

# Managing risk during care transitions when approaching end of life: A qualitative study of patients' and health care professionals' decision making

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## Abstract

**Background:** Increasing importance is being placed on the coordination of services at the end of life.

**Aim:** To describe decision-making processes that influence transitions in care when approaching the end of life.

**Design:** Qualitative study using field observations and longitudinal semi-structured interviews.

**Setting/participants:** Field observations were undertaken in three sites: a residential care home, a medical assessment unit and a general medical unit in New Zealand. The Supportive and Palliative Care Indicators Tool was used to identify participants with advanced and progressive illness. Patients and family members were interviewed on recruitment and 3–4 months later. Four weeks of fieldwork were conducted in each site. A total of 40 interviews were conducted: 29 initial interviews and 11 follow-up interviews. Thematic analysis was undertaken.

**Findings:** Managing risk was an important factor that influenced transitions in care. Patients and health care staff held different perspectives on how such risks were managed. At home, patients tolerated increasing risk and used specific support measures to manage often escalating health and social problems. In contrast, decisions about discharge in hospital were driven by hospital staff who were risk-averse. Availability of community and carer services supported risk management while a perceived need for early discharge decision making in hospital and making 'safe' discharge options informed hospital discharge decisions.

**Conclusion:** While managing risk is an important factor during care transitions, patients should be able to make choices on how to live with risk at the end of life. This requires reconsideration of transitional care and current discharge planning processes at the end of life.

## Keywords

Patient choice, advanced and progressive disease, risk, hospital, community, transitions in care/transfer, discharge/admission

### What is already known about the topic?

- There are added health care needs at the end of life as patients experience an increasing number of disease-related problems and a functional decline in health.
- Transitions in care, from home to hospital and discharge from hospital, at the end of life can be complex requiring the involvement of many health care teams across hospital and community care settings.

### What this paper adds?

- When making decisions about transitions in care, an important consideration is the risks of remaining in/transferring back to home, and how these risks are managed.

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- Patients and health care professionals use the presence of community and carer services to inform decisions about risk and possible transfer to a different care setting.
- Patients and health care professionals take different approaches in managing risk: patients prefer to make choices about how to cope with risk, while decisions made in hospital are risk-adverse.

#### Implications for practice, theory or policy

- This study highlights how the concept of risk is used in decision making about transitions in care, raising the importance of more open dialogue between the patients and health care staff on discussing patient choice in this area of decision making.
- Further research is needed to understand how community-based staff and allied health professionals can be better integrated into decision making in this area.

## Introduction

Patients in the last year of life often have ongoing decline in health<sup>1</sup> resulting in increasingly complex health needs requiring management by multiple health care teams.<sup>2</sup> However, with evidence of fragmented care,<sup>3</sup> increased hospitalisations<sup>4</sup> and suboptimal clinical outcomes,<sup>5</sup> increasing importance is being placed on coordination of services for those with advanced and progressive disease.<sup>6</sup> Provision of care for this population is particularly important given the growing number of older people worldwide,<sup>7</sup> many of whom have increasing numbers of co-morbidities.<sup>8</sup> Health services therefore need to be integrated and seamless as patients transition across care settings.<sup>9</sup>

In the 12-month period prior to death, transitions between health care settings are frequent.<sup>10</sup> With studies demonstrating a minimum of two hospital admissions for patients in the last year of life<sup>6</sup> and 47% of patients being transferred across health care settings at least once during the last month of life,<sup>11</sup> it is unsurprising that such transitions result in increased patient anxiety at the point of transition<sup>11</sup> and increased mortality rates after transfer.<sup>12</sup> A more proactive approach has been advocated at this time, leading to the development of tools to assist clinicians achieve safe patient transition<sup>13</sup> and more coordinated service models.<sup>11</sup> While patient-centred principles of care coordination and continuity are emphasized,<sup>14</sup> it is recognised that economic pressures also impact on transfer decisions:<sup>15</sup> this is particularly pertinent given that costs of care in the last year of life are substantial.<sup>16</sup>

Research in care transitions at the end of life has mainly been conducted in North America and the United Kingdom: to date, this area has received little empirical exploration in New Zealand<sup>17</sup> with little context-specific evidence to guide practice. Given the increasing importance of providing effective and efficient health services across the life continuum (including the end of life), more work is required to identify the processes by which transitions in care occur and how decisions are made at this time. This study seeks to address this gap.

## Methods

A longitudinal qualitative study was undertaken over a 9-month period (January–September 2015) across three sites in New Zealand. Data collection methods used included field observation and interviews. Two in-depth semi-structured interviews (at recruitment and 3–4 months later) were conducted with patients known to have advanced and progressive disease and likely to be in the last 12 months of life. The study design was informed by previous work in this area.<sup>6</sup> The aim of this study was to describe how decision making influences transitions in care when approaching the end of life.

### Sample and setting

The study was conducted with health care professionals (HCPs) and patients in three New Zealand care settings: a rest home, a medical assessment unit and a general medical unit in a tertiary hospital. The three areas were geographically proximal to each other with patients transferring across sites. This facilitated longitudinal follow-up of participants. In recognising the role that carers have at the end of life and concern about the vulnerability of patients at this time, carer/family members were also present at, and participated in, the interviews, as requested by patients.

*Site 1: residential care home.* Site 1 is a 150-bed unit providing 24-h registered nursing care to respite patients and residents. This unit was a charitable, non-profit trust with a general manager and three care managers. In all, 120 staff members were employed. A range of HCPs provided care including two general practitioners, registered nurses, nursing assistants, physiotherapist, podiatrist, massage therapist and diversional therapist.

*Site 2: medical assessment unit and site 3: general medical unit.* The acute care sites (sites 2 and 3) were located in a tertiary hospital with a range of specialist and regional tertiary medical and surgical services. This 430-bed acute care hospital provided services for a population of

1 million people. In 2014, there were 61,716 hospital admissions with an average length of stay of 2.5 days per admission and a mortality rate of 1.5%. Nine medical teams consisting of consultants, registrar and house officers managed patients on sites 2 and 3.

Site 2 was a 24-bed medical assessment unit for patients expected to remain in hospital for less than 36 h. The aim of the unit was to reduce emergency department waiting times. In 2014, there were 5707 admissions to this department with an average length of stay of 2.9 days. A range of HCPs provided care including medical staff, registered nurses, nursing assistants, physiotherapists, pharmacists, occupational therapists, social workers and specialist nurses.

Site 3 was a 36-bed general medical unit providing services for a range of medical specialities including gastroenterology, respiratory, infectious disease and high dependency. In 2014, there were 1501 admissions with an average length of stay of 5.1 days. The ward was led by a charge nurse manager and a nurse educator. A range of HCPs provided care including medical staff, registered nurses, nursing assistants, physiotherapists, pharmacists, occupational therapists, social workers and specialist nurses.

### Data collection

In each site, a 4-week period of fieldwork was undertaken involving field observation and face-to-face interviews. Patient, carer and HCP perspectives on transfers in care were gathered through observation, formal (audio-recorded) and informal field interviews. Patient participants had advanced and progressive illness with high risk of dying in the next 12 months. They were identified by the patient's doctor (sites 2 and 3) or nurse manager (site 1) using the validated Supportive and Palliative Care Indicators Tool.<sup>18</sup> Initial patient approach was made by these gatekeepers who had been well-briefed on the study, and who then informed the researcher of possible participants. This led to the initial study discussion between the potential participant and the researcher (R.P.). Written consent was then obtained prior to the recorded interview and a process consent model was adopted.<sup>19</sup> Two semi-structured formal interviews were conducted with patients using developed interview guides. The first interview occurred on recruitment and explored the patients' diagnosis, prognosis and care journey to date. These occurred at the bedside or in meeting rooms on site. The second interview (after 3–4 months) focused on patient's experiences of ongoing care and transitions and mainly held in the home setting. If patients requested carer involvement in interviews, study information was discussed with R.P., and written consent was obtained.

Four weeks of fieldwork was conducted in each site. The study was presented in advance at medical and nursing ward meetings where study documents were available. In the field, the researcher role of complete observer<sup>20</sup>

was adopted by R.P. Through this, an emic perspective about the thoughts, beliefs and behaviours of patients, carers and staff member participants during transitions in care was obtained. Episodes of care concerning transition to another setting, for example, admission and discharge rounds and discussion with patients and families about transfer, were examined. Contact with medical on-call teams and the nurse-in-charge at the start of each day helped direct field observations. Contemporaneous field notes were written detailing observations and informal interviews undertaken with staff across a range of disciplines; 2- to 3-h periods of observation were undertaken followed by a break. Two main periods of observations were conducted each day. Due to the large number of staff involved and the unpredictable nature of the fieldwork, verbal consent was sought from each staff member prior to each field observation period.

### Data analysis

All interview and field data were transcribed, interviews checked against audio recordings (R.P.), anonymised and imported into qualitative software (NVIVO). Initial data coding was undertaken by R.P. All data were read line by line and re-read. Data were then systematically compared for similarities and differences within and across the data and coded accordingly. Codes were then reviewed for similarity and differences and collated together to develop representative themes.<sup>21</sup> Two authors (M.A.C. and R.P.) met at the end of initial data analysis to verify the developed codes. A further discussion occurred towards the end of data analysis to refine and verify the identified themes. The third author (K.d.V.) validated the developed coding scheme through review of one in every six interview transcripts. All team members met for a detailed discussion about the data analysis, the developed codes including testing against any conflicting data, and agreed the final themes.

### Ethics and governance

Ethics approval was gained from the Regional Advisory Group – Māori (ref. no. RAG-M 2014/346), the Health and Disability Ethics Committee (Southern Health Region) (14/STH/180) and Victoria University of Wellington Human Ethics Committee (RM 21627). Local site approval was given to access and collect data. All site-specific research governance procedures were upheld.

### Findings

Across all sites, 12 weeks of fieldwork were undertaken. Interviews were of 15–45 min duration. A total of 40 interviews were conducted: 29 initial interviews and 11 follow-up interviews (Table 1). Carers were present at six interviews. A total of 18 participants were lost to follow-up due to

**Table 1.** Participant demographics.

	Site 1: residential care home	Site 2: medical assessment unit	Site 3: general medical unit	Total
<b>General information</b>				
First interview	7	11	11	29
First interview with carer	3	3	0	6
Second interview	6	3	2	11
Second interview with carer	2	1	0	3
Male	3	6	4	13
Female	4	5	7	16
<b>Ethnicity</b>				
Maori	0	1	2	3
NZ European	6	7	8	21
Other	1	3	1	5
<b>Age (years)</b>				
50–59	0	2	0	2
60–69	0	3	3	6
70–79	0	0	3	3
80–89	3	3	4	10
90+	4	3	1	8
<b>Medical diagnosis<sup>a</sup></b>				
Cancer	3	1	5	9
Neurological	3	1	0	4
Respiratory	0	7	4	11
Cardiac	2	7	1	10
Other	1	0	2	3
<b>Attrition</b>				
Deceased	0	5	5	10
Unable to contact	0	1	4	5
Withdrew	1	1	1	3

<sup>a</sup>Many patients had multiple co-morbidities so the numbers exceed the number of patients recruited.

withdrawal ( $n=3$ ), inability to contact ( $n=5$ ) and death ( $n=10$ ). Participants were aged 51–98 years and had a variety of medical diagnoses. Data excerpts are presented from interview with patients and carers together with contemporaneous notes of informal interviews held with staff during fieldwork. These were particularly concerned with events and activities observed during post-admission ward rounds.

Findings from this study demonstrate that a key influence on decision making during transitions in care was how risk was managed. This was especially evident at critical junctures when patients were considering transfer from home to hospital/rest home and during discharge planning from hospital. Patients and HCPs preferred managing risk differently in their decision making with patients making choices about coping with increased risk at home and HCPs making decisions based on minimising risk.

### *How patients managed risk in decision making about transitions in care*

Patients in the last year of life expressed preference to stay at home. Even when in hospital or rest home, patients

spoke about the importance of home and what it meant to them. In wanting to stay at home, patients often chose to cope with increasing risks at home, rather than being admitted to hospital. In this study, all patients stated that they had made the decision about their admission into hospital. This was also the view held by carers. This decision was informed by weighing up the importance of being at home with whether patients felt they could manage the increasing risk of staying at home: 'I live alone but I decided that I'd had enough and I was having too many freaky happenings for me to be at home so that's when I said yes I agree to go in' (General medical unit – Patient R).

Risks associated with staying at home were managed through increasing use of practical resource, mainly equipment and carer support and by the patient anticipating future needs. Patients talked about equipment (e.g. bedpans, commode, walking aids, wheelchairs, personal alarms) which helped them to stay at home enabling activities of daily living to be undertaken. This minimised perceived risks and was seen to prevent hospital admission. As the patients' condition advanced/deteriorated, different

pieces of equipment were sourced to manage the associated risks and enable the patient to remain at home:

... she bought her a stroller as well but unfortunately the stroller had been sitting at home for two years and she refused to use it because she was still independent until one day she realised, I think she had a fall ... and she started using it. (Medical assessment unit – Patient + carer M9)

With increasing ill-health, carers played a vital role in enabling patients to stay safe in their home. The carer's role in enabling patients to stay at home was often acknowledged, as was the impact of this: 'She's been here. So she's put her life on hold' (General medical unit – Gen K). The level of carer involvement increased over time with carer burden often seen as the tipping point for admission to hospital:

And this went on for some time until finally the burden in my opinion was too much on my children so I got them to ring the doctor and they came and assessed me. (General medical unit – Patient B)

Anticipating future needs and making appropriate changes helped patients cope and remain at home. This planning ahead often involved patients emotionally preparing themselves for change. For example, one patient (General medical unit – Patient L) likened her change in accommodation to a divorce with downsizing and the inevitable loss of possessions. Patients who spoke of preparing themselves in advance of a deterioration in health made adjustments within their existing home to keep themselves safe and able to stay at home: 'I've got a little bit of money ... so I've spent about half of that on the bathroom because I just couldn't get in and out' (General medical unit – Gen K). Patients who were able to do this were less likely to choose to be admitted to hospital. However, if the deterioration was too sudden, patients were unable to adjust quickly: 'sometimes you get a chance to think ahead and other times the disease comes too quickly' (Residential care home – Carer Res C).

### *How HCPs managed risk in decision making about transitions in care*

HCPs' decision making about discharge from hospital was driven by a goal of minimising risk to the patient. The primary purpose of HCPs' communication with patients and carers was to elicit information in order to establish risks associated with discharge home. Issues that influenced HCPs' perception of this risk included carer involvement, provision of community resources and need for early discharge decision making. If these issues could be managed to a point that HCP perceived the risk of discharge to be low, the patient was discharged home. If, despite attempts to manage these, HCP perceived the risk to be high, the

patient was discharged to a rest home. At times, the internal hospital bed pressures and inability to assess patients in their home setting meant that the least risk-adverse option of admission to a rest home was selected. In making safe discharge decisions, staff felt, as illustrated in these field notes, that they were fulfilling their duty of care: 'The nurse has just finished discussing discharge options with a patient'. She said 'she wants to go home and I understand that but we have a responsibility too' (Field notes – General medical unit).

The presence (or lack of) a carer was an important consideration when assessing risks associated with a discharge home. If a patient did not have a carer or the carer lacked capacity to carry out the required caring duties, HCPs would choose not to discharge patients home. This fact was well recognised by patients themselves:

Well see I'm not here [residential care home] because of me, well, there's nothing wrong with me really, it's because \*wife's name\* couldn't look after me and put a big strain on her. (Residential care home – Patient Res B)

The provision of necessary community services was a further factor that minimised HCPs' perception of risk and supported transfer home. A lack of community resources often meant that the risk for discharge was perceived by HCPs to be too high, whereas if community services were available to meet patient need, this minimised risk and supported transfer home:

I got out [of hospital] and the specialist or the consultant who was leading my case insisted on homecare support through first the hospital board and then the Ministry of Health so I get a helper come in three times a week for a shower assistance. (Medical assessment unit – Patient M6)

Patients, allied health professionals (e.g. physiotherapists, social workers) and community discharge coordinator nurses spoke of the perceived need for early discharge decisions in hospital and that this resulted in premature patient discharge to a care home. Early discharge decisions were made due to perceived bed pressures and before patient 'recovery' had occurred. This often resulted in HCPs deciding that discharge home was too risky:

As I am leaving the ward, the nurse tells me she's worried about [patient identifier]. Safety wise, worried that she's going home on a Friday, wants to assess her standing. I feel like I've had a bit of a revelation and feel like I understand the perspective of the patients. It is as if she doesn't know if this patient can be trusted on her own, in her own home. (Field notes – General medical unit)

Patients understood that decisions were being made based on risk and that the choice was between discharge home and to a care home. As a result, patients felt pressurised to make premature decisions: 'Obviously I felt



pressured to leave ... I understood what he was saying ... you're going to have to go into a rest home' (General medical unit – Patient L). Others knew of the risk of being admitted into a rest home, and therefore chose not to share their concerns about returning home: 'I worry about things like the falling over thing. But I don't want to mention it too much because they'll say oh well you'll have to live in a rest home or something' (General medical unit – Patient K).

Allied health professionals and community discharge coordinator nurses spoke of how discharge to a rest home was often seen as the easy option where the risks of discharge home could be mitigated: 'the word rest home gets thrown around really quickly' (Field notes – occupational therapist). This was evident during one post-admission round where the occupational therapist challenged a doctor planning for admission of a patient to a rest home: 'Why are you asking for my assessment if that was your plan all along' (Field notes – occupational therapist).

There was a perception that once in hospital, discharge home with risk was not acceptable: 'Once health care professionals are involved they are adverse to risk. Everyone lives risky lives, the older people have a right to live risky lives just as the young do' (Field notes – community discharge coordinator nurse). This informed a view held by some that 'we should always trial a package of care in community. We can always assess in community'. And that 'I'd much prefer they sent people home who are risky cos it's much easier to sit in the middle of disaster and talk about rest home' (Field notes – community discharge coordinator nurse). The rapid decision making of discharge to a rest home was seen by as 'a flaw in the system' (Field notes – rest home). Following one post-admission ward round, a social worker (Field notes – medical assessment unit) commented about one patient: 'An 88 year old lady, unresponsive episodes, unknown cause. Handover says home help but she says she completely independent. Why does she need rest home? If the person is sick and if allowed to recover, they could go home'. It was felt that earlier referral to allied health professionals who could assist in rehabilitation and to community staff who were key to facilitate discharge and who knew of the patient's home environment would mitigate some of the risk.

## Discussion

In this study, decisions about care transitions at the end of life were informed by assessments of risk. However, the concept of risk in this context was ambiguous, and one that was constructed, understood and responded to in different ways. Patients nearing the end of life and HCPs use different approaches to manage risk when making decisions about transitions in care. Patients make decision about admission to hospital based on whether to cope with increasing risk at home, in contrast to HCPs who are

involved with making decisions about discharge from hospital based on mitigating risk of discharge home.

There were similar areas of risk considered by patients and health care practitioners with availability of equipment, community service provision and carer support clearly important. These are well-recognised enablers<sup>22</sup> that maintain patients at home and facilitate discharge back home.

However, there were differences in how risk was perceived when making decisions about transitions in care. Whereas patients (and to an extent, non-medical health care staff) made risk assessments based on the right to choose with live at risk and with risk, medical staff appeared to make decisions based on avoidance of high-risk consequences associated with transfer, hence making the 'safe' option to a rest home.

In making such risk-averse discharge decisions, it could be construed that HCPs continue to disregard the patient's voice<sup>10,23</sup> indicating that further work is required to realise international health policy vision<sup>24–27</sup> of recognising patient choice in care.

However, decisions about transitions in care at the end of life, especially from home to hospital and hospital to home, are complex and need understanding of how disease trajectories impact on the patient at home<sup>23</sup> with realistic perceptions to be held by patient/carers of managing at home.<sup>28</sup> Comprehensive home care programmes involving community-based staff<sup>2</sup> and earlier interdisciplinary rehabilitation fully engaging with allied health professionals<sup>14</sup> are also needed to facilitate timely transitions. It is also important to recognise that inappropriate transfer decisions can have negative and distressing consequences on patients and carers (professional and lay) and place further drain on limited health resources.

The relationships between perceived organisational bed pressures, premature discharge decisions and the drive for a safe discharge destination are complicated. With widespread acknowledgement of the negative impact of increased lengths of stay and delayed discharges on patients and the health care system,<sup>29–31</sup> it would appear that similar international drivers are influencing New Zealand health care practice.

However, perception of risk is subjective with studies demonstrating that risk of familiar events (e.g. as at home) is frequently underestimated with high consequence risk (e.g. fall at home resulting in fractured femur) frequently overestimated.<sup>32</sup> Given this, the most striking finding in this study was the different mental models held about risk and how to manage risk during transitions in care. Two different approaches were identified: how patients made decisions to cope/not cope with risk at home, even if that meant living in less than ideal circumstances, or that risk at home was something to be mitigated by HCPs. The principal difference between these two positions is acknowledgement of the right for someone to choose to live with

risk. This positions a person as having free will and autonomy to make a rational choice to live with risk, albeit with the associated responsibilities clearly laid out.

Achieving this in practice is more problematic given the lack of guidance on how people can make such informed decisions at a vulnerable time. This requires a language to be developed to make clear responsibilities of the patient and develop discharge planning processes that enable options that may be 'less safe' but of preference to the patient, to be followed through. Certainly, a shift to complete community models of care<sup>33</sup> with focus on shared decision making and interdependence has potential to work towards this. Developing honest information exchange about transition options and risks involved could potentially minimise risk-averse approaches in discharge decision-making processes, a feature evidenced elsewhere in the literature.<sup>6,34</sup>

We know what principles need to be embedded into models of care to recognise patient choice at this time. The importance of listening to and hearing the discharge preferences of patients and carers<sup>10,35</sup> results in HCPs providing more individualised and tailored information.<sup>23</sup> We suggest that this approach needs further development to establish a collaborative process where risks associated with transfers are recognised,<sup>36</sup> and where patients, at the end of their life, are recognised as competent adults empowered to take responsibility for their choices.<sup>24</sup>

## Strengths and limitations

Details of the research processes used during data collection and analysis enabled assessment of the study's trustworthiness. Provision of site details, recruitment procedures, application of rigorous research methods, analytic strategies and quality checks builds on the study's credibility, dependability and transferability. This study had several limitations that require noting. Data collection was limited to one tertiary site and one rest home in New Zealand. Further research engaging with community-based staff who may hold different perceptions on decision making about admission to and discharge from hospital is required. Furthermore, the sample size may not have been adequate to capture the full range of experiences of the population. A substantial proportion of the sample was lost to attrition with in excess of one-third of the sample dying prior to the second interview. Despite this, there was evidence of data saturation.

## Conclusion

Decisions about managing risk during transitions in care for patients nearing the end of life should be a collaborative process involving patients and HCPs. Solutions need to be developed that recognise different mental models of risk and acknowledge that patients may make choices to live at risk.

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