The Emotional Context Facing Nursing Home Residents’ Families: A Call for Role Reinforcement Strategies from Nursing Homes and the Community

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Objectives: Identify useful concepts related to the emotional context facing family members of nursing home residents. These concepts can be used in future studies to design and test interventions that benefit family caregivers.

Design: Secondary data analyses of qualitative ethnographic data.

Setting: Two nursing homes in a large Midwestern city; 8 months of data collection in each.

Participants: 44 family members of nursing home residents whose health was considered, “declining.”

Measurements: Role theory was used to design and help interpret the findings. Data included transcripts of conversations between family members and researchers and were analyzed using a coding scheme developed for the secondary analysis.

Results: Comments about emotions related to the social role of family member were grouped into three categories: relief related to admission, stress, and decision making support/stress. Subcategories of stress include the role strain associated with “competing concerns” and the psychological pressures of 1) witnessing the decline of a loved one in a nursing home, and 2) guilt about placement. Decision-making was discussed as a challenge which family members did not want to face alone; support from the resident, health care professionals, and other family members was appreciated.

Conclusions: Family members may benefit from role reinforcement activities provided by nursing home staff and community members. All nursing home staff members (in particular social workers) and physicians are called upon to provide educationa and support regarding nursing home admissions, during the decline of the resident, and especially regarding medical decision-making. Community groups are asked to support the family member by offering assistance with concrete tasks (driving, visiting, etc.) and social support. (J Am Med Dir Assoc 2008; 9: 36–44)

Keywords: Qualitative; ethnography; family; end-of-life; nursing home; role theory; chronic illness; older adult

With 1.5 million residents on any given day, the nation’s 16,1001 nursing homes are an important resource in the American health care system, especially for older adults with advanced chronic illness. Kane2 reports 5 subgroups of persons served by contemporary nursing homes: (1) people needing recuperation or rehabilitation from acute care episodes; (2) people who are terminally ill; (3) people who are chronically physically disabled but alert; (4) people with severe dementia; and (5) people in permanent vegetative states (p. 149). Another group being served by nursing homes, albeit indirectly, includes family members, many of whom have made tremendous sacrifices to maintain their loved one in the community for as long as possible. This study focuses on family members of nursing home residents. The purpose is to identify and describe key emotional issues facing family members of nursing home residents.
**BACKGROUND**

**Theoretical Framework**

Role theory provides the organizing framework for the design, analyses, and interpretation of data for this study. According to role theory social positions (such as parent, adult child, waitress, pilot, etc.) influence individual behavior through social role expectations. Turner (p.87) defines a social role as a comprehensive pattern of behavior and attitudes that constitute a strategy for coping with a recurrent set of situations. Social roles affect how a person—in this study a family member—behaves and how one is treated by others in the social system. There are norms and behavior expectations for each social role which function to guide behavior and to provide a basis for evaluating how well a person is performing the role. These functions apply to the individual as well as to society. Social roles become personalized by the persons enacting them. Stryker and Macke report that wide variations exist in how people understand and also perform social roles and that “achieving common meanings is an objective of interaction...” (p. 71). A frequently cited definition of “role strain” comes from the seminal work of Goode who defines it as “the felt difficulty in fulfilling role obligations” (p. 483). Role strain, then, involves feeling overwhelmed with the challenges associated with attempting multiple roles.

How a family member understands his or her role toward the older adult nursing home resident, the extent to which role expectations are met, and what the role means to that person can affect the level of stress experienced by the family member. Building on previously published research by Krause, authors Shaw and Krause report, “stressful events arising in social roles that are highly valued have a more pernicious effect than do events that emerge in roles that are less important...” (p. 98). Because fulfilling role expectations and being a “good” spouse or adult child is important to the identity of most adults, we can expect that the experience of role strain, then, involves feeling overwhelmed with the challenges associated with attempting multiple roles.

There is a lack of depth in the literature concerning the role that family caregivers play following an older person’s relocation to a care home. It is important to build understanding in this area because stress related to social role performance can negatively affect physical and mental health of family caregivers. The focus of this study is the emotional interaction. A frequently cited definition of “role strain” comes from the seminal work of Goode who defines it as “the felt difficulty in fulfilling role obligations” (p. 483). Role strain, then, involves feeling overwhelmed with the challenges associated with attempting multiple roles.

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There is a lack of depth in the literature concerning the role that family caregivers play following an older person’s relocation to a care home. It is important to build understanding in this area because stress related to social role performance can negatively affect physical and mental health of family caregivers. The focus of this study is the emotional context of enacting the role of family caregiver and not on the role expectations themselves. A separate manuscript (in press) using the same dataset reports family members’ sense of their own role expectations related to the nursing home resident.

**Family Members**

No nationally representative data of the United States were identified to document the number of nursing home residents with family members involved in their care, the type and extent of the involvement, the satisfaction with the involvement, and the demographic characteristics of these family members. However, smaller national studies and studies of individual nursing homes have documented that many family members remain an active part of their loved one’s life after admission to a nursing home. Solomon reports 4 events she considers as crises in the lives of nursing home residents and their family members: (1) the decision to admit; (2) the admission process; (3) the move to a more intensive level of care; and (4) the death of the resident. These critical events affect the resident and the family member in different ways.

Three qualitative studies illuminate similar role expectations of family members. Bowers research indicates that family members of nursing home residents hold themselves responsible for monitoring the quality of care provided to their loved ones and also for providing direct care when needed. Davies and Nolan report that family members see themselves as responsible for “making it better” for the resident as they develop a new caregiver role for themselves within the context of the nursing home. This role includes maintaining continuity with the resident, helping the staff get to know the resident, monitoring care, and contributing to the nursing home community by getting to know other residents. Bern-Klug and Forbes-Thompson report that family members hold themselves responsible for being overseers of care, representing the resident’s perspective to the staff, and serving as the keeper of the family connection. Other researchers have documented the similarities and differences between what is considered to be the staff role versus the family role toward nursing home residents.

Because of the advanced chronic illness state and advanced old age of many nursing home residents, eventually many families will witness the dying and death of their loved one in the nursing home. In fact, 22% of all U.S. deaths occur in nursing homes, which amounts to over half a million deaths annually. Using Minimum Data Set (MDS) data for New York state, Flacker and Kelly report that of newly admitted nursing home residents with complete data, 32% died within 1 year of admission. Using MDS data from Missouri, van Dijk and colleagues calculate that within 1 year of baseline assessment, 35% of nursing home residents died. The line between advanced chronic illness and dying is often blurred in nursing homes. Researchers committed to improving the experience of dying have called for research focusing on the experience of dying within the context of advanced chronic illness. Nursing home family members have an important perspective regarding advanced chronic illness end-of-life.

**METHODS**

The study is a secondary analysis of data collected from 44 family members during an in-depth ethnographic study in two nursing homes in a large city in the Midwest. The research team (including the author) spent 8 months in each facility. The purpose of the original study (NIH NINR grant number R15NR04974, P.I. Sarah Forbes from the University of Kansas) was to use a mixed methods design to describe the processes and outcomes of care for nursing home residents whose health was assessed to be “declining.” Data included interviews with residents, family, and staff members; field notes; and chart notes. For details about the original study,
The findings reported here are based on comments made by families during the course of being interviewed regarding their opinions about care received by their loved one. “Family member” means the next-of-kin on the resident’s medical chart. In one case the family member was a close friend. Interview transcripts with family members were analyzed using a coding scheme developed for the secondary analysis. The process of data analyses included reading transcripts and using the qualitative software, QSR NUDI*ST version 5 (QSR International, Doncaster, Victoria, Australia) for lineby-line coding (identifying all phrases, sentences, and paragraphs that mentioned anything about the social context under which the family members were fulfilling their role and responsibilities to their loved one). Once the data were categorized into “role rights” and “role expectations” the data were re-read for examples of emotional context.

Lincoln and Guba’s methods for building trustworthiness in qualitative studies including peer debriefing, triangulation, maintaining an audit trail, negative case analysis, prolonged engagement, and member-checking were employed. It is important to note that during the original study, family members were not directly asked about their emotions related to the social role of the family member to a nursing home resident. Therefore, to improve trustworthiness of these findings, the researcher returned to the nursing homes and asked family members for feedback on the preliminary findings (a type of “member-checking”).

The amount of information collected from family members varies from person to person. Some family members were interviewed once or twice while others were interviewed 6 or more times. Length of interviews lasted from minutes to hours. In some cases the resident was discharged or died early in the study, and so the family member’s contact with the research team was limited. In other cases the family member became ill or unavailable for other reasons. Some family members frequently sought out the researcher at the nursing home during visits to the resident as attested by the amount of field notes related to these family members. Other family members were available only by appointment and/or by phone, including one family member who lived hundreds of miles away and one family member who was basically housebound from the effects of polio.

The following are characteristics of the 44 family members: 23 were women; ages spanned decades (3 were younger than 23, 23 were 45 to 64, 11 were 65 to 74, and 7 were 75 or older); most were 1 generation younger than the resident, ie, 23 children and 6 nieces or nephews, although there were 6 spouses, 5 siblings, and 1 same-generation friend. Two were parents of the resident. Most (n = 32) family members visited at least twice a week.

RESULTS

Comments about emotions related to the social role of family member to a nursing home resident in declining health were grouped into 3 categories: relief, stress, and decision-making support/stress.

Relief

During the course of interviews about the care their loved one received, 8 family members directly stated that having him or her in a nursing home—while emotionally trying—was also a relief. When family members could no longer manage the loved one in the community, they turned to the nursing home for help. These family members were relieved that the loved one had a safe place to live, “I’m tired of coming and going, but better (quality of life) because I don’t worry about her as much.” Another family member, who had moved the resident from a different nursing home said, “Now that she is in this nursing home, we’ve had a lot of stress relieved.” A sister who could no longer care for her brother at home because of her own declining health summed it up this way, “I’m at ease. I know he is safe and being cared for.”

Although family members were relieved that their loved one was in the nursing home, they were not stress free. In some cases the family had to make the transition from being totally responsible for their loved one outside the nursing home, to learning how to share responsibility with nursing home staff. For some family members this was a bumpy transition. Even for family members who made the transition smoothly, stress remained, albeit in a different form. A woman whose mother had been in the same nursing home for 4 years said, “I do worry and feel as though I have a lot of responsibility for her even though she is in a nursing home. I see things happen. I need to check up on her.”

Sometimes the stress of the admission as perceived by the resident and/or the family exceeded the relief about resident safety. During the study, 2 of the residents enrolled in the study left the nursing home within 2 weeks of admission because they were so unhappy with nursing home life. Their family members conceded to the research team that they did not know how they were going to manage at home.

The next section describes findings related to stress and is divided into 2 groups: “competing concerns” and “psychological pressures.”

Competing Concerns

Many family members were juggling what the researcher is calling “competing concerns.” This term is used because there was no common term used by family members. “Competing concerns” consume emotional energy and resources and compete with the attention and resources that the family member had available to the nursing home resident. Examples of competing concerns identified in the data include caring for other family members or one’s own health needs; financial worries (including worrying about qualifying for Medicaid); paid employment; transportation (problems getting to the nursing home); and closing down the loved one’s house and
dispersing the contents. These competing concerns contributed to role strain. Table 1 includes the competing concerns mentioned by 21 of the 44 family members during interviews about resident care. Table 1 lists the concerns grouped by person to provide the reader with not just a listing of categories of concerns, but also a sense of what constellation of concerns individual family members face.

**Psychological Pressures**

In addition to the competing concerns, the psychological pressures that some families reported were staggering. Comments within this category were grouped into (1) it's hard to see the loved one in the present condition; and (2) guilt about the placement. Although comments about the burden of decision making could have been included here, they are listed separately in the next section.

It's hard to see loved one in present condition. Typically, family members of nursing home residents have a long history with the resident that can span decades. Health declines on the part of the resident can result in sadness for the family member. Six family members commented that it was emotionally difficult for them to see their loved one in their current physical or mental condition, “I don’t like to come out here” confided the wife of a resident with advanced renal failure, "I have to make myself. I can hardly stand to see him like this—this is not my husband.” The son of a resident who suffered from depression and had been off and on hospice said, “Even after 2 years, I have to gear myself up to go there. I'll never get used to seeing her there. I still can’t get over this is how she has ended up.” Another family member disclosed, “It’s the most difficult thing in the world to see your parents...that you have relied on...to see them declining.”

Guilt about the nursing home placement. Thirteen family members made comments to the researcher about feeling enduring guilt related to their loved one being in a nursing home, one said, “It’s a guilt you never get over.” One son reported that the hardest thing he had done in his life was to admit his mother to the nursing home. A daughter said she had promised her father (before his 2 legs had both been amputated) that he would never be in a nursing home. A daughter said she admitted her mother to the nursing home. One said, “It’s a guilt you never get over.” One son reported that the hardest thing he had done in his life was to admit his mother to the nursing home. A daughter said she had promised her father (before his 2 legs had both been amputated) that he would never be in a nursing home and she had to “eat those words.” A different daughter disclosed, “I hate that she is here but I can’t take care of her.”

This daughter realized that her brothers expected her to bring her mother into her home and care for her. But the mother was clinically obese and required heavy care the daughter—a former nursing home certified nurse aide—was not able to provide:

When I first put momma in a nursing home I sat down and cried for 2 hours. ... I called my 2 brothers a couple of days later—they were in Florida. I told them, ‘Your momma’s in a nursing home.’ They were mad. They told me to keep her at home. My one brother said to me, ‘There is an unwritten law that daughters take care of mothers—now you take her to your home and you add a room to your house and you take care of her.’ I told him, ‘I know about that law, but I can’t do it anymore. She needs more than I got. I don’t have the equipment.’ I had 3 children at home at the time. ...

In some cases the on-going guilt that family members reported appeared to be related to the suboptimal staffing patterns found in both nursing homes. One son said that staff shortages are human rights issues, “What’s a family supposed to do? How are you supposed to support your family when they need more help than you can give them?” Indeed, during interviews about resident care, 17 of the 44 family members made comments related to the nursing home lacking sufficient number of trained direct care staff members.

**Decision-making Support and Stress**

Decision-making support and stress is the final category of findings. This section includes both positive (supportive) and negative (stressful) aspects of medical decision making. There were 23 family members who mentioned the challenge of medical decision making on behalf of their loved one in the nursing home. Of the 23, 7 shared examples of feeling supported by the resident, other family members, or health professionals. Indeed, 5 mentioned drawing support from knowing the resident’s wishes related to hospitalization and to interventions such as tube feeding, cancer surgery, and cardiopulmonary resuscitation (CPR). For example, one resident had arranged for the director of nursing and administrator to meet with her daughters so that they could all review her wishes about end-of-life care. The resident felt the staff understood her preferences, but wanted to make sure her 3 daughters were clear. The resident reminded her daughters, in front of the staff, that she did not want to be hospitalized should her heart or lungs fail and also reminded them that her wishes were documented in her advanced directives. Although the meeting was unsettling to 1 of the 3 daughters who thought that it was uncomfortable and perhaps “inappropriate” to be talking with such frankness about dying and death, the daughters (including the one who felt the meeting was uncomfortable) agreed that it was helpful to be clear about their mother’s preferences.

Another resident and her family were part of a religious community with strong beliefs about specific medical interventions. The religious community has a history of working with all members on how to interact with health care professionals to ensure receipt of religiously appropriate care. The resident had signed an advance directive 10 years before she was diagnosed with Alzheimer’s disease. For years before her dementia prevented her from communicating, she clearly articulated in writing and many times orally to her family members that she did not want specific medical interventions if she should become incapacitated. These discussions and documents emboldened the family to advocate on her behalf (specifically to prevent hospitalizations) as she was dying with advanced dementia.

A sister to a nursing home resident felt that the medical interventions invoked during his hospitalization were hurting him more than helping in that they were prolonging his suffering and dying. Her brother had been sent to the hospital weeks before to receive intensive therapy for a severe bed sore. During the hospital stay it was decided that a feeding tube would help provide him more nourishment and that might help the wound heal. He grew weaker and the decision was
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<th>Examples of Family and Health-Related Competing Concerns</th>
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<tr>
<td>1</td>
<td>Mother of resident has a son who experienced a psychiatric breakdown during the study and required hospitalization. Her husband has probable Alzheimer’s disease and lives with her at home.</td>
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<td>2</td>
<td>Daughter of resident has a child at home with developmental disabilities. After her father was admitted to the nursing home, she and mother (resident’s wife) started living together. Mother has been diagnosed with Alzheimer’s disease. Mother’s sister was helping out, but now has been diagnosed with cancer.</td>
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<td>3</td>
<td>Family member comes to nursing home to visit her sister; buried her own daughter that morning.</td>
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<td>4</td>
<td>Husband can no longer care for his wife (resident) due to his own progressing cancer.</td>
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<td>5</td>
<td>Resident’s daughter works outside the home and has children at home.</td>
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<td>6</td>
<td>Resident’s husband of 58 years is a nursing home resident in a different nursing home; comes to visit her twice a week health permitting and if transportation is available.</td>
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<td>7</td>
<td>Resident’s homebound sister has polio with symptoms exacerbating with age. She has another brother in a different nursing home, and 2 sisters in a group home. Her 71-year-old husband visits all 4 in-laws each day, and works part-time.</td>
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<td>8</td>
<td>Resident’s wife takes care of their daughter’s 2 daughters (young girls) and brings them to the nursing home so that she can spend the day with her husband who has moderate Alzheimer’s disease and is extremely anxious when she is not around.</td>
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<td>9</td>
<td>Resident’s brother went back to work part-time at age 78 to pay for rising insurance costs. His work starts at 6:00 AM and is a 40-minute drive from home. His wife had cataract surgery and double knee-replacement during the study. He visits his sister in the nursing home twice a week, then goes for groceries, then drives the 40 minutes home. He is concerned about his escalating diabetes, and hopes he lives long enough to see his sister through.</td>
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<td>10</td>
<td>Resident’s wife is hospitalized for heart attack during the study.</td>
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<td>11</td>
<td>Resident’s daughter who works outside the home and has children at home expresses concern about her mother who now lives alone and needs some help. She told researcher her child asked, “Mom, can I have an appointment to be with you?”</td>
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<td>12</td>
<td>Resident’s daughter works outside the home has children at home and is concerned about mother’s health and living conditions.</td>
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<td>13</td>
<td>Resident’s daughter tells of having to admit her mother to the nursing home years before because she was dealing with the dying of her son from cancer. Now her husband is seriously ill and cannot drive after his lung and heart by-pass surgery. She has been trying to help out her sister who had a stroke. She required hand surgery during the study and found it hard to mow the lawn and do other household chores after the surgery. Also, during the study one of her best friends died.</td>
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<td>14</td>
<td>Resident has been in the facility for over 5 years and is cognitively impaired. Her 91-year-old husband has never seen the facility because he is homebound. His vision and hearing are fading. “If you see her, would you tell me what’s going on with her” he asks the researcher.</td>
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<td>15</td>
<td>Resident’s daughter-in-law has fibromyalgia and rheumatoid arthritis. During the study, she was in a car accident, which totaled her car and left her in an arm cast. She and her husband are now beginning to care for her mother, the third parent for whom they have assumed responsibility for providing care.</td>
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<td>16</td>
<td>Resident’s daughter brought her father to live in her home with her husband and sons. Her father has Alzheimer’s disease (which claimed the life of her mother—the nursing home resident) and is concerned that the stress of dealing with her mother’s dying and her father’s care needs may negatively affect her husband who recently had a lung transplant.</td>
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<td>17</td>
<td>Resident, her husband, and her sister all moved here at the same time from a different state to be closer to the sister’s daughter who agreed to help look after the 3 of them, after her aunt (resident) had a stroke. The niece helped the aunt qualify for Medicaid, found her own mom an apartment, and had her uncle living with her (and her husband and son) for months (driving him to the nursing home daily) until he was admitted to the nursing home as well. The niece owns and runs a company.</td>
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<td>18</td>
<td>Resident’s daughter is the only living family member. Nursing home putting pressure on daughter to move mother because of behavior problems. Mother needs cataract surgery but daughter is concerned that the mother’s dementia will interfere with recovery. Daughter had open-heart surgery during the study, while her cat was sick in the cat hospital.</td>
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<td>19</td>
<td>Resident’s daughter has crippling arthritis and cannot travel to the nursing home. The resident’s son-in-law visits instead.</td>
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<td>20</td>
<td>Resident’s son has heart problems and is working on a “family personal matter” during the study.</td>
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<td>21</td>
<td>Resident’s daughter now starting to take care of her mother who recently had bladder surgery, knee replacement surgery, and is a breast cancer survivor from 1997. Mother is beginning to become “forgetful.”</td>
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made to put him on a respirator. He developed pneumonia and still the wound was not healing. The sister spoke with her daughter, who was a nurse. Her daughter told her, “mom, that pneumonia can be a killer.” The sister telephoned the physician and asked him if he thought it would be all right to remove the feeding tube and respirator and allow her brother to die a more natural death. The physician discussed the options with her, and agreed that it would be ok. The interventions were removed and the brother died peacefully in the hospital surrounded by family later that day. The sister shared that she felt support from her family and the physician in helping her think through the options.

Not all families expressed support. Some families talked about the burden of decision making. Twelve of the 23 family members who mentioned decision making, shared comments revealing stress from the responsibility and burden of making health-related decisions on behalf of their loved one. These comments generally arose in the context of feeling alone or solely responsible for having to make decisions. A daughter who was left to make health-related decisions—including end-of-life decisions—on behalf of her mother with Alzheimer’s disease, said she wished her brothers would have been more involved in the decision-making process, “My brothers meant well, but didn’t realize what a burden they were placing on me. I didn’t want to make all these decisions about my parents.” This same woman stated that she regretted deciding against an autopsy after her mother died, and wished that someone from the nursing home or the hospice that was providing care to her mother would have prepared her for the decision. After the burial she realized that the information could have been helpful to herself, her siblings, and their children.

The wife of a nursing home resident who was receiving renal dialysis talked with the researcher about how hard it was for her to think about making end-of-life-related decisions that could affect her husband of 52 years. She was torn between wanting to see her husband released from needing dialysis (allowing him to die) and not wanting to be in any way associated with a decision that would result in his death, “I don’t want him to suffer. I am not going to be the one to stop dialysis. I can’t make that decision. That is up to the Lord to call him home, not me.” The researcher assigned to this resident was a nurse with experience in hospice care. After a 45-minute discussion between the wife and the researcher about how difficult it can be for families to make health-care decisions, the wife said, “Well it has been good to talk. I haven’t had anyone to talk to and I don’t feel like I am carrying it all by myself.”

Making decisions on behalf of someone not well known or not well-loved can bring a unique type of stress. A daughter reported that her father abandoned the family when she was 14 years old. Now in his old age, with her mother dead, she was the family member involved with decision making. In another family, the daughter had been sexually abused by her father as a child. Now she was the only one of her siblings who continued to come to the nursing home. She remained uncomfortable in his presence.

**DISCUSSION**

The purpose of this qualitative study is to identify conceptually useful ideas to better understand the emotional context in which family members enact their role vis-à-vis their loved one in a nursing home, so that future research can lead to helpful interventions. The findings should be considered preliminary due to limitations of the study, which include that it is a secondary analysis of qualitative data and family members were never directly asked about their emotions related to having a loved one in a nursing home. Some family members may have reported additional examples of relief or stress, had they been directly asked. Therefore, these findings are likely an understatement of the scope and severity of stress facing family members of nursing home residents, as well as a limited view of role relief.

It is not appropriate to draw conclusions about the importance of each category of findings based on comparing the reported counts because the amount of time and the amount of data from each family member differed. Also, the sample consisted of family members of residents who were considered to be in declining health. Not all nursing home residents are considered to be in declining health, however with about one third of residents dying within 12 months, death is no stranger in nursing homes. For residents for whom the nursing home is their home (and not just a place for short-term rehabilitation), some have argued that a palliative care model is the appropriate model of care.

These findings indicate that for some families relief accompanies the admission of a family member into a nursing home. Most of these comments included the idea that the loved one was in a physically safe place. The relief was often mixed with other emotions like guilt and sadness. A study is needed, designed using a strength’s perspective, that documents ways in which family members use their personal strengths to find satisfaction, meaning, and enjoyment in their role as a family member of a nursing home resident. Findings from such a study would augment reports in the literature of the benefits of being a family caregiver which have been collected primarily from caregivers with their loved one at home.

Findings also suggested categories of stress facing family members including “competing concerns,” which are examples of possible role strain and “psychological pressures.” The latter include (1) it’s hard to see the loved one in the present condition, and (2) guilt about the placement. A third category of findings about medical decision making includes findings related to role support and role stress. These findings are related to what Solomon identifies as the 4 crises of institutionalization, although she did not mention relief as part of her discussion about admission.

Taken as a whole, these findings are interpreted by the author to mean that some families would likely benefit from help with role reinforcement. This means support to assist them in meeting their own role expectations as family caregivers. The comments made by family members did not provide any evidence that these families were looking for others (staff or other family members) to replace them as a family...
member, although many made comments indicating they would welcome support in helping them to fulfill their role expectations. The examples of stress that families spontaneously shared with researchers demonstrate a strong commitment to the role of caregiver. After all, despite the areas of stress, family members remained involved in their loved one’s life. The areas of stress reported in this study are potential areas for designing role reinforcement strategies. The remainder of this article is organized around ways in which nursing home staff members and community members can provide role reinforcement to the family caregivers of nursing home residents.

**Nursing Home Staff as Family Role Reinforcers**

While nursing home admission may minimize stress related to physical safety worries, it can introduce new sources of stress. This has been documented in the literature. Some families experience enduring guilt about nursing home placement even in the face of feeling relieved that their loved one is physically safer.

All nursing home staff members should assume (until proven otherwise) that every admission to the nursing home represents a crisis to the resident and to the family and that some family members experience guilt throughout the stay. Just as is the case when any person is in crisis, family members should be treated with extreme patience and gentleness, especially around stressful episodes, such as admission. Some role expectations that the staff may hold of the family will need to be relaxed while the family is in crisis. Family members should be expected to need not just information about admission, but also social support. Staff members should expect to repeat the same information multiple times and to provide information in written form as well as orally. Staff members should be continually reminded about how emotionally difficult having a loved one admitted to a nursing home can be. Hansen and colleagues document that some family members found placing an elderly relative in a long-term care facility was more stressful than making life-sustaining treatment decisions.

The relief experienced by the family member after nursing home admission appears to be related to the extent to which the nursing home is perceived as a good match for the resident. Is it a place that is physically and psychologically safe? Is it a place where residents just survive or where they thrive? Are psychosocial needs taken as seriously as medical needs? Are there enough trained people working there to anticipate and meet resident needs? As nursing homes become more “person-centered” the guilt and role stress experienced by family members may decrease as quality of living and dying in nursing homes increases.

Results from this research underscore the stress of witnessing the health decline of a loved one. Indeed the declining health status of the resident and the fact of institutionalization appear to interact and produce unique stresses for some family members resulting in feelings of anxiety, depression, guilt, and grief. According to role theory, these feelings of stress can negatively affect the family members’ health. How the family member deals with the stress can also affect interactions with the physician, the staff, and the nursing home resident. Intervention research is needed to better understand how family members can be supported through the resident’s health decline, dying, and death.

Family members make comments that shed light on the social meaning of being in the position to make medical decisions on behalf of a loved one. Family members benefit from social support of the resident, family, and staff and many said they did not like to feel alone in decision making. The process and consequences of making these end-of-life–related medical decisions can continue for years for some family members. Hansen et al report, “Factors affecting the strain and ease felt by family caregivers exist not only during the actual decision-making period, but also arise during the days, weeks, months and years prior to the event and continue on after the life-sustaining treatment decisions have been made.”

Nursing homes can facilitate education and social support for family members who are witnessing the decline of loved ones and facing medical decision making. Research is needed to determine if family members may benefit from psychoeducational (information and social support) sessions regarding treatment decisions that can arise in advanced chronic illness. Nursing home medical directors, nurses, and social workers could take the lead in developing and offering educational and supportive sessions for groups of family members on a regular basis. These sessions can help to educate and support the family member as they learn their new role and as they become familiar with the nursing home culture. These sessions can also begin explaining about the terrain of health changes in advanced chronic illness. Such psychoeducational support sessions can build on the current emphasis on “person-centered care” in nursing homes and broaden it to “family-centered care,” or to use Port et al’s term, “person-family-environment-fit.” Maas et al have conducted educational sessions with family members of dementia residents which included developing a written partnership agreement with staff. Their research indicates that the intervention helped to improve the family caregiver experience and the nursing home staff attitudes toward family members.

This study articulates some of the emotional and practical issues some family members face as they strive to remain true to their social role as a family caregiver. These emotional issues can affect mental health status. Social workers are the nation’s largest providers of mental health services. “Social workers provide more mental health services than psychologists, psychiatrists, and psychiatric nurses combined.” The National Association of Social Workers reports that social work services in a nursing home setting should include the social and emotional impact of physical or mental illness or disability on both the resident and the family. A person with a social work education with training in family systems theory, crisis management, communication theory, counseling, advocacy, decision making, priority setting, active listening, adult abuse, guardianship, community resource connections, and other human service–related skills is the key staff member to serve as a bridge between the resident, the nursing staff, the physician, and the family. (Not all nursing home social service staff members have a degree in social work. Furthermore,
the federal government requires only nursing homes with more than 120 beds to employ 1 social worker [who is not required to have a social work degree]. See the Code of Federal Regulations 42, for more information.) Just as the medical director is responsible for the overall physical health practices of the nursing home, the social work director—given the appropriate resources—could be responsible for designing, implementing, and evaluating systems to benefit the emotional health of nursing home residents, family members, and staff.

All staff must be trained, encouraged, and rewarded for working well with family members of residents. Skilled and thoughtful staff members who have the time and training to support family members’ emotional concerns can bring relief to the emotional suffering facing some family members as they remain connected to their loved one in the nursing home. As nursing home staff members strive to provide excellent health care to residents, they should ask themselves, “to what extent is this nursing home designed to reinforce family members who continue their role as caregivers?”

The Community as Role Reinforcers

Some of the stress and role strain experienced by family members occurred in an attempt to fulfill multiple and competing role obligations outside the nursing home. Community members, including clubs, service groups, and places of worship should seek to support people who have loved ones living in a nursing home in ways that will reinforce their ability to fulfill their role expectations to the resident. The “community” also includes friends, neighbors, and other family members.

This study documented that many family members face a constellation of competing concerns that are complex and that defy easy answers. Social interventions aimed at helping to relieve some of these competing concerns are important. Role reinforcement examples suggested by the findings include providing transportation for nondriving family members to visit loved ones in a nursing home, or to meet a resident in the emergency room; offering to take the resident and family for an outing away from the nursing home; visiting the resident when the family member is not available; visiting the resident with the family member; helping with child care (and grandchild care); helping to handle the dispersion of household items from the resident’s home and getting the house ready to sell; writing a caring note to the family and/or resident to demonstrate commitment to the relationship; patiently listening to the stories of family caregiving. In these ways and others, the community recognizes and honors the commitment that family members demonstrate through their continued contact with loved ones in a nursing home. And in this way, family members teach the community about caring. As more people find themselves in the position of having a loved one living and dying as a nursing home resident, this type of hard-earned wisdom will become all the more valuable to individuals and to society as a whole.

REFERENCES