



Who will make it home to die—an editorial on a new validated tool

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Introduction

This new Japanese study by Nakajima *et al.* titled 'Diagnostic accuracy of a predictive scoring tool for patients who are eligible for home discharge from a palliative care unit' describes the development of a predictive scoring tool to identify patients dying of a malignant disease that can be discharged from a palliative care unit, and achieve a home death (1). This is the first paper to formulate and validate a predictive tool for patients discharged from a palliative care unit that may achieve a home death. Two conditions need to be considered: the patient survives their palliative care unit stay and can have a home death. While the clinical importance of such a tool is easy to see, a single predictive tool may be challenging due to cultural, geographical and structural variations.

Factors associated with place of death

There is often a mismatch between patients' preferred place of death and actual place of death, with fewer patients dying at home than fulfilling their preference for home death (2,3). There is also a growing recognition that the place of death is distinct from the place of care, and these preferences change with time (3). Four systematic reviews have explored the factors that predict home death (4-7). All describe substantial variability among results and weaker study designs, which could partly be attributed to the difficulty of having robust

study design in this setting (5). One of these reviews developed a framework for how the different factors may interact (4). They identified three categories of factors: those related to the patient's illness, individual, and environmental factors. Illness factors include disease trajectory, symptoms and functional status. Individual factors were more fixed and related to patients' core values and beliefs, such as gender, demographic variables and patient preferences. Environmental factors encompass patients' social supports such as caregiver availability, experience, and preferences for location of care. Environmental factors also included the healthcare supports available in a patient's geographical area, particularly service from the palliative care community team. These factors are summarised in *Table 1* below.

What tools exist to identify patients likely to achieve a home death?

Whilst there are several tools to assist with the prognostication of patients (8), few tools answer the specific questions of which patients can be discharged from a palliative care unit who can have a home death. Some studies have identified the outcomes of those discharged from the palliative care unit (9,10), which may include the location of death.

Other than the study by Nakajima *et al.* (1), two other studies that have developed predictive tools to identify patients more likely to achieve home death will be discussed

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Table 1 Summary of factors associated with place of death

Categories	Variables	Factors	Most likely location of death
Factors related to illness	Type of cancer	Non-solid tumours (leukemia/lymphoma)	Hospital
		Lung cancer	No effect
		Prostate gastrointestinal tract, breast	No effect
	Non-malignant diseases	Cardiovascular disease [¶]	Hospital
	Dying trajectory	Long trajectory of disease	Home
		Low functional status	Home
	Symptoms	Fatigue/weight loss/weakness/dyspnoea/breathlessness/nausea/vomiting/psychological	No effect
Individual factors	Demographic variables	Pain	No effect/home
		Good social conditions	No effect
		Ethnic minorities	Hospital
Environmental factors	Personal variables	Sex	No effect
		Patient preference	Home
	Health care input	Use of home care	Home
		Intensity of home care	Home
		Availability of home care	Home
		Availability of inpatient beds	Hospital
		Previous admission to hospital	Hospital
		Long length of admission	Hospital
		Community and family physician support	Home
		Rural environment	Home
		Areas with greater hospital provision	Hospital
		Timing of referral to palliative care prior to discharge <8 days [¶]	Home
		Involvement of multidisciplinary palliative care community team [¶]	Hospital
		Social support	Living with relatives
Extended family support	Home		
Being married	No effect		
Caregivers' preference	Home		
Congruence between patient and family preference versus no preference [¶]	Home		
Caregiver age	No effect		
Macrosocial variables	Caregivers sex	No effect	
	Caregivers' relationship to patient	No effect	
	Historic trends	Home/hospital	

Table modified from Gomes *et al.* (4) with permission from copyright holder BMJ Publishing Group Ltd. Addition information ([¶]) from Costa *et al.* (7).

here (11,12). The first study, a prospective Spanish study from Alonso-Babarro *et al.* (11), sought to develop a decision-making model after identifying factors associated with at-home death among patients with advanced cancer who received care from a palliative home care team. When three variables, the caregiver's preferred place of death, the patient's preferred place of death and the caregivers' perceived social support, were included in the model, it had a sensitivity of 96% and a specificity of 81% in predicting the place of death (11). The C-statistic of the model was 0.94. The C-statistic, also known as the concordance statistic, measures how well a risk algorithm performance can distinguish subjects who will develop an event- in this case, who will die at home. Models with a C-statistic higher than 0.7 are considered reasonable, and greater than 0.8 are considered strong (13).

The second study, a Japanese study from Fukui *et al.* aimed to determine the predictive value of a clinical tool to predict home deaths in discharged patients from acute hospital care hospitals in Japan (12). The tool was derived initially from the Japanese version of the Support Team Assessment Schedule (STAS-J), which measures patient symptoms, anxiety and insight, family anxiety and insight, quality of communication with health care professionals and carers and the need for practical support (14). When the authors included five variables such as patient's and caregivers' preferences for home death, availability of visiting physicians, 24 h contact between physicians and nurses, whether a caregiver had a previous experience of watching someone die at home, and patient's insights as to their prognosis into their model, home death was predicted with a sensitivity of 72% and a specificity of 81% with the C-statistic of 0.84.

What's different about the Nakajima study?

The Nakajima study focused on patients with cancer who were discharged from palliative care units rather than patients who were known to palliative home care services or discharged from an acute hospital (11,12). It included 5 factors in their model, including two patient illness factors, such as caloric intake on the day of admission and symptoms that resulted in hospitalisation, which was not fatigue, one individual factor, such as sex; and two environmental factors, such as the availability of daytime carers and the family's preferred place of care. It had a C-statistic of 0.949, signaling a strong model. It used a training-test procedure to validate their model (1), which was not done in Alonso-

Babarro *et al.*'s (11) and Fukui *et al.*'s (12) studies.

Key considerations in Nakajima's study

Whilst illness and individual factors are discussed below, an emphasis is placed on environmental factors as modifiable variables.

Illness factors: symptoms

Symptom burden and management, a key element of palliative care provision, was included in Nakajima *et al.*'s study but not in Alonso-Babarro *et al.* and Fukui *et al.*'s developed predictive tools (11,12). Symptoms were not asked in Alonso-Babarro *et al.*'s study and did not reach statistical significance in the univariate analysis in Fukui *et al.*'s study. The results of other studies that have examined symptom factors associated with a home death have been variable; one Canadian study found that patients admitted for symptom control were more likely to be discharged home, with patients with more severe symptoms being more likely to die in an acute palliative care unit (15). Another Japanese study found the presence of delirium to be associated with home death and the presence of symptoms such as breathlessness and pain to be associated with in-hospital death (16).

Individual factors: sex

Being of the female gender is a novel independent factor with the lowest odds ratio in Nakajima *et al.*'s study that has not been identified in previous studies (4,11,12,17). The authors of this study hypothesise that female patients were more likely to have children as caregivers than spouses and therefore younger and more capable of physical care than elderly spouses.

Environmental factors: caregivers and local health services

All three studies, Alonso-Barro *et al.*, Fukui *et al.*, and Nakajima *et al.*, identified several factors related to the caregiver (11,12), including their preferred place of death for the patient and support for the caregiver or the availability of the caregiver. However, it is unclear which caregiver factors are most important and how to distil this into a simple question. All three studies explored how much support caregivers have by asking if other assistance was provided to family caregivers or if there was a daytime

caregiver.

Nakajima *et al.* did not include local health care or palliative care services as a factor associated with home death (1). The study did mention that active home discharge services are part of usual care, although it was unclear what services are provided. Alonso-Barro *et al.* and Fukui *et al.*'s studies explored these factors with Fukui *et al.*, including the availability of physicians able to make home visits and 24-h contact with the community team being available in their model. Alonso-Babarro *et al.* demonstrated that the number of community team home visits as a percentage of the total number of days linked to the service was associated with home death. Previous research has shown that involvement of the palliative care team increases the likelihood of home death (18,19). The timing of referral to palliative care before discharge is also associated with home death, with referral needing to occur at least 8 days before discharge (20).

Environmental factors-routine clinical practice or culture

Environmental factors, such as routine clinical practice or culture, may influence the tool's usefulness. For example, caloric intake is not routinely measured reliably in all healthcare settings. This requires training or resources to initiate routine measurement by staff, often time-poor in a busy ward. Family dynamics and set-up are strongly influenced by culture and may differ between Western and Eastern cultures. Some ethnic groups may place more importance on family units and caring for elders and have different approaches than Western cultures (21). In Western cultures, patient preference may be more critical in determining the location of death (12). This would affect the relevance of factors included in the tool in different cultural settings and may affect the question about the female gender as fewer children care for parents in Western culture. However, caregiving dynamics are changing (22). Western cultures may have other supports, such as the availability of personal care workers, that have also been shown to increase the likelihood of having a home death (17).

What are the implications of this study?

It is easy to see the utility of a predictive tool to help clinicians determine which patients are most likely to discharge home successfully, particularly in an environment with growing demand for palliative care inpatient admissions, community involvement, and finite hospital

resources. Clinicians could refer the patients earlier for allied health assessments and arrange for community support, potentially resulting in shorter inpatient admission and a higher probability of being discharged home and remaining at home. When clinicians can confidently identify which patients can be discharged home, targeted preparation for caregivers can be initiated earlier. Caregivers may consider being involved in more hands-on caregiving whilst the patient is still in the hospital, such as being trained to give subcutaneous medications or learning to care for a bedbound patient. The importance of the caregiver and support for the caregiver is clearly demonstrated in Nakajima *et al.*'s study and other studies for patients who achieve a home death (1,11,12). This has critical implications for health service delivery and policymakers considering supporting or investing in community services.

This tool also has important implications for those identified as less likely to go home at the start of the palliative care unit admission. It provides objective support for clinicians to facilitate discussions around potential end-of-life care in the unit or other options for the place of care. However, there are some limitations to the applicability of this study.

Other considerations which this study does not address

Non-malignancy status

Most studies, including the Nakajima study (1,11,12,15), have only focused on patients with malignancy. There has been an increasing awareness that patients with non-malignant diseases have similar symptom burdens, need palliative care and are increasingly referred to palliative care services (23,24). It would be essential to know if such factors and tools were relevant to patients with non-malignant disorders known to the palliative care service.

Residential aged care facilities

It is unclear if the Nakajima study considers a residential aged care facility as the patient's home if that was their place of care before palliative care unit admission. Indeed, the Nakajima study does not address predicting a death in an aged care facility. A tool that could predict death in an aged care facility rather than a home death may be useful given that, internationally, many deaths occur in aged care facilities (25).

Conclusions

In conclusion, this is an important study providing clinicians with a tool to identify which patients could be discharged home at the time of admission to a palliative care unit, guiding clinicians, patients, and their families about the potential outcome at the end of a palliative care unit admission. The tools may need further validation in other geographical areas with cultural and healthcare services differences. More than just aiding physicians to predict those patients more likely to achieve home death, such research would assist policymakers in determining where changes can be made at a system level to help more patients achieve home death.

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