.6	44.0
	Stable	Deteriorating	39	6.6	55.0
	Unstable	Deteriorating	26	4.4	60.0
	Deteriorating	Terminal	10	1.7	60.0
	Stable	Terminal	2	0.3	95.0
	Unstable	Terminal	1	0.2	120.0
Total			595	100	

The value of Kappa was 0.67 with a 95% confidence interval of 0.61 to 0.70. When analysed according to the 10 participating services, all services achieved at least a moderate level of agreement. The services that conducted the smallest and largest number of assessments achieved the best level of agreement, with the percentage of actual agreement ranging from 94% to 71% (Table 4).

Table 4. Rater agreement by service.

Service	No. of assessments	% actual agreement	Kappa	95% confidence interval	Strength of agreement ^a
1	17	94	0.91	(0.74, 1.00)	Almost perfect
2	100	93	0.89	(0.80, 0.97)	Almost perfect
3	26	85	0.73	(0.47, 0.98)	Substantial
4	71	80	0.6	(0.43, 0.78)	Moderate
5	63	79	0.6	(0.42, 0.78)	Moderate
6	53	77	0.5	(0.26, 0.73)	Moderate
7	60	77	0.66	(0.50, 0.82)	Substantial
8	66	73	0.6	(0.44, 0.76)	Moderate
9	76	71	0.59	(0.44, 0.74)	Moderate
10	63	71	0.52	(0.34, 0.69)	Moderate
Overall	595	79	0.67	(0.61, 0.70)	Substantial

^a As per Landis and Koch⁸

Acceptability

Table 5 summarises the results for degree of fit and ease of assignment for all assessments, including 130 patients assessed by one clinician (69 rated as stable, 22 as unstable, 28 as deteriorating and 11 as terminal).

Table 5. Degree of fit and ease of assignment by PC Phase.

Palliative Care Phase	Degree of fit		Ease of assignment	
	n	Mean rating	n	Mean rating
Terminal	114	3.84	114	3.80
Stable	721	3.33	718	3.28
Deteriorating	275	3.18	275	3.09
Unstable	210	2.90	210	2.86
	1320	3.28	1317	3.22

High scores for ‘degree of fit’ indicate a good fit between the phase definition and the phase assigned to the patient; high scores for ‘ease of assignment’ indicate that it was relatively easy to assign a patient to a PC Phase using the revised definitions. The results for all patient assessments (matched and mismatched assessments) indicate a consistent pattern, with the terminal phase fitting best with the definition of that phase and being the easiest to rate, and the unstable phase having the worst fit and being the most difficult to rate.

Comments by raters

The data collection form provided an opportunity for participants to comment about assessing patients and assigning a PC Phase, resulting in 206 comments from 47 clinicians. The majority of comments (69%) provided details of the patient being assessed, with other comments primarily focusing on how phases are defined (9%) or referring to a degree of unfamiliarity with the patient (11%). Comments on 71 assessments (5% of all assessments) indicated difficulty with the assessment, examples

of which are included in Table 6. The table is structured to juxtapose comments with the context of those comments e.g. the comments in the last row were both made in situations where the patient was considered by one clinician to be unstable and by the other clinician to be deteriorating. Even when two clinicians agreed on the assessment of phase, it was not necessarily straightforward. For example, the clinician who commented that the patient was ‘not quite stable but not unstable’ who assessed the patient as stable, as did the other clinician assessing the same patient. All comments in Table 6 are by different clinicians, and no two comments are about the same patient.

Table 6. Examples of comments regarding difficulties assigning PC Phase.

Clinician ratings	Clinician comments
Two assessments of stable	Stable and slowly deteriorating. Multiple comorbidities. Not quite stable but not unstable.
Two assessments of unstable	Difficult to assign due to patient having periods of sudden deterioration then becoming 'stable' again which can really only be described as unstable - but greatly varies at times. Rapid and urgent are too strong descriptions. The patient has an increase in severity of symptoms but are neither rapid or requiring urgent change etc. I can't say deteriorating but this has a better description of how I perceive my patient.
Two assessments of deteriorating	Increase in severity of some problems could warrant unstable phase however these are known ongoing issues. It is probably between deteriorating and terminal.
One assessment of stable, one assessment of unstable	Difficult to gauge patients fluctuating condition. (Stable) The patient's condition is improving but in view of ongoing problems and possible disease progression issues she continues to be unstable. (Unstable)

One assessment of stable, one assessment of deteriorating	Patient has been slowly deteriorating, though has been stable throughout. It is difficult to assess if she should be stable or deteriorating. (Deteriorating) Sometimes it's hard when patients are stable and their pain changes but their condition remains stable, but following the disease trajectory. (Stable)
One assessment of unstable, one assessment of deteriorating	Difficult to know whether patient should be in unstable or deteriorating phase - she has a UTI which would be a new symptom but also could be generally deteriorating. (Deteriorating) Patient was questionably unstable due to change of FIVD from morph to hydro (drowsy) and hypoxic. (Unstable)

Phase in parenthesis is the phase assigned by the clinician making the comment.

Feedback from meetings with participating services

In total, 61 people attended the meetings with participating services, 33 participants, 13 other clinicians, 10 managers and 5 educators. Discussion primarily focused on the issue of which pairings of phases were the most difficult to differentiate. The viewpoints expressed on this issue were varied but all instances of difficulty differentiating between phases involved the deteriorating phase in some way. Equally, there were instances where raters saw the differentiation between each of these pairings of phases as 'very clear' or 'not a problem'. No major problems were identified with the revised phase definitions, except at one service where concern was expressed at linking the definitions of PC Phase to care planning. This same service felt that the definitions of the end of each PC Phase were not helpful.

Discussion and conclusions

The kappa coefficient in this study (0.67) compares favourably with the only other inter-rater reliability study of PC Phase, which reported a kappa of 0.52.² The overall level of agreement was substantial, based on a scale that has been used extensively in

palliative care to judge the performance of assessment tools.¹¹⁻¹⁴ The kappa coefficient did not quite reach the expected level of 0.75, in part because of differences between the distribution of the types of phases observed in the study compared to the distribution used to calculate the sample size.

The mean degree of fit of 3.28 indicates a good fit between patient characteristics and the definition of each PC Phase. The mean 'ease of assignment' rating of 3.22 indicates no significant difficulties assigning patients to a PC Phase. However, the study results indicate that it is difficult to classify some patients. This is hardly surprising as no single set of definitions can ever capture the full range of patient experiences, with comments from clinicians highlighting the challenges of dealing with complexities such as comorbidities. Given the overall utility of PC Phase, further research to understand the processes involved in assessing these more complex clinical situations is recommended to further guide clinical decision making. PCOC's training program has recently been updated, incorporating interactive case studies that provide clinicians with opportunities to improve assessment skills in the more challenging clinical situations identified in this study.

In the previous PC Phase inter-rater reliability study, the only requirement was that the two assessments were completed on the same day. The time period between assessments was not measured.² One of the strengths of this study is that the two assessments of each patient were undertaken within a relatively short period of time (90.7% within 2 hours) compared to the average phase length for inpatients across all PCOC services of 7.4 days for the stable phase, 2.7 days for the unstable phase, 5.3 days for the deteriorating phase and 2.1 days for the terminal phase.⁹ A further strength of this study is that each patient was assessed by two clinicians. In the previous study each

patient was assessed by up to seven clinicians, who would inevitably have variable levels of familiarity with the patient.

One of the limitations of the study is that it was restricted to testing inter-rater reliability. This was a priority given the recent refinement of the phase definitions but there is a need for further research on wider psychometric properties such as validity and test-retest reliability. The focus on inpatients was another limitation and further research in other settings is warranted.

Participating services and clinicians had been using the PCOC tools for a long time and the majority of clinicians had received training in use of PC Phase (see Table 2). For 92% of the assessments in this study, the clinician identified (using a yes/no response) that there were sufficiently familiar with the patient's clinical condition to be confident about their assessment of the PC Phase. The results of this study may therefore not be generalizable to situations where assessment of PC Phase is introduced to a new service or clinicians new to palliative care start using the tool.

In summary, the results of this study demonstrate that PC Phase is a reliable and acceptable measure. PC Phase is routinely used in clinical communication, underpins the PCOC approach to quality improvement, and is the foundation of the Australian national system of activity based funding for palliative care that was introduced in 2012. Substantial inter-rater reliability is critical to maintaining the integrity of each of these activities. The revised definitions reported here have already been adopted as the Australian national standard.¹⁵ Similar definitions and concepts are in use or are being piloted in other countries as well.

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Conflict of interest statement

The authors declare that there is no conflict of interest.

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Appendix 1: Revised PC Phase definitions

START	END
1. Stable	
<p>Patient problems and symptoms are adequately controlled by established plan of care and</p> <ul style="list-style-type: none"> ▪ Further interventions to maintain symptom control and quality of life have been planned and ▪ Family/carer situation is relatively stable and no new issues are apparent 	<p>The needs of the patient and or family/carer increase, requiring changes to the existing plan of care.</p>
2. Unstable	
<p>An urgent change in the plan of care or emergency treatment is required because</p> <ul style="list-style-type: none"> ▪ Patient experiences a new problem that was not anticipated in the existing plan of care, and/or ▪ Patient experiences a rapid increase in the severity of a current problem; and/or ▪ Family/ carers circumstances change suddenly impacting on patient care 	<ul style="list-style-type: none"> ▪ The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or ▪ Death is likely within days (i.e. patient is now terminal)
3. Deteriorating	
<p>The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> ▪ Patients overall functional status is declining and ▪ Patient experiences a gradual worsening of existing problem and/or 	<ul style="list-style-type: none"> ▪ Patient condition plateaus (ie patient is now stable) or ▪ An urgent change in the care plan or emergency treatment and/or ▪ Family/ carers experience a sudden change in their situation that impacts on patient care, and

<ul style="list-style-type: none"> ▪ Patient experiences a new but anticipated problem and/or ▪ Family/carers experience gradual worsening distress that impacts on the patient care 	<p>urgent intervention is required (ie patient is now unstable) or</p> <ul style="list-style-type: none"> ▪ Death is likely within days (i.e. patient is now terminal)
<p>4. Terminal</p>	
<p>Death is likely within days</p>	<ul style="list-style-type: none"> ▪ Patient dies or ▪ Patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating)
<p>5. Bereavement – post death support</p>	
<ul style="list-style-type: none"> ▪ The patient has died ▪ Bereavement support provided to family/carers is documented in the deceased patient’s clinical record 	<ul style="list-style-type: none"> ▪ Case closure <p>Note: If counselling is provided to a family member or carer, they become a client in their own right</p>