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## Transitioning to Life in a Nursing Home: The Potential Role of Palliative Care

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### Abstract

**Background and Objectives:** Transitioning to a nursing home (NH) is a major life event for 1.4 million NH residents in the United States. Most post-acute NH admissions plan for rehabilitation and discharge home, but with nearly 70% of NH residents being palliative care (PC) eligible, many evolve into long-term placements secondary to poor health and associated decline in function and/or cognition. This article describes the perceptions of NH PC-eligible residents and families transitioning to life in a NH.

**Methods:** Residents at 3 NHs in Northern California (N = 228) were screened for PC eligibility. A convenience sample of PC-eligible residents and their family members (n = 28) participated in qualitative interviews that explored the experience of living as a NH resident with serious illness. Data were analyzed using grounded theory methodology.

**Results:** Our study provides insights into the experiences of transitioning to a NH from the perspectives of PC-eligible residents and their families. These data describe how PC-eligible residents and their families experienced disempowerment as they perceived being left out of decisions to go to a NH, loss of autonomy once at the NH, dealt with the realization that they would not be going home, and described perceived barriers to going home.

**Discussion and Implications:** The inclusive and person-centered model of care that PC provides naturally empowers residents and family members. Adequate provision of PC services, together with changes in policy related to NH culture and benefit management, could improve the experience of transitioning to a nursing home.

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Declaration of Conflicting Interests

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## Keywords

care transitions; nursing homes; palliative care-eligibility; post-acute care; person-centered care; disenpowerment

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## Background and Objectives

Despite many older adults expressing a preference to live in their community and die at home, the transition to living and dying in a nursing home (NH) is often inevitable.<sup>1</sup> Nursing homes are a key part of the palliative care (PC) continuum, where 1 in 4 older Americans die each year.<sup>2</sup> Nursing home placements are a major life event for more than 1.4 million NH residents in the United States, most admitted following a hospital stay with short-term goals of rehabilitation and discharge home.<sup>1,3,4</sup> Short-term stays often evolve into long-term care as a result of physical and cognitive decline or when needs exceed family capacity to provide care.<sup>1,5</sup> Long-term care costs were reported as US\$162.7 billion in 2016.<sup>6</sup>

Transitions from hospital to home that provide support and patient and family involvement in goals-of-care discussions have been shown to prevent lapses in care quality and safety.<sup>7</sup> However, research has found that these same interventions have not been implemented when transitions take place between hospital and NHs because of the complexity of personal and organizational conditions. Rather, patients and families describe chaotic transitions, feeling unprepared for transfer to a NH.<sup>8</sup>

It is therefore critical to understand the experiences of PC-eligible residents and families transitioning to life in a NH after an acute hospital stay. As part of a larger health system-NH quality collaborative to reduce hospital readmissions, we undertook a Palliative Care Quality Initiative. As part of that work, we conducted semistructured interviews with PC-eligible residents and families to better understand their symptoms, quality of life, and goals of care. In this article, we present key findings that emerged from these interviews relating to transitioning to life in a NH and the overarching theme of disenpowerment.

## Methods

Residents at three Northern California NHs (n = 228) were screened with input from nursing staff and medical record review to determine PC eligibility using the INTERACT “Identifying Residents Who May Be Eligible for Hospice or Palliative Care/Comfort Order.”<sup>9</sup> Chart data for all PC-eligible residents (n = 157) were abstracted, and a convenience sample of PC-eligible residents (n = 9) and family members (n = 19) of PC-eligible residents participated in semistructured interviews. Eligible residents were English-speaking and cognitively intact (Brief Interview for Mental Status (BIMS) score of >12). Eligible family members were English-speaking and regularly involved in residents’ care.

Inductive guidelines from grounded theory were used for the collection, synthesis, analysis, and conceptualization of qualitative data.<sup>10</sup> Questions included asking how symptoms were managed, plans about future health-care choices, and decision-making processes. Interviews were recorded and transcribed verbatim. Research team members met regularly to identify

and conceptualize patterns (codes, categories, and common themes) in the data through constant comparative analysis. Thematic saturation was reached when no new patterns emerged from the data. The interview guide iteratively evolved from this analysis and themes identified. Rigor was ensured through approaches that included methodological transparency, the collection of rich and sufficient data, and reflexivity that included discussion of preconceptions and biases held by the research team. This Palliative Care Quality Initiative was deemed by the institutional review board of University of California, San Francisco to be a quality improvement activity that did not require review.

## Results

Table 1 presents demographic data for 28 PC-eligible residents: those interviewed (n = 9) and those whose families were interviewed (n = 19). Residents' average age was 89.5 years, 68% of them were women, 64% identified as African American, and 36% white. Most of these residents (93%) needed total or extensive care in 3 or more activities of daily living. Their average BIMS score was 10 (range: 3–15) and 61% had a diagnosis of Alzheimer disease/dementia. None of these residents had a documented prognosis of 6 months or less, and all but one had a completed *Physicians Order for Life-Sustaining Treatment* on file, with 52% indicating a preference for full treatment. Fifteen of the 19 family members interviewed were women and were related to the resident as follows: child/stepchild (n = 7), niece (n = 4), grandchild (n = 3), cousin (n = 2), sibling (n = 2), and wife (n = 1).

### Feeling Disempowered

The overarching phenomenon of feeling disempowered permeated these data. Three themes evolved describing the experience of disempowerment: “perceptions of landing in a NH,” “a continuing perceived loss of autonomy once at the NH,” and “not going home.”

### Perceptions of Landing in the NH

The sense of arriving at the NH at a time of crisis without having had control or influence over events was a clear theme. For example, this resident described overhearing her hospital discharge plan: “...I heard them say: ‘I guess we’re going to send her back to [NH].’” Residents described the phenomenon of being *sent* to the NH, as in these examples: “My oncologist did tell me I was in remission. And he kind of had me sent here,” and “My doctor sent me here.”

This daughter described the inevitability of landing in a NH when describing her mother’s admission following a fall: “...it was very apparent that she was not able to go home, nor afford to pay for 24-hour help...”

There was an understanding among some participants that moving to the NH was necessary as health issues, involving functional status changes, made going home unsafe or unrealistic. Nevertheless, moving to a NH was seen as a last resort—a decision made for them at a time of crisis.

### Perceived Loss of Autonomy at the NH

Once at the NH, both residents and family members described feeling disempowered by being left out of decision-making. This phenomenon was reflected in the inability to control daily routines, like food choice: "...they can give you the same thing 3 or 4 times a day, and you can't do nothing about it," or room changes: "They move you, you know, and you don't even know when they move you." When talking about needing transport to keep a local appointment, one resident said: "...I think I could get up there by myself, but they don't want me to do that." Another key example involved a resident describing that the nurses "get mad at me" because: "...[I] don't take no water pill before I get ready to go out...you have to go to the bathroom...I've got my pride."

One resident referred to the "house rules," which he considered to be in conflict with the way he wanted to live life in what is his home. For example, he reported feeling upset when his own wishes were subjugated to the "house rules": "I don't get enough rest at night...and they don't like us to go to sleep during the day. They say that's the house rule...I don't show it, but I get unhappy."

Some family members also expressed frustration about not being involved in decisions at the NH: "They [NH staff] never tell me what to expect...I don't know what decisions they're making, but I don't feel like they involve me enough."

One granddaughter of a resident severely disabled after a stroke, recognized her grandmother needed NH care but expressed frustration that their wishes were not taken into account: "They tube feed her. They don't take the time to feed her. I feed her every time I go. She enjoys food. They don't try, and I think that takes away from her quality of life..."

The perceived loss of autonomy described by both residents and family was felt as a cumulative impact on their sense of control, leading to feelings of frustration, being disregarded, censured, helpless, and unhappy.

### Not Going Home: The NH as Permanent Home

Although moving to a NH was not perceived as a planned permanent placement, in many cases, the NH evolved into a permanent residence. Data revealed 3 themes relating to not going home: realization and acceptance that going home was not an option, ambivalence in accepting NH as home, and logistical and financial barriers to going home.

Families and residents attributed the need to remain in the NH to the same factors that drove transition from acute care to NH—the inability to return home and be safe without extensive support. This is illustrated, for example, by a man who describes his stepmother's placement in the NH as an improvement in the care he could provide at home where he was also caring for his father who had dementia:

I feel like they're doing better than what I was doing at home. I was the one giving her medicine. Is it the right one? Is it the right time? I was doing it all. It's a lot and I'm not certified...

Some residents expressed acceptance of placement at the NH, appreciating that their basic needs were being met, as in this example: “I kind of like it here. I’m not abused; I don’t see anybody else here being abused ...I get three good meals a day, and I don’t have to worry about being too tired to eat them.”

The understanding that the NH provided a level of safety that could not be achieved elsewhere was however compromised by ambivalence where even as the NH was described as the best or only option, residents still longed for home. For example, one daughter said: “Sometimes she [mother] says I just want to get out of here, I want to go home.” Family members described feelings of guilt at not caring for their own, as for example, this daughter stating: “...I let my mother down...” This guilt was compounded by the perceived stigma of placing a loved one in a NH. For example, speaking of her mother’s placement in a NH, this daughter said: “...people...say to me ‘you put your mother in a NH? How could you do that to her?’...they don’t know how difficult the decision was...”

Barriers to caring for loved ones at home included the level of care needed, caring for multiple dependents, work, living far away, and having dysfunctional, estranged and/or incarcerated family members. One participant, who lived in Pennsylvania, described feeling torn by multiple competing generational caregiving demands for her aging parents in New Hampshire, her aunt (resident) in California, and her own child: “I feel like I should be going to California; I feel like I need to go to New Hampshire ...I’m feeling torn. And I have a kid who’s a senior in high school.”

However, the most significant barriers to going home described were financial and included the costs of care, the inability to move to another NH without private pay insurance, and having no home to go to. This wife expressed her frustration also felt by others, saying: “... if I had the money, he would be home.”

Families described wanting to move their loved ones to other NHs, often closer to where they lived. This daughter told a compelling story about her struggles to reunite her family: “I’ve done my best to move my dad to...a facility in (home city)—because I want her (mom) to live with me. But I cannot find a facility ...that would accept him because he doesn’t have private pay insurance...”

Several residents told how they came from insecure housing or had lost homes and had no place to return to. The NH became the only secure option. One resident said he would like to stay in the NH as long as possible “...because I’m on social security. But it’s not enough... I’m not 100% destitute, but I’m pretty close.”

## Discussion

Our study provides insight into the experiences of transitioning to a NH from the perspectives of PC-eligible residents and their families. These data inform our understanding of how PC-eligible residents and their families experienced disempowerment as they perceived being left out of decisions to go to a NH, loss of autonomy once at the NH, and dealt with the realization that they would not be going home.

Participants in this study described perceptions of being left out of the decision to go from hospital to a NH. Although planned discharges are a legal and Medicare participation requirement, in the case of discharge to a NH, hospital responsibilities do not go far beyond supplying a list of NHs in a given geographical area.<sup>8,11</sup> Participants' descriptions of a perceived loss of autonomy when making decisions about NH placement is echoed in other studies that describe residents feeling unsupported, unprepared, physically vulnerable, and rushed on leaving hospital.<sup>8,12-14</sup>

Once in a NH, participants described continued perceptions of disempowerment that included not being consulted about decisions made, having limited choices, and being restricted by "house rules." These findings indicate that there remains a need to provide resident-centered care, improve communication, and set expectations for residents to mitigate feelings of disempowerment and grief for loss of home.

These data suggest that a paradigm that promotes post-acute care as a temporary place to achieve baseline health followed by a return to home is not always realistic for PC-eligible residents and their families, and alternative cultural models of post-acute care have not yet evolved.<sup>3,5</sup> Study findings also indicate that the goal of ultimately going home may be a default assumption made by residents and families in the vacuum created by disempowerment. Missing from our data were accounts of how the decision of transition to NH as a permanent home was reached.

Permanent NH placement was complicated when feelings of relief that the NH was a safe environment that could provide the required level of care competed with feelings of longing for home and the guilt and stigma of not taking care of one's own. This ambivalence is reflected in prior studies examining family carers' experience of NH placement.<sup>14,15</sup>

Insufficient financial resources, including not having a home to go to, and the need for 24-hour care with accompanying costs were strong themes in this study. These findings build on results from other studies that NH placement becomes a necessity when care needed exceeds a family's capacity to provide such care.<sup>1,5</sup>

## Limitations

This study has several limitations to consider. Our convenience sample was drawn from 3 NHs in 1 county in Northern California and may not therefore reflect the perceptions and experiences of NH residents and families in other places. Residents with communication deficits or cognitive impairment who were unbefriended were not eligible to participate. Some residents with cognitive impairment were given voice through interviews undertaken with their families. Our sample consisted of only African American and white participants despite our initiative being conducted in a very diverse urban setting. Nevertheless, while our sample was small, it provided rich qualitative data from 3 NHs with distinct cultures and organizational qualities.

## Implications

The implications from these data suggest much can be done to improve the experience of transitioning to life in a NH and perceptions of disempowerment described here. Transition from acute care to NH care should be viewed as an opportunity to reevaluate an individual's goals, values, and preferences rather than focus on Medicare-funded goals of improvement through rehabilitation that may not be patient-centered or realistic.<sup>3</sup> Given that nearly 70% of NH residents are eligible for PC and few receive it,<sup>16</sup> this PC approach may ameliorate the feelings of being disempowered expressed by these study participants through involvement in discussions that would focus on quality of life and associated improvements in care and satisfaction.<sup>17,18</sup> Improving access to PC would require education for providers in both acute and NH settings and improving NH staffing levels.<sup>19</sup> Given the effectiveness of PC consults in NHs<sup>20</sup> but the shortage of PC specialists,<sup>21</sup> telehealth, that is becoming increasingly familiar, accessible, acceptable, and reliable, has a promising role to connect NH residents and families to the care and support they need<sup>22</sup> and such care innovations need to be further explored.

Nursing home environments need to be places where residents and their families feel safe to advocate for themselves and their loved ones. To that end, the promotion of the NH Culture Change Movement to improve quality of life for residents through reimagining NHs as resident-centered environments should include support from NH owners, extensive education and training, and funding for innovations and quality research.<sup>23</sup>

Our understanding of the experience of transitioning to a NH remains limited and further research needs to focus on care coordination and transition to post-acute care. Such research could inform policy changes that prioritize resident-centered PC over financial decisions and explore realistic support for appropriate discharges. For others, whose circumstances make a return home impossible, NH care must be required to provide a home for residents where they feel safe, respected, and empowered.

## Conclusions

This study highlights key themes identified by PC-eligible residents and family members who described feeling disempowered and unprepared for what may ensue after an acute care hospitalization. Implicit in these findings is that by using a resident-centered approach, residents and their families should be more integrally involved in the decisions about placement. If returning home is not an option, NH residents and their families need to be prepared for a long-term NH stay by being made aware of prognosis, expectations for care, and planning for the future.

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**Table 1.**Characteristics of Palliative Care–Eligible Nursing Home Residents.<sup>a</sup>

Average age (years)	89.5
Female	68%
Married	21%
Race/ethnicity	
African American	64%
White	36%
Diagnoses	
Cancer	11%
Heart failure	32%
Alzheimer disease/dementia	61%
Chronic obstructive pulmonary disease	18%
Extensive/total assist in 3+ ADLs	93%
Cognition	
Average BIMS (range)	10 (3–15)
Depression	
Average PHQ-9	2
Presence of pain	29%
Average # of medications (range)	18 (3–30)
Prognosis <6 months <sup>b</sup>	0%
POLST completed	96.4%
POLST preferences	
Full treatment	52%
Selected/limited treatment	30%
Comfort focused treatment	18%
% Readmitted to hospital	30%

Abbreviations: ADL, activities of daily living; BIMS, body mass index; PHQ-9, Patient Health Questionnaire; POLST, Provider Orders for Life-Sustaining Treatment.

<sup>a</sup>n = 28.

<sup>b</sup>Determined by the minimum data set.