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Tensions in Independent Living Facilities for Elders: A Model of Connected Disconnections

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Abstract

Objective—To gain an increased understanding about the geriatric health and safety concerns related to vulnerable elders residing alone in independent living facilities (ILFs).

Methods—Qualitative focus group methodology was used to elicit the perceptions of elderly residents representing three ILFs, their family members, housing staff, and Nurse Practitioner consultants.

Results—Staff comprised 3 focus groups, residents 4 groups, and families 1 group for a total of 26 participants across eight focus groups. Content analyses of transcripts revealed that falls, forgetfulness/confusion, medication management and unexpected critical health events were concerns shared across the groups. Subgroups differed greatly in other concerns and service expectations.

Discussion—Findings resulted in a thematic model of Connected Disconnections with shared concerns, differences in beliefs and tension points. Problems arise when the wrong residents are living in the wrong type of housing. More attention to pre-admission resident evaluation and clarifying service expectations with families before acceptance and during periods of elder functional decline are recommended.

Keywords

aged; elderly housing; assisted living; qualitative research; nurses

Background & Significance

At present, there are 21.8 million households that contain a person age 65 years and older, with 46 % of these older people living alone at home (Stevenson, 2006). Between 2007 and 2015 the number of Americans age 85 and older is expected to increase by 40% (AAHSA, 2008). This cohort, 85 years and older, are the most at risk population for chronic and acute health problems. Although vulnerable, research has consistently demonstrated that older adults prefer to remain living in their own home, frequently referred to as aging-in-place, and avoid institutionalization in nursing homes (Fielo, 2001, Fisk, 1998, Stevenson, 2006).

The assisted living movement developed in response to consumer interest and demand for alternatives for institutional services. The early 1990's saw a period of national discussion

about assisted living in all of its forms, and in 1994 newly formed assisted living concepts went public (Wilson, 2007). The assisted living (AL) model incorporates several key concepts. First is privacy, providing both a private and public residential/environmental space; second is more philosophical empowering elderly consumers to maintain control over their care and lifestyle preferences; and finally service/capacity- providing both routine and specialized services for this group of elders in the community, including health related services (Wilson, 2007).

There has been tremendous growth in the senior housing market. Currently there are 16,100 certified nursing homes in the U. S. with 1.4 million residents; 39,500 assisted living facilities in the U.S. with 900,000 residents; and 2,240 continuing care retirement communities in the U.S. In addition to this there are 300,000 units of section 202 affordable senior housing units, and for each unit that is available, ten eligible seniors remain on the waiting list (AAHSA, 2008). Much has been learned over the years about elders' preferences and responses to assisted living and this has been reported in depth (Hughes, 2007). The positive aspects are: ability to provide assistance with activities of daily living and independent activities of daily living when needed and wanted; interventions to manage the effects of chronic disease or disability; arrangement for treatment of acute care episodes and mental health issues; attention to all aspects of well being; and responsibility for the coordination (case management) of services needed for enhanced well being (Wilson, 2007). The negative aspects include relocation, the cost of AL and adjusting from complete control of one's activities to a new environment with prescribed services, formal caregivers, and other residents who may have disabilities and impairments that can be upsetting (Cutler, 2007).

Most recently the development of Independent Living Facilities (ILFs) emerged to address AL's negative aspects. ILF differs from AL in the way they offer consumers their choice of a variety of options, including more privacy and greater affordability. By virtue of differences in the preferences and financial statuses of older adults and their families, consumers help to determine where supportive facilities fit within the continuum of care (Stone, 2007). Independent living facilities offer private apartments and a low intensity of professional services thus relying on elder self-care and family involvement to support activities of daily living. Assisted living facilities also offer private units with a much higher intensity of professional services designed for the functionally and sometimes cognitively impaired elder, but at a much higher cost. In addition to factors such as price, services, and location which are central to the consumers' decision making, a homelike environment with privacy are important to the elderly and their families. Stevenson (2006) still reports the goal for the elderly population is to create environments that maximize independent living, where people have the ability to function safely and comfortably in their own home, avoiding the need to move to an institution.

Theoretical framework

M. Powell Lawton's early theoretical research on the environment and aging, supports the perspective that the period of adult development is profoundly influenced and shaped by the environment (1980,1982). The person-environment model is important in geriatric research because age-related losses in vision, mobility, and cognitive capacity negatively affect the congruence between the elder and the environment; impaired elders are particularly vulnerable to environmental demands. According to Lawton (1998), the person-environment transactions in later life can be seen as a tension between the need for security and the need for autonomy. Attainment of autonomy and security is a universal need and significant when planning housing environments for frail, ill, or cognitively impaired elders. Lawton (1998) suggests that housing environments offer relevant social choices to address residents' diversity of interests and promote autonomy.

According to Oswald, Wahl, Martin, and Mollenkopf (2003), Lawton's notion of environmental pro activity, serves as the theoretical background to suggest a new dimension of domain-specific control, namely housing related control beliefs. Lawton's model proposes that there are psychological benefits both for the caregiver and the care receiver of an appropriate balance between the socio-environmental demands (caregivers' expectations regarding care receivers' competence) and the capacity of an individual. Individuals who reside in better accessible homes, who perceive their home as meaningful and useful, and who think that external influences are not responsible for their housing situations, are more independent in daily activities and have a better sense of well-being (Oswald, Wahl, Schelly, 2007). "If aging in place occurs, the rules that govern the standing patterns of behavior may need to be modified deliberately, all to enhance quality of daily life and generalized well being "(Lawton, 1998 p.26).

Helping older adults remain independent in the setting of their choice is a complex, multi-factorial endeavor (Rantz, 2005). During this decade explorations into integrating new technologies into residential settings has commenced (Cesta, 2007, Sixsmith, 2000). "Home modification and relocation should not be prescribed, but needs to be negotiated with older adults to take into account their personal needs and preferences" (Oswald, Wahl, Schilling, Nygen, Fange, Sixsmith, Sixsmith, Szeman, Tomsone, & Iwarsson 2007, p.96). According to Mann et al., (1999) home environmental interventions and assistive technology devices have the potential to increase independence for frail elders, but their effectiveness needs to be demonstrated through research. Could residential based monitoring technologies provide a critical service component to mediate increases in environmental demands over time and promote residents' autonomy and security? Our research program aims to address that question but to do so there is a critical need to initially identify and understand the residential needs and issues arising in the new ILF setting. The purpose of this study was to explore the concerns of key stakeholders living the experience of residing, working in or having family members in an independent living facility to inform the field and lend direction to the subsequent development of relevant monitoring technologies for remediation.

Setting

The research occurred at three ILFs for senior citizens in MA that have been in operation just under five years. The facilities were all high rise apartment buildings in style, each offering elevator access to several hundred predominantly one bedroom rental units. The facilities offered a fitness room, library, and two out of the three had a computer room and provided daytime meals and shuttle transportation for food shopping and events. Each offered a daytime receptionist, activity staff, maintenance staff, building manager, part- time nurse practitioners for health management consults and part- time social workers for counseling. In the evening and weekends, an on-call building superintendent covered the three buildings and was the only staff person routinely available. Optional housekeeping and personal care services were available at an additional cost. The ILFs were owned and operated by the same non-profit organization that maintained an excellent reputation in the region for elder long-term care and their facilities were chosen as exemplars. The research protocol was submitted both to the investigators' Institutional Review Board for human subject study as well as the housing sites' research review committee and received dual approval before study commencement.

Methods

Study sample

Purposive sampling was used to select participants who were information rich data sources about the phenomenon of interest and willing to engage in detailed interviews. All building staff and Nurse Practitioners (NPs) were recruited and agreed to participate. Residents and

families were indirectly recruited as described in the procedures and represented as desired an information rich segment of the population. The aim of qualitative research is to explore, describe and interpret human experience in ways that provide greater understanding and insight about human social experience. Sample consideration is not based on size but study participants. Qualitative methods are most appropriate when little is known about the phenomenon of interest and offers a means to give a voice to study participants (Hurley, 1999, Sofaer, 1999). In addition to Lawton's model underpinning the focus of this study, Bandura's theory of perceived self-efficacy directed our attention to the key stakeholders understanding of independent living and behavioral responses necessary to maintain elder independence (Bandura, 1977). The analysis used a grounded theory approach, an inductive analytic method, appropriate for qualitative a method that is guided by broad research questions designed to stimulate discussion among focus group the participants. This approach emphasizes the primacy of the context and integrates flexible interviewing methods to provide coherence and continuity in the research design with the fostering of categorization and conceptualization (Strauss, 1997, Strauss and Corbin, 1998).

Procedures

Prior to participant recruitment, informal meetings were held with housing staff from the ILFs under study to engage their interest and orient them to the study. Next an informational program and coffee hour was scheduled for residents and families with posters and flyers announcing the event. At this presentation the researchers described the study, answered questions and offered interested residents a sign up sheet that gave permission to be contacted. Afterwards, these residents were called by the researchers, screened for mental acuity to ensure they had the ability to consent (Callahan, 2002). Two failed. Those who passed were invited to participate and asked for the name of a family member who could offer opinions. Four agreed, the remainder did not want to "use up" their family visit time. The named family member was called, informed about the study, and offered participation. Those who verbally consented were sent 2 copies of the consent form and scheduled for a focus group at their respective family members' housing site. The ILFs designated a staff person as the local site coordinator and she helped us to contact the employees and make arrangements for their focus groups. To be eligible for the study elders had to reside in an ILF, the family members had to be the primary relative who had elder oversight responsibilities, and the Staff were an employee or subcontractor of services (the NPs) at the targeted ILFs.

The focus groups were moderated by our team sociologist (BT) who began each group with a brief overview of the study, answered questions and obtained participants written informed consent prior to conducting the session. Anonymity and confidentiality was assured. She facilitated all the groups and conducted them in the same way starting with a broad open ended question to sensitize the group to the topic area i.e. What does living (or working/having a relative) in an Independent Living facility mean to you? And following up with progressive probes to focus or clarify issues i.e. Do you see any residents with health or safety problems? Can you tell me more about that? Are there other concerns? All participants were strategically engaged so that their views were obtained and interactions fostered among the participants to further the discussions.

Each of the subgroups was interviewed in separate group sessions. Two staff members and one family member were interviewed individually, due to staffing constraints and personal preference. All sessions were audio-taped with the participants' permission. On average the sessions lasted approximately 1.5 hours and were conducted in 2005. Participants received a \$20.00 honorarium.

Analysis

A transcriptionist transcribed all the focus group audio-tapes and the transcripts were checked line by line by the moderator for accuracy. The transcriptions were read in their entirety for general impressions and then re-read for coding the text, writing memos and generating tentative categories. The moderator entered the data into a computer assisted qualitative analytic program, WinMax-95. This program facilitates standardized implementation of qualitative analytic practices and systematic analysis. Investigators searched for relationships between categories and developed concepts. Repeated concepts were understood to be patterns and contrasting concepts were understood to represent variation in the data. Concurrent data collection and analyses occurred with continual comparing and contrasting on an iterative basis until the data produced saturated concepts, signaling completeness of data analysis. (Krueger, 1998, Morgan, 1997, 1994, Weitman, 1999). Findings were presented and validated for interpretive accuracy by participants from ILFs and at several geriatric conferences wherein other ILFs' staff identified with the issues and confirmed the model's relevancy.

Results

Participants

In total, 26 participants were enrolled. Table 1 summarizes the characteristics of the participants. Of note, participants from the targeted senior housing sites were all white elders. African American elders residing alone in elderly housing apartments were recruited through a family service center in Boston to elicit a comparative perspective. See Table 1 for enrollment response. Overall, the average age of the resident was 79, the majority was female, widowed, and moved to the ILFs within the last two years to be near family. The majority of the staff was middle aged and female except for the building superintendents. Family members included two adult children, a brother, and a niece. The majority of elders (70%) refused to name a family member because they did not want to "burden" their family member by asking them to come to the ILF for a meeting. The primary reasons given were they "are very busy", or "too far away" and the residents did not want to inconvenience them or take away one of their visit times.

There was substantial variability in the themes identified between and within groups but there was a consensus of agreement on four concerns. In order of frequency they were: 1) falls, 2) medication management, 3) forgetfulness and 4) occurrence of an unspecified critical event. In addition to the shared concerns, residents and staff reported overlapping and unique concerns. Table 2 lists the major concerns per group and in total.

Shared concerns

Falls

Falling was the most frequently discussed theme across all the subgroups and was especially worrisome to residents. A resident talking about a personal emergency response product said: "But the reason I got it was because I actually did fall, I mean I've fallen quite a few times." Another resident dramatically described her efforts to avoid being embarrassed by a fall:

...and I was on the floor. It took me an hour of turning and twisting on the floor till I moved over to a piece of furniture to hoist myself up. And I thought of calling... All I needed to do was, be picked up off the floor. And I didn't do it [call] because I was embarrassed. Then I found out later that they don't pick you up, they call 911! Which would have been even worse.

While several residents were forthcoming regarding their concerns about falling, others were not. One man, who reported he had recently fallen four times outside, denied any concerns

about falling. Staff was very concerned about residents who fell and noted that on average one fall is reported daily. The day of the first staff group, three falls had been reported. The NPs thought that the falls were due to multiple causes, “especially as these folks are aging in place.” They mentioned residents with impaired balance, Parkinson disease, failing vision often associated with diabetes, muscle weakness post stroke, resistance to using adaptive equipment and the presence of cats and dogs. The NP’s suggested that many apartments are cluttered and this creates substantial safety risks:

She has severe Parkinson’s, lives alone and her apartment is very crowded, has a cat and also has problems with her shoulder and sat on the toilet and couldn’t get up. She was there for probably 6 hours. She didn’t have a LifeLine. I had seen her about 2 months ago and suggested getting a raised toilet seat...I got one there, I positioned it, we had to move the cat litter around and she called me 2 days later to take it away because it was making the bathroom too crowded. So some of this resistance on the part of some of the elders [is] to use adaptive equipment.

Family members expressed great concern that their family member would fall. Some believed their elder’s vision was failing, others that their elder’s balance was impaired, while others were worried that a prior stroke had left their family member at greater risk of a fall. As one son noted exclaimed: “Yes!” [I am concerned]...She has a hard time seeing, because of that, tripping over something that she didn’t see, certainly contributes to her being unsteady on her feet.”

Medication Management

Many residents are on complex medication regimens and find managing their medications difficult. As one resident said “I used to take two medications a day for several years. But after my stroke I now take nine different medications a day” She is worried about remembering to take everything at the right time, or in the right way. Residents needed help organizing their medications for a variety of reasons, including failing memory and poor eyesight. An NP reported “I have people for medication management” another adding “I do lots of pills.” Many elders are dependent on weekly pill organizers to bring order to their daily regimen but at times this is not enough. As an NP related:

... her neighbor came down to tell me [that] she was doing her neighbor’s meds [filling her friends medication organizer for her] and said her medications were not matching. I went up ... and I noticed one of the bottles has no label. She tried to tell me what it was, but it wasn’t matching up, so I ended up calling the cardiologist and we did get it straightened out.

It became evident later in the discussion with the NPs that some residents move into senior housing, at least in part, because they had been experiencing medication compliance problems in their prior living situation:

I’ve tried several times to fill up her medications ...but [the residents] have no real concept of what they’re taking... And that’s how they’ve got into trouble. And that’s what prompted them to move into the building in the first place, hope of trying to get their medicines squared away.

Forgetfulness/Confusion

Forgetfulness and confusion shared second place as being an important and frequently discussed theme among all participants. Forgetfulness and confusion were the most frequently discussed themes among all housing staff. Staff reported that residents frequently lock themselves out of their apartments. One of the more frequent calls for assistance staff receive from residents is to help them locate some mundane object they have lost. Residents complain

that they are unable to locate their glasses or mail and suggest to the staff person responding, that “someone entered their apartment” and took the missing objects or moved them. A staff member noted that “paranoia issues are just very difficult to resolve, ...I guess it’s the most common and oddest.”

Another staff member agreed:

Yeah, paranoia is often sort of one of the precursors to real Alzheimer’s and so that [is] one of the things that you get called on...

And another noted:

...a lot of them [residents] are forgetful. A lot of them call me to reinforce the day of the week. A lot of times they’ll call me asking for the time or what activity. Or “What’s today’s date, what day of the week is it?” They’ll call in the beginning of the day, the middle of the day, and again towards the end of the day...during the beginning of the week it’s more of a harder time for them, because of the weekend and we’re not here, the offices aren’t open. Some Mondays would be days when you would get a lot of those calls.

Housing staff also reported that at least 3–4 false Personal Emergency Response calls occur each week that result in response by EMTs.

“A few residents get [confused or anxious] and press the Lifeline buttonand during a fire drill this has Emergency Medical Professionals responding to a potential problem in the building at the same time as the City Fire Department.”

However, most residents see forgetfulness and confusion as a problem for others, not themselves:

...and there was a resident from this building floating around on my floor. He was out of it. He knew he lived on the second floor, but he couldn’t find his apartment. He couldn’t remember where he parked his car.

Unspecified Critical Event/Urgent Care Needs

Themes labeled unspecified critical events emerged in every discussion group, most frequently among residents. “You know, you never know when something could happen... you could get sick at anytime, you could have a heart attack at anytime, you could fall. The thing is healthy people could fall and get hurt.”

From another group discussion: “My daughter calls me every morning, so if there’s anything wrong she would know.” And this: “If anything happens we have a nurse part time...” The ambiguous remark, ‘if anything happens’ was an often-repeated reference to some unknown critical health event and implied death.

The emergence of urgent care needs in the discussion of residents (8), suggested the tension that results from residents claiming to be independent by virtue of living in an ILF and the reality of their diminishing health and vigor.

In one group a resident stated confidently that: “If anything happens, we have a nurse part time and the staff take care of some things.” While another resident countered: “No, they have no coverage, none at all. And another adds: “There’s nobody here from say 5 at night until 7:30 the next morning.”

Staff was also worried about a critical event happening, particularly something that could go undetected for awhile:

having a homecare worker say, "... I can't get into this apartment" and I go up and finding someone on the floor that's been obviously there for a while. That's sort of the most traumatic to deal with."

The NPs reported that they do get requests directly from residents if they or a neighbor needs urgent attention. At other times the NPs are paged by the receptionist, after a resident has reported an injury or fall. "Sometimes residents forget we are here and they don't think to call us to go up."

Contrasting Themes

We value our independence

Residents overwhelmingly spoke with palpable emotion, asserting that they were living in an independent living facility for seniors. This classification was extremely important to them and validated their independent status.

"The name says it ...independent living...I am independent and [not a burden on anyone]

"We are in independent living, not assisted living. It's not a nursing home. It's not assisted living and they [new residents] know that when they come in."

We are not Assisted Living

The housing staff noted that they are not working in assisted living but report a difference in the population in each of the three different ILF apartment buildings and the family and financial pressures that influence their services.

...but in building A, they're independent living, and there are no meals and everybody kind of does their own thing. Here, [in building B] ...we consider it independent living, butthey can get 2 meals a day here...Building C [M]ore people confused here.... There are more people who need care.

You get a few from assisted living who can't afford it. So they come here. Very often financially, it's not in the family person's best interests to notice that mom is getting more and more demented. If in fact mom needs assisted living, they're going to pay a lot more money than they pay here. I mean this is like one of the least expensive ways to sort of assure a safe environment for mom there is.

Sometimes we call it "Throw Momma from the Train" I've been seeing more and more, families who come and bring their parents and they try to present that their parents can live independently. And myself or ____ would express our concerns and they promise that they'll get services in place, that they live in the area and they'll be here all the time. And you never see the family again. We realize we have to look at those people a little closer as to why they're coming here.

The NPs talked about the tension they experience between being helpful and respecting the resident's autonomy and privacy, "... this is independent living, the residents are not obligated to communicate with the nurses." The nurses feel a responsibility to oversee the health of particularly frail and cognitively impaired elders in the building, but can be kept at bay by residents not wanting their help. "My other scare is, actually people in the apartments that I don't know anything about because you never see them."

We expect a supportive environment

Family members readily expressed confidence in the administration of the facility providing a high level of service and quality of care. Choice of the facility was greatly influenced by the

ILFs relationship with a well known and highly regarded long term care organization and the families expected a similar well run operation.

When X took over running this place we knew that is where we wanted our mother to be. They have a great reputation and we want the best for her. We don't have to worry. They will take good care of her.

Tension Points

New Resident Transition

New residents encountered multiple and complex problems adjusting to the new living environment, which frequently required the assistance and skills of several staff members. When asked about how long it takes new residents to adjust, one staff member said:

It depends on a lot of things, support from their family. But I would say two or three months. It's a huge adjustment, giving up their homes. All their furniture, lifestyle... [and now] ...learn phone numbers, learn the names of these new people, that they've never seen before in their lives. And some of the people have indicated part of the reason they come here is because they're not able to drive anymore.

The magnitude of the problem prompted the creation of a new position, that of resident coordinator, to facilitate the adjustment of new residents. She noted:

...when they [new residents] came in [for application interview], they were fine, no problems, no memory loss or anything. They, then I guess coming here, it's a whole other atmosphere for them. It's not in their daily routine, so when they come in here they're kind of all over the place. So... we would get these calls all the time; that they wouldn't know how to use a thermostat or the microwave is not working when actually it's working.

An NP describes the new resident transition period from her unique perspective:

Well as we all know, you move them from a comfortable environment to a new environment that if there's any hint of a cognitive with a client, it's going to accelerate as soon as they move into the building. So basically, they've had issues at their other housing and that's what prompted them to move into the building in the first place... to [be] close to the kids.

We noticed this a lot when residents who have some sort of dementia, [before they come] ... they have a difficult time adjusting and that's where we see a lot of the wandering in the beginning and the confusion.

Only one resident talked about issues related to moving into ILF. She said after 5 years: "I had a hard time getting used to living in a big building, I guess I'll never get used to it. Transitioning into a new living environment was absent from the discussions of family members.

No Health Problem—Denial of any health problems emerged as the most frequently discussed theme among residents (31×).

As one resident said:

I don't even think I have Parkinson's, even though the doctor told me I do. I don't think I have it. I think I have something like, ... but whatever.

It must be remembered that some residents were forthcoming, explaining that they had real health and safety issues and found these conditions worrisome and problematic. Interestingly, a theme of sick, but not a problem emerged along side of "No health problem". Some residents

spoke about being in poor health, but that their illness was not a problem, meaning for most that they were able to cope with those conditions. For example:

I 'm not at the point that I need one of those, that emergency lifeline... I'm not at that point. To me, I'm healthy. I am a diabetic, and I've got every other thing, but I'm all right. I can walk; I can do what I want.

It was clear, good health is not the absence of disease, good health is being able to take care of oneself, albeit sometimes with assistance. Families also were reported as having difficulty recognizing cognitive problems but confrontation was not used. As one staff member noted

"You know sometimes the residents are forgetful and they [do not] realize that it was actually done. But the family members, they don't want to realize that the parent has dementia or whatever and they don't realize that someone was in the apartment and did take care of those things. I just try to play it on their side. "OK, I'll just have someone go backup and check."

Others have health problems—In frequent tandem with the theme of No Health Problem, came statements that other residents have health problems. One resident when asked about his diabetic condition replied:

"I might go up high, but I'm under control. I'm all right. But you take like [name of resident] here, or you take [name of another resident], and there's a few other people..."

NPs indicated that many residents overestimate their health status. One example given was a woman who:

"has diabetes and her vision is failing and overall her balance is going. She's having some falls in her apartment. So she is given serious consideration to it [personal emergency response system], but hasn't done it yet. It's a lot of resistance to giving into the limitations that have developed."

Model of Connected Disconnections

Emerging from the data was a model of connected disconnections. The key stakeholders shared a connection in the consensus of concerns about health and safety issues commonly found among residents in their ILFs. This was placed at the core, central area visually connoting the shared agreement. By contrast, the three circles represent the very different viewpoints of the stakeholders and contrasting perspectives. Expectations of Independent living in the facilities greatly varied depending on one's role and leads to disconnections in perspectives. Underpinning this is the central paradigm of the meaning of independent living. We see three different meanings that overlap and at the junctions have important tension points related to resident relocation, confusion, and family denial of problems.

Discussion

Four thematic issues were identified by all categories of participants, with falls being the most important health and safety concern overall. In general all categories of participants agreed upon the meaning and importance of the four shared themes. Medication taking, along with forgetfulness and confusion were discussed with equal frequency next, very often in the context of memory related non-compliance. Also of concern was the occurrence of an unspecified critical/urgent event happening, often exemplified by a fall. Falls, medication compliance and impaired cognitive functioning are identified in the literature as well as being a major source for increased risk of serious adverse events for community dwelling elders. The staff was sensitive to the possibility that a critical event could go undetected as the resident lives alone in their apartment and given the independent living philosophy, they have no protocol in place

to routinely check on residents. Tension escalates when resident behaviors that prompted staff concerns about Alzheimer's disease were denied by family who were unwilling to accept the housing staff's reports of disturbing or unsafe behaviors. While individual privacy and autonomy are core values in ILFs, the balance of the safety and security needs of a resident with cognitive impairment to the other residents of the facilities exerts tremendous tension. Future research is needed to identify ways to best address these tension points and to proactively respond to the shared concerns.

Limitations

As indicative of qualitative research, the findings emerge from in-depth discussions with a sample purposely chosen to provide rich details and input that contributes to increased understanding. Consequently, the target group is small, and the findings are not meant to quantitatively represent or generalize to the population of ILFs.

Conclusion

Findings from this study offer new and important insights from key stakeholders experiencing the emerging field of Independent Living Facilities. This type of housing is both a physical setting as well as an open social system that engenders stakeholders' involvement. Problems arise when the "wrong type" of resident is accepted and when existing residents age-in-place and become the "wrong type" – dependent on professional caregivers to manage their activities of daily living.

Older adults clearly valued the meaning of independent living and this label surfaced as critically important to the residents. The operationalization of independent living, however, is influenced by residential planning and staff composition and service offerings. The lines became blurred as the residents aged-in-place and needed additional supports, some of which mimicked those found in assisted living. Whether the facility embraces the more supportive mode directly, or allows outside formal caregiving services in to respond to residents needs, is actively negotiated.

Tensions can arise from families who expect supportive services that may not be able to be offered in this type of environment or deny the need for more formal elder services when suggested by the staff. A model of Disconnected Expectations is presented that portrays the shared concerns and tensions among the stakeholders. To reduce the disconnections and tensions we suggest that pre-admission interviews to assess the capacity of an elder to reside in an ILF should be conducted on more than one occasion, in part without the family present, and ideally include standardized cognitive and physical function screening by a nurse practitioner as a baseline for comparison over time. There is a need for families to gain clarity about their expectations for a supportive environment and their role in it. Clear delineation of staff hours and available services in an ILF versus an Assisted Living would be helpful. Ultimately, there is also a need to disclose that the overall safety and security of the building residents takes precedence over an individual's independence if he or she engenders risk to residents' welfare. Taken together these actions are aimed at aligning the key stakeholders' expectations to decrease staff- family – resident tensions and increase consensus about shared concerns to move forward to address them and reach the optimal resident-environmental fit.

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Figure 1.
Model of Connected Disconnections

Table 1

Focus Group Enrollment

Focus groups conducted: 8			
Staff/clinician subgroups: 3			
Resident/family subgroups: 5			
Race	Female	Male	Total
African American	4	1	5
White	15	6	21
Total	19	7	26
Endusers			
Residents	9	4	13
Family	2	2	4
Building staff	5	1	6
Nurse practitioners	3	0	3
Total	19	7	26

Table 2

Major Themes Listed by Frequency of Occurrence.

Shared Concerns	Resident N=13	Family N=4	Staff N=9	All Groups N=26
Falls	14	4	11	29
Medication taking	11	1	9	21
Forgetfulness/Confusion	6	1	14	21
Unspecified Critical Event/Urgent Needs	14	1	4	19
Overlapping Themes				
We are independent	13	0	3	16
We are not Assisted Living	1	0	4	5
We expect a supportive environment	1	4	0	5
Tension points				
No Health Problem	31	0	0	31
Others Have Problem	18	0	0	18
New Resident Transition Issues	1	0	12	13
Family denial	0	0	6	6
Toilet Overflow	0	0	3	3