Identifying transitions in terminal illness trajectories: a critical factor in hospital-based palliative care

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This article describes the significance of the identification and explicit communication of transitions in incurable illness trajectories. Distinct clinical phases in palliative care are identified (Table 1) as they correspond to transitions experienced by incurably ill patients and their families. Conditions and barriers related to the identification and explicit communication of transitions are outlined, and the importance of appropriate and timely intervention in different phases is argued.

A single-site, qualitative study of central concepts underlying the palliative care given in a Danish hospital is reported. However, the results may contribute to the development of palliation in other hospital settings where curative and palliative care are offered side by side.

The last 15 years have seen an increased focus on specialist palliative care in Denmark (Danish National Board of Health (DNBH), 1996). In 2005 the DNBH highlighted the effort to improve palliative care in hospitals. A study carried out by the Danish Cancer Society (2006) concluded that hospitals are geared to offer curative care. Another study concluded that professional, cultural and organizational challenges have to be overcome in order to offer appropriate palliative care in hospital settings (Dalgaard, 2007a). A number of studies indicate that staff in hospital settings are particularly challenged by the conditions presented by the concurrence of curative and palliative care in the same wards (Prior and Poulton, 1996; Middlewood et al, 2001; Hermsen and Have, 2005; Thompson et al, 2006). Existing knowledge indicates that curative treatment and palliative care are based on different paradigms. Dalgaard’s 2007 study shows that in incurable illness trajectories, a number of significant transitions may be identified in which the patient’s view of life and death changes, each of them claiming to be for different challenges and strategies of palliative care (Dalgaard, 2007a).

On the assumption that systematic palliative care had not yet been implemented in Danish hospitals to any significant extent, the current study aimed at developing methods for the introduction of such care in hospital settings. The first phase of the study, which is presented here, focused on assessing palliative care delivered in hospital settings (Dalgaard, 2007b). The assessment was based on a model of palliative care related to patients, families, professionals, interactions and organizational structures (World Health Organization (WHO), 2002; Dalgaard, 2001, 2007a). The definition of palliative care and the target group of palliative care used in this study are outlined in Table 2.

**Methods**

The study was inspired by the original research by Glaser and Strauss (1965; 1967) and the methodology by Strauss and Corbin (1990/1998). It is based on fieldwork, and focus group interviews were employed (Spradley, 1980; Hammersley and Atkinson, 1998; Morgan, 2001; Atkinson and Coffey, 2001). The fieldwork

**Abstract**

This article describes the significance of the identification and explicit communication of the different clinical phases in incurable illness trajectories in a hospital setting. The article is part of a qualitative study carried out in a Danish haematology department. The data were obtained through a total of 157 hours of participant observation and informal interviews with patients, families, doctors and nurses and four focus group interviews with doctors and nursing staff. Grounded theory was applied for the data analysis. The findings outline how the unpredictability of certain haematological malignancies and barriers in professional practice tended to postpone identifications of transitions between clinical phases. The study has identified ten barriers including personal, professional, time-related, cultural and organizational—for an open dialogue between staff, patients and families about illness progression. The quality of palliative care was affected as different clinical phases require different treatment and care strategies. Complex intervention is called for.

**Key words:** Palliative care • Hospital • Incurable illness trajectories • Transitions • Clinical phases
Identifying the target group for palliative care

Curative and palliative interventions took place side by side in the department. A precondition for the provision of palliative care was the ability to identify the target group for palliative care.

From a medical point of view, the initial assessment of the malignity of a haematological cancer disease and the relevant treatment was said to be relatively simple. A doctor explained:

‘At first, it’s easy to differentiate between curative or palliative treatment. A good number of patients start off with curative treatment, if nothing rules it out. But quite a number turn out to be incurable later on.’
A group of patients were identified as incurably ill at the time of diagnosis and were therefore categorized into the early palliative phase. Typically, these patients suffered from illness with long and chronic courses (i.e. myelomatosis, chronic leukaemia, and low-malignancy lymphoma). Doctors appeared to differ from one another in their opinions on the explicit communication to such patients about incurable disease. As a consequence, it was not made completely clear to some patients that their illness was incurable.

Another group of patients were initially diagnosed with a curable illness and offered curative treatment. Some of these patients were cured, others experienced a long period of remission before eventual relapse. In case of relapse there was no certainty as to whether treatment should be curative or palliative because it is difficult to foresee the development of haematological malignancies. A doctor explained:

‘We’re in an area with almost no evidence. How treatment works out is highly individual. Let’s say we’ve two “identical” patients with a relapse of highly malignant lymphoma—the one patient may be very chemo-sensitive and curable, while the other is basically refractory.’

Consequently, there was a large group of patients whose illness it was impossible to categorize as either curative or palliative. In such cases, the illness was primarily considered as curable.

**A difficult decision: transition to the late palliative phase**

Patients’ transition to the late palliative phase took place when the medical treatment for disease control was discontinued. From this point of time, palliative care aiming at the alleviation of suffering and improvement of life quality is essential. However, ten interacting barriers were identified, which may nonetheless have postponed the identification and explicit communication of this transition:

- Staff have to be consciously aware of the situation and verbalize that the patient’s situation has changed, and colleagues must be ready to listen. A doctor said: ‘Both the nursing and the medical staff must have a deep awareness of the situation before such a conclusion can be drawn.’ The awareness often occurred very late in the illness trajectory when physical disease symptoms were progressing.
- Staff were reluctant to discuss the issue with the patient. They worried about undermining the patient’s hope and found it difficult to engage in serious dialogue, particularly if the patient was at a different stage of awareness. A doctor explained: ‘It’s difficult when there’s a discrepancy between what the patient knows and believes and our knowledge and experience.’ Staff said that it was easier when the patient took the lead.
- Patients’ acceptance played a role. Some were not prepared to give up their hope for disease control. A nurse said: ‘The patients invest a lot of hope in the treatment. We mustn’t undermine people’s hope.’ Doctors said that they were less inclined to stop disease-controlling treatment in such circumstances.
- Families’ acceptance may contribute to postpone the decision process, particularly when they were at different stages of acceptance than the patient. In some cases relatives even tried to press the patient into accepting further medical treatment.
- In a busy working day, it may be difficult for staff to take up the issue of illness progression in a dialogue with patients and families.
- The lack of continuity in staff presence has resulted in limited knowledge of patients’ situations and important information may be lost or misunderstood as it passes through a chain of people.
- With the knowledge available today, the unpredictability of haematological malignancies made it difficult to foresee the effects of treatment and its side effects.
- Staff claimed that tradition in haematology dictates curative and disease-controlling treatments to be continued for a considerable part of the illness trajectory.
- Personal attitudes and preferences played a role. A doctor explained: ‘We know colleagues who never say no (to further treatment). We have to admit that (not being able to stop treatment) only helps the doctor and can be a defence to avoid engaging in a difficult conversation.’
- Interprofessional cooperation between doctors and nurses did not run smoothly. Not enough time was allocated for dialogues on individual situations and important information may be lost or misunderstood as it passes through a chain of people.

**Table 3. Group constellations for focus group interviews**

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Doctors (n=6)</th>
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<tbody>
<tr>
<td>Group 2</td>
<td>Nursing staff in the ward (n=4) in outpatients unit (n=3)</td>
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<tr>
<td>Group 3</td>
<td>Nursing staff in the ward (n=3) and in outpatients unit (n=3)</td>
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<tr>
<td>Group 4</td>
<td>Doctors (n=3), nursing staff in the ward (n=3), outpatients unit (n=3)</td>
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patient cases, and respect for each other's assessment was missing. Doctors would focus on treatment and objective facts, whereas nurses' assessments would give priority to the patients' general condition and current quality of life.

Why establish an explicit transition to palliative care?
Several members of staff pointed out that the identification and explicit communication of transitions from curative treatment to the early palliative phase, and from the early to the late palliative phase were postponed until very late in the illness trajectories, typically not until the onset of the terminal phase. A doctor said: 'In 90% of the cases the onset of the terminal phase coincides with the discontinuation of active treatment', and a nurse remarked: 'When they (doctors) discontinue treatment there are usually only a few days left'. This affected the quality of the palliative care that was offered.

Transition from curative treatment to early palliative phase
The transition from curative treatment to early palliative phase typically occurred when the patient was considered to be incurably ill, with the goal for medical treatment being continued for reasons of disease control. The failure to communicate insight of this new situation to the patient, family and staff has a number of consequences. For example, the patient misses the opportunity to express anxiety or doubt as to the effect of treatment. He or she may meet a wall of non-understanding. Typically the staff encouraged the patient to hope and fight, offering him false comfort. A doctor trying to be optimistic was heard saying to a patient with progressing illness:

'You must believe in it—things are beginning to improve now.'

A lack of openness may mean that staff and patients privately harbour thoughts about death and dying. A nurse said:

'We can’t talk to patients about the things that bother them when realities are hidden to the patient and his family.'

Patients were thus left in loneliness.

The hope patients attached to treatment may be unrealistic. They fought a meaningless battle and forfeit the opportunity to channel hope in other directions. The opportunity to prepare for death is denied, an issue the staff found deeply problematic. A doctor said:

‘If the patient is not informed that death is imminent, you deny them the chance to make important choices.’

Transition from early to late palliative phase
The early palliative phase may be associated with a line of reasoning that supports medical treatment and care aimed at rehabilitation alongside with relevant palliative care, typical alleviation of physical symptoms, psychological and existential problems. Focus was continuously directed at disease control, monitoring of treatment and side effects, surveillance of vital parameters and body functions. Rehabilitation seemed to justify pressing the patient to stay fit, eat, be optimistic and fight to recover and to live.

A nurse explained:

‘If they [the patients] continue on active treatment, I do more to motivate them. They have to combat the disease, you see.’

If the transition to the late palliative phase had been explicitly communicated, staff defined the illness trajectory as a progression towards death. The aim of intervention was to alleviate suffering and improve the quality of life. To a greater extent, care was given on the patients’ own terms and according to what they perceived to be meaningful. A nurse explained the situation:

‘There is more focus on life quality. As the end draws near, I let them decide for themselves. At this stage training isn’t all that important.’

The explicit communication of the transition to the patient allowed an open dialogue with the patient. The patients were able to share their thoughts, doubts and concerns, and staff could offer help in finding new hope and meaning of life. The patients were given the opportunity to come to terms with the inevitable—death.

In contrast, when the transition to the late palliative phase had not been explicitly communicated, situations would arise where staff began to wonder whether certain life-prolonging interventions should be avoided or discontinued. This approach was based on an avoidance logic that would foster questions such as: What should we avoid doing? Should the patient be resuscitated in case of cardiac arrest? Should the patient be offered intensive care at all? Is nutrition relevant? And, if the patient's condition...
was such that, in spite of intended disease control, ethical considerations suggest limitations to life-prolonging interventions. This situation constricts the space for what is ethically acceptable, but the strategy also represented a defensive approach, being based on avoidance rather than active palliative care.

Discussion
Regarding the transition to the late palliative phase, identification and explicit communication are particularly important, as this task may present several barriers to appropriate clinical decision-making. This study has identified ten barriers for an open dialogue between staff, patients and families. They were related to factors such as personality, profession, time, or cultural and organizational issues. Complex intervention is needed, not only to bring about attitudinal, cultural and organizational changes, but also to strengthen interprofessional cooperation and professional competency (Prior and Poulton, 1996; Fischberg and Meier, 2004; Hermsen and Have, 2005; Thompson et al, 2006; Dalgaard, 2007).

When transition to the late palliative phase has been identified, the situation is openly defined as a progression towards death. Interventions will solely aim to alleviate suffering and improve the quality of life. If transitions are explicitly communicated, patients and families would be given the opportunity to share their thoughts in an open dialogue with staff and find new hope and meaning in death and dying.

Our study has shown that explicit communication concerning transition to the late palliative phase tended to occur very late in the illness trajectory, often not until the onset of the terminal phase. The tendency in favour of continuing an intervention strategy was based on the logic of medical treatment and rehabilitation, mixed with elements of a defensive avoidance logic rather than active palliative care. A similar approach dominates in other hospital settings in Denmark (Dalgaard, 2007a).

It is essential that palliative care in hospital settings is introduced early in the illness trajectory together with disease control (WHO, 2002; Fischberg and Meier, 2004). In the early phase of an incurable illness, palliative care is typically given at the basic level, while specialists’ knowledge would often be necessary in the late palliative phase (Back and Curtis, 2001).

It is essential that the transition to the early palliative phase is explicitly communicated to patients and families, thus giving them the opportunity to make informed choices for the future. Furthermore, personal counselling of incurably ill cancer patients with long and chronic trajectories is called for (Dalgaard, 2007b). Patients express a need for dialogue with professionals in order to bridge between illness, treatment, life and death. They live with an awareness of death, which is exacerbated when their illness becomes unstable or progresses. They are constantly confronted with the challenge of integrating changes and limitations caused by their illness. Initiatives that promote greater openness about incurable illness and supportive dialogues with patients and families may therefore improve the quality of palliative care.

The unpredictability of certain haematological malignancies presents a particular challenge for staff taking care of patients in the early palliative phase. However, these challenges should not preclude an open dialogue with patients and families.

Limitations
As this article reports a single-site, qualitative study of central palliative concepts in a Danish hospital, further research in other hospital settings may allow for an exploration of the themes developed here.

The identification and explicit communication of transitions in incurable illness trajectories turned out to be a critical factor for the quality of palliative care in this hospital setting. However, the study also highlighted other factors in need of attention, namely identification and relief of the physiological, psychological, existential and social aspects of suffering; dialogues with patients in order to bridge between illness, life and death; care and support for families; professional development; multidisciplinary approaches, and the institutional and organizational framework for palliative care.

Conclusion
Different clinical phases within incurable illness trajectories are based on different treatment and care strategies. It is essential that the transitions between the different clinical phases are identified and explicitly communicated to patients and families in a dialogical way. Improvement of the quality of palliative care in hospital settings may be contingent on interventions taking into account these critical factors. 

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