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# Connecticut Long-Term Care Needs Assessment

# The Connecticut Long Term Care Ombudsman Program:

# Fear of Retaliation


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# FEAR OF RETALIATION

## EXECUTIVE SUMMARY

### Background

There is much written in the literature about fear of retaliation with regard to people who are living in nursing homes and also elders under the care of a family member. Yet, few studies have explored what it actually feels like for the care recipient to experience this emotion. Cheikin (1979) described a "paradoxical need-fear relationship" (p. 187), that can develop if someone is dependent on a caregiver for basic needs; that person may be very intent on holding onto that relationship, even if it were not in keeping with their rights to privacy, dignity and autonomy. Understanding the dynamic of the caregiver/care recipient imbalance is critical to comprehending this dilemma. The dilemma quite simply is: will the situation get better or worse by reporting an incident?

This study explores the notion of fear of retaliation, and, more importantly it focuses on what emotions the care recipient experiences with regard to this fear. The information for this study comes from two sources. First, a specific question on a survey was administered either in-person or by telephone with residents of 57 supportive housing residences: "Do you worry about retaliation if you were to report a complaint or concern? Can you tell me about this?" The second source consisted of in-depth interviews with seven older adults either in assisted living or in nursing homes. These interviews were done in order to obtain a better understanding of what it feels like to experience fear of retaliation. These individuals were recruited from the VOICES forum, an annual conference sponsored by the State Long Term Care Ombudsman Program which provides Connecticut nursing home residents with the opportunity to express their concerns to public officials interested in their welfare.

### Results from the survey question

Survey interviews were conducted with residents of three types of LTC environments: nursing homes or skilled nursing facilities, assisted living communities, and residential care facilities throughout the state of Connecticut. There were a total of 150 residents from 57 supportive housing residences: skilled nursing facility (n=95) from 38 facilities; assisted living (n=25) from 11 ALSAs; and residential care homes (n=30) from 8 RCHs.

The question "Do you worry about retaliation if you were to report a complaint or concern?" and "Can you tell me about this?" was the primary focus of this investigation. Over two-thirds (71%) of the residents said that "no", they do not worry about retaliation if they were to report a complaint or concern. This was consistent across all supportive housing types (see Table 1). Fewer residents of assisted living said that they worry about retaliation (13%) compared to nursing homes (23%) and RCHs (19%). Overall, six percent of the participants stated that they did not want to complain. Other responses included items such as they "don't think about it or don't know", or "it wouldn't do any good to complain", or "I don't want to get people in trouble." While there were no significant differences by age or type of residence, it was notable that a greater percentage (26%) of residents who had lived in their current living arrangement for over two years said that they do worry about retaliation. This compares to only 13 percent of those who had lived in their current situation for less than a year and 16 percent of those who had lived in their current situation for a period of one to two years.

Table 1.

| | SNF %/(n) | ALSA %/(n) | RCH %/(n) |
|---|---|---|---|
| Yes, they worry | 23 (22) | 13 (3) | 19 (6) |
| No, they do not worry | 70 (67) | 71 (18) | 71 (21) |
| Don't want to complain | 4 (4) | 8 (2) | 7 (2) |
| Don't think about it/ Don't Know | 2 (2) | 4 (1) | 0 (0) |
| Don't want to get people in trouble | 1 (1) | 4 (1) | 4 (1) |

One of the limitations to the study was the fact that many of the residents from assisted living were fairly independent compared to the residents of nursing homes. Generally, nursing home residents require a more intense level of care compared to those in assisted living. Some residents from assisted living only received help with meals and services like house cleaning. Participants who do not receive hands-on care may not be as likely to experience abuse or neglect as those who do receive hands-on care. Future research could focus on correlations between the perception of fear of retaliation and the level of need of the care recipient.

**Results from the in-depth interviews**

Five women and two men participated in the in-depth interviews. Ages ranged from 48 to 93, however most of the participants were in their 60s. Length of stay in their supportive housing ranged from less than one year to over 10 years.

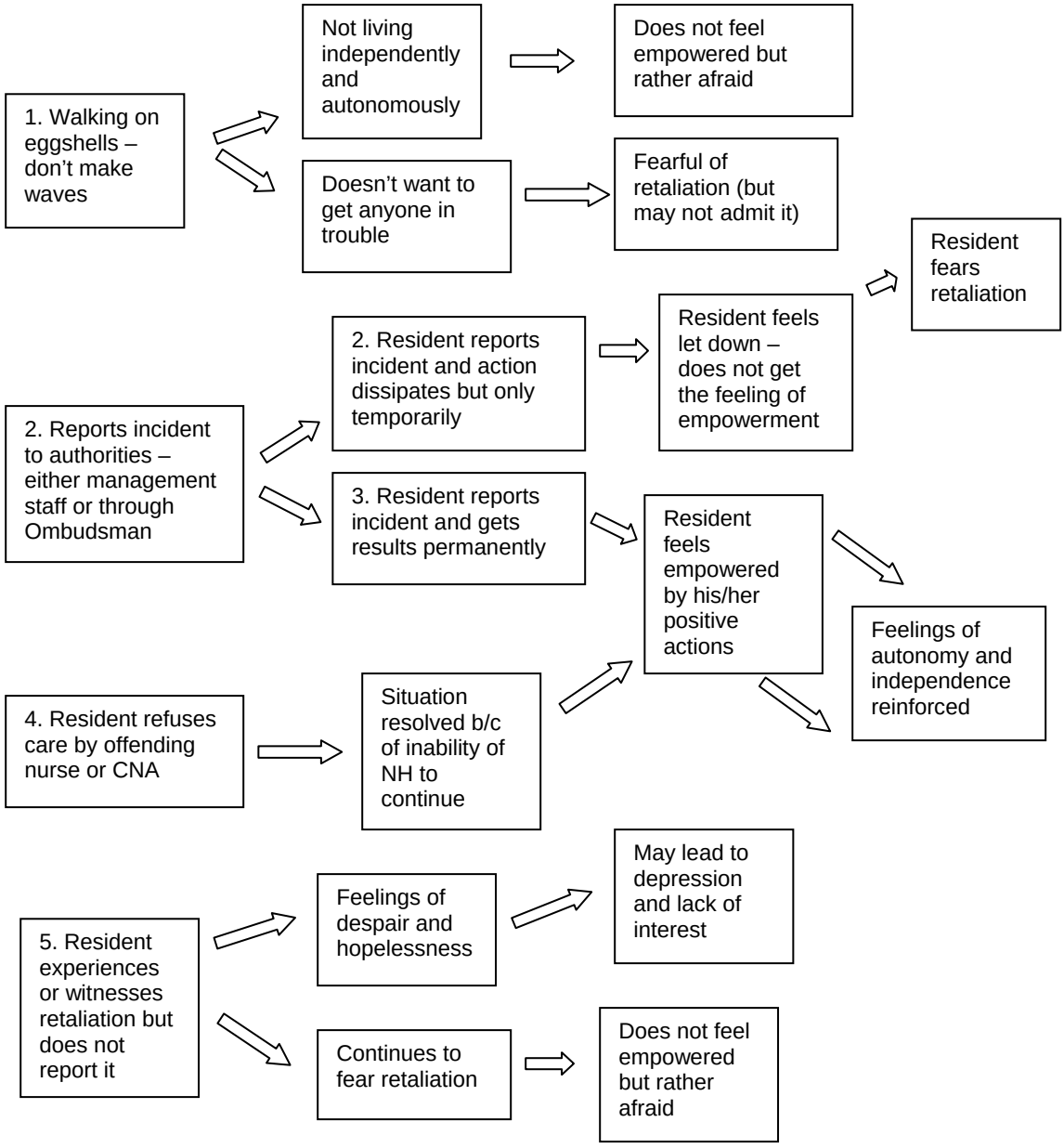
Although there were only seven in-depth interviews, they represent a broad spectrum of scenarios regarding incidences of retaliation. Some individuals reported abusive situations and found that the incidents decreased, others used the expertise of individuals in the Connecticut Long-Term Care Ombudsman Program to help solve the problems, while another individual refused to accept any additional treatments or medications from the nurse who was reported. In most of these cases, the situations were resolved as a result of the resident reporting instances of abuse or neglect. However, for those individuals who did not report incidents of abuse, feelings of hopelessness and despair were expressed. Even with confidentiality assured, these individuals were wary about reporting anyone because they believed that it would get back to that person and that that person would take it out on them somehow. Depending on the individual, the perception that retaliation might occur provoked as much fear for that individual as to experience retaliation itself.

The presentation of the results from the in-depth interviews is organized in several sections in the paper, according to the themes that were found in the interviews: living in a nursing home, caregiver/care recipient relationship, attitudes of staff, incidents of retaliation; reporting incidents, not reporting retaliation, what retaliation feels like, and positive experiences.

The following trends seemed to permeate the findings from the in-depth interviews and, to an extent from the answers of the survey respondents as well. For individuals who said that they don't want to make waves, or are tip-toeing on eggshells, there was an essential fear of retaliation that diminished

that person's independence and autonomy. For individuals who were successful in their reporting of incidents of abuse, there was an affirmation of their independence and autonomy and a feeling of empowerment. For those who did report incidents and did not get a positive response or conclusion to their report, there was a risk that the individual might become fearful of retaliation and subsequently fearful of reporting future incidents. For those who hesitated to report incidents and were torn about whether the situation would become worse as opposed to better, there was a feeling of despair and hopelessness. The various scenarios are depicted in the following flow chart:

**Figure 1. Five scenarios from the in-depth interviews**



## Conclusion

Retaliation and the fear of retaliation is a reality in any supportive housing situation. Because retaliation can be either egregious or subtle, many forms of retaliation may not even be recognized by residents or staff. Through the efforts of the Long-Term Care Ombudsman program in Connecticut and the continuing strides of the "Fear of Retaliation Workgroup," information on residents' rights are promoted on a continuing basis. A list of best practices that support residents' rights is being compiled by the workgroup in order to encourage facilities to be pro-active with respect to retaliation issues. These include, but are not limited to, adopting a "no tolerance" policy regarding fear of retaliation and encouraging formation of internal committees to provide a meaningful and interactive in-service to staff and residents specific to this issue. In addition, residents are encouraged to contact a trusted staff member, ombudsman, or resident council president to voice his or her concerns anonymously. The findings from this study will be used to develop videos that will be part of the interactive in-service to teach both residents and staff at nursing homes how to recognize and respond to retaliation.

As exploratory research, this study has certain inherent limitations. First, the utilization of a survey methodology eliminates the possibility of hearing from individuals who are unable to express themselves or their views about the subject. As one of the interviewees said, she worries more about the people who are unable to speak up for themselves than for herself. She felt that they may experience abuse even more because they are unable to speak or to communicate their feelings. She went on to say,

> *It's difficult enough to get by with disabilities and multiple disabilities, and you have someone taking care of you who isn't kind, it just takes away all of your hope.*

Then this participant described solutions that are available to all residents in any supportive housing situations.

> *The advantage is that I have avenues of help … so many of us, we're all connected and we all have feelings and together we can get things done – and if we all report people who are not nice, they can start to eliminate people who do not treat us with respect. This is our home. We're here to be taken care of, somebody has to do it. Nobody ever plans to be in a nursing home, it's not funny. Like when you're younger, you never say, "I think I'll go into a nursing home whenever." For all that anybody knows, they could be in a nursing home tomorrow.*

## *INTRODUCTION*

Fear of retaliation, fear of retribution, and fear of reprisal are phrases used frequently in articles about elder abuse and nursing home abuse. Retaliation means the act of deliberately harming someone in response to a harm that he or she has done. Fear of retaliation is often noted as a reason for an individual's failure to report incidents of abuse or neglect in nursing homes and other caregiving situations. This abuse can take the form of physical, verbal, or even financial abuse. Because of this perception, residents of various supportive housing residences and recipients of care by a family member are reluctant to report these incidents of abuse or neglect because they fear that the abuse will become even worse or that adequate care may not be provided. For individuals who rely on others for assistance with the activities of daily living (ADLs) or instrumental activities of daily living (IADLs), there is a belief that if they were to complain, their situation could become worse.

In a review of elder abuse literature, Wyandt (2004) points to the fact that oftentimes it is someone other than the victim who reports suspicion of elder abuse. She notes that the victim may, in fact, not be aware that any abuse is happening or they "fear that greater abuse may occur if something is said … (p. 46)." She points to the fact that most of the time there is a dependence on the person who is abusing them. This, in essence, is the crux of the matter, the tenuous balance that exists between the caregiver and the care-recipient. There is a relationship between the two that involves, for the elderly person, a certain amount of dependence on others, such as family members, caretakers, agency and staff (Burgess & Clements, 2006). Swagerty, Takahashi and Evans (1999) suggest that some cognitive impairment, along with fear of retaliation, make it difficult to assess the individual's situation. They say that this fear includes actual physical punishment or threats of violence or abandonment, where being placed in a nursing home is often seen as less desirable than being abused in their current dwelling. According to the National Center on Elder Abuse (1998), about two-thirds of the abusers of older adults are family members. There is a reluctance to report a spouse or child because of the feeling, by the victim, that they themselves are to blame because they married that person or brought their child up (Pooley, 2006). Victims have a tendency to minimize the serious nature of the abuse and show a great deal of loyalty to their abusers because they are the only person that that elder can depend on for help with some of the activities of daily living (Kahan & Paris, 2003). Victims often feel that they are the ones responsible for the abuse because they have created this burden for their caregivers.

According to Kahan and Paris "[t]hese feelings frequently lead to diminished self-esteem, with the elderly person feeling that, in a sense, the mistreatment is deserved (p. 67)". With financial exploitation, both the elder and the family member have reasons not to disclose (Welfel, Danzinger & Santoto, 2000). These researchers state,

> *… [R]elatives have a strong self-interest against disclosure. Older adults themselves worry that they will be abandoned, institutionalized, or treated even worse if their living situation changes. They are often unaware of resources that would assist them and make them less dependent on the abusing person, and this ignorance fuels their fears. They also still feel protective toward their adult children and do not want them to suffer legal penalties.* (p. 289).

Studies in nursing homes also suggest that residents don't complain about the care they are receiving due to a fear of retaliation (Calnan, Woolhead, & Dieppe, 2003). The literature suggests that one limitation of nursing home resident surveys is due to the fear of reprisal on the part of the resident (Peak & Sinclair, 2002). The residents may perceive themselves as

vulnerable to retaliation by the staff and may not respond accurately to their situation (Simmons, 1998). Simmons says,

> *… older adults – women in particular – tend to report higher rates of satisfaction with healthcare services than younger groups; thus, there is a good chance that extremely old and frail nursing home residents, who are predominantly female, will report high rates of satisfaction with substandard or inadequate care. The fact that nursing home residents are dependent on staff for daily care can only decrease their willingness to express truthful dissatisfaction (p. 1).*

Intimidation and fear of retaliation are often cited as reasons why the victims of abuse may not report the abuse (Payne & Fletcher, 2005; Atlanta Legal Aid Society, 2008). In the Atlanta Legal Aid Society's project, reports indicate that nursing home residents are

> *… summarily dismissed as credible witnesses and victims of mistreatment. The sense of disenfranchisement, vulnerability and helplessness among the residents was pervasive throughout our findings. Repeatedly, study subjects told our interviewers, "It won't do any good," or "Nothing would happen," if they reported mistreatment. In fact, they were afraid reporting may have produced additional harm and mistreatment in the form of retaliation (p. 12).*

While there are regulations in place which allow the elderly or people with disabilities to report any abuse or neglect, many elderly, because of their physical or mental condition and because of their dependence on caregivers, are not able to act as assertive and informed consumers (Walshe, 2001). In some cases it is the family member who is fearful that, if reporting an incident, the resident might be asked to leave that nursing home and that it would be up to them to find a new place for their family member to live (McCarthy, 2002, Allen, Kellett & Gruman, 2003).

Residents' rights are a solid concept which is part of the federal Nursing Home Reform Act. One of the rights is the right to complain to any state agency without fear of retaliation (Lenhoff, 2005). Yet this concept, fear of retaliation, continues to be persistent throughout the literature in instances of nursing home or caregiver abuse and neglect. However, while it is mentioned frequently, only a few studies have attempted to understand what it feels like to experience this fear.

One early study involving hospice patients examined this fear in depth (Cheikin, 1979). The author explains the fear by suggesting that the hospice patient has regressed into childlike behaviors because of his or her dependency and weakness. "Patients cannot share their fears with nurses, who represent, quite literally, a lifeline to their survival (p. 187). Cheikin speaks of the "paradoxical need-fear relationship (p. 187)" between the patient and the nurse. For those who are in pain, the pain medication is very important for their well-being and, because the nurse administers the pain medication, her role is equally critical. Cheikin indicates that while no threats are either made or implied, regression into childhood experiences leads the patient to believe that if he or she were to expose his or her feelings to the nurse that he or she may say something that unintentionally could be misconstrued by the nurse. The patient may feel that saying anything that could possibly alienate the nurse could jeopardize their care.
Whether this explanation is true or not, understanding the dynamic of the caregiver/care recipient imbalance is critical to comprehending this dilemma. The dilemma quite simply is: will the situation get better or worse by reporting the incident?

The current study focuses on residents of varying ages in three types of supportive housing: nursing homes, residential care homes, and assisted living. As part of a larger study about individuals in supportive housing, one of the questions on the survey was "Do you worry about retaliation if you were to report a complaint or concern?" and "Can you tell me about this?" In addition, the construct of fear of retaliation is explored in depth with seven individuals who shared their personal experiences.

## *STUDY PURPOSE*

This study explores the construct of fear of retaliation, and, more importantly it focuses on what emotions the care recipient experiences with regard to this fear. The frequent use of the phrase might imply that most people understand what that fear involves and can comprehend why it exists. Yet, what it is like to experience this fear has never been explored.

This study first explores the notion of fear of retaliation by surveying 150 residents of various supportive housing environments. The study then narrows its focus to specific individuals who related their experiences with situations involving fear of retaliation. The information is used to inform activities of the CT Long Term Care Ombudsman Program (LTCOP) Fear of Retaliation Workgroup. They will utilize these findings to develop a multipurpose video. Along with the replication of the various scenarios, the video will be implemented as a training tool for both residents in nursing homes or other supportive housing and staff in these same locations. Each version is to be modified for its specific purpose, however the primary intention is to make individuals aware of situations that involve fear of retaliation. Since retaliation may occur not only in egregious but also in subtle forms, many individuals, both residents and staff, may not even be aware of some forms of retaliation or the fear that it precipitates.

## *METHODS*

Survey interviews were conducted with residents of three types of LTC environments: nursing homes or skilled nursing facilities, assisted living communities, and residential care facilities throughout the state of Connecticut. The interviews were primarily conducted in person, with a few done over the telephone. Survey development was informed by a comprehensive review of the long-term care and disability, scientific, and policy literature, as well as an examination of surveys used in other states. Staff from the Connecticut Long Term Care Ombudsman Program (LTCOP) provided significant input in this process, especially regarding areas of focus or concern. Questions were developed using information from all of these sources, along with ongoing input from the LTCOP and the literature.
In addition, in-depth interviews with seven older adults, either in assisted living or in nursing homes, were conducted in order to obtain a better understanding of what it feels like to experience fear of retaliation.

### *Sample*

The survey sample was composed of residents who were recruited from three sources: the 2006 CT Long Term Care Ombudsman Program Voices Forum; regional Ombudsman referrals; and outreach to key supportive housing staff including executive directors, activity directors, social workers and nursing supervisors.

The Regional Ombudsmen referrals identified specific supportive housing residences representing a range of resident experiences. These referrals led to the initial contacts with each supportive housing residence. In addition, all member organizations of the Connecticut Association for Health Care Facilities and the Connecticut Association of Not-for-Profit Facilities

for the Aged received a notification of the survey and request for facilities to identify willing residents. Contact people were asked if they would identify residents who were willing to participate in the study. They were told that residents' participation should be voluntary and that there should be a diverse group representing differing levels of care.
For the in-depth interviews, individuals were recruited from the 2008 Voices Forum and by direct referrals from the Regional Ombudsmen and other members of the LTCOP. Six of the interviewees were from nursing homes, one was from assisted living. Two of these nursing homes and the one assisted living residence were not-for-profit and the four other nursing homes were proprietary establishments.

***Data collection***

Eighty percent of the survey interviews were done in person, the other 20 percent were done by telephone. Participants from the 2006 CT Long Term Care Ombudsman Program Voices Forum completed a form if they wanted to be contacted for an interview. In-person interviews were set up in such a way that the interviewer was able to meet with several people from the same residence in either one or two visits to the facility. The director of the supportive housing residence often provided a private room for the interviews. In some cases, the interview was conducted in the resident's room or apartment. In these instances, every effort was made in order to ensure the provision of privacy. As many as nine people and as few as one person represented each of the 57 residences. In two cases, the family member of the resident answered the survey questions on behalf of their relative.

For the in-depth interviews, five were done in person and two were done over the phone. The in person interviews were usually done in the person's room or a private conference area. These surveys usually lasted 45 to 60 minutes and were tape-recorded and subsequently transcribed. All participants signed informed consent forms or gave verbal agreement (over the telephone). Each was reminded about the confidentiality of the information they were about to give and assured that there would be no reference to their name or the name of their facility in any written documents. The research was approved by the University of Connecticut Health Center Institutional Review Board.

***Measures***

The information for this study was from one specific question on the survey and represents responses from 150 residents from 57 supportive housing residences. The question was "Do you worry about retaliation if you were to report a complaint or concern? Can you tell me about this?" Responses to the questions were coded into the following categories: yes, they worry; no, they do not worry; they don't want to complain; they don't think about it or don't know; and they don't want to get people in trouble. Supportive housing types included skilled nursing facility, assisted living residence, and residential care homes. The categories for age included those under 50, 50 to 64, 65 to 84, and 85 and over. Length of stay was categorized as follows: less than 3 months, three to six months, six months to one year, one to two years, and more than two years.

***Analysis***

All survey data were entered into Microsoft Access tables. This program is suitable to enter both quantitative and qualitative (open-ended responses) data. Quantitative analysis consisted of descriptive data (frequencies) of the fear of retaliation question, followed by a bivariate comparison by supportive housing type, age of resident, and length of stay. Because of the

small numbers for each of the coded responses, tests of statistical significance were not performed. Content from the open-ended question on the survey was analyzed using standard qualitative analysis techniques (McCraken, 1988). Data from the question was transcribed and analyzed line by line in order to identify and interpret each individual's response. Two researchers independently analyzed the responses for the question, reaching a consensus if interpretations were different. Major concepts or areas of interest supported by direct quotations were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Like statements were then explored and compared to refine each theme and ensure a fuller understanding of each. Percentage of response was determined by dividing the number of times any particular theme was mentioned by the total number of responses.

The in-depth interviews with seven individuals identified by the LTCOP were examined using a qualitative along with a phenomenological perspective. While there is no specific method employed in phenomenological investigations, there are generalized domains which are explored by the researcher (Van Manen, 1990). These include (but are not limited to) " … investigating experience as we live it rather than as we conceptualize it; reflecting on the essential themes which characterize the phenomenon; describing the phenomenon through the art of writing and rewriting … [and] balancing the research context by considering parts and whole (p. 30-31)." There is an essential understanding that the researcher must be open to the experience and not come in with any preconceived notions or expectations, although some of the initial explorations might be reflective of the researchers' own familiarity with the subject. According to Dahlberg, Drew and Nystrom (2001)

> *[t]he interviewee is engaged subjectively and is given a chance to express her/his unique experiences of the phenomenon of interest. The focal point of the interview is the way that the interviewee experiences the phenomenon and expresses its meaning. Nevertheless, the primary interest in lifeworld research is not just the person as informant, but the phenomenon (p. 155).*

The questions employed for these in-depth interviews are contained in Appendix A. These questions were developed with considerable input from members of the LTCOP. In phenomenological research, the analysis of the data proceeds by reading the whole narrative and then reflecting on the parts as a way of understanding the true sense of experiencing the particular phenomenon with all of its meaning. From an understanding and interpreting of the parts, the researcher then constructs a cohesive whole which emanates the essence of the explored phenomenon. The in-depth interviews were entered into Atlas ti5.0, a software program designed exclusively for analyzing and compartmentalizing qualitative data.

## *RESULTS*

### *Survey respondents*

There were a total of 150 residents from 57 supportive housing residences: Skilled nursing facility (n=95) from 38 facilities; assisted living (n=25) from 11 ALSAs; and residential care homes (n=30) from 8 RCHs.

Those in assisted living were generally older with over half of them (54%) 85 and older and 46 percent between 65 to 84 (see Table 1). Only 20 percent of those in residential care homes were over 85 years old. Over half (53%) were 64 years of age or younger, and 17 percent of this group were under the age of 50. In nursing homes 12 percent of the residents were under the age of 50. The majority of residents in nursing homes (41%) were ages 65 to 84. One-fifth

of those in nursing homes (22%) were 85 or older and about one-fourth (26%) of the residents were age 50 to 64.

Table 1.

| **Age** | **nursing homes %/(n)** | **assisted living %/(n)** | **RCH %/(n)** |
|---|---|---|---|
| Under 50 | 12 (11) | 0 (0) | 17 (5) |
| 50 - 64 | 26 (24) | 0 (0) | 37 (11) |
| 65 - 84 | 41 (38) | 46 (11) | 27 (8) |
| 85 and up | 22 (20) | 54 (13) | 20 (6) |
| **Length of Stay** | **nursing homes n/(%)** | **assisted living n/(%)** | **RCH n/(%)** |
| Less than 3 months | 4 (4) | 4 (1) | 0 (0) |
| 3 - 6 months | 3 (3) | 0 (0) | 0 (0) |
| 6 months - 1 year | 15 (14) | 0 (0) | 7 (2) |
| 1 - 2 years | 30 (28) | 40 (10) | 27 (8) |
| more than two years | 48 (46) | 56 (14) | 67 (20) |

Over half of the respondents had lived in their supportive housing environment for over two years and this proportion is highest for the RCH residents. Forty-eight percent of the nursing home residents had resided there for more than two years and seven percent had been there fewer than six months. Sixty-seven percent of the RCH respondents had been there over two years and no one had lived there fewer than six months. Fifty-six percent of those surveyed at assisted living residences had been there over two years and only four percent (1 person) resided there for under than six months.

The question “Do you worry about retaliation if you were to report a complaint or concern?” and “Can you tell me about this?” was the primary focus of this investigation. Two-thirds of the residents said that “no”, they do not worry about retaliation if they were to report a complaint or concern. This was consistent across all supportive housing types (see Table 2). Fewer residents of assisted living said that they worry about retaliation (13%) compared to nursing homes (23%) and RCHs (19%). Overall, six percent of the participants stated that they did not want to complain. Other responses included items such as they “don’t think about it or don’t know”, or “it wouldn’t do any good to complain”, or “I don’t want to get people in trouble.” While there were no significant differences by age or length of stay, it was notable that a greater percentage (26%) of residents who had lived in their current living arrangement for over two years said that they do worry about retaliation. This compares to only 13 percent of those who had lived in their current situation for less than a year and 16 percent of those who had lived in their current situation for a period of one to two years.

Table 2.

| | SNF %/(n) | ALSA %/(n) | RCH %/(n) |
|---|---|---|---|
| Yes, they worry | 23 (22) | 13 (3) | 19 (6) |
| No, they do not worry | 70 (67) | 71 (18) | 71 (21) |
| Don't want to complain | 4 (4) | 8 (2) | 7 (2) |
| Don't think about it/ Don't Know | 2 (2) | 4 (1) | 0 (0) |
| Don't want to get people in trouble | 1 (1) | 4 (1) | 4 (1) |

When prompted for more details on the fear or worry about retaliation, responses varied. Among the majority of the sample who reported that they do not worry about retaliation, there were some that just do not worry and those who don't worry, but had considered what they would do if it did occur. Responses included:

> *Never.* – Nursing home resident
>
> *No, if I have complaints I talk to my son and he straightens it out* – Nursing home resident
>
> *No – they try to help you.* – Assisted living resident
>
> *No, people who work here know their job would be in jeopardy.* – Nursing home resident
>
> *I don't, but other residents do.* – Nursing home resident

For those who do worry about retaliation, some seemed to do so because of what others had said or because they thought that retaliation might occur:

> *I think it is possible – I don't have any personality gripes. The administrator would probably be very good at listening, but maybe wouldn't do too much to remedy the situation.* – Assisted living resident
>
> *Yes, I heard a girl say that they know how to get even so I try to keep my mouth shut.* – Nursing home resident
>
> *It's possible, I wouldn't allow it to happen, I'd talk to the Head Nurse .* – Nursing home resident
>
> *Yes, they would send you to some place bad-for rehabilitation.* – Nursing home resident

*Yes, I think everybody worries about retaliation to a degree. I've talked to my residents about the fear of retaliation. We had a workshop on that at the Voices forum. No matter how much you may be a strong advocate for yourself, that's always a worry. Even a simple thing as an aide coming back to you and saying, "somebody reported me" or "I was talked to." That, itself, is retaliation.* – Nursing home resident

*There's always that possibility. I think every resident in a nursing home is worried about that possibility where they would hold back. But I found from what I've seen and heard, people were told that it wasn't going any further, but it blew up into something big. I think there's some amount of retaliation in a nursing home. I'd be lying if I said there wasn't.* – Nursing home resident

However, some responses seemed to be based upon actual occurrences of retaliation.

*Oh yeah, always. That's why nobody makes the complaint. The administrator scares everyone and he's very belittling and yells at people.* – Nursing home resident

*Yes, there's a lot of retaliation .* – Nursing home resident

*Sometimes, the attitude of the aides makes you feel like they are getting even with you.* – Nursing home resident

*Yes, she reported one of the aides because of the way she was treating another resident [who could not talk] and ever since then they treat her badly.* – Nursing home resident

*Yes, there's a lot of retaliation. Right now, the only thing I'm worried about is if I'm to go to another place. I don't want lies stated in my medical record.* Nursing home resident

Others talked about not wanting to "make trouble" or not wanting to "get people in trouble" or "tell on them". And some spoke about it "not doing any good to report it":

*No – I don't want to get folks in trouble.* – RCH resident

***In-depth interviews***

There were five women and two men involved in these interviews. Ages ranged from 48 to 93, however most of the participants were in their 60s. Length of stay in their supportive housing ranged from less than one year to over 10 years.

*Living in a nursing home*

To understand what fear of retaliation is, one must first visualize what it is like to be in a nursing or other supportive housing. Many of the participants indicated a feeling of loss, loss of independence, loss of hope, and loss of self. Maryann[1] put it best.

[1] Actual names have been changed to protect confidentiality.

*There are days and there are bad days. The first day I went into a nursing home, I wanted to die. I was put in a room. … My first night I was in with three other women. One was a screamer all night, the other one spit on the floor all night, when she hacked it up, and the other one, half the time, I thought she was dead because she didn't do anything, no sounds, no nothing. But she was alive. There I was crouched up in a ball, and I said to myself, this is like out of a Steven King novel –…. It's terrible living in a nursing home. There are some people who just don't care as long as they have a roof over their head and three meals a day. But when you're totally "with it", and you like to explore and you like to do things, you're confined. I loved living by myself…. I loved it because if I wanted to go out and be with friends, I could. When I wanted to go home and have complete solitude, that's what I did. But here there's no such thing. And I'll tell you, it's not a place, for someone like me, - it's not a place to be. Your whole world changes. You're not you any more. You don't have privacy. You have a roommate all the time. You can't just come and go as you please. … And it's just not a place to be.*

Daniel described his perceptions of being in a nursing homes as he first experienced it – that maybe, hopefully, it was just a bad dream.

*It's a total re-adjustment of life, especially if you're older. You've been in your home for the last 10 or 15 years and now you're in a nursing home – and now it's like, "Oh my God, what am I doing here?" You just were afraid of life, at that point. You don't want to say a word, you just want to be like a fly on the wall, just leave me alone and maybe it will all go away. Maybe it's just a bad dream and I'll wake up one night and I'll be back in my bed at home.*

This feeling of loss can be compounded by a feeling of helplessness and dependence on others. One must imagine being dependent on others for things as simple as getting dressed, eating and going to the bathroom. Rhonda stated,

*The bad thing is that, when you are here, you usually need some kind of help. And it's hard enough when you have nice people who help you. For example, I can't dress myself, I even need help eating. I've had rheumatoid arthritis since I was 21 and now I'm even losing my eyesight, so now I even need help reading things. So when you are afraid of the people who help you, well it feels hopeless, that I have nothing left, because … I have a sign on my door, and it speaks of respect and dignity and how you should treat people – because nobody knows what it feels like to be here in the first place.*

*Caregiver/ care recipient relationship*

The relationship between caregiver and care recipient triggers the "paradoxical need-fear relationship (p. 187)" described by Cheikin. Although he was speaking of hospice patients, the situation is parallel with regard to residents in nursing homes, and even those in assisted living. If someone is dependent on a caregiver for basic needs, then certainly that person would be very intent on holding onto that relationship, even if it were not in keeping with their rights to privacy, dignity and autonomy. Ann, who is in assisted living, described that feeling of not wanting to make waves.

*It makes you feel like you have to be on your toes all the time. You don't make waves. To a certain extent I get to do the things that I like. I let them know in a round about way what I am used to doing and not what they make me do. There are just a few that have*

*this superiority attitude. She [CNA] would do something that was contrary to what I was hoping for and it was annoying.*

She went on to say:

*Like I said, you don't like to make waves and you don't like to make trouble. You feel that you have to get along and make the best of it. Sometimes I have to do things that I'm not thrilled about. Like when they come in to give me my meds, but that is necessary, and I understand that. But when someone is superior or pushy, you feel like you've lost all of your dignity and I don't think we're apt to like that. It doesn't feel right. I have to live and bear it. It's not the way we want to live, it's the way we have to live.*

*Attitudes of staff*

A surprising number of the interviewees mentioned what they perceived to be the attitudes of the staff, both nurses and CNAs. While most of the participants said that the majority of CNAs were hard-working and dedicated to helping their residents, there were always a minority who made it bad for everyone. Respondents felt that some of these considered their work demeaning or beneath them. They certainly did not constitute the majority of aides who are caring and helpful. Maryann described a situation where the nurses pitched in to help, but that some of the CNAs were reluctant to cooperate and work as a team.

*[The nurses] will go in a change a person who's full of poop, they will take someone to the bathroom if the other girls are busy – they just pitch right in. And that's the way it should be. And my biggest gripe about CNAs is that most of them will come in, and say I'm in my bed and need to be changed, they'll come in, shut off your light, and say, "OK, I'll call your aide" when they could have taken that step to do it themselves, and say, "I'm here, I'll do it." But most of them don't do it. And they come in – it's attitude. And I can't take attitude at all. For example, they will say, "Well why didn't you tell me when I was here before?" … but this is their job. They're here for us. We're not here for them. And they make their own schedule. No lie, I have laid in poop for two hours. Do you know what that does to your bottom? Where they can't even touch it to wash it because it's so sore from having sat in poop. And when you ask them where they were, they'll say something like, "Oh, I forgot" or "I was with someone else." I don't care what they think. I think that they get paid pretty well for what they are doing. …. And I think a lot of them start out really wanting to do a good job. And I found that some CNAs, some nurses have been in here a long time. That when they've been here a long time, they feel that they can get away with things. That they're the top dog now. There are these little ones coming in, give them the work. Let them do the dirty stuff. Let them do – that's not the way it's supposed to be. Everybody is supposed to work together. And if they could convey that, it would make these places a lot better than what they are now. Because they could do wonders, they really could.*

Some of the participants reported egregious cases of abuse or mistreatment, but in many cases, these acts were subtle. One of the instances of mistreatment was reported by Ann, a resident of assisted living.

*Yes. Well, I really don't know what it is but some people, aides, take on this superiority and you feel not so good about. It happened one time when one aide was kind of superior and she tried to tell me what to do and didn't give me a chance to tell her how I felt. The aide came in and kind of ordered me around and told me what she wanted. I*

*told her I need to do it some way and she's not doing that and I prefer it done this way and so, she was haughty about it, and so I felt kind of offended because she wasn't there to really try to please me.*

*Well, she came up to give me my meds, she rushed me to it and I was sitting on the toilet and she came in and she insisted on giving me my meds there, my eye drops too, and I didn't like it at all. Then she started getting me ready for bed and she wasn't cooperative at all and she wouldn't listen. She didn't give me my meds until 8 o'clock and I usually have it earlier and she wouldn't let me have it and she sat on the couch and she was chewing on some food and so she wasn't giving me the proper attention.*

*She said, "you ever get up by yourself during the night?" And I said "I guess I do. But I have pads under my ankles, and I can't do that very well when I'm alone, so would you help me?" Because I had to put cushions between my ankles and there were two of them and it was very difficult to arrange them when I went back to bed. And it was hard to pull the covers up. And I explained it to her. Well, she said, "no, I'm just going to leave you, you can take care of yourself". So I had to get into my bed by myself. So I kind of hold that against her, because I think she's inclined to be cruel and bossy*.

*Incidents of retaliation*

Actual retaliation was accounted by more than one of the residents. Daniel had apparently helped out his roommate by advising him to report the fact that the charge nurse had not gotten a prescription filled that he needed. It had been a week and had been mentioned to the charge nurse on numerous occasions. Daniel also advised his roommate that both of them may experience retaliation as a result of reporting the nurse. Nonetheless he and his roommate reported this to the administrator. Daniel went on to say:

*Sure enough the next day, [the daytime nurse] starts talking and gossiping to other people. Of course, she really snubs me the next day, everything now is you know … let's see. She came and gave me my medication and then she came back with everything and then she watched me take my medicine, and there were no narcotics, but then she made sure that I took everything, she was being very very harsh to me. She handled my roommate, Bob, the same way. Everything for the next few days just became extremely ridiculous, everything – anytime you said anything to her, it just got blown out of proportion. I mentioned the nighttime nurse doing something – and then she started to make a big deal about it and said, "she doesn't want to work. You guys are so nice to her", and this that and the other thing … and I'm thinking that I don't think that's your place. If I'm a little bit friendlier to one nurse as opposed to being friendly with you so be it. Why should that affect you? If you want to build up a friendship with me then work with me, and this is just one way that you are building a huge gap between us. I didn't want to go down and do this [report her]. You brought it on yourself. We gave you over a week … As it is, I worked with [the daytime nurse] and I showed her that I have no ill will towards her I'm not here to fire her. I just want her to do what she needs to do and I want to do what I need to do. And I just want to be happy. I'm not here to get anybody fired. I'm not here to mess up your life. I'm here to heal myself.*

He reported other incidences of retaliation which happened in his particular nursing home. The tensions that build up because some of the CNAs and nurses expressed their feelings out loud and expressed it in such a way as to create stress amongst the patients.

*The people that make a lot of waves, like the people who say, "I want this done now" – the people who call for the nurses a lot, they really get snubbed. They really do. They get downgraded, and "did you hear what this one said? Oh please, Lord help us" … And I understand we all have things at work that bother you, we all talk about employees, bosses, … people that we have to deal with. Do it some place in private.*

*It's just the way it is. People love to talk. And there is quite a bit of it. They think that you really make their life miserable. That's the way that they perceive it. That you're affecting their work ethic, their work routine, and you're making it harder on them that they, somewhere down the line, are going to make it harder on you. And that is a very serious issue.*

*Reporting incidents*

When asked if she had reported the incident, Ann simply indicated that she did not have this particular aide a whole lot and therefore would not report her. Perhaps, she said, she would give her another chance. She went on to say about reporting incidences:

*Well, I don't like to report things because I think they take it out on you some other way. There was another time when one of the aides came late and she proceeded to do what she had to do but she made no excuses. I asked her why she was so late and she said that that's the time for your meds. I said none of the others come this late, because I need to get to bed. I don't know about this particular one*.

*There are a lot of people [residents] here don't like to make waves. I think that most of the residents kind of hesitate to tell me their little experiences. I had a dear friend who died and lived in this same apartment before I came here. I heard from others that she cried a lot of times when they didn't treat her right. And some of the aides would say to her, "Why don't you tell [the administrator]?" and she didn't want to do that. So she would just cry. She was afraid that they would hold it against her.*

Pearl told of an incident when the aides did not attend to her in a timely fashion.

*On one particular night, I was having some difficulty because of some pain issues, and it was on a night when I was supposed to get my shower. And I told them it needed to be done as soon as supper was reasonably over with. Well at 8:30 at night I still had not received my shower. And I told them to forget it. I just wanted to lay down. And there were a lot repercussions from that, the fact that I didn't want to take my shower and I told them, look, at this point I want to lay down so that I can concentrate, so that I can deal with the pain.*

Pearl also reported an incident which had happened in nursing homes where she used to live.

*There are some homes where there is retaliation. I won't mention the names of the homes where this has happened. I've seen retaliation going on where patients, because of their attitude per se, their attitude is precipitated by the neglect of the nursing staff, and because of that they weren't given care until 9:30 at night where this individual had been up since 9 in the morning, and they did that on purpose because the person was loud, because the person was asking for help and this was wrong and I tried, I didn't have any type of supervisory capacity, but I tried to report to the nurse and the nursing*

*supervisor. I was told that they were aware of the situation and that it was being dealt with.*

Rhonda described an incident that had happened to her early in her residence at her particular nursing home. She also described the fact that she did not report this incident.

*Now when I first came here, I wish I had spoken up. This happened when I first came here. And I didn't say anything because I was intimidated. This was a very bossy type of an aide. And I was very upset. You know, I was sitting on the toilet and I was upset because it was late and I wanted to go to bed, and she [CNA] said, "If I see any tears I'm going to have to leave you alone for a while." And I didn't report her, and I'm so sorry that I didn't – but I think eventually she got fired because of something else. That's right she said, "If I see any tears, I'm going to leave you alone for a little while to think about it." I was here only a couple of years, and when I think back to that … Yeah, I think she got fired about a year later for being verbally abusive. That was horrible what happened to me. I didn't say anything, but I will never forget that*.

Now that Rhonda had been in her nursing home for several years, she made no qualms about reporting an incident. One had just happened recently.

*Later on Friday, I asked [the aide] to help me with my yogurt. She wasn't my regular aide, but she's still supposed to help you. She came back and told me that my aide had told her to tell me to eat half of it and she'll come back and feed me the rest of it. And I rang the call bell. Then I spoke the director of nursing about the incident and she told me that [the aide] is going to get written up – that she was supposed to help me and not tell me to eat half.*

Rhonda went on to say,

*Well actually when I first came here there was an aide who came in and raised her voice to me and when I called the director of nursing the aide yelled at her and the director of nursing asked, "is this how she spoke with you?" And, of course, I said yes. I think that the aide got fired. I wasn't very feisty when I first came here, but I am now. Now I report anything. That aide who told me to eat half of my yogurt, if they hear anything else about that aide, then she'll probably get fired, because she's already been written up once.*

*Not reporting retaliation*

Maryann spoke of retaliation also, and how sometimes it was so subtle that it can't really be reported.

*I have found that certain things you just shut up about – because nothing gets done. There's retaliation in different ways. I know what retaliation is. Retaliation is not answering a call bell, letting it ring and ring. Retaliation is knowing that you're full of poop or full of pee and that you need changing and not taking care of it right away. They come when they feel like coming. Retaliation is not getting your food tray – saving it for last. For example, say my food tray used to come out first and now it comes out last. It's subtle. This retaliation is caused by things like letting them know that, well, "oh, you were supposed to wash me when you changed me and you didn't – all you did was take*

*my diaper off and put another one on." And you bring it to their attention – and they get ticked off. And when you take it further, then they don't speak to you at all*.

Maryann also had an incident where she reported a situation and then spoke directly to the aide.

*Three times I told the girl not to throw my socks into the laundry, because my socks and I pay two dollars and fifty cents. Because this was a broken ankle in three places. So there is a steel plate, plus there are screws in there. So that when it has pressure on it, it builds up and expands – so I have to wear an extra large sock over it… So I've been buying these socks. And the girls keep throwing them down in the laundry, even after I told them not to. Well this girl did it, and I had told her this three times, and I told the supervisor. I said, "This is a waste." And then they can't find them in the laundry, which is weird. So the supervisor talked to the girl, and now she won't speak to me. That happened last weekend. I really don't care – because she's one of those with the attitude … So when I told her about it – and said, "After I told you not to throw them down in the laundry, you did and they got lost and they can't find them." And I said, "they cost two dollars and fifty cents a pair." And she said, "So what do you want me to do, buy you a new pair?"*

When she was asked whether she reported this, she replied,

*No – I can't be bothered, every five minutes running down, because it's so often that you experience things like this – you give up. You really give up . Maybe people who have been here a long time, maybe they've given up. I don't know. But nobody wants to deal with it.*

*I hate to – I really hate to report. I'm getting frustrated to the point where I don't care about it anymore. I just want to go along, like everybody else does – and not care. Just accept it. I guess I have too strong a point where I hate anybody thinking that they can make me do what they want when I know that it isn't right. And I fight for that, I still fight for that. But I don't want anybody to be fired. Like I said, not unless,, that person continues to do it. And in that case they don't belong here. I'm lucky I haven't had anybody - I would rather have them not talk to me, and that I don't have them as an aide. Or I'll have them for a couple of hours because somebody else is busy – that's fine. But I don't have many people like that. I have a good staff. The staff here that does me is really pretty good. So and the administrator here has an open policy. I mean I can pick up a phone and talk to her whenever I want or need to.*

Other residents indicated that they did not want to get anyone fired or for themselves to be disliked by the staff for reporting an incident. This is Rhonda, who was reluctant to report that first incident that she experienced and then regretted it.

*Well you worry about that but I'm going to call her [director of nursing] back up – I already told her that I don't want that aide. I used to worry about things like that. Usually I wouldn't report it. Because you worry that, of course that person might lose their job, and you worry about the fact that people won't like you – it's really ridiculous because, you know, this is our home. I feel totally OK that I told the director of nursing about this. But you know, I can speak for myself, but I worry about those people who can't stand up for themselves. I mean this is a person [the aide] should be stocking shelves at Walmart by themselves.*

*One time, a resident reported an aide and the aide came back to her and said, "You complained about me?" And the resident said, "Yes, I complained about you." And I explained to the resident that she should have reported that. And I think that that is the reason why a lot of people don't report anything because they are afraid of that aide coming back to them and saying that.*

A couple of the residents had their own views about why people do not report abuse or mistreatment. Pearl said:

*I think that when someone is put in a nursing home, a lot of time they are neglected by their family, and I think that that neglect from the family is transposed to neglect from the aide. In other words, if they were to report something, that the aide didn't do or did wrong – I think that type of retaliation – I think it comes from that mentality – I've seen it in other nursing homes - where they have been neglected by their own families they are fearful of the girls or guys that take care of them in the nursing home, if they say anything negative against them, they're going to be neglected like they were at home and retaliated against like they were at home. Mostly from their previous experience.*

Daniel spoke of the fact that people in nursing homes have just come to expect certain conditions:

*I don't think that these people realize what is happening. I think that they have come to expect a certain level of care and because I don't think they really understand the care that they are supposed to receive. I think that they just accept it.*

*What retaliation feels like*

Maryann described what it feels like to be on the receiving end of retaliation, and neglected in her nursing home:

*You feel like you're dirt. I'm dirt. And I tell them all, you can ask my nurse, I say, "Look, you aren't any better than I am" and when they give me attitude that's exactly what I tell them, "You're not any better than I am. We're all the same." So don't give me that holier than thou attitude and walk around prissy and disgusted because you have to change me twice because I had diarrhea or something like that. You have to change me twice within an hour. And I hear them coming down the hall saying, "Oh my God, not again." So I don't know what anybody can do. But when you're in this profession, if you really want this profession, then do it the way that it's supposed to be, not the way that you want it to be. Do it the way that it should be done. Just think about how you would feel if you were in bed, and these things were happening to you. Or, God forbid, it was your mother or your father. And you know what goes on. And you see them and there's no – you know, they talk about they work hard, and yes, some of them do work hard. But if you've got time, say 15 or 20 minutes out of every single hour, just conversing with your friends at the job, not about the job, about things that you did this weekend or that you're going to do tonight, then, to me, - I'm talking about every hour that this goes on – then you shouldn't be complaining about the fact that you have too much work to do.*

Many of the participants who struggled with whether or not to report retaliation expressed feelings of hopelessness and despair. It was almost as if there was no one that they could turn to. Daniel expressed it this way,

*Hopelessness, alone, the fear of fear, rejection, despair. You're in a cloud, in a fog. You feel like there is nowhere to turn. You're at your wit's end and it's so frustrating that you cannot take care of it on your own and you live in fear. And you don't know what to do. It's almost like there's a big axe or pendulum and it's just swinging back and forth and at some point in time you know it's going to fall off and it's going to knock off your head, but you don't know when and it's like walking on eggshells all the time. You're tip-toeing around and you don't know what to do and you want to say something and you're at total odds with yourself over it. You have no place to turn. I think it's just that sinking empty gut feeling of just despair …Where do you turn when you're like that? When you're depressed, the only thing you want to do is crawl inward, you just want to curl up in that fetal position and hide and you don't want to get out of bed, you don't want to wake up, you just want to sleep. It's not that you don't want to live, you just don't know where to turn – there's no one there to help you.*

Rhonda also described her feelings.

*That's because you feel like you have nothing. As I say, it's difficult enough to get by with disabilities and multiple disabilities, and you have someone taking care of you who isn't kind it just takes away all of your hope.*

But she went on to speak about solutions that are available to all residents in any supportive housing situations.

*The advantage is that I have avenues of help and like to tell all of the residents – so many of us, we're all connected and we all have feelings and together we can get things done – and if we all report people who are not nice, they can start to eliminate people who do not treat us with respect. This is our home. We're here to be taken care of, somebody has to do it. Nobody ever plans to be in a nursing home, it's not funny. Like when you're younger, you never say, "I think I'll go into a nursing home whenever" For all that anybody knows, they could be in a nursing home tomorrow.*

*Positive experiences*

While retaliation was present in many nursing homes, there were some nursing homes where it did not occur or was not tolerated. Pearl, who was president of her resident council, was one individual who really established herself as a voice for the residents. She told of an incident where the aides were actually very accommodating and respectful of the demands of this individual after the incident had been reported.

*I have done that [reported someone] on several occasions. They were just accommodating – because of my diplomacy – because of my appearance and my forthcoming., I have on a couple of occasions, come to the point of raising my voice, concerning wanting something to be done that wasn't done, because I am not a person to take no for an answer. I want to know why you are telling me no and I don't give a hoot who I offend I'm going to get to the bottom of it. As I have told all the residents here, if you ask me a question and I don't know the answer, I will go to the ends of the earth to find the answer.*

*And [I] still try to be diplomatic and follow the chain of command, so to speak, before I go to the administrator. I go from the aide to the nurse, to the director of nursing, and if I still don't get results I go to the administrator.*

She went on to explain a situation regarding their resident council meeting and speaking to some of the residents about their rights.

> *We expressed to her [a resident] – whatever you don't like, anything that goes on, if somebody doesn't wash you correctly or is too rough with you, please, please, just ask any of the aides or nurses, tell them to get a hold of [me] and I'll come to you and we'll talk it over and we'll get it straightened out. We've had an instance where the aide was a little curt, due to something that was going on at home. I spoke to the aide, I knew the aide, and, I said, "When you come to work, any job, you've got to leave your home situation at home and come to work with a clear head, do your job, do it correctly and don't take anything out on a patient or resident because it's not their fault what's going on at your home. The girl was apologetic. She said, "I know." I said, "don't tell me – go to the resident, explain that you were having a bad day and that you won't let it happen again." And she did. She did. She is a good person but she's going through a problematic time. She has to learn that work is work, home is home – keep the two separate.*

Rhonda, also, was involved in her resident council and told about how she felt regarding any incident reporting.

> *… early on I thought it [retaliation] might happen which is why I kept my mouth shut. I didn't want to always be complaining, too . But now, you know what, I don't care. This is my home and they are not getting paid just to hang around, they're getting paid to take care of the residents and they're not our friends and they are here to take good care of us. I explain it to the residents that they don't have to worry about their name being given out. If any of them have a complaint, they can report it to me and I would go to the director of nursing.*

Daniel is also the president of his resident council. Although he knows that if a report is being made, even if anonymous, the person who is reported can usually figure out who reported them, especially if it involves a particular incident. Still, he encouraged his fellow residents to speak out.

> *If you have issues please come to me and there are forms that you can fill out. Remember that if you fill out these forms they are totally anonymous. You can write whatever you want…. That's what you are allowed to do. So they are always encouraged, but like you can bring a horse to water, but you can't make him drink. Maybe if they did speak up, and maybe then they might be able to communicate a little better – If you want to get up at a certain time in the morning, we can do that but you may have to go to bed a little bit earlier.*

*Other options*

Kenneth is also a resident in a nursing home who had suffered a spinal cord injury. Apparently the nurse had told him that it that he was scheduled for a treatment at a particular time, when, in fact, it was up to Kenneth to determine the time for that treatment. Because of this, Kenneth felt that that nurse had lied to him about it and he was not about to trust that nurse anymore. So he made a formal complaint. Here is how he dealt with the situation.

> *She was still here after that for a while. But I just wouldn't accept any formal treatment. I wouldn't take any pills that she had to give me, anything that she had to do … I refused*

*it. And they couldn't have that. Every time she came in here, the shift supervisor was with her out there in the hall. And I told her, I don't want nothing to do with you.*

That was when Kenneth contacted the ombudsman and, as a result of that, the situation was resolved. Kenneth went on to say,

*Things happened. It took a little while. They tried to play it down. They kept the nurse up here, but eventually she left because they couldn't have it like that. I don't fear any reprisal because I know that I was right. Everything proved out that I was right by the actions that were taken. Because if I was wrong, I would have been proven wrong and they wouldn't have made the adjustment – and they did, by getting the nurse out of here.*

This provides evidence that some of the residents who had asserted their right to report someone and saw results felt empowered by their actions.

## *CONCLUSION*

Seventy-one percent of those surveyed said that they do not worry about retaliation if they were to report an incident of retaliation. This was consistent throughout all three supportive housing types. However, fewer people in assisted living (13%) and RCHs (19%) said that they do worry about retaliation, compared to 23 percent of those in nursing homes. This discrepancy is due to the fact that more of the people in assisted living and RCHs said that they don't want to complain or to get people in trouble. The age of the resident was not related to responses to this question. However, a greater length of stay was associated with worry about reporting incidents of retaliation. Although no tests were done for statistical significance, it was notable that 26 percent of residents who had lived in their current living arrangement for over two years said that they do worry about retaliation. Only 13 percent of those of those who had lived in their current situation for less than a year and 16 percent of those who had lived in their current situation for a period of one to two years said that they do worry about retaliation.

The seven in-depth interviews represent a broad spectrum of scenarios regarding the incidences of retaliation. Some residents reported abusive situations and found that the occurrence of those incidents decreased, others used the expertise of individuals in the Ombudsman Program to help solve their problems, while another participant refused to accept any additional treatments or medications from the staff person who was reported. In most of these cases, the situations were resolved as a result of the resident reporting instances of abuse or neglect. However, for those individuals who did not report incidents of abuse, feelings of hopelessness and despair were expressed. Even with confidentiality assured, these individuals were wary about reporting anyone because they believed that it would get back to that person and that the person would take it out on them somehow. Depending on the individual, the perception that retaliation might occur was just as fearsome for that individual as to experience retaliation itself.

Retaliation and the fear of retaliation is a reality in any supportive housing situation. Because retaliation can be either egregious or subtle, many forms of retaliation may not even be recognized by residents or staff. Through the efforts of the Ombudsman program in Connecticut and the continuing strides of the "Fear of Retaliation Workgroup," information on residents' rights are promoted on a continuing basis. A list of best practices that support residents' rights is being compiled by the workgroup in order to encourage facilities to be pro-active with respect to retaliation issues. These include, but are not limited to, adopting a "no tolerance" policy regarding fear of retaliation and encouraging an internal committee to provide

a meaningful and interactive in-service to staff and residents specific to this issue. The findings from this study will be used to develop videos that will be used as part of this interactive in-service to teach both residents and staff at nursing homes to recognize and respond to retaliation.

*Limitations to the study*

As an exploratory research endeavor, this study has certain inherent limitations. First, the utilization of a convenience sample eliminates the possibility of hearing from individuals who are unable to express themselves or their views about the subject. As one of the interviewees said, she worries more about the people who are unable to speak up for themselves, that they may experience abuse even more because they are unable to speak or to communicate their feelings. In addition, conclusions based on comparisons among type of facilities must be considered preliminary due to the small sample size for assisted living and RCH residents. Many of the residents from assisted living were fairly independent compared to the residents of nursing homes. Obviously, there is a certain level of care that is commensurate with the type of facility. Some of those from assisted living only received help with meals and services like house cleaning. Therefore, participants who do not receive hands-on care may not be as apt to experience the sort of abuse or neglect that would be associated with receiving hands-on care. In fact, future research could well focus on any correlation between the perception of fear of retaliation and the level of need of the care recipient.

## ***RECOMMENDATIONS***

1. The Ombudsmen should strive to serve as an outlet for complaints of actual retaliation and fear of retaliation and to focus program activities on this issue.

2. The Ombudsman Program should provide and/or support continuing education to facility staff, residents, and families to define retaliation and explain procedures for reporting and responding to complaints. Facilities should support and promote these educational efforts.

Forums for such education might include:

- Regular “in-service” sessions for staff
- New resident orientations
- New staff orientations

3. Reporting procedures should be formalized. Resident councils could present information about retaliation and procedures for reporting and dealing with complaints.

4. Cases of retaliation should be monitored for a period of time (e.g., 12 months), to enhance continued compliance and ensure that the facility is continuing to enforce policies against retaliation and not just “listening” to the complaints and concerns without taking action.

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## Appendix A

**Questions for in-depth interviews regarding fear of retaliation:**

1. How long have you lived here?

2. How do you like living here?

   (Probes: What works well with your day? Are there things that do not work well for you?)

3. How are the staff here?

4. Are there things that bother you about the way in which you are treated by the people who work here?

   (Probes: Do you have a trusting relationship with any of the people who care for you? Are there people who care for you that you do not trust? Do you have someone other than the people who care for you that you can confide in?)

5. Have you ever experienced any kind of bad experience from the people who take care of you? This could include anything from intimidation, to actual physical abuse, verbal abuse, stealing money or other financial exploitation, or threats.

6. What, if anything, did you do when this happened?

7. Did you report this to anyone?

**If they reported the incident, ask these questions:**

8. Who did you report it to?

9. What, if anything, was done about it? Could you please describe what happened?

   (Probes: Was anything done to remedy the situation? Do you think that the person you reported it to was responsive to your complaint? What was the final outcome?)

10. Can you describe the feelings that you have when you think about your situation?

**If they did not report the incident, ask these questions:**

8. What do you think might happen if you were to report or complain about your treatment?

   (Probes: Can you describe the feelings that you have when you think about your situation? Do you think that if you were to report it that anything could be done about it?)

9. What do you think the staff person who treated you this way would do if you reported it?

10. Can you attempt to describe what this situation feels like (not wanting to report abuse because of fear of retaliation)?