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Developing the Family Involvement Questionnaire (FIQ): A Measure of Family Involvement in the Lives of Residents at Long-Term Care Facilities

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Developing the Family Involvement Questionnaire-Long-Term Care (FIQ-LTC): A Measure of Family Involvement in the Lives of Residents at Long-Term Care Facilities

By

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Abstract

Developing the Family Involvement Questionnaire (FIQ): A Measure of Family Involvement in the Lives of Residents at Long-Term Care Facilities

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Intro: One factor that has been shown to improve long-term care facility resident's quality of life is family involvement (Gaugler, 2005). Despite this, the measures that currently exist to measure family involvement in the lives of older adults residing in long-term care facilities are rather simplistic, using visitation frequency as the prominent gauge of involvement and a situation specific fashion (Port et al., 2005). The purpose of this study was to design a measure of family involvement that could be used to gauge more aspects of family involvement than visitation alone and be useful in a variety of settings.

Methods: Long-term facility staff where asked to assist in creating a 40-item questionnaire that used 4-point Likert scales to measure various aspects of family involvement. The finalized FIQ-LTC was distributed to the family members of older adults residing in long-term care facilities around the country.

Results: A total of 410 participants responded. Researchers found that the FIQ-LTC was highly reliable ($\alpha = .965$). Results also indicated that a significant correlation between distance and overall involvement ($r = -.121$, $p = .015$) was no longer significant ($r = 0.17$,

$p = 0.740$) when the effect of a question asking the frequency of visitation was controlled for.

Discussion: These results indicate that existing measures that use visitation frequency as the sole measure of involvement are insufficient. The newly developed FIQ-LTC can serve as a more complete measure of family involvement in more settings than typical measures.

Developing the Family Involvement Questionnaire-LTC

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Introduction

Background Research

Previous research indicates that older adults residing in long-term care facilities can benefit in many ways from having family members who are involved in their lives (Gaugler, 2005; Zimmerman, Cohen, Reed, Gwyther, Washington, Cagle, Sloane, & Preisser, 2013). Because of this, many administrators at long-term care facilities are interested in measuring the level of involvement that family members have in the lives of residents. However, many of the measures of family involvement that currently exist have a very limited definition of involvement (Port, Zimmerman, Williams, Dobbs, Preisser, & Williams, 2005). They primarily rely on the frequency of in-person visitation as the only measure of family involvement (Gladstone, Dupuis, & Wexler, 2006). Those who work in long-term care facilities recognize that family involvement can manifest itself in many ways (Port et al., 2005). The purpose of this paper is to discuss the development of a new measure of family involvement for family members of older adults in long-term care facilities that is more inclusive of other methods of involvement.

There is a growing body of evidence indicating that as time goes on, adults age 65 and older will constitute a larger and larger percentage of the United States' population (Ortman, Velkoff, & Hogan, 2014). The United States Census Bureau published a report in 2014 examining this trend. This report, written by Ortman et al., showed that the percentage of U.S. residents age 65 and older had increased from 9.8% in 1970 to 13% in

2010. By 2030, this age group is expected to make up around 20% of the total U.S. population. This change has been attributed to several different factors, including lower current birth rates, the increased birth rate during the "baby boom" period from 1945 to 1964, and longer life expectancy due to advances in medical care. In 2012, over 43.1 million U.S. residents fell into the older adult category (age 65 and older). If current trends in population are maintained, this number will continue to climb (Ortman et al.).

As the population of older adults in the United States continues to grow, it can be safely assumed that long-term care will be utilized by more and more people. The United States Department of Health and Human Services published an article presenting the projected need of long-term care for older adults (Favreault & Dey, 2015). This article projects that 52.3% of adults turning 65 in 2015-2019 will need to utilize some form of formal long-term care at some point in their lives. They also project that of adults turning 65 in 2015-2019, 33.4% will need more than one year of long-term care.

Long-term care includes a wide range of services and supports to meet personal and health needs. Much of long-term care consists of assistance in everyday life, rather than formal medical care (Favreault & Dey, 2015). In most cases, these long-term care needs are provided by the family members of the older adult (Keefe & Fancey, 2000). It has been found that over 75% of all long-term care provided to older adults is done by their family (Qualls, 2016). This support can include everything from helping with daily living activities to performing nursing/medical tasks. The decision to move into a long-term care facility is often made once this type of family caregiving is no longer viable. Factors that increase the likelihood of admission to long-term care facility include the

onset of health problems, advancing age, and proximity of relatives willing to provide assistance (Keefe & Fancey, 2000).

The transition from having long-term care provided by family members to a long-term care facility can drastically change the relationship between the older adult and their family members (Gladstone, Dupuis, & Wexler, 2006). The role of primary caregiver is suddenly shifted from the family members onto the long-term care facility. This change can be especially jarring because long-term care provided by family has very different priorities than long-term care provided in a dedicated facility. Long-term care provided by family is often flexible and motivated by a long-standing relationship with the older adult. Long-term care facilities, on the other hand, are structured around formal rules and technical efficiency (Russel & Foreman, 2002).

Once an older adult is admitted into a long-term care facility, their family members shift from the role of primary caregiver to a supportive, visitor role. This transition can be a difficult one. Often, family members feel that their role becomes ambiguous following admission (Friedemann, Montgomery, Maiberger, & Smith, 1997). Because of this, family involvement with older adults drastically changes when they are admitted to a long-term care facility and established routines are disrupted.

There is some evidence suggesting that this transition goes smoothly and family members remain involved in their relative's life after enrollment (Gaugler, 2005). However, there is also evidence indicating that levels of contact between family members drastically decrease following admission (Port et al., 2001), and that some qualities of the contact had changes (i.e., brief superficial exchanges). These mixed results suggest that

more research is needed in order to provide an accurate grasp of family involvement in the lives of residents at long-term care facilities.

One thing that is essential to keep in mind is that family involvement can look very different for individual families (Friedemann, Montgomery, Rice, & Farrell, (1999). When family members are responsible for providing long-term care to older adults, they typically do so unilaterally. However, once an older adult is admitted to a long-term care facility, the bulk of the long-term care is provided by the facility. Family members who remain involved in the older adult's life typically serve to shore up areas of care that their long-term care facility does not provide (Gaugler, 2005).

Baumbusch and Phinney (2014) described family involvement with care in long-term care facilities as being either "hands on" and "hands off." "Hands-on" care describes day-to-day caregiving, assistance with facility routines (i.e., assisting with lunch), and other direct interactions between the resident and their family members. "Hands on" care often involves assisting residents with what are referred to as activities of daily living (ADL; Gaugler et al., 2004). These include things like assisting them with dressing and bathing. "Hands off" care refers to the interactions between family members and the staff at the facility during which they attempt to influence the resident's care indirectly. An example of this would be the family members of a resident suggesting to facility staff the ways in which they can better meet the resident's needs (Irving, 2015). These terms are useful, as they demonstrate that family involvement with residents at long-term care facilities can be direct or indirect.

Another important aspect of family involvement in long-term care facilities is the emotional caregiving that the family members of residents can provide. In addition to the instrumental support that they provide, family members who remain involved in a resident's life typically provide emotional support (Qualls, 2016). This can involve things such as providing comfort and consolation, as well as sharing in their personal successes and failures. Long-term care facility residents who end up relying entirely on their residential facility for caregiving often experience a scarcity of this type of emotional support.

Because of these factors, long-term care facility administrators are very interested in gauging the levels of family involvement in their facilities (Port, 2004). Unfortunately, there is a dearth of modern measures examining this phenomenon. While measures of family involvement for older adults residing in long-term care facilities do exist, it appears that most of them may not be measuring involvement accurately or in a fashion that might be beneficial to more than one specific facility (Port et al., 2005).

The first problem that many of these measures have is that they only gauge family involvement by looking at how often family members make in-person visitations to their family member's facility (Gaugler, Zarit, & Pearlin, 2003). In other words, they are specific to the situation. One exception to this was an article in which Port et al. (2005) created a structured interview that could be used to measure family involvement through a series of questions including things like how often they called or wrote letters and how often they assisted with activities of daily living. However, researchers were unable to find a questionnaire that could be easily distributed to the family members of residents

that used more factors than visitation frequency as the only gauge of involvement. This is problematic because previous research has indicated that distance is a large mediating factor in the frequency of visitation (Tsai, Tsai, & Huang, 2012). As can be expected, family members residing in locations far away from the facility their loved one is staying at typically make less frequent visitations than those who live nearby. Previous research has shown that many family members in this situation utilize phone calls as their primary means of involvement with the resident (Port et al., 2005). Comprehensive measures of family involvement need to measure this and other methods aside from visitation that family members use to remain involved in their loved one's life. One must also be mindful that not all facilities have phones readily available for the residents.

This limited definition of involvement has several complications. For example Gaugler, Anderson, and Leach (2003) conducted a study in which they looked at familial phone contact as a predictor of the likelihood that they would visit, rather than as a form of involvement by itself. Similarly, Post et al. (2005) indicated that some families use phone calls as their primary means of communication with their loved one. Using the Gaugler et al. standard, would indicate family members who visit twice a year are more involved than those who call their loved one daily. At present, these measures do not serve as an accurate gauge of family involvement in lives of residents.

Many other existing measures examine family involvement in long-term care facilities solely by looking at family member's role in the caregiving process (Whitaker, 2009). These typically involve gauging how often the family member assists the resident with activities of daily living (ADL; Gaugler et al., 2004). As discussed earlier, acting as

a caregiver is one of the primary ways that family members remain involved in the lives of residents following their admission into a long-term care facility. This can involve either providing "hands on" care through the form of direct assistance with ADLs or "hands off" care through methods such as discussing their loved one's care plan with facility staff (Baumbusch & Phinney, 2014). The problem with only looking at the functional, caregiving aspect of involvement is that, similar to looking at only visitation frequency, it neglects many potential methods of involvement and the impact they have on residents. For example, it does not address more emotional aspects of caregiving (Qualls, 2016).

Another problem with these measures is that they do not account for new methods of involvement that are available to family members of those residing in long-term care facilities. While some existing measures do account for phone calls as a method of family involvement, this is typically as far as it goes (Gaugler, 2005). As technology has advanced, new ways to remain involved in their loved one's life have become available. For example, a recent research study examining the use of videophones to conduct video conferences between residents at long-term care facilities and family members found that it can be an enriching method of communication (Demiris et al., 2008). Modern measures of family involvement need to account for advancements in technology that have made new methods of involvement possible. It is important that they include as many methods of involvement possible to serve as the most accurate measure of involvement possible.

Rationale

The purpose of the present study was to develop a comprehensive new measure of involvement for family members of older adults residing in long-term care facilities. Researchers planned for this new measure to include questions examining both the visitation frequency and caregiving aspects covered by other, existing measures, as well as new questions suggested by professionals in the field (Gaugler, Zarit, & Pearlin, 2003). As discussed earlier, the majority of existing measures of family involvement for the family members of older adults in long-term care facilities cover only one of these aspects of involvement (Gaugler, Anderson, Zarit, & Pearlin, 2004). Also, unlike a structured interview, such as that developed by Port et al. (2005), a questionnaire would allow for researchers and long-term care facility staff to gather family involvement information quickly and from a larger group of people than was previously possible. Researchers were also curious if distance would be as large of a mediating factor for involvement if less emphasis was placed on visitation as the sole measure of involvement (Gaugler, 2005).

Methods Part 1

Design

In order to create and distribute an effective measure of family involvement researchers divided the project into two parts. The first step involved meeting with local long-term care facilities whose primary residents were older adults and discussing the items that should be included on the Family Involvement Questionnaire-LTC with administrators. This was followed by distributing an initial draft of the Family

Involvement Questionnaire-LTC to employees at long-term care facilities for reliability analysis and additional feedback. The second step consisted of distributing a finalized version of the FIQ-LTC to the family members of older adults residing in long-term care facilities. Because of the two-stage design of this study, the methods and results sections of this paper have been divided into separate parts.

Participants

Participants recruited for this portion of the study consisted of employees at a long-term care facility for older adults located in neighboring city. These participants were contacted through the facility administrator, whom researchers met with to discuss the project and request their assistance. Participants were given a package containing a consent form, the initial version of the Family Involvement Questionnaire-LTC, the staff feedback form, and a cover letter explaining the project and what was requested of them. These packages also contained a postage-paid envelope to allow the participants to mail their completed forms directly to the researchers. A total of 15 packages containing these forms were given to the facility administrator for distribution. Eight completed packages were returned, placing the total participant count for this portion of the study at 8.

Procedure

Instrument Development. Items included on this initial draft of the Family Involvement Questionnaire-LTC were drawn from several different sources. Among these were similar measures of family involvement developed for other populations. For example, Fantuzzo, Tighe, and Childs (2000). developed a similar questionnaire intended to measure parental involvement in young children's educational experiences. Their

question, “I attend conferences with the teacher to talk about my child’s learning or behavior,” was adapted to, “I attend conferences with staff to learn and talk about my family member’s general happiness and well-being.”

Questions were also drawn from the input of individuals who had personal experience with having loved ones taking up residence in long-term care facilities. Interviews with these individuals provided some much-needed input from the target demographic, and allowed for creation of questions that addressed some of the ways that family members are involved that might otherwise have evaded attention. For example, the item “I ensure that my family member is pleased with their level of privacy,” was generated from this type of interview.

Content Validation. Finally, a well-published psychologist who specialized in giving behavioral care to older adults provided more input on what items could be added to the Family Involvement Questionnaire-LTC to make it a more exhaustive measure. His professional experience made him aware of additional ways that family members remain involved in their loved one’s life that would have otherwise been overlooked.

When all of this was done, the initial draft of the Family Involvement Questionnaire-LTC had a total of 38 questions designed to evaluate family member’s involvement with the lives of older adults residing in long-term care facilities. Following this, a version of the FIQ-LTC that could be used for reliability analysis was developed (see Appendix D for the initial draft of the Family Involvement Questionnaire-LTC). This was done by creating a 3-point Likert scale for each item on the questionnaire to indicate how useful the evaluator thought the item in question was for measuring family

involvement. This Likert scale allowed participants to rank each item as being either "not necessary," "useful," or "essential."

Feedback. A feedback form was constructed to allow for more detailed input on the initial draft of the Family Involvement Questionnaire-LTC (see Appendix E). This form allowed those providing feedback on the FIQ-LTC to indicate if they believed that there were any items that could be added to the FIQ-LTC to make it a more complete measure of family involvement. This form also asked participants to provide general feedback on the FIQ-LTC and provided them with an opportunity for suggestions.

Results – Part 1

Participant responses are detailed in Table 1. To determine if there was agreement among the participants regarding the importance of each question, the internal consistency of the initial draft of the FIQ-LTC was measured. Researchers found that the initial draft of the FIQ-LTC consisting of 38 items was highly reliable ($\alpha = .879$). However, due to the large amount of individual feedback from participants provided in the feedback forms, as well as input from long-term care facility administration and staff, the decision was made to modify the FIQ-LTC. Both individual feedback provided by participants on the feedback forms, as well as frequency data obtained by pooling the responses on the initial draft of the FIQ-LTC, were examined in order to determine what modifications needed to be made.

Many of these modifications were small alterations to the language used in the questions to improve their clarity while maintaining their original intent. For example, question 3 was changed from "I talk with facility staff regarding my family member's

eating schedule," to "I talk with facility staff regarding my family member's eating habits". This type of alteration was made to questions 3, 10, 12, 27, and 35.

Other questions on the FIQ-LTC required more extensive alterations. Question 14 "I participate in raising funds or donate money to my family member's facility," was removed from the questionnaire entirely. Participants indicated on their feedback forms that in most cases employees and administrators at long-term care facilities are barred or discouraged from asking the family members of residents about their financial contributions to the facility. Were this question to be included on the final version of the FIQ-LTC, many long-term care facilities could not use it. This question was replaced with "I interact with my family member during the holidays." Participants stated that a question gauging family involvement during the holidays would be beneficial as family members tend to be more actively involved with residents around the holidays.

Questions 24 and 25 were also removed. Participants suggested that these questions be removed because they made it seem as if the long-term care facility was assigning work to its residents. Long-term care facilities are generally not permitted to assign tasks to residents. Participants stated that including these questions on the final version of the FIQ-LTC could cause confusion on the part of the family members. Question 24 was changed into "I give input into my family member's care plan." Participants indicated that a question measuring family member's involvement with the resident's care plan would be useful as this is one of the most common types of family involvement that they encounter. Question 25 was replaced with "I communicate with my family member over the internet." This question was added to open the FIQ-LTC to

incorporate even more methods of communication that family members can use to remain in their loved one's life.

Participants also suggested that question 26 be changed. It originally read "I make sure my family member is able to perform home-living skills (laundry, dishes, etc.)." Participants suggested that this question could unnecessarily limit the number of residents that the FIQ-LTC could be used for. Many residents at long-term care facilities are no longer capable of performing these tasks on their own. Although this is in no way true of all residents of long-term care facilities, it is for a significant number of them. Participants believed that including this question might make the FIQ-LTC a less accurate measure for these residents. Question 26 was changed to "I try to help my family member transition into living in a long-term care facility." This question was added in that participants had recommended that a question measuring family involvement in the transition to life in long-term care facilities would be useful as this transition can be a very difficult period for some residents.

Participants suggested that Question 28, "I feel that people with family members in the facility support each other," be removed as it did not match the theme of the rest of the items on the questionnaire. They stated that while most questions measured family involvement directly, this question revolved around the family member's impression of the long-term care facility's community. This question was replaced with "I come and have meals with my family member." Participants recommended that a question gauging how often family members ate meals with residents be added to the questionnaire as it was a form of involvement that they observed regularly.

Participants recommended that question 32, “I talk with facility staff about problems they feel my family member may be experiencing,” be removed because that same material was covered in another question. It was replaced with “I communicate with my family member through letters,” so as to include another form of communication commonly used by family members of residents at long-term care facilities. Participants also recommended that the language of question 33, “I am mindful of my family members well-being,” be made clearer. Question 33 was changed to “I keep up to date on my family member’s health status,” in order to be more succinct.

Participants also recommended that question 36, “I talk to my family member about the benefits of residing in a long-term care facility,” be removed as the involvement aspect of this question was covered by other items. It was replaced with “I assist my family member in managing their finances,” as participants had mentioned this was a common form of family involvement that had not been covered in the questionnaire. Similarly, Questions 39, “I participate in family council,” and 40, “I talk with facility staff about problems they feel my family member may be experiencing,” were added to the FIQ-LTC as participants noted that these were two common ways family members are involved that had not been asked about. These modifications left the final version of the Family Involvement Questionnaire-Long-Term Care with a total of 40 questions. This final version of the Family Involvement Questionnaire-LTC is the one that was distributed to the family members of older adults residing in long-term care facilities during the second portion of this study.

Methods – Part 2

Instruments

The updated version of the Family Involvement Questionnaire-LTC was used in part 2 of the study (see Appendix F). As discussed earlier, the questions included on the final version of the FIQ-LTC were decided upon based on the feedback obtained from long-term care facility employees during the first portion of the study. The final version of the FIQ-LTC consisted of 40 questions designed to measure various aspects of family involvement in the lives of older adults residing in long-term care facilities.

Participants

A total of 410 participants completed the Family Involvement Questionnaire-LTC. Participants identified as 45% male and 55% female. 86.3% of participants identified as Caucasian, 4.1% identified as African American, 5.4% as Latino or Hispanic, 1% as Native American, 1.7% as Asian, and 1.5% as Other. Participant responses came from Minnesota and 44 additional states. A state-by-state breakdown of participant response rates is available in Table 2.

Procedure

In order to ease the distribution of survey materials to the family members of residents at long-term care facilities, researchers created an online copy of the Family Involvement Questionnaire-LTC. This was done using Qualtrics®, a web-based software program primarily used for the creation and distribution of surveys. This enabled a link that could be sent to participants to allow them to access the FIQ-LTC and related documents.

In this study, the usual 5-point Likert scale was avoided in that including an "Always" option would not make sense for many of the items included on the questionnaire. For example, while a response of "never," "rarely," "sometimes," or "often," would make sense for question 32, "I communicate with my family member through letters," a response of "always" would not. A 4-point Likert scale was chosen in that it would allow the gathering of desired information while reducing participant confusion as much as possible.

Other forms for participants to complete included a demographic sheet and a consent form, as well as a cover letter explaining the purpose of the study and what was expected of participants. The demographic sheet had a number of typical questions determined to gather demographic information about participants, as well as a question asking participants to list their distance, in miles, from their family member's long-term care facility. As discussed earlier, previous research has indicated that distance can be a large mediating factor in the frequency of visitation (Tsai, Tsai, & Huang, 2012). Given that visitation frequency is one of the only ways that existing measures gauge involvement, distance has typically been found to be mediating factor on the level of overall family involvement (Gaugler, 2005). This leads to curiousity if distance between family members and their loved one's long-term care facility would continue to act as a mediating factor on the level of involvement measured by the Family Involvement Questionnaire-LTC, as it includes more diverse methods of involvement that do not require in-person visitation. Participants' relation to the resident was also included in a question on the measure.

The test was created in a manner so that participants' responses were recorded only if they completed all the questions on the FIQ-LTC. This means that all 410 participants responded to all of the questions. Of the respondents that chose to indicate their relation to the person residing in the long-term care facility, 6 identified as siblings, 283 as children or step children, 5 as cousins, 16 as grandchildren, 14 as spouses or partners, and 9 as nieces or nephews. 71.6% of participants indicated that they lived 100 miles or less from the long-term care facility that their relative was residing in.

Participants involved with this portion of the study were contacted in several ways. First, researchers met with staff at a number of long-term care facilities for older adults scattered throughout Minnesota. This did not include the long-term care facility that was involved with the first portion of the project. Researchers spoke to facility administrators and activity directors to discuss the best ways that the Family Involvement Questionnaire-LTC could be distributed to the family members of the older adults residing in their facility.

Due to the widely varying regulations of the different long-term care facilities involved with the project, surveys were distributed in several different ways. Some facilities had access to the email addresses of the family members of their residents, while others did not. For the facilities that did have the email addresses of the family members, researchers were able to distribute the FIQ-LTC and related documents through the facility administrator or activity directors. This involved sending them an email with a link to an online version of the survey and a cover letter describing the project which they then forwarded to the family members of residents. As mentioned earlier, this link was

generated using Qualtrics® and contained the FIQ-LTC itself, a cover letter explaining the project, a consent form, and a demographic sheet.

When long-term care facilities did not have this contact information, researchers family members of residents were contacted through alternative means. Many long-term care facilities mail a packet of documents to the family members of residents on a monthly basis. This packet typically contains information about coming events, notices, and other information that long-term care facilities want those involved with residents to have. For the few long-term care facilities that did not maintain a record of the email addresses of the family members of residents, researchers asked that facilities include a notification about the study with information about how to access the online survey with their monthly packet.

To bolster the number of respondents and expedite the process at which the project was proceeding, researchers utilized the distribution services offered by Qualtrics®. This also served to diversify the pool of respondents. By paying Qualtrics® a flat fee, the researchers were able to specify the population that they needed to contact and have them use their contacts to reach the number of needed participants. This also allowed for an opportunity to diversify the participant pool to include family members outside of Minnesota.

Results – Part 2

Figure 1 illustrates the distribution of participant responses to each of the items on the Family Involvement Questionnaire-LTC. More detailed information about participant responses to specific questions is shown in Table 3. Cronbach's Alpha was used to

measure internal reliability. It was noted that the final version of the Family Involvement Questionnaire-LTC was highly reliable (α = .965).

Many previous research studies involving similar questionnaires measuring family involvement implemented confirmatory factor analysis based on the findings of previous studies (Garbacz & Sheridan, 2011). This is primarily because they all involved relatively similar populations. For example, Grover (2015) conducted a study in which she performed confirmatory factor analysis based on the earlier finding of Manz et al. (2004). This makes sense because both studies were examining family involvement in a population of minors in the American K-12 school system. There is a significantly smaller body of research examining family involvement with older adults with nothing resembling the FIQ-LTC having been implemented. Because of this, an principle component analysis was performed on the FIQ-LTC.

Principle component analysis was performed on the FIQ-LTC dataset using Direct Oblique rotation. Because it was assumed that factors in this analysis would be correlated, an Oblique rotation method was performed. Principle component analysis found four factors with an eigenvalue greater than 1. A cutoff point of .4 was used for factor loading. The factors were named based on the items in the questionnaire that heavily loaded on each of them. The four subscales found were: interactions with facility administration and staff, mediums used for interaction, communication and providing care, and in person visitation. The interactions with facility administration and staff subscale consisted of 16 items (α = .952); mediums used for interaction consisted of 7 items (α = .870); communication and providing care consisted of 12 items (α = .916); and

in-person visitation consisted of 4 items (α = .771). The item content and factor loading for the subscales are presented in Table 4.

As discussed earlier, previous research indicates that distance can be a mediating factor on the level of overall family involvement. This is primarily because most existing measures of family involvement use the frequency of in-person visits as the singular indicator of family involvement (Gaugler, 2005). This leads to the question if this was still the case with the levels of involvement measured by the Family Involvement Questionnaire-LTC? To determine this, a new variable was created that added the participant's scores on all the items together. Responses were assigned a numerical value ranging from 1 to 4, depending on the participant's choice on the Likert scale. A higher score on this new variable was indicative of a high level of involvement in all the areas measured by the FIQ-LTC.

It was noted that there was a significant negative correlation between participant's scores on this new variable and the distance from the long-term care facility, $r = -.121$, $p = .015$. To determine if this correlation between distance and overall involvement would remain if the impact of the question measuring the frequency of in-person visitation was controlled for, a partial correlation was performed controlling for question 18, "I visit my family member in their long-term care facility." It was found that when the influence of Question 18 was controlled for, the correlation between a person's distance from the family member's facility and the overall involvement score was no longer significant $r = 0.17$, $p = 0.740$. This makes sense, given that question 18 was the one that was most

strongly negatively correlated with the participant's distance from the loved one's facility $r \leq .001$, $p = -.236$.

Discussion

The purpose of this study was to develop a measure that could be used to gauge the level of involvement that the family members of older adults living in long-term care facilities have in their lives. This involved implementing a two-stage process in which researchers first developed the Family Involvement Questionnaire-LTC by collaborating with long-term care facility employees and then sought to validate the new FIQ-LTC measure by distributing the measure to the family members of older adults residing in long-term care facilities.

The results of Cronbach's alpha indicated high internal consistency during both phases of the project. Principle component analysis found 4 factors with an eigenvalue greater than 1. These factors were labelled: interactions with facility administration and staff, mediums used for interaction, communication and providing care, and in-person visitation. Results of Cronbach's alpha found that all 4 factors had high to acceptable levels of internal consistency.

Frequency data (as shown in Table 3) was especially interesting not only because it indicated the ways that family members are involved with residents, but also because it indicated ways that they are not involved. For example, it is surprising that over half (51.5%) of respondents indicated that they never communicated with their loved one over the internet. It had been expected that this number would be significantly higher than it was, due to the wide variety of communication methods available on the internet. These

results indicate that online communication methods are underutilized compared to more traditional methods of involvement. This information might prove useful to both researchers and facility administrators who wish to encourage family involvement.

Perhaps the most interesting outcome of this study was the finding that the significant negative correlation between a participant's distance from their family member's long-term care facility and their overall score on the questionnaire, $r = -.121$, $p = .015$, ceased to be significant when the effect of question 18, "I visit my family member in their long-term care facility" was controlled for $r = 0.17$, $p = 0.740$. This indicates that while distance was a mitigating factor on participants' overall score on the FIQ-LTC, this was largely due to the influence of question 18. This should serve as a warning to those who would consider in-person visitation as the sole measure of family involvement with older adults residing in long-term care facilities. Distance is an important factor to examine when measuring family involvement, but it may not be as predictive of a person's overall level of involvement as was previously assumed. Future attempts to measure family involvement in the lives of long-term care facility residents should make sure to examine methods of family involvement that do not require in-person visitation alongside those that do.

Limitations

One of the primary limitations of this study is that there are other methods of family involvement that researchers were not able to include on the FIQ-LTC (Kandel & Merrick, 2007). For example, a question asking how often the participant took their family member out of the long-term care facility was not included (Port et al., 2005).

Although this measure is certainly more exhaustive than existing measures of family involvement, it likely does not include every way that family members remain involved in the lives of long-term care facility residents after admission. However, researchers believe that the FIQ-LTC is expansive enough to give administrators a rough idea of the level of family involvement present in their facility.

Another limitation of the study is that the questions in the survey are not weighted based on an individual's distance from their family member's long-term care facility. This might be accomplished in a future distribution of the measure. The only way that an individual's score of overall involvement on the Family Involvement Questionnaire-LTC can be compared to another's is to look at the summed scores of their responses on all of the questions. This means that a person who lives close enough to make frequent in-person visitations will have a higher score than those who do not, even if, in all other aspects, they are equally involved. This is likely because they have more methods of involvement available to them on the FIQ-LTC than those who live far away. The Family Involvement Questionnaire-LTC is not a measure that should be used to compare one family member's level of involvement with another's. Rather, it is a tool for noticing trends in the ways that the family members of older adults residing in long-term care facility remain involved in their lives following admission.

Another limitation of the current study is its reliance on Likert scales to measure family involvement. This is potentially problematic, as participants' level of involvement is determined entirely by their own perception. Different participants may have very different definitions of what they consider doing something "Often". For example, one

person may think that visiting once a week is considered doing so "Often," while another may think doing so once a month qualifies as such. This problem is common with questionnaires that utilize Likert scales. While this is the tool that researchers believed would best serve them for this questionnaire, it does have several faults that come with it, an overreliance on participants' perception of their own activities being one of them.

Implications for Future Research

This study provides a foundation for future research into family involvement among the residents of long-term care facilities that house older adults. Geriatric researchers may be interested in adapting the Family Involvement Questionnaire-LTC to include more items or to serve as a more specific measure of an aspect of involvement. One aspect of family involvement that warrants further examination is the methods that family members use to contact their loved ones. Several communication methods were examined in this present study, but this was by no means an exhaustive collection of all communication methods. For example, questions about home and cellular phone usage, video chat, texting, and other methods of communication could be added to the Family Involvement Questionnaire-LTC to make it a more complete list. This could provide more detailed information to both researchers and long-term care facility staff and administration about how family members stay connected with facility residents after admission.

Future research might focus on creating a measure of family involvement that utilizes a method of responding that allows for more detailed data collection. Although Likert scales worked well for this project, using them came with several drawbacks. As

discussed earlier, participants may have a very different definition of what they consider "Rarely" and "Often." Allowing participants to provide numerical data indicating exactly how often they do something would allow researchers to have a more concrete dataset to analyze.

Conclusion

As a larger percentage of the Untied State's population is made up of older adults, it is becoming increasingly important that we understand how to best serve this growing group. The Family Involvement Questionnaire-LTC is structured such that it will be a useful tool in the future and should provide insight into how families along with the residential centers might improve services to those in care. Long-term care facility administrators and staff can benefit from using the FIQ-LTC in many ways, including as a method for determining ways in which they can encourage family members of residents to become more involved. Researchers interested in looking at family involvement in the lives of older adults at long-term care facilities might benefit from having an existing tool that goes beyond using visitation frequency as the sole measure of involvement and is applicable in many settings. This study also indicates that distance may not be as much of a barrier to involvement as was previously believed. The wide range of the questions on the FIQ-LTC allow for more diverse methods of involvement to be measured. This also opens the door to more focused research on the specific methods that family members use to interact with facility residents.

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Appendix A

Table 1. Part 1 Participant Response Frequencies

Question	Not Necessary	Useful	Essential
1. I attend conferences with staff to learn and talk about my family member's general happiness and well-being	0	3	5
2. I contact my family member's facility if I have any questions.	0	1	7
3. I talk with facility staff regarding my family member's eating schedule.	0	4	4
4. I inquire whether my family member is engaging in community activities	0	4	4
5. I suggest possible activities to staff.	0	4	4
6. I attend family activities offered by my family member's facility.	0	5	3
7. I talk to facility staff about community and facility rules.	0	3	5
8. I make sure my family member has access to transportation	0	5	3
9. I ensure that my family member has access to what they need for daily living (i.e., food, toiletries etc.)	0	3	5
10. I communicate with facility staff if I am concerned with something my family member has told me.	0	1	7
11. I talk to facility staff to ensure my family member has access to stimulating activities.	0	1	7
12. I ensure that my family member is pleased with their level of privacy.	0	3	5
13. I volunteer at my family member's facility.	0	6	2
14. I participate in raising funds or donate money to my family member's facility	3	5	0
15. I talk to facility staff about my family member's engagement in their community	1	3	4
16. I bring or send my family member gifts	0	4	4
17. I talk to facility staff about my family member's friends and social life.	0	5	3
18. I visit my family member in their long-term care facility.	0	1	7
19. I talk to facility staff about problems my family member may be experiencing	0	1	7
20. I talk to my family member about	0	3	5

how their day was.			
21. I encourage my family member to engage in social activities.	1	1	6
22. I talk to other people who have family members in the same facility.	1	5	2
23. I make sure my family member has the means to easily move around the facility.	0	4	4
24. I talk to facility staff about what my family member is expected to do attheir facility.	1	4	3
25. My family member has chores to do.	5	3	0
26. I make sure my family member is able to perform home-living skills (laundry, dishes, etc.).	3	4	1
27. I feel that facility staff encourages residents to be involved in their community.	1	4	3
28. I feel that people with family members in the facility support each other.	2	3	3
29. I help my family member with tasks they may be struggling with.	1	3	4
30. I talk to my family member about their interests.	0	3	5
31. I listen to my family member's concerns regarding their facility.	0	2	6
32. I talk with facility staff about problems they feel my family member may be experiencing.	0	2	6
33. I am mindful of my family members well-being.	1	1	6
34. I contact facility staff by phone or email.	1	2	5
35. I talk about how my family member is doing with facility staff or my family members.	0	2	6
36. I talk to my family member about the benefits of residing in a long-term care facility	2	2	4
37. I provide my family member with pictures frames or wall decorations.	0	3	5
38. If my family member mentions one of their personal items are missing, I speak to facility staff about their concern.	0	1	7

Note. This table demonstrates how participants responded during part 1 of the study.

Appendix B

Table 2. State-by-State Participant Responses

State	N	%
Alabama	3	0.7%
Arizona	10	2.4%
California	38	9.3%
Colorado	4	1.0%
Connecticut	3	0.7%
Delaware	3	0.7%
Florida	24	5.9%
Georgia	16	3.9%
Hawaii	5	1.2%
Iowa	4	1.0%
Idaho	3	0.7%
Illinois	17	4.1%
Indiana	9	2.2%
Kansas	12	2.9%
Kentucky	6	1.5%
Massachusetts	13	3.2%
Maryland	7	1.7%
Maine	4	1.0%
Michigan	13	3.2%
Minnesota	30	7.3%
Missouri	8	2.0%
Mississippi	5	1.2%
Montana	1	0.2%
North Carolina	7	1.7%
North Dakota	1	0.2%
Nebraska	4	1.0%
New Hampshire	1	0.2%
New Jersey	11	2.7%
Nevada	3	0.7%
New York	26	6.3%
Ohio	19	4.6%
Oklahoma	3	0.7%
Oregon	6	1.5%
Pennsylvania	18	4.4%
Rhode Island	3	0.7%
South Carolina	3	0.7%
South Dakota	1	0.2%
Tennessee	6	1.5%

Texas	24	5.9%
Utah	4	1.0%
Virginia	5	1.2%
Washington	17	4.1%
Wisconsin	5	1.2%
West Virginia	4	1.0%
Wyoming	1	0.2%

Note: This table demonstrates how divided the 410 responses were across the United States.

Appendix C

Figure 1. Stacked Bar Graph Representation of Participant Responses

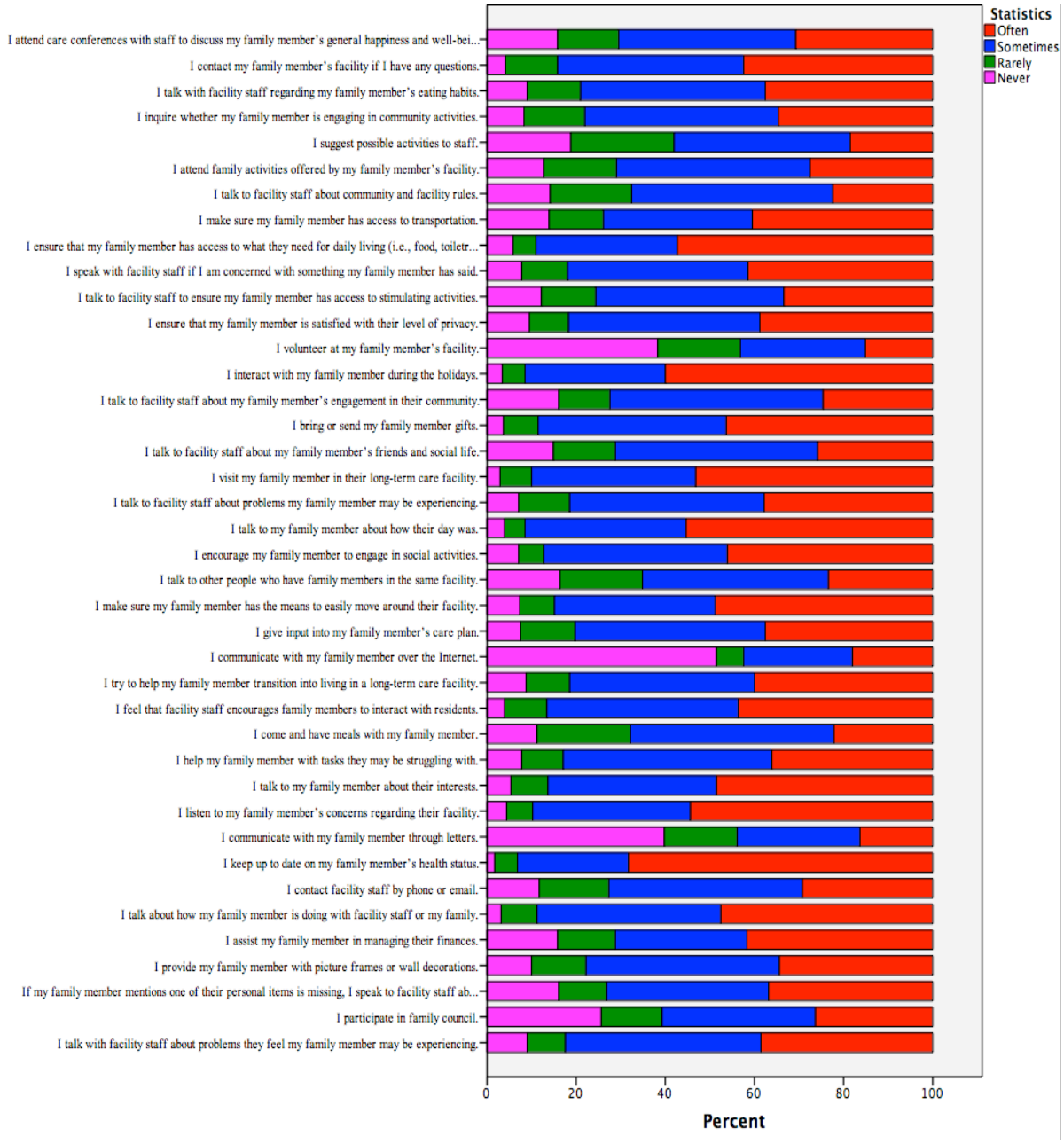

Figure 1. This figure illustrates the distribution of responses given by the 410 family members involved with the second portion of the study

Appendix D

Table 3. Participant Responses

Question	Never	Rarely	Sometimes	Often
I keep up to date on my family member's health status.	N = 7 (1.7%)	N = 21 (5.1%)	N = 102 (24.9%)	N =280 (68.3%)
I interact with my family member during the holidays.	N = 14 (3.4%)	N = 21 (5.1%)	N = 129 (31.5%)	N =246 (60%)
I ensure that my family member has access to what they need for daily living (i.e., food, toiletries)	N = 24 (5.9%)	N = 21 (5.1%)	N = 130 (31.7%)	N =235 (57.3%)
I talk to my family member about how their day was.	N = 16 (3.9%)	N = 19 (4.6%)	N = 148 (36.1%)	N =227 (55.4%)
I listen to my family member's concerns regarding their facility.	N = 18 (4.4%)	N = 24 (5.9%)	N = 145 (35.4%)	N =223 (54.4%)
I visit my family member in their long-term care facility.	N = 12 (2.9%)	N = 29 (7.1%)	N = 151 (36.8%)	N =218 (53.2%)
I make sure my family member has the means to easily move around their facility.	N = 30 (7.3%)	N = 32 (7.8%)	N = 148 (36.1%)	N =200 (48.8%)
I talk to my family member about their interests.	N = 22 (5.4%)	N = 34 (8.3%)	N = 155 (37.8%)	N =199 (48.5%)
I talk about how my family member is doing with facility staff or my family.	N = 13 (3.2%)	N = 33 (8.0%)	N = 169 (41.2%)	N =195 (47.6%)
I bring or send my family member gifts.	N = 15 (3.7%)	N = 32 (7.8%)	N = 173 (42.2%)	N =190 (46.3%)
I encourage my family member to engage in social activities.	N = 29 (7.1%)	N = 23 (5.6%)	N = 169 (41.2%)	N =189 (46.1%)
I feel that facility staff encourages family members to interact with residents.	N = 16 (3.9%)	N = 39 (9.5%)	N = 176 (42.9%)	N =179 (43.7%)
I contact my family member's facility if I have any questions.	N = 17 (4.1%)	N = 48 (11.7%)	N = 171 (41.7%)	N =174 (42.4%)
I assist my family member in managing their finances.	N = 65 (15.9%)	N = 53 (12.9%)	N = 121 (29.5%)	N =171 (41.7%)
I speak with facility staff if I am concerned with something my family member has said.	N = 32 (7.8%)	N = 42 (10.2%)	N = 166 (40.5%)	N =170 (41.5%)
I make sure my family member has access to transportation.	N = 57 (13.9%)	N = 50 (12.2%)	N = 137 (33.4%)	N =166 (40.5%)
I try to help my family member transition into living in a long-term care facility.	N = 36 (8.8%)	N = 40 (9.8%)	N = 170 (41.5%)	N =164 (40%)
I ensure that my family member is satisfied with their level of privacy.	N = 39 (9.5%)	N = 36 (8.8%)	N = 176 (42.9%)	N =159 (38.8%)
I talk with facility staff about problems they feel my family member may be experiencing.	N = 37 (9%)	N = 35 (8.5%)	N = 180 (43.9%)	N =158 (38.5%)
I talk to facility staff about problems my family member may be experiencing.	N = 29 (7.1%)	N = 47 (11.5%)	N = 179 (43.7%)	N =155 (37.8%)

I give input into my family member's care plan.	N = 31 (7.6%)	N = 50 (12.2%)	N = 175 (42.7%)	N =154 (37.6%)
I talk with facility staff regarding my family member's eating habits.	N = 37 (9.0%)	N = 49 (12.0%)	N = 170 (41.5%)	N =154 (37.6%)
If my family member mentions one of their personal items is missing, I speak to facility staff ab...	N = 66 (16.1%)	N = 44 (10.7%)	N = 149 (36.3%)	N =151 (36.8%)
I help my family member with tasks they may be struggling with.	N = 32 (7.8%)	N = 38 (9.3%)	N = 192 (46.8%)	N =148 (36.1%)
I inquire whether my family member is engaging in community activities.	N = 34 (8.3%)	N = 56 (13.7%)	N = 178 (43.4%)	N =142 (34.6%)
I provide my family member with picture frames or wall decorations.	N = 41 (10%)	N = 50 (12.2%)	N = 178 (43.4%)	N =141 (34.4%)
I talk to facility staff to ensure my family member has access to stimulating activities.	N = 50 (12.2%)	N = 50 (12.2%)	N = 173 (42.2%)	N =137 (33.4%)
I attend care conferences with staff to discuss my family member's general happiness and well-being	N = 65 (15.9%)	N = 56 (13.7%)	N = 163 (39.8%)	N =126 (30.7%)
I contact facility staff by phone or email.	N = 48 (11.7%)	N = 64 (15.6%)	N = 178 (43.4%)	N =120 (29.3%)
I attend family activities offered by my family member's facility.	N = 52 (12.7%)	N = 67 (16.3%)	N = 178 (43.4%)	N =113 (27.6%)
I participate in family council.	N =105 (25.6%)	N = 56 (13.7%)	N = 141 (34.4%)	N =108 (26.3%)
I talk to facility staff about my family member's friends and social life.	N = 61 (14.9%)	N = 57 (13.9%)	N = 186 (45.4%)	N =106 (25.9%)
I talk to facility staff about my family member's engagement in their community.	N = 66 (16.1%)	N = 47 (11.5%)	N = 196 (47.8%)	N =101 (24.6%)
I talk to other people who have family members in the same facility.	N = 67 (16.3%)	N = 76 (18.5%)	N = 171 (41.7%)	N = 96 (23.4%)
I talk to facility staff about community and facility rules.	N = 58 (14.1%)	N = 75 (18.3%)	N = 185 (45.1%)	N = 92 (22.4%)
I come and have meals with my family member.	N = 46 (11.2%)	N = 86 (21%)	N = 187 (45.6%)	N = 91 (22.2%)
I suggest possible activities to staff.	N = 77 (18.8%)	N = 95 (23.2%)	N = 162 (39.5%)	N = 76 (18.5%)
I communicate with my family member over the Internet.	N =211 (51.5%)	N = 25 (6.1%)	N = 100 (24.4%)	N = 74 (18.0%)
I communicate with my family member through letters.	N =163 (39.8%)	N = 67 (16.3%)	N = 113 (27.6%)	N = 67 (16.3%)
I volunteer at my family member's facility.	N =157 (38.3%)	N = 76 (18.5%)	N = 115 (28%)	N = 62 (15.1%)

Note: This table details the responses of the 410 participants obtained during the second portion of the study. Each cell indicates the number and percentage of participants who selected a specific response.

Appendix E

Table 4. Principle Component Analysis Structure for the FIQ-LTC

Structure	Oblique loadings
Factor 1: Interactions with facility administration and staff	
I talk to facility staff about problems my family member may be experiencing.	.886
I talk with facility staff regarding my family member's eating habits.	.852
I talk with facility staff about problems they feel my family member may be experiencing.	.799
I talk to facility staff to ensure my family member has access to stimulating activities.	.736
I contact facility staff by phone or email.	.732
I speak with facility staff if I am concerned with something my family member has said.	.713
I talk to facility staff about community and facility rules.	.708
I contact my family member's facility if I have any questions.	.702
I talk to facility staff about my family member's engagement in their community.	.650
I suggest possible activities to staff.	.612
If my family member mentions one of their personal items is missing, I speak to facility staff ab…	.601
I inquire whether my family member is engaging in community activities.	.598
I talk to facility staff about my family member's friends and social life.	.581
I give input into my family member's care plan.	.527
I attend care conferences with staff to discuss my family member's general happiness and well-bei…	.504
I ensure that my family member has access to what they need for daily living (i.e., food, toiletr…	.482
Factor 2: Mediums used for interaction	
I suggest possible activities to staff.	.406
I communicate with my family member over the Internet.	.855
I communicate with my family member through letters.	.776
I volunteer at my family member's facility.	.756
I participate in family council.	.539
I come and have meals with my family member.	.485
I talk to other people who have family members in the same facility.	.442
Factor 3: Communication and providing care	
I talk to my family member about how their day was.	.857

I talk to my family member about their interests.	.855
I listen to my family member's concerns regarding their facility.	.804
I encourage my family member to engage in social activities.	.673
I try to help my family member transition into living in a long-term care facility.	.565
I bring or send my family member gifts.	.545
I make sure my family member has the means to easily move around their facility.	.523
I feel that facility staff encourages family members to interact with residents.	.464
I keep up to date on my family member's health status.	.452
I ensure that my family member is satisfied with their level of privacy.	.441
I make sure my family member has access to transportation.	.422
I help my family member with tasks they may be struggling with.	.401
Factor 4: In person visitation	
I come and have meals with my family member.	.451
I visit my family member in their long-term care facility.	.714
I interact with my family member during the holidays.	.581
I attend family activities offered by my family member's facility.	.490

Appendix F

Family Involvement Questionnaire-LTC (Initial Draft)

Directions: For each item please rate how necessary (*Not necessary, Useful, or Essential*) each item may be in assessing family involvement in extended-care facilities.

Items	Not Necessary	Useful	Essential
1. I attend conferences with staff to learn and talk about my family member's general happiness and well-being			
2. I contact my family member's facility if I have any questions.			
3. I talk with facility staff regarding my family member's eating schedule.			
4. I inquire whether my family member is engaging in community activities			
5. I suggest possible activities to staff.			
6. I attend family activities offered by my family member's facility.			
7. I talk to facility staff about community and facility rules.			
8. I make sure my family member has access to transportation			
9. I ensure that my family member has access to what they need for daily living (i.e., food, toiletries etc.)			
10. I communicate with facility staff if I am concerned with something my family member has told me.			
11. I talk to facility staff to ensure my family member has access to stimulating activities.			
12. I ensure that my family member is pleased with their level of privacy.			
13. I volunteer at my family member's facility.			
14. I participate in raising funds or donate money to my family member's facility			
15. I talk to facility staff about my family member's engagement in their community			
16. I bring or send my family member gifts			
17. I talk to facility staff about my family member's friends and social life.			

18. I visit my family member in their long-term care facility.			
19. I talk to facility staff about problems my family member may be experiencing			
20. I talk to my family member about how their day was.			
21. I encourage my family member to engage in social activities.			
22. I talk to other people who have family members in the same facility.			
23. I make sure my family member has the means to easily move around the facility.			
24. I talk to facility staff about what my family member is expected to do attheir facility.			
25. My family member has chores to do.			
26. I make sure my family member is able to perform home-living skills (laundry, dishes, etc.).			
27. I feel that facility staff encourages residents to be involved in their community.			
28. I feel that people with family members in the facility support each other.			
29. I help my family member with tasks they may be struggling with.			
30. I talk to my family member about their interests.			
31. I listen to my family member's concerns regarding their facility.			
32. I talk with facility staff about problems they feel my family member may be experiencing.			
33. I am mindful of my family members well-being.			
34. I contact facility staff by phone or email.			
35. I talk about how my family member is doing with facility staff or my family members.			
36. I talk to my family member about the benefits of residing in a long-term care facility			
37. I provide my family member with pictures frames or wall decorations.			
38. If my family member mentions one of their personal items are missing, I speak to facility staff about their concern.			

Appendix G
Staff Feedback Form

Are there any important items that you feel could be added to the FIQ-LTC to make it a better tool for evaluating how involved family members are in the lives of residents?

How well do you feel that the questions regarding family involvement will measure the level of involvement that family members have in the lives of residents? Please leave any suggestions below

Please list any additional comments or suggestions you have about the FIQ-LTC below.

Thank you for your participation. Your suggestions and comments will be used to update the FIQ-LTC for use in the future.

Appendix H

Family Involvement Questionnaire-LTC (Final Version)

Directions: For each item please check the box that best indicates how often you engage in the activity in question. Thank you.

Items	Never	Rarely	Sometimes	Often
1. I attend care conferences with staff to discuss my family member's general happiness and well-being.				
2. I contact my family member's facility if I have any questions.				
3. I talk with facility staff regarding my family member's eating habits.				
4. I inquire whether my family member is engaging in community activities.				
5. I suggest possible activities to staff.				
6. I attend family activities offered by my family member's facility.				
7. I talk to facility staff about community and facility rules.				
8. I make sure my family member has access to transportation.				
9. I ensure that my family member has access to what they need for daily living (i.e., food, toiletries etc.)				
10. I speak with facility staff if I am concerned with something my family member has said.				
11. I talk to facility staff to ensure my family member has access to stimulating activities.				
12. I ensure that my family member is satisfied with their level of privacy.				
13. I volunteer at my family member's facility.				
14. I interact with my family member during the holidays				
15. I talk to facility staff about my family member's engagement in their community.				
16. I bring or send my family member gifts.				
17. I talk to facility staff about my family member's friends and social life.				
18. I visit my family member in their long-term care facility.				
19. I talk to facility staff about problems my family member may be experiencing.				
20. I talk to my family member about how their day was.				

	Never	Rarely	Sometimes	Often
21. I encourage my family member to engage in social activities.				
22. I talk to other people who have family members in the same facility.				
23. I make sure my family member has the means to easily move around their facility.				
24. I give input into my family member's care plan.				
25. I communicate with my family member over the Internet.				
26. I try to help my family member transition into living in a long-term care facility.				
27. I feel that facility staff encourages family members to interact with residents.				
28. I come and have meals with my family member.				
29. I help my family member with tasks they may be struggling with.				
30. I talk to my family member about their interests.				
31. I listen to my family member's concerns regarding their facility.				
32. I communicate with my family member through letters .				
33. I keep up to date on my family member's health status.				
34. I contact facility staff by phone or email.				
35. I talk about how my family member is doing with facility staff or my family.				
36. I assist my family member in managing their finances				
37. I provide my family member with picture frames or wall decorations.				
38. If my family member mentions one of their personal items are missing, I speak to facility staff about their concern.				
39. I participate in family council.				
40. I talk with facility staff about problems they feel my family member may be experiencing.				