Clinical Decision-Making at the End of Life: A Mixed Methods Study

Corresponding author:

Dr Paul Taylor
St Luke's Senior Clinical Lecturer in Palliative Medicine
School of Health and Related Research
The University of Sheffield
30, Regent Street
Sheffield
S1 4DA

Email: drpaulmtaylor@gmail.com

Telephone: (+44) 7765 272085
(+44) 114 2220840

Fax: (+44) 114 2724095

Contributing authors:

Professor Miriam Johnson
Hull York Medical School
University of Hull
Hull
UK

Professor Dawn Dowding
School of Health Sciences
University of Manchester
Manchester
UK

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Structured Abstract

Objectives:

To improve the ability of clinical staff to recognise end-of-life in hospital in-patients dying as a result of cancer and heart failure, and to generate new hypotheses for further research.

Methods:

This mixed-methods study used decision theory as a theoretical basis. It involved a parallel databases-convergent design, incorporating findings from previously published research, with equal priority to study groups and synthesis by triangulation.

The individual arms were (1) a retrospective cohort study of 102 cancer patients and 81 heart failure patients in an acute trust in the North of England, and (2) a semi-structured interview study of 19 healthcare professionals caring for the same patient groups.

Results:

The synthesis of findings demonstrated areas of agreement, partial agreement, silence and dissonance when comparing the cohort findings with the interview findings. Trajectories of change are identified as associated with poor prognosis in both approaches, but based on different parameters. Management of patients has a significant impact on decision-making. The decision process requires repeated, iterative assessments and may benefit from a multi-disciplinary approach. Uncertainty is a defining characteristic of the overall process, and objective parameters only have a limited role in predicting end of life.

Conclusions:

The role of uncertainty is important as a trigger for discussions and a defined stage in a patient's illness journey. This is consistent with current approaches to recognising irreversible deterioration in those with serious illness. This study contributes ongoing evidence that these concepts are vital for decision-making.

Background.

The implementation of good care of the dying depends on the recognition that a person is in their final days (1). Timely recognition of dying allows appropriate implementation of symptom measures, whilst minimising unnecessary invasive and costly interventions (2). In the USA, appropriate recognition of end-stage disease allows hospice care to be delivered *via* benefits comparable with Medicare (public health insurance for the over-65s), with consequent improvement in symptom control and quality of life (3). From the earliest days of medical practice(4), to the preferences of patients and their families (5), through to recent recommendations on palliative care research topics (6), the recognition of dying features as a vital topic.

Despite the centrality of this skill to palliative care, the key findings from primary research continue to reinforce that the task is challenging, with recent national guidance recommending research into the recognition of dying as a priority(7). A simple single-question tool, the "surprise question", remains one of the leading techniques for recognising the last six months to a year of life (8), yet demonstrates a wide variation in accuracy when applied to different contexts, patient populations, timescales or by different professionals (9). Ongoing research approaches include using case vignettes to model the accuracy of clinician's decisions (10), using audit data to explore the timing of the decision (11), using routine data to model the biology of dying(12), using prognostic methods at a short time scale (13), and using qualitative methods to explore decision processes (14). An integrative review of the literature has reinforced the inherent difficulty and uncertainty in this process, and the breadth of research techniques with which it can be explored (2).

Theories of Clinical Decision-Making provide a framework for understanding these processes. Whilst a number of models exist, they can largely be understood as fitting into one of three categories; normative, prescriptive or descriptive (15). Normative models use mathematical and probabilistic techniques to outline an idealised decision. Prescriptive models produce tools to enable practitioners to translate normative, "idealised" decisions into practice. Descriptive models explore the processes by which decision-makers act in practice (16).

None of these categories is inherently superior to the others. Normative models translate real-world data into meaningful information, prescriptive models take this information and generate outputs which are clinically applicable, and descriptive models explore the boundary between these idealised, rational predictions and the real-world decisions and actions taken by human practitioners (16). Therefore, by undertaking a study in which two or more approaches are combined, we can come to a greater understanding of the decision in question within the framework of decision theory.

This article reports on the findings of a mixed-methods study where the individual arms have already been reported (17–19). The *a priori* design was of post-completion synthesis, which allowed two distinct decision-making approaches to be combined into a single study. By publishing the studies in sequence and focusing on the synthesis here, we allow each one to contribute to the research base on its own terms, maximise

transparency and allow a detailed discussion of the mixed-methods synthesis as a study in its own right.

The aim of this mixed-methods study was to explore the ability of clinical staff to recognise end of life in hospital in-patients dying as a result of cancer and heart failure, and to generate new hypotheses for further research.

Methods

Study design

This mixed-methods study combined a retrospective cohort study and a qualitative interview study. Detailed descriptions of the methods are available elsewhere.(17–19)

The retrospective cohort study was planned as a normative approach to decision-making, using physiological data to model the biology of the dying process. It involved extracting routinely collected physiological data covering the final two weeks (three months for certain variables) of life from healthcare records. Data was collected on patients with heart failure (n=81) (19)and cancer (n=102) (17). Multilevel modelling was used to explore evidence for change in these parameters as death approached. Results were reported separately for each condition.

The qualitative study was planned as a descriptive approach to decision-making research, using interviews to understand the processes by which professionals make these decision in the real world. It involved undertaking semi-structured interviews with medical and nursing staff sampled according to three levels of seniority and experience. The interviewees were drawn from cardiology or oncology in-patient services. A total of 11 oncology staff (6 doctors, 5 nurses) and 8 cardiology staff (3 doctors, 5 nurses) were included. Findings were analysed using thematic analysis according to Braun and Clarke's methodology (20).

Data from each arm was collected separately, and synthesis took place only after both analyses were completed; a parallel databases-convergent design (21). Each arm of the study was interpreted against the findings of the other, so that each set of results was used to critique and appraise the findings of the other. In combining these findings in this study, the approach was broadly qualitative. The findings from the interview study were thematic and hence a quantitative synthesis was not appropriate.

Setting

The setting for both arms was an acute National Health Service (NHS) hospital trust in the North of England, which is a tertiary referral centre for both oncology and cardiology.

Ethics

Ethical approval was obtained separately for the individual arms of the study, and approved by an NHS Research Ethics Committee (Ref 10/H1304/18; 10/H1304/70). Research governance aspects were addressed by the University Research Governance

Committee, in conjunction with PhD supervision and advisory panels. The hosting trust provided R&D approval. The National Information Governance Board provided approval regarding information governance aspects of the cohort study.

Analysis

The synthesis was undertaken by one of the researchers (PT), with iterative discussion and reviewing of the generated concepts at all stages of the work by the other authors (MJ, DD), each of whom has experience in the respective study methods. The analysis process used for the mixed-methods synthesis was triangulation, which involved cross-referencing the research findings for areas of agreement, partial agreement, dissonance and silence (22).

In this analysis, agreement is recorded where the interview findings describe a phenomenon observed in the cohort study. Partial agreement exists where the studies report on similar phenomena, but cannot be uncritically said to agree; these cases are described in-text. Dissonance occurs where the studies report findings which are directly contradictory. This further relates to the concept of "attention to deviant cases"; an important aspect of qualitative research; any areas where the two studies significantly deviate from one another were intended to be reported under this heading. Silence occurs where one study makes an observation on which the other does not comment, and where such comment could be expected.

The different methods used in this synthesis mean that there will necessarily be areas where one study is not able to reflect the results of another. For example, one participant described using the former Liverpool Care Pathway criteria as a diagnostic tool, whilst the cohort study would not be able to provide information on this subject. A degree of interpretation is therefore necessary when comparing the two arms.

The findings in the cohort study were initially cross-referenced with instances in the interview study where participants described objectively defined parameters, or where significant omissions occurred. Following this, the more detailed themes and analyses of the interview study were cross-referenced with the interpretation of the cohort study, to determine whether these themes were supported in both cases. Neither study was accorded priority in the analysis. The process is summarised in a flow chart in figure 1.

Results

Cohort study summary

In both patient populations (17,19), respiratory and renal function deteriorated in the final two weeks of life, whilst serum albumin deteriorated over a timescale of three months. White cell count rose in cancer, but did not show statistically significant change in heart failure. Heart rate and serum sodium showed a statistically significant increase, but with limited clinical significance, in both conditions. Other parameters (reported in tables 1 and 2 and described in more detail in the synthesis) were assessed in the cohort study without showing evidence of statistically significant change.

Interview study summary

The interview study generated six themes and thirteen sub-themes, with defined areas of overlap (18). These themes and sub-themes are listed in table 3. One theme of note in the study, "information used", was the basis of a significant part of the triangulation of the cohort study. This theme defined objective pieces of information used by clinical staff as part of the decision process. Other themes are reported here to the extent that they required triangulation with the cohort study.

Defined characteristics of the decision process as a whole were identified. It was fluid, in that the distinction between active management and recognition of dying was blurred. It was ongoing, as decision-makers described using information acquired over a period of time. It was iterative, as the process involves a continuous reappraisal of the decision in the light of changing information. These findings supported the fact that the decision process involves a degree of intuition and pattern recognition, integrated with objective measures, which is consistent with the dual-process theory of clinical reasoning (23).

Mixed-methods synthesis

Triangulating cohort data against interview data.

To ensure a meaningful comparison, the qualitative data used at this point in the synthesis is limited to interview participants describing phenomena which relate to objectively measurable characteristics; these phenomena had been incorporated into a single theme in the qualitative study ("Information Used").

These findings were directly compared with the results of the cohort study; for each finding which demonstrated a statistically and/or clinically significant change in the final two weeks of life, the list of objective measures derived from the theme "Information Used" was searched for related measures. Note that qualitative findings were not limited to absolute values, but also to interpretation of data and rate of change information. The findings are summarised in table 1 (cancer) and 2 (heart failure).

Agreement

Agreement was demonstrated between the studies where the cohort demonstrated tachypnoea, hypoxia, raised urea and creatinine, whilst the respondents in the interview study described using the same parameters, or used related terms such as "breathlessness" and "renal dysfunction". This agreement was preserved across both cancer and heart failure patients. In addition, raised white cell count demonstrated agreement between the studies for cancer patients.

Partial agreement

For areas of partial agreement for cancer patients, falling haemoglobin and albumin were associated with poor prognosis and reported as such in the interview study. However, the cohort findings only demonstrated statistical significance over a timescale

of three months, therefore limiting their role in the recognition of dying other than providing a context of deterioration over this time period.

In both cancer and heart failure, rising heart rate and rising serum sodium showed statistically significant change in the final two weeks of life, but without clinical significance; both observations were reported in the interview study for heart failure patients; neither were reported for cancer patients. The borderline high white cell count in heart failure patients suggests a further possible area of agreement between the studies.

Dissonance

An area of explicit dissonance for both patient groups was blood pressure. The cohort study showed no association between blood pressure changes and approaching death, yet participants in the interview study reported hypotension as sought information. In cancer, a further area of dissonance occurred where a single participant described bradycardia as significant, contrasting directly with the cohort findings.

Silence

Here, silence is defined as cases in which one arm highlighted a factor as significant, the other arm contained insufficient information to allow a comparison, and where such a comparison would be meaningful. These are outlined in the table summary. Other characteristics not suitable for this type of comparison are reported in the original papers.

Triangulating interview data against cohort data.

In triangulating the findings further, and ensuring each study is treated equally, a number of more detailed concepts highlighted in the qualitative study may be defined and critiqued in terms of the findings of the cohort study. This also involved searching for agreement, partial agreement, silence and dissonance. The nature of the findings reported in the interview study required a degree of critical interpretation of the cohort findings and justification of the link; this is outlined below. There were no new areas of dissonance or silence highlighted in this section.

Agreement

The first area of agreement was the impact of patient management on assessment. In the interview study, participants were asked to describe their decision processes with reference to a specific patient case, and then to generalise to the wider context of recognising dying. One observation arising from the interviews was a tendency for participants to mix responses on recognising dying, managing dying and treating acute illness. In some cases, a participant would explicitly describe observing a patient's response to treatment as part of their decision process. In others, discussion of common symptoms indicating the final days of life were combined with a discussion on how such symptoms should be managed.

The implication of this is that the processes by which dying is recognised cannot be clearly separated from the processes of clinical care which take place at the same time. In the cohort study, this observation is reinforced by the fact that certain parameter values, demonstrated as associated with poor prognosis, had the potential to change as a result of medical treatment. A key example is the masking of deteriorating oxygen levels in the light of access to prescribed oxygen.

The second area of agreement was the importance of repeated, iterative assessments, which was one of the key characteristics of the decision process outlined in the interview study. Given that time-dependent change is shown (both in the literature (24) and in this study) to be important, single measures of a person's physiology are less useful than sequential measures. In outlining the impact of patient management on assessment, it is clear that the decision process requires an iterative approach, developing as a result of change over time and change in response to intervention.

Each of these concepts is borne out by a detailed assessment of the cohort data. Whilst the multilevel models demonstrate evidence of common change in certain parameters at the population level, there was significant variation, even within individuals. Whether this heterogeneity represented genuine clinical fluctuations (e.g. acute deterioration), effect of management (e.g. treating hypoxia with oxygen), measurement error or a further confounding factor is not clear. Nevertheless, this finding cautions against aiming to rely on a single one-off assessment when recognising dying.

Partial agreement

The importance of "patterns of change" was a sub-theme in the qualitative study, which contributed to one of the key themes and the subsequent analysis. Participants described observing how a patient's condition changes over time; the cohort study (and literature review) agreed with this observation by demonstrating that rate of change is associated with prognosis.

However, interview participants typically described rate of change in terms of general measures such as performance status, rather than individual parameters; the cohort study did not obtain sufficient information on performance status to facilitate an analysis, but did highlight the importance of patterns of change on other parameters. Whilst, therefore, the concept of rate or pattern of change is an area of agreement between the study arms, there is only partial agreement in the areas to which it applies. This highlights that there is some uncertainty in the decision process, and some limit to the perceived value of observations in assessing the dying patient.

The final area of partial agreement was "knowledge of the patient". With the above discussion highlighting the importance of repeated assessments, it might be assumed that increased familiarity with the patient would enhance the ability of a clinician to recognise approaching death. This was not necessarily supported by the interview data. For example, a staff member reviewing a patient daily may notice a discrete change, but may miss a subtle, gradual change over a longer time period. Differences in frequency of patient review were related to profession (nurses having more frequent contact than doctors) and seniority (junior staff having more frequent contact than seniors), suggesting that a multi-disciplinary approach would be valuable.

This evidence is reflected in the cohort study in that different parameters exhibit change over different timescales, with respiratory dysfunction exhibiting the most rapid change with day-on-day deterioration, whilst albumin/haemoglobin deteriorate much more slowly, showing significant change over weeks.

Discussion

This synthesis reinforces findings identified in both arms, adding context to the results presented in those papers. The key findings to which this reinforcement applies are: (1) That time-dependent information is important and belies an iterative decision process, (2) that the distinction between managing and recognising dying is blurred, (3) that repeated assessments by professionals are a key component of the decision process as a whole, (4) that clinical observations do not provide the entirety of relevant data for the decision, and (5) that uncertainty is a significant and arguably unavoidable component of the process.

The importance of time-dependent information is strongly reported in both studies and reflects findings in the research literature. The association between prognosis and rate of change of performance status was highlighted as early as 2000 (24), whilst a seminal qualitative work highlighted the importance of understanding the disease trajectory for end of life care(25). and has recently acquired further attention; a detailed literature review exploring the biology of dying focuses on changes in parameter values, rather than solely on absolute levels(12).

The overlap between management and assessment is interesting, rooted most strongly in the qualitative data and supported in the cohort studies. The fact that the recognition that a person is dying may, in part, rely on response to treatment, blurs the distinction between “active” management and end of life care.

The importance of repeated, iterative assessments relates to both of the above observations and is supported equally by both studies. A professional must undertake sequential assessments in order properly to understand a pattern or rate of change, and must review effects of prior management plans in order to assess ongoing response to repeated treatments and review their diagnosis.

The limited role of clinical observations in the decision process is supported in both studies and further evidenced by the overall synthesis of findings. Both the qualitative and quantitative studies highlighted that observations and bedside parameters were useful pieces of information, but limited in their application; those parameters highlighted as potentially useful in each separate arm do not fully overlap. Interviewees described relying on parameters which were not confirmed as useful in the cohort study or, in one case, stated explicitly that observations were not useful.

Finally, this study also highlights that the recognition of dying appears to be a process characterised by uncertainty. Whilst this conclusion is directly described in the discussion for the qualitative study, and supported by the cohort findings, it also naturally follows from the observations presented above. Rather than searching for a system of clinical parameters which can be used as an indicator of dying, these findings

point to a complex and involved process, with ongoing scope for error. The inherent uncertainty and time-dependent nature of the decision process with highly variable physiological parameters and levels of involvement, is further complicated by the fact that it relies partly on intuition; a characteristic of intuitive decision-making is that it is difficult to describe. The existing literature also supports the role of uncertainty in the decision processes in end-of-life care, in addition to the potential benefit of communicating this uncertainty to patients and their families (14).

This latter observation relates closely to two current UK initiatives in palliative care, which are the subjects of ongoing research. These are the AMBER (Assessment, Management, Best practice, Engagement, Recovery uncertain) Care Bundle (26,27), and the phase data from the OACC (Outcome Assessment and Complexity Collaborative) suite of measures (28). AMBER is a prescriptive decision-support tool for use in hospitals when the possible outcomes of a patient's condition are uncertain (29). The OACC suite of measures includes phase data, classifying patient management plans according to whether their condition is stable, unstable, deteriorating or dying(30); the unstable phase maps closely to the uncertainty described here. Given that direct studies aimed at validating these initiatives are still being conducted, the study presented here provides further support for their value.

Internationally, there is a significant variation in the provision of palliative care. However, the appropriate recognition of dying links directly into improved patient care; through timely use of appropriate symptom measures, through the minimising of invasive (and potentially costly) interventions and through directing patients into the appropriate routes of service as the soonest opportunity (31) (32)(3).

Conclusions

Through comparing and triangulating data from two distinct studies and methods, this mixed-methods synthesis has reinforced and contextualised the findings of both arms. This has added further insights into the processes by which medical professionals recognize and make decisions for dying patients, and contributes to the evidence base for initiatives which are currently undergoing real-world assessment.

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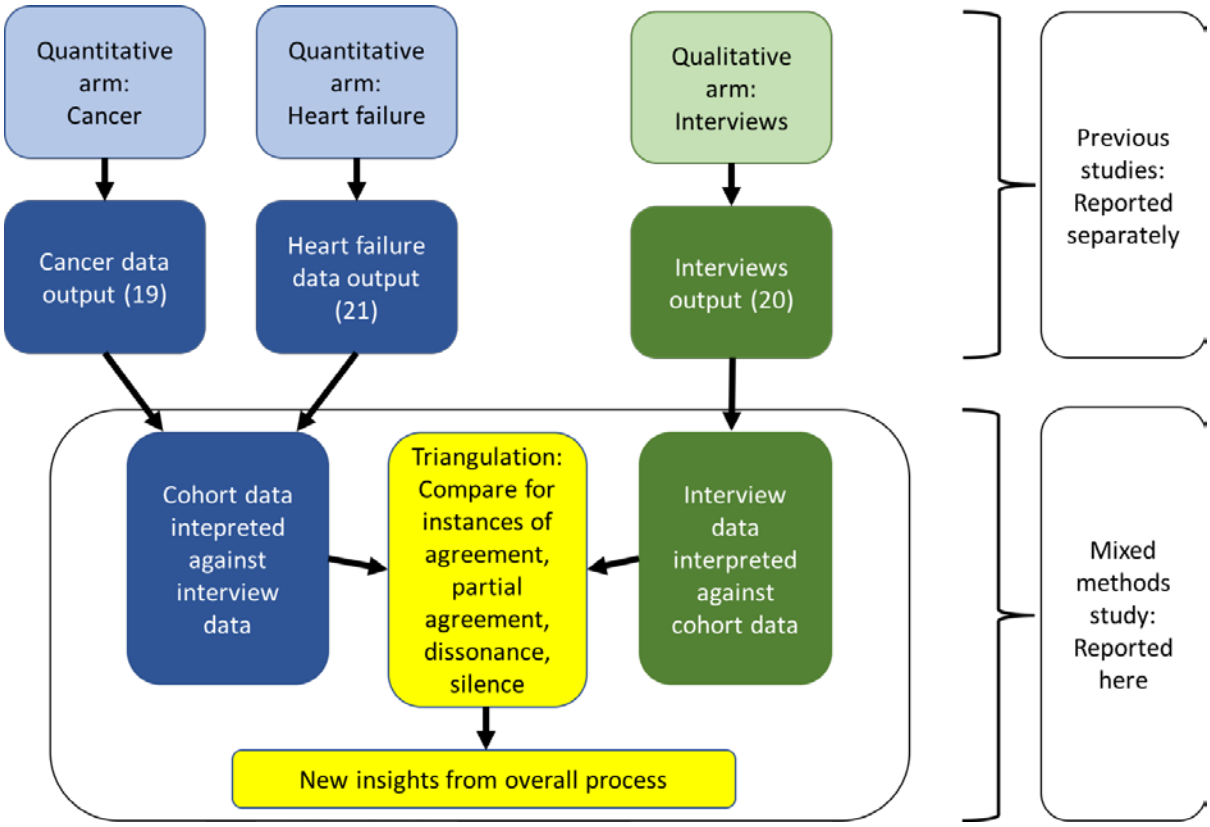

Figure 1. Overall structure of study.

Table 1. Objective factors associated with poor prognosis in cancer.
Green = Full agreement, yellow = partial agreement, blue = silence (where a finding is identified in only one study), red = dissonance (where study findings contradict one another)

Nature of significance in cohort study	Parameters in cohort study	Description in interview study, under theme "Sought information"	
Statistically and clinically significant association with poor prognosis in final two weeks of life	Increased respiratory rate Reduced oxygen saturation Increased urea and creatinine Raised white cell count	Increased respiratory rate Breathlessness Increased urea and creatinine Renal function Raised white cell count	
Demonstrated association with poor prognosis over longer timescales	Falling haemoglobin Falling albumin	Haemoglobin Albumin	
Statistically but not clinically significant association with poor prognosis	Raised heart rate Increased sodium	Not described in this population	
Others	Not sought or obtained in this population	Temperature Early Warning Score Chest drain output Imaging CRP Blood cultures ECG	Performance status ↓ Weight ↓ Confusion Nausea/vomiting ↓ Urine output Analgesic use ↑
No evidence of association	Blood pressure **Falling** heart rate	Blood pressure Bradycardia	

Table 2. Objective factors associated with poor prognosis in heart failure.
Green = Full agreement, yellow = partial agreement, blue = silence (where a finding is identified in only one study), red = dissonance (where study findings contradict one another)

Nature of significance in cohort study	Parameters in cohort study	Description in interview study, under theme "Sought information"
Statistically and clinically significant association with poor prognosis in final two weeks of life	Increased respiratory rate Reduced oxygen saturation Increased urea and creatinine	Increased respiratory rate Breathlessness Increased urea and creatinine Renal function
Clinically abnormal values suggest possible association with poor prognosis over longer timescales	Raised white cell count	Raised white cell count
Statistically but not clinically significant association with poor prognosis	Increased heart rate Increased serum sodium	Increased heart rate Increased serum sodium
Demonstrated association with poor prognosis over longer timescales	Falling albumin	Not described in this population
Clinically abnormal values suggest possible association with poor prognosis over longer timescales	Falling lymphocyte count	Not described in this population
Others	Not sought or obtained	NYHA class ↑ Weight change Echo-estimated LVEF ↓ Confusion

		Urine output ↓
No evidence of association	Blood pressure	Blood pressure

Table 3. Summary of themes and sub-themes in interview study. The detail of these themes is explored further in the source article. The triangulation with the cohort study is discussed in the results section. Concepts outlined in bold text are referenced explicitly in the study text.

Sub-themes		Themes	Characteristics of overall decision
Limits of interventions **Knowledge of the patient** **Managing dying** **Sought information** **Existing interventions** **Patterns of change**	Pathological processes General factors Patient perspective Professional factors Interactions with patients and carers Interactions with professionals Individual processes	**Information used** **Implementation** Modifying factors Decision processes Reflecting on decisions Related decisions	**Iterative** Fluid Ongoing