

A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme

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Scientific summary

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Background

The hospice movement has provided an excellent model of specialist palliative care for those with advanced disease in the last year of life. However, little is known about costs of care and there are marked inequities in provision across England. Older patients or those with non-cancer conditions access specialist palliative care less often and receive proportionately fewer resources when they do. There are also major geographical variations in resourcing palliative and end-of-life care, often resulting in a poor match between the needs of a patient/family, the resources provided to meet those needs and the improvement in well-being achieved.

Aims

The aims of this programme were to develop and test a person-centred, nationally applicable casemix classification for adult specialist palliative care provision in England, to accurately capture the complex needs of patients with advanced disease in last year of life, to better quantify those needs and to support more equitable allocation of resources to meet them.

Objectives

The C-CHANGE programme had five objectives:

1. to validate or refine new and existing person-centred outcome measures designed to assess the main health status and symptoms/concerns of patients receiving specialist palliative care
2. to utilise the perspectives of key stakeholders on the complexity in palliative care to inform subsequent casemix development
3. to understand the criteria which distinguish different models of palliative care to help inform how a casemix classification can be utilised across different models of specialist palliative care
4. to develop a person-centred palliative care casemix classification, based on individual patient needs and costs of care, for adults with both cancer and non-cancer conditions in the last year of life
5. to test this person-centred palliative care casemix classification in terms of ability to predict resource use in the last year of life and to better understand transitions between services in order to improve care.

Methods

Workstream 1: measures

In Workstream 1, several studies were undertaken from 2013 to 2015 to improve our knowledge of the psychometrics, relationships and clinical utility of the measures proposed for workstreams 3 and 4:

- A cognitive interview study to refine the prototype Integrated Palliative care Outcome Scale (IPOS), a brief measure of symptoms/concerns in advanced illness. Purposively sampled patients were recruited from four inpatient and community settings. Interviews were analysed using thematic analysis, and the prototype measure refined accordingly.
- A validation study for the IPOS to validate both the patient self-report and staff proxy-report versions. In a longitudinal cohort study, we tested construct validity (factor analysis, known-group comparisons and correlational analysis), reliability (internal consistency, agreement and test-retest reliability), and responsiveness.

- A secondary analysis of routinely collected clinical data to describe palliative Phase of Illness, and determine associations between Phase of Illness and the other measures proposed for this programme.
- A survey to examine patients' Views on Care (VoC), a brief measure of patient perspectives on the quality of their care. Adults receiving specialist palliative care in eight hospital, hospice inpatient and community settings across England were recruited. We reported associations between VoC and changes in health status.
- Secondary analysis of pre-existing qualitative interviews to understand patient experiences of uncertainty and how these influence understanding of care. Interviews were sampled using maximum variation sampling and analysed using a thematic approach.

Workstream 2: stakeholder perspectives

To explore the perspectives of key stakeholders on complexity in palliative care, we undertook a qualitative study using semistructured interviews with key stakeholders in specialist palliative care between 2014 and 2015. Participants were professionals from participating sites or were policy/national leads. Data were analysed using framework analysis.

To understand the criteria which characterise/distinguish different models of palliative care, we undertook a mixed-methods study during 2015–16, which comprised the following:

- Semistructured interviews about preliminary criteria with clinical leads from 14 participating sites. Findings were used to expand/refine these criteria.
- A two-round Delphi survey [conducted following CREDES (Conducting and REporting DElphi Studies in palliative care) guidance], which identified additional criteria, sought consensus on criteria definitions and ranked criteria by importance.
- Structured interviews with service providers to assess the acceptability and feasibility of the final criteria, with participants recruited from participating sites from workstreams 3 and 4.

Workstream 3: development of the casemix classification

To determine the costs of specialist palliative care and develop a casemix classification for UK specialist palliative care, we undertook a multicentre prospective cohort study between 2017 and 2018, collecting potential casemix variables and actual costs over episodes of specialist palliative care. Guidance for Transparent Reporting of a multivariable prediction model for Individual Prognosis Or Diagnosis (TRIPOD) was followed. Patients were recruited from four hospital advisory, five inpatient hospice and seven community-based services. Consecutive adult patients (aged ≥ 18 years) were included. Casemix variables included were age, sex, ethnicity, living circumstances, need for interpreter, primary diagnosis, palliative Phase of Illness, functional status, dependency and symptoms/problem severity. Our primary outcome was the cost of specialist palliative care per day. The sample size estimation was 2674 episodes of care. For the analyses we examined the distribution of costs by setting and developed a cost-predictive model using classification and regression tree analysis.

Workstream 4: testing of the casemix classification

To test the palliative care casemix classification developed in workstream 3, we undertook a multicentre prospective cohort study between 2018 and 2019, following patients during episodes of specialist palliative care, with a qualitative nested component (i.e. interviews with a subsample of participants to better understand the experience of transitions between care settings).

Patients were recruited from: three hospital advisory, eight inpatient hospice and five community-based services. Inclusion criteria were adult patients (≥ 18 years) able to consent. Exclusion criteria were < 18 years, unable to consent. Collected data included demographic and clinical variables, episode start and end dates, casemix variables and costs of providing care. The casemix classes developed in workstream 3 were applied to predict costs for episodes of care and this was compared/contrasted with the actual costs captured for each episode.

A subsample of participants experiencing at least two transitions between care settings were interviewed, using purposive sampling criteria of age, sex, diagnosis and types of transitions. We undertook thematic analysis, with attention to patient/family perspectives on the experience of transitions between care settings and how these were supported/resourced.

Results

Workstream 1: measures

Twenty-five cognitive interviews were conducted. Overall, comprehension and acceptability of the prototype IPOS was good. Identified difficulties were comprehension problems with some specific terms and judgement difficulties. Based on these findings, the prototype IPOS was refined.

In the IPOS validation study, we recruited 376 patients and 161 clinicians. We confirmed a three-factor structure (physical symptoms, emotional symptoms and communication/practical issues). The measure showed strong ability to distinguish between clinically relevant groups; total IPOS scores and IPOS subscale scores were higher – reflecting more problems – in those with ‘unstable’ or ‘deteriorating’ versus ‘stable’ Phase of Illness ($F = 15.1$; $p < 0.001$). The IPOS showed good internal consistency ($\alpha = 0.77$) and acceptable-to-good test-retest reliability (60% of items $k_w > 0.60$).

In the study of Phase of Illness, function and symptoms/other concerns varied significantly by Phase of Illness. Mean function (scored using the Australia-modified Karnofsky Performance Status from 0–100, where 100 is best function) was highest in the stable phase [65.9, 95% confidence interval (CI) 63.4 to 68.3] and lowest in dying phase (16.6, 95% CI 15.3 to 17.8). Mean pain (scored 0–4 where 4 is worst pain) was highest in the unstable phase (1.43, 95% CI 1.36 to 1.51). Palliative Phase of Illness reflects additional construct beyond function and symptoms.

In the survey to examine VoC, 212 participants were recruited, with a mean age of 65.84 years [standard deviation (SD) 13.5 years]. Most indicated that palliative care was giving positive benefit. Participants reporting that ‘things had got better’ were more likely to have improved overall health status ($\chi^2 = 6.057$; $p = 0.48$). There was significant positive association between those reporting that ‘things had got better’ and improved physical symptoms ($\chi^2 = 11.254$; $p = 0.004$).

In the secondary analysis of pre-existing qualitative interviews to understand patient experiences of uncertainty, 30 transcripts were analysed. Participants had a median age of 75 years (range 43–95 years). A typology of patient responses to uncertainty was developed, depending on the level of engagement of each individual patient with their illness and treatment, their preferences for information and their temporal focus.

Workstream 2: stakeholder perspectives

In study of stakeholder perspectives on complexity, 65 participants (comprising patients, family, health-care professionals and policy makers) were recruited. Based on the emergent themes, we developed a theoretical framework – adapted from Bronfenbrenner’s Ecological Systems Theory – to conceptualise complexity in specialist palliative care. This framework emphasises that considering physical, psychological, social and spiritual domains is not enough to characterise complexity. The number, severity and range of needs – as well as ‘hidden’ or overlooked aspects of complexity – all need to be considered in the development of a meaningful casemix classification for specialist palliative care.

Semistructured interviews were conducted with 14 service leads discussing 12 settings of care (five hospice inpatient units, two hospital advisory teams and five community teams). Of the 28 initial criteria to describe models of care, 11 were removed, 17 were refined and a further 17 were created. Thirty-four criteria were taken into the Delphi survey. Fifty-four participants took part in the Delphi survey. In round 1, six criteria did not reach the pre-defined consensus standard and four new criteria were

created; this resulted in a refined list of criteria. In round 2, the revised criteria were ranked and rated, and 16 criteria reached the pre-defined consensus standard. In the third component of this study, interviews were then conducted with 21 service leads from 19 different services (six hospice inpatients, four hospital advisory and nine community settings). Criteria were acceptable and feasible, but four contextual criteria were added, resulting in 20 final criteria to define a model of specialist palliative care.

Workstream 3: development of the casemix classification

In the multicentre prospective cohort study to develop the casemix classification, 2469 patients were recruited, providing data on 2968 complete episodes of specialist palliative care. Patients had a mean age 71.6 years (SD 13.9 years) and were 51% male, 74% white and 25% non-cancer patients. Episodes of care lasted a median of 8 days (range 1–402 days) in hospital advisory care, 12 days (range 1–140 days) in inpatient units and 30 days (range 1–313 days) in community-based care. The median costs per day (lower-upper quartiles) were £56 (£31–100) in hospital advisory care, £365 (£176–698) for inpatient care and £21 (£6–49) in community care. Seven hospital advisory, six inpatient, and six community casemix classes for specialist palliative care were developed, based on seven casemix variables (pain, other physical symptoms, psychological symptoms, functional status, palliative Phase of Illness, living alone and family distress). These casemix criteria, measured at the start of the episode of care, provided the optimal classes to predict costs per day for the episode of care. The per cent variance explained (and root-mean-squared error) were 20% (0.30), 51% (0.51) and 27% (0.36) for hospital advisory, inpatient hospice and community episodes, respectively.

Workstream 4: testing of the casemix classification

In the multicentre prospective cohort study to test the casemix classification, 309 patients (mean age 66.9 years, SD 13.1 years; 55% female, 85% white) were recruited, providing data on 751 episodes of specialist palliative care. As expected, the median duration of an episode of care was shortest for hospital advisory episodes (10 days) and longest for community episodes (26 days). The casemix classification was able to accurately predict the actual cost per day of care, especially for hospital advisory and community care. The actual costs of inpatient hospice care were consistently higher than the predicted class costs, although the cost weights remained consistent.

For the qualitative nested interviews, to understand transitions between care settings, 20 interviews with 26 participants were conducted (mean age 68 years, range 36–91 years). Fourteen interviews were individual and six were joint interviews. Four themes emerged:

1. uncertainty about the new care setting – a lack of information about the new setting of care added to feelings of uncertainty and stress
2. biographical disruption – a loss of independence and difficulty maintaining a sense of normality challenged participants' self-identity as they moved place of care
3. importance of continuity of care – continuity of care had an impact on feelings of safety in the new care setting and also influenced decisions about the transition
4. need for emotional/practical support – most participants expressed a greater need for emotional and practical support when transitioning to a new care setting.

Conclusions

The Integrated Palliative care Outcome Scale is a valid and reliable outcome measure, both in its patient self-report and staff proxy-report versions. It can assess/monitor symptoms and concerns in advanced illness, reflect the impact of healthcare interventions and demonstrate quality of care. This represents a major step forward internationally for palliative care outcome measurement.

Palliative Phase of Illness has value as a clinical measure of overall palliative need, capturing additional information beyond function and symptoms. In addition, VoC (reflecting patient perspectives on quality

of care) is brief and easy to use with patients receiving palliative care across different settings. To the best of our knowledge, it is unique in its brevity and ease of use for ill patients receiving palliative care, which allows the measure to provide patient-level feedback in real time.

To the best of our knowledge, workstream 2 provided for the first time in palliative care an evidence-based framework to conceptualise the complexity of palliative care needs of those with advanced illness. Overall, participants reported that they thought it acceptable to measure complexity at the individual patient level using the proposed criteria.

To our knowledge, until now there has not been a clear set of criteria to define models of UK specialist palliative care, making it challenging to compare different models of care provided by services. This component of the programme identified the criteria needed to characterise and differentiate models of specialist palliative care, a major paradigm shift to enable accurate reporting and comparison in practice and research.

Our detailed evidence on specialist palliative care costs and the casemix classification for specialist palliative care deliver a major advance for the sector. Each person needing specialist palliative care is different, with varying degrees of complex needs. We now have the means to understand this, systematically and at scale, for practice, policy (including resourcing of palliative care) and research. The casemix classes show cost weight variations up to 4.5-fold in inpatient hospices and almost 3-fold in community care. The needs of each person are varied – not fixed – and require different resources to deliver care effectively. Understanding this has the potential to help address inequities and provide more equitable specialist palliative care to all who need it. The casemix classification will inform NHS England currency development.

Study registration

This trial is registered as ISRCTN90752212.

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