A Descriptive Study of Losses Associated with Permanent Long-term Care Placement

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No grant support was received during the conduct of this study.

ABSTRACT

Objectives: This qualitative study describes the process of and factors associated with losses connected to permanent long-term care (LTC) placement of the elderly.

Methods: Five subjects were recruited on a voluntary basis upon consultation with a staff member of a small rural long-term care facility in Northeast Arkansas. Researchers conducted 1 to 2, hour to hour-and-a-half interview sessions with each participant. In order for subjects to be included in the study, participants met the following criteria: placement within the past 12 months, absence of acute disease, and cognitive ability to respond to and communicate during interview sessions. The interviews were taped with the patients' consent, and then transcribed word for word. The transcriptions were analyzed for emergent themes using the grounded theory approach.

Results: Qualitative analysis revealed several themes related to losses associated with LTC placement. These include: cohort losses, defined as losses that participants identified with as a cohort through lived experiences; antecedent losses, defined as losses that have contributed greatly to long-term care placement; and consequent losses, defined as losses that have been experienced as a consequence of placement.

Conclusion: The cumulative nature of losses that eventually results in LTC placement is an important consideration in geriatric physical therapy practice. The study highlights the physical therapist's role in prolonging function, preserving quality of life, and preventing for as long as possible LTC placement. Losses identified as leading to LTC were found to be in alignment with current research. Transitioning to LTC may interfere with the need to attend to end-of-life role expectations, resulting in the experience of additional loss. Gender-related differences appear to be significant as well, with males expressing a marked sense of loss of meaningful activity.

Key Words: long-term care, placement, transition, permanent losses

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INTRODUCTION

Residents in permanent long-term care (LTC) are an important client group for the practice of physical therapy. There are roughly 2 million nursing home residents and over 1.5 million people in assisted living homes--a number that is expected to double by 2020.[1,2] This statistic is not unlike the growing trend among the elderly population, which documents a rise in the number of the elderly. By the year 2030, it is predicted that the age group over 65 will comprise 20% of the American population, or 71.5 million people, which is roughly twice the number of today.[3,4] Those aged 85 and over are projected to increase from 4.6 to 9.6 million in the same time frame. As this population increases, so will their demand for health care services, including physical therapy.

The decision for admission to a long-term care facility may be planned or unplanned, positively or negatively perceived, and made by self, others, or a combination thereof. The permanent shift to a LTC facility may be associated with a loss of independence, as well as a downturn in quality of life.[2] Choices made under planned versus unplanned circumstances may affect initial adjustment responses to the LTC environment.

According to Drench,[5] physical therapists and physical therapist assistants often think primarily of death and dying when considering the issues of loss and grief and their effects on clients. Loss, however, is a broad concept that is not limited to death and dying. At its most basic, loss suggests no longer having someone or something one used to have.[6] Losses, especially those related to aging and chronic illness, may make individuals more vulnerable to risks to health and well-being, thereby affecting the ability to adjust to the new role and to take an active part in physical therapy,[7] especially when such losses necessitate immediate or eventual placement of these individuals in LTC facilities.

Risk factors associated with LTC placement include the presence of illness, dependence with activities of daily living (ADLs), and inability of caregivers to provide adequate support.[8] In a retrospective study of almost 16,000 LTC residents, Aud and Rantz[9] found that that losses in both physical and mental functioning are associated with LTC placement. Conditions such as stroke and falls have resulted in patients and families deciding to seek LTC placement.[10,11] Deficits in ADLs have also been predictive of placement in LTC.[12,13] Limitations in the performance of ADLs especially those involving toileting, grooming, and mobilization are often cited by caregivers as pivotal in the decision to place their loved one in LTC.[12-14]

As a milestone event, LTC placement impacts the dynamics between patients and their loved ones, and between patients and individuals in LTC tasked with caring for them. A study of losses associated permanent LTC placement is especially needful for physical therapists who develop therapeutic relationships, care decisions, and outcomes measures for this patient population. Viewed from the subjective, unique experiences of elderly patients, this qualitative investigation explores losses that have led to and subsequent effects resulting from LTC as a permanent alternative.

METHODS

This study was approved by the Institutional Review Board of Arkansas State University. Five participants whose ages ranged from 84 years to 94 years were recruited to serve as informants for the study. These participants were selected by convenience sampling with the assistance of the facility staff at the Craighead County Nursing Center. In order to participate in the study, the subjects met the following inclusion criteria: placement within the past 12 months; absence of acute disease; and cognitive ability to respond to and communicate during interview sessions.

One to 2 interview sessions which ran from 1 to 1 ½ hours were conducted after obtaining consent from the participants of the study. During the interview sessions, subjects were asked to give candid responses about their experiences in relation to their permanent LTC placement, including any noteworthy events leading up to the placement, the patient and family dynamics in the decision making process, and the roles of disease, impairment, functional limitation, and disability during placement. Representative open ended questions and probes were used, including, but not limited to:

- *Please tell me something about yourself.*
- *How did you come to live in this facility?*
- *How did you feel about your move into this facility?*
- *In what ways did the move to this facility affect you?*

The interview sessions were taped and transcribed word for word. In order to strengthen research validity, member checking was employed by the researchers during the interview session. While the interviews were being conducted, the interviewers paraphrased or restated the participants' responses in order to ensure that what was heard was, in fact, accurate. Interview sessions were concluded once saturation was achieved. Based on the results of the interviews, determinations were also made as to the appropriateness of subsequent interviews for the purpose of confirmation and/or clarification; this provided another avenue for member checking.

The transcribed proceedings were reviewed independently by the researchers. Open coding was used to categorize participant responses in relation to the objectives of the study.[15] After independent review and coding, the researchers compared codes and discussed emerging themes which served as the central focus of the study.

For this particular study, the open codes and emerging themes focused on the respondents' views surrounding their subjective experiences regarding events leading up to, during, and immediately after the period of transferring residence to a LTC facility. The subjects' reflections on their entire lives formed a framework that placed current circumstances and responses to them into perspective. More specifically, the emerging themes that were derived from the study revolved around the themes: early losses as a cohort, antecedent losses prior to placement, and consequent losses resulting from placement.

Results

Data gathered from the participants' responses to the 4 open-ended 4 interview questions served as the foundation for the determination of losses associated with LTC placement. These areas were: patient characteristics (first question), patient justification (second question), participant reaction to placement (third question), and effect of placement (fourth question). The illustration on Figure 1 served as the conceptual framework for the results reported in this section.

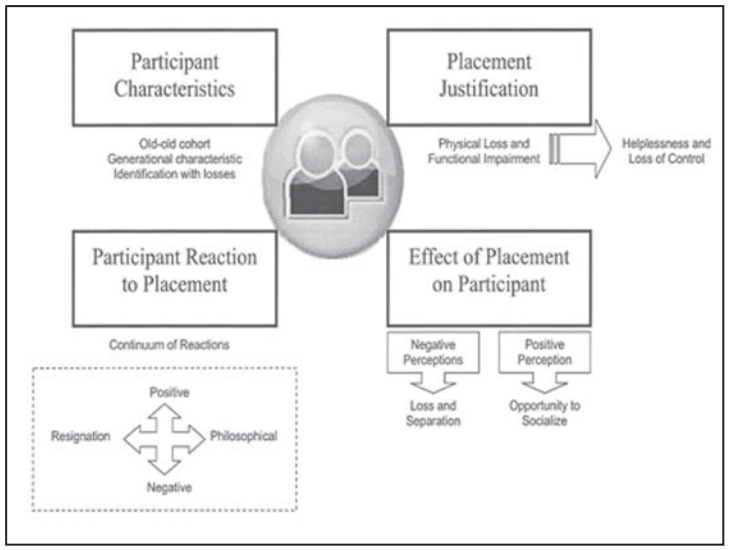

Figure 1. Conceptual Map of Permanent Long-term Care Placement

Participant Characteristics

Two men and 3 women participated in the study. They shared common traits and possessed characteristics unique to each individual. All informants were 75 years or older. Four were widowed, while one man was accompanied by his wife who was also residing in the facility. All were born, raised, and had spent most of their adult lives in close geographic proximity to each other. One of the men was a college graduate who coached in high school, and the other was a retired farmer and factory worker. The 3 women worked outside the home on and off throughout their lives in either office or retail employment. Four of the 5 had lived and worked on farms as children. All came to the facility from their own homes where they had previously lived independently.

The participants described backgrounds that were highlighted by conditions such as the early loss of a parent, early widowhood, and childhood poverty. They discussed common traits that helped them cope with these conditions, such as independence and resourcefulness--qualities that seemed to hold special significance to each of them. They reported perceptions of themselves as being very old and having lived lives of productivity and hard work (Table 1). All of the participants provided information not only about where they were born and where they had lived, but also about significant losses in their lives. All experienced either the loss of a parent, spouse, or child (Table 2).

Placement Justification

Notable among the participant responses to the question on placement was the cause of the placement and their reaction to such a placement. More specifically, falling that resulted in an injury or increased risk of falls and a significant decline in health, and limitations in both basic and instrumental ADL performance were implicated as pivotal factors in the placement (Table 3A). The participants agreed that the decision for LTC placement either resulted from circumstances beyond their control or were decided for them by other family members. One participant decided to be in the facility to remain with his wife who had Alzheimer's, and 2 described very distinct displeasure with children whom they felt pressured them to relocate (Table 3B).

Table 1. Examples of Informants' Perceptions about Work

Andrew	"I enjoyed work. I worked hard…They made me quit (work)…I can still work, you know…"
Beatrice	"I stayed nearly 10 years there, helping the little children with math or reading or whatever they needed … I worked all the time."
Dottie	"We raised everything we ate and had a cow for milk and butter… We never needed a lot…"
Edward	"I had a hard life, but it was good. Me and 4 brothers lived during the Depression… We had to make do with what we got… Coached for 49 years."

Table 2. Examples of Informants' Perceptions about Loss in Their Lives

Andrew	"They're all [the children] we got [now], just the two. We had 5 altogether."
Beatrice	"...My father died when I was 3 years old...My husband died. I had 1daughter...she died."
Connie	"...I had a little boy and he died… and my first husband died."
Dottie	"...He's (older brother) the only one still living.... (oldest son) got killed in a car crash… My husband died."
Edward	"My mother died when I was 8 years old. This was during the Depression… My wife died..."

Table 3. Examples of Informants' Perceptions about Reasons for Admission to Permanent Long-term Care

A.

Andrew	"Uh, what put me here - I fell and hurt myself."
Beatrice	"...I knew that I was getting to where, uh I fell… I had a light stroke in this hand and arm... which, you couldn't tell it. I got to where I couldn't open cans."
Connie	"...I had several light strokes... I fell in the bathroom… I'm almost blind."
Dottie	"...knee replacement…I fell though...getting my weight...surgery on my back."
Edward	"I got up one morning and I fell down…"

B.

Andrew	"I realize that, uh, she would really go off her rocker without me. Our kids put us here...under our, uh, not-be-knowings...they just got tired of fooling with us... I give my daughter a power-of-attorney, and that's where I made my mistake."
Dottie	"I had one member of the family (daughter) that wanted me to be at the nursing home."

C.

Andrew	"I knew I was going to have to… I turned it all over to my grandson… I couldn't have done it myself."
Dottie	"I already told my daughter to put me on the list here… They (her children) were doing everything, you know, but breathing (for her)... I just didn't want the kids to be bothered all the time."

All participants came directly from their own homes, as opposed to rehabilitation facilities, assisted care, acute care hospitals, or the homes of children or relatives. Two made deliberate plans to relocate due to failing health and expressed an amount of relief and thankful acceptance of their current situations (Table 3C).

Participant Reaction and Placement Effect

Responses to the question, "How did you feel about your move into this facility?" followed 2 continuums. On the one hand, the participant responses ranged from positive to negative; on the other, emergent themes of resignation and philosophical acceptance were also identified (Table 4). For example, 4 participants commented that their relocations were representative of what they must endure with aging. The 2 participants who made deliberate plans to move to the LTC facility expressed a much more positive view about their placement. The positive responses to placement were based largely on the opportunity to socialize. The females expressed gains in social interaction as a result of placement. The negative responses to placement were based largely on losses expressed by the male participants over changes in activity levels, independence, and relationships. While they accepted their situation, they still had feelings of loss and grief.

DISCUSSION

Early Losses as a Cohort

Participants for this study come from the old-old cohort group, an age group that encompasses individuals 75 years and older,[16] and comprises 13% of the general population and 46% of the residential population of long-term care facilities.[17] They describe themselves as resourceful, responsible, and independent—qualities that have historically been associated with this cohort. Statements such as

Table 4. Informants' Response to Permanent Placement in Long-term Care

A. Resignation/Philosophical

Andrew	"I don't feel good about it!... We'd a hundred percent rathered stayed at home… It wasn't our desire to be here. We didn't think we deserved it. We don't have anything against this place… We would recommend this place to anybody. …We're gonna live the best we know how...be ready when the Lord comes."
Beatrice	"Well, I knew I was going to have to....I've had a full life."
Connie	"I have never regretted it. I think its fine. I've never been sorry… I don't mind it at all. Oh, yes!"
Dottie	"I didn't think I needed it. I could take care of myself pretty well… I couldn't go on like that. Well, I know it was what I had to do… I'm thankful it is here. Oh well, I try to get the past - over it."
Edward	"At my age I'm not gonna go anywhere anyway. I'm not gonna advance in anything… I know I'm better off right here for someone to watch me. Even though I don't like to be watched, I'm glad there's a place for me."

B. Positive Perceptions

Andrew	"There are 3 people here I went to grade school with!"
Beatrice	"I get too much food. Oh, I wouldn't have done all this at home (participation in a social competition at the facility)… I was glad that I won something for the nursing home. I'm looking forward to that (planned future activity). And I do go to all the activities that I can."
Edward	"There's several that I've gotten acquainted with...her and I had gone to school together."

B. Negative Perceptions

Andrew	On the Loss of Relationships: "You hate to do anything to hurt your kids, and all, but it don't seem like they care to hurt us... She's (wife) threatened to disown the kids and everything else. And I think, uh, really, if she'd been at home she wouldn't be in this kind of shape."
Andrew	On the Loss of Independence: "Well, I couldn't explain it. I know is uh, just laying here looking at these 4 walls is not very pleasant. Whenever you know you could take care of yourself, and be outside and its pretty weather. If I had my way about it, I'd be out here mowing the yard or something else – I'm able to do it."
Edward	On the Loss of Activity Levels: "I just don't do anything, and I was into everything. I was on the city council for a time - about 6 or 7 years. At my age I'm not gonna go anywhere anyway. I'm not gonna advance in anything."

"We raised everything we ate," and "I worked all the time," and "They made me quit work" are illustrative of this fact. Individuals belonging to this cohort[18] share common life experiences, including being born around World War I, growing up during the Great Depression, and fighting in World War II and even the Korean War. Individuals in this cohort are aware of the potential for personal losses, and of the need at times to sacrifice. Their identification with such losses and the consequent grief is typical, especially for people of advanced age.[19]

The impact of these shared experiences is evident in how the participants characterized themselves and the events in their lives. When asked to describe themselves, the participants shared many early losses, including losing parents, children, siblings, and spouses early on, consequently rising above the associated emotional and material hardships from these losses. From a sociological standpoint, the collective identification of the participants to events in their lives can be explained using the "life course perspective" of Hagestad and Neugarten,[20] which underscores how historical and social forces not only shape the lives of different cohorts, but also provide them the social context to interpret these events.[21]

Antecedent Losses Prior to Placement

A prominent theme that emerged from the results of this study is the loss of physical function and the perceived loss of control regarding decisions toward LTC placement—a fact attested to by the participants and documented in their medical records. From a functional standpoint, the respondents have indicated antecedent events that have contributed to either a decline or a loss of physical function, which consequently creates disequilibrium between specific environments and the physical capacities the elderly require to deal with these environments. In this connection, Lawton and Nahemow[22] use the term "environmental press" to describe the fit between individuals and their environments. During instances when—perhaps because of age, disease, or both—individuals become unfit for their environments, then adaptations become the norm. For participants in this study, the adaptations take the form of LTC placement.

A possible explanation for the perceived loss of control may be due in part to the collective belief of this cohort that complaining will not accomplish anything, is not worth the effort, or will take too much time.[23] This is evident in the participants' resignation to and acceptance of their LTC placement. Moreover, when analyzed using the "role-theory" framework[24] whereby aging individuals relinquish social relationships and roles marked by independence and self-determination for more passive and dependent ones, the loss of control issue becomes more apparent. The consequence of such a perceived loss of control—in this case, with LTC placement—eventually affects both life satisfaction and quality of life in LTC.[12,25]

Consequent Losses from Placement

Three emergent themes from the responses highlighted what participants perceive as losses as a consequence of placement: the loss of independence, the loss of relationships, and the loss of activity levels. Such losses have been confirmed extensively through research.[9,25,26]

Loss of Independence

Respondents unanimously expressed dissatisfaction with their loss of independence. They responded variously concerning the inability to come and go at will, the inability to determine their own eating and grooming schedules, and the lack of privacy that is an unavoidable consequence of communal living in such close quarters, as is typical in LTC.

Loss of relationships

The focus on family relationships was a constant theme in discussions with respondents. Andrew expressed the concept of "disowning" children over perceived acts of betrayal connected to entrance into LTC, and Dottie made many comments about the betrayal from one daughter and the loss of her old connectedness to another daughter, noting the many regular activities that ended with her entrance into LTC. Both of the above cited role-diminishing phenomena occurred mainly due to entrance into LTC, according to the subjective experience of these individuals. As these individuals enter a phase of life in which they are more concerned than ever about their end-of-life contributions to their descendents, it is understandable that loss of relationship-relevancy is a considerable concern.

Loss of activity levels

The loss of accustomed levels of activity was a frequent disappointment cited by our respondents. However, it was not appreciably addressed as a gender-related issue during a search of literature. A difference in male versus female respondents' attitudes regarding their new status in LTC was marked. From the outset, males seemed to be more dissatisfied with their new status, and resented their lack of meaningful activity--noting how they had led very useful lives and could still now if permitted. Andrew, at 94 years of age, was adamant about his ability to continue the demands of home-keeping, stating that he could still mow the yard, etc. Edward lamented his old abilities, noting that he used to be "into everything" as a coach and city council member. They both indicated that they had submitted to the desires of their children in their change of status, as noted earlier.

Gerontological research posits several explanatory models that may be relevant in elucidating losses of independence, relationships, and activity levels described by the participants in this study. The first explanatory model is known as the "activity theory" by Lemon, Bengtson, and Peterson,[27] which posits the role of activities in improving the adjustment of individuals as they age, thereby resulting in increased life satisfaction. In this study, participants have described their discontent and dissatisfaction with LTC placement because of the perceived limitations the facility has imposed on their independence.

A second explanatory model that may be relevant in consequent losses associated with placement involves the "socioenvironmental theory."[28] This theory proposes that the immediate environment directly impacts the activity patterns of aging individuals. More specifically, the more homogenous the group and the closer they are in proximity, the more conducive the environment for socialization. Unfortunately, for the population under study, the subgroups among the elderly population in the facility vary, making it less than ideal for socialization. Another factor to consider in juxtaposing this theory on the population under study is the fact that the participants have not been in the facility more than 6 months; this may contribute to the perceived loss of socialization that may eventually change as the participants continue in the facility.

Summary of Losses Associated with LTC Placement

The losses that emerged from the research study revolved around early losses as a cohort, antecedent losses prior to placement, and consequent losses from placement (Table 5).

CONCLUSION

Entrance into LTC is rising in our society, specifically for the age cohort of our study. Losses experienced by those transitioning to this lifestyle are notable and cumulative, and they affect the elderly around and even after placement. The cumulative nature of losses that eventually results in LTC placement is an important consideration in geriatric physical therapy practice, including the physical therapist's role in prolonging function, preserving quality of life, and preventing for as long as possible LTC placement.

Taken from the context of various role-development theories noted in this study, the individual normally seeks to fulfill end-of-life role expectations. As the individual ages, there is a general attunement to the need for attending to end-of-life issues which, if not met, may be perceived as loss. Transitioning into LTC may interfere with the normal completion of these role expectations. The participants in this study, of advanced age, are keenly aware of the need for such adjustment. These expectations may vary based on life experiences that are common to a cohort, as well as gender-based and individual differences.

Because of the small sample size for this study, cohort variances represented by the growing multicultural population, may represent a rich opportunity for future investigation. In addition, although gender-based differences in the study have been noted, none could be generalized as characteristics of a larger population.

Table 5. Summary of Losses Associated with Long-term Care Placement

Cohort Losses	Losses that participants identified with as a cohort through lived experiences, including the Great Depression, World War II, the Korean War; losses of family members, and familial relationships.
Antecedent Losses	Losses that have contributed greatly to long-term care placement, including loss of physical capacity in relation to function and loss of control relative to decision making.
Consequent Losses	Losses that have been experienced as a consequence of placement, including loss of independence, relationships, and activities.

Circumstances of transition considered coerced have been viewed as especially egregious by participants this study. While recognizing the distressing nature of such circumstances, all individuals in this study have nevertheless made attempts toward acceptance, especially as it relates to avoiding the loss of family relationships. This highlights the role and presence of family relationships as possible determinants of satisfaction with LTC placement.

Learnings gained from this study research, which has not been well explored in the current literature, involves the role of gender in influencing the subjective experience of contentment with LTC placement. In this study, male respondents were distinct in voicing their displeasure with a significant loss—the lack of opportunity to contribute meaningful activity–whether it be housekeeping (such as mowing the yard), or a wider community contribution (such as coaching and city council work).

Further research is needed to focus on the cohort differences when it comes to LTC placement. Toward this end, various age cohorts should be studied, recognizing that other age groups will have unique characteristics of their own. This may, in turn, necessitate a thorough re-tooling among caregivers of role expectations each time a new generation presents itself and of more appropriate cohort-specific interventions in geriatric physical therapy.

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