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Do Family Proxies get it Right? Concordance in Reports of Nursing Home Residents' Everyday Preferences

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Abstract

Limited work has examined how well family proxies understand nursing home residents' preferences. With 85 dyads of a nursing home resident and relative, we utilize descriptive statistics and multi-level modeling to examine the concordance in reports of importance ratings of 72 everyday preferences for residents. Results reveal significant mean differences at the $p < .001$ level between proxies and residents on 12 of 72 preferences; yet perfect agreement in responses is poor and only increases when dichotomizing responses into an *important* versus *not important* outcome. Multi-level modeling further indicates that dyads are discrepant on reports of the importance of growth activities for residents, with residents reporting higher levels of importance than proxies. This discrepancy is associated with residents' hearing impairment and proxies' perception of resident openness. The findings highlight how proxies may be able to inform care for residents in nursing homes, but also where further discussions are warranted.

Keywords

preferences; nursing home residents; assessment; family support

Recent work has called for the transformation of nursing homes from a medical model of care to one that honors older adults' needs and preferences (Koren, 2010). This culture change movement to provide person-centered care puts the person and his or her values at

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the center and focus of care (Edvardsson & Innes, 2010), encouraging choice, a sense of purpose, and meaningfulness in life (Koren, 2010). Such care has been theorized to improve the quality of life and well-being of individuals receiving care (Koren, 2010) and has been linked to outcomes such as improved food intake, continence, decision-making, and satisfaction with care (Applebaum, Straker, & Geron, 2000; Simmons & Schnelle, 2004; Thompson & Smith, 1998; Whitlatch, Judge, Zarit, & Femia, 2006).

In light of these findings, current research has focused on measuring and tracking person-centered care delivery (de Silva, 2014). Developed tools rely on self-report (Edvardsson & Innes, 2010; Van Haitsma, Crespy et al., 2014; Van Haitsma et al., 2012), objective activities and emotions (Brooker, & Surr, 2005; Williams et al., 2012), and staff reports (Chappell, Reid, & Gish, 2007; Edvardsson, Koch, & Nay, 2010) and track a series of domains such as self-dominion, autonomy, or communication. A particular emphasis has been placed on the assessment of preferences in everyday care as a key component to delivering person-centered care (Housen et al., 2009; Van Haitsma, Crespy et al., 2014). A subset of preference items are now also included in the Minimum Dataset 3.0 utilized by all Medicaid funded skilled nursing facilities in the United States as a mechanism for tracking care quality. However, less addressed in the literature is the possible role family members can play in reporting on nursing home residents' person-centered care experiences (Reid, Chappell, & Gish, 2007) and, more pointedly, their everyday preferences.

As individuals age they increasingly rely on the support of others in their daily lives (Baltes, Freund, & Li, 2005; Berg & Upchurch, 2007). Family members remain the largest group of individuals called upon to provide this support (National Alliance for Caregiving, 2009). Spouses and adult-children commonly step in to provide functional, psychological, social, and cognitive supports in times of need (Wolff & Kasper, 2006). This support proves vital in enabling older adults to continue to influence their care and direct their daily lives even as they transition from the home setting to a higher level of care, such as a nursing home (Cohen et al., 2014; Gaugler, Anderson, Zarit, & Pearlin, 2004; Gaugler, Zarit, & Pearlin, 2003; Port et al., 2005). Family members remain advocates for supporting the delivery of individualized care—monitoring care, initiating activities of interest for the older person, sharing life histories with professional care staff, and serving as spokespersons in care planning meetings (Rowles & High, 1996). Their involvement is linked to beneficial health and well-being outcomes (Cohen et al., 2014; Friedemann, Montgomery, Maiberger, & Smith, 1997; Mitchell & Kemp, 2000; Zimmerman, Gruber-Baldinin, Hebel, Sloane, & Magaziner, 2002). Yet, little work has empirically examined the role of family in reporting on nursing home residents' everyday preferences in care.

While asking family members to report on a nursing home resident's preferences may be one step removed from providing truly person centered care (i.e., asking the person directly), family members may be key respondents to call upon in understanding residents' preferences, particularly as older adults lose cognitive and functional capabilities (Whitlatch, Piiparinen, & Feinberg, 2009; Zimmerman et al., 2013). However, recent work documents that family members do not always fully understand older adults' preferences for care in the home and community setting (Carpenter, Lee, Ruckdeschel, Van Haitsma, & Feldman, 2006; Feinberg & Whitlatch, 2001; Reamy, Kim, Zarit, & Whitlatch, 2011). Evidence suggests that

proxies are often found to be “right” at rates less than chance alone would predict (Fagerlin, Ditto, Hawkins, Schnieder, & Smucker, 2002). More specifically, in home care, family members of individuals with mild to moderate dementia are documented to underestimate the importance of their older relatives’ values across five domains (i.e., autonomy, safety, burden, control, and family; Reamy et al., 2011). Other research shows that adult children underestimate the importance of parents’ continued enrichment and personal growth (Carpenter et al., 2006). However, work has yet to examine if this discrepancy is also present between family members and older relatives living in a nursing home. Care planning processes within nursing homes often include family members in decision making; thus, work is needed to see if and to what extent family members may be called upon to support the delivery of preference-based, person-centered care.

It is likely that family members are able to report accurately on some preferences but not others (Carpenter et al., 2006). The level of mutual understanding may be affected by resident related factors, characteristics of the family member, or contextual factors of their relationship or care. In regard to the resident, understanding may be linked to personal characteristics of older adults that predispose them to be more expressive about their preferences and engaged in decision-making or to communication patterns within families (Flynn & Smith, 2007). Understanding preferences may also be linked to functional, emotional, cognitive, or sensory capabilities of the resident. As these capabilities decline, preferences may change for the older adult or relatives may underestimate the continued importance of preferences when it becomes harder for an older adult to achieve them (Reamy, Kim, Zarit, & Whitlatch, 2012). Second, understanding may be linked to the characteristics of the family member, such as the type of relationship the family member and resident have (e.g., spouse versus child; Carpenter et al., 2006) or factors impacting how receptive they are to inquiring about preferences and listening when they are expressed. Or, third, discrepancies in understanding may be linked to contextual factors such as the family member’s involvement in care; those more invested in care may have a more accurate sense of their relatives’ preferences, as this may allow for more opportunities to discuss preferences or “observe” the preferences of interest (Carpenter et al., 2006). An exploratory approach to understanding concordance and determining the factors linked to possible discrepancy of nursing home residents’ and family members’ reports of nursing home residents’ preferences is needed.

This current study took both a group-level and dyadic-level approach to examining how well relatives of nursing home residents understand residents’ everyday preferences for care. The following research questions guided our exploratory inquiry:

- Q1** (a) How well do family members understand their older relatives’ everyday preferences in the nursing home? (b) How does understanding vary across preference domain? We hypothesized that family members would report similar levels of importance on preferences regarding self-dominion and leisure/diversionary pursuits but be discrepant on preferences related to personal growth (as found in home care; Carpenter et al., 2006).
- Q2** What resident characteristics, family member characteristics, and/or contextual factors are related to discrepancies in reports of residents’ preference importance

between relatives and nursing home residents? We hypothesized that discrepancy would be related to characteristics of the older adult (less openness, less extraversion, less positive affect, less sensory ability, more functional limitation), and the caring context (less family involvement in care).

Methods

Participants and Procedures

The sample includes 85-dyads of an older adult living in a nursing home and a family member the resident referred who “knows them well” (see Table 1 for participant characteristics). Participants were recruited from 20 nursing homes in the greater Philadelphia, PA region. Nursing homes were drawn from a convenience sample selected within a 30-mile radius of the parent facility where the research team was located and recruited on a rolling basis to meet targeted recruitment goals for a larger study (*Assessing preferences for everyday living in the nursing home: Reliability and concordance issues*; PI: Blinded for Review; see Table 2 for facility characteristics). Potential nursing home residents that met eligibility criterion (English speaking, lived in facility for at least one week and were expected to be there for at least 3 months, medically stable, and judged as cognitively capable to participate) were identified through social workers at their respective nursing homes. All referred residents were signed off by either their attending physician or director of nursing for capacity to consent and medical stability. Social workers asked residents if they were interested in learning more about participating in the study. Courtesy calls were made by the facility contact person to the primary family and/or friend contact of the resident to inform them of their loved one’s interest in participating in the research study. Recruited participants were then screened for cognitive ability by the research team for inclusion in the larger study. Residents’ with a mini-mental state exam (MMSE; Folstein, Folstein, & McHugh, 1975) score of 13 or greater were included in the sample ($M = 24.48$, $SD = 3.87$). The cutoff score of 13 for the MMSE was chosen based on work suggesting that individuals with mild to moderate dementia can reliably report on their values and preferences (Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001; Karel, Moye, Bank, & Azar, 2007; Whitlatch, Feinberg, & Tucke, 2005a; 2005b; Whitlatch, Piiparinen, & Feinberg, 2009). While some individuals below 13 may also be able to report on their preferences, the goal of this study was to avoid participant burden, asking a resident who lacks higher order processing skills to respond to such cognitive questions. Upon completion of an initial in-person interview about their preferences for everyday living, residents had the opportunity to refer a family member or friend who “knows them well” to also answer questions about their preferences. Half of the initial sample of $N = 337$ provided a referral, and 89 of the referred individuals agreed to participate in the additional optional phase of the study. Reasons for not referring a family member or friend included not wanting to burden a family member or lack of a person to refer. To limit analysis to the use of a family-based sample, four participants who referred a friend were dropped from these analyses. The majority of the final sample included adult children or children-in-law referrals (68%, $n = 58$). Referred proxies were either mailed a survey, had the survey left in the resident’s room, and/or provided with a link to complete the survey on-line, based on preference. Family members were contacted 1 to 6 times by phone and/or mail to encourage

them to complete the provided survey. Thirty-six surveys were completed online and 49 were returned by mail.

Measures

Dependent Measure

Preference Interview: Nursing home residents and their relatives completed the 72-item Preferences for Everyday Living Inventory developed for use in a nursing home population (PELI-NH; Van Haitsma et al., 2012). Participants rated the importance of residents' everyday preferences on a 4-point scale from 1 (*very important*) to 4 (*not important at all*). Items covered a variety of topics that fell into five domains derived from prior work using concept-mapping: *social contact* ($\alpha = 0.80$; e.g., spending time with family or friends), *growth activities* ($\alpha = 0.83$; e.g., participate in cultural traditions), *leisure and diversionary activities* ($\alpha = 0.63$; e.g., go shopping), *self-dominion* ($\alpha = 0.90$; e.g., choosing what name to be called), and *enlisting others in care* ($\alpha = 0.22$; e.g., choosing your medical care professional; Carpenter, Van Haitsma, Ruckdeschel, & Lawton, 2000). Items were reverse scored in this study to have a higher score indicate more importance. Mean-item scores were created for each of the five conceptual domains (Carpenter et al., 2000; see Table 3 for scales). The scale for enlisting others in care was not used in subsequent analyses however, due to low inter-item reliability in this sample ($\alpha = 0.22$).

Independent Measures

Demographics and Chart Data: Skilled nursing facilities that are Medicare or Medicaid certified routinely provide comprehensive clinical assessments of residents' demographic characteristics and capabilities. Chart data on demographic characteristics (age, gender, race, marital status, and education), vision, hearing, functional impairment, and mood were extracted from the MDS 3.0 (Saliba & Buchanan, 2009). Gender was coded 0 (*male*) or 1 (*female*), race was coded 0 (*non-African American*) or 1 (*African American*), and education was coded 1 (*no schooling*) to 8 (*graduate degree*). Vision and hearing were coded 0 (*no impairment*) or 1 (*impairment*). Functional impairment was measured with a mean-item total score of 11 items on self-performance ability for activities of daily living such as eating and mobility that were rated 0 (*independent*) to 4 (*total dependence*) by residents' facility staff ($\alpha = .91$, $M = 23.48$, $SD = 7.98$). Resident depressive mood was measured by 9 items extracted from the PHQ-9, such as "*little interest or pleasure in doing things*" rated from 0 (*rarely*) to 3 (*nearly every day*) by the resident that were mean scored ($\alpha = .57$, $M = 1.62$, $SD = 2.55$; Kroenke, Spitzer, & Williams, 2001). Family members also self-reported on their own demographic characteristics (age, gender, race, marital status, and education).

Cognitive Ability: Research staff completed the 30-point mini-mental state examination (MMSE; Folstein et al., 1975) at the start of each interview to ensure participants had no more than mild to moderate cognitive impairment (MMSE score greater than 13; $M = 24.48$, $SD = 3.87$).

Affect: The Positive and Negative Affect Scale (PANAS) was asked to residents to self-report the extent they had felt 20 different emotions in the past two weeks from 1 (*very slightly to not at all*) to 5 (*extremely*; Watson, Clark, & Tellegen, 1988). Two separate mean

item total scales were created to capture positive affect ($\alpha = .83$, $M = 29.42$, $SD = 7.66$) and negative affect ($\alpha = .82$, $M = 17.58$, $SD = 6.35$).

Family Involvement: A facility contact person supervising the care of the residents at each facility (a social worker or administrator) was asked to rate the family member's level of involvement with resident care on a scale of 5 (*very high*) to 1 (*very low*) and how many times per month the family is in contact with staff about non-medical aspects of care for each resident (Port et al., 2005). Family members also responded to two questions about their contact with their relative: (1) *How often do you have contact (in person or by phone) with your family member or friend in the nursing home* rated on a scale of 8 (*daily*) to 1 (*once a year*), and (2) *How would you rate the quality of your relationship with your family member or friend* rated from 1 (*poor*) to 5 (*excellent*). The 4-items were z-scored and summed to create a total score of caregiver involvement in care ($\alpha = 0.63$, $M = 0.15$, $SD = 2.67$). Higher scores indicate more involvement (range: -10.35 to 4.10).

Resident Personality: To reduce burden on residents, family members completed a 40-item personality battery that assessed their relative's personality traits of conscientiousness (8-items; $\alpha = 0.86$, $M = 29.39$, $SD = 6.80$), extraversion (8-items; $\alpha = 0.80$, $M = 28.54$, $SD = 6.65$), openness (8-items; $\alpha = 0.81$, $M = 27.06$, $SD = 6.70$), emotional stability/neuroticism (8-items; $\alpha = 0.77$, $M = 22.19$, $SD = 6.21$) and agreeableness (8-items; $\alpha = 0.92$, $M = 34.22$, $SD = 6.66$; Thompson, 2008). Items were rated on a scale 1 (*inaccurate*) to 5 (*accurate*) on how well a word described their resident. Mean item total scores were created for each trait.

Analyses

Group-level Item analysis—We first utilized a series of descriptive approaches to examine group-level differences in reports of residents' preferences. Mean differences between reports by residents and family members were calculated with paired samples t-tests to examine overall group differences in levels of perceived importance of the PELI-NH items. Paired samples t-tests were used in lieu of independent samples t-tests given the related nature of the two groups (i.e., family members; Szafran, 2012). To account for the impact of multiple t-tests run on Type 1 error, we only interpret differences at the $p < .001$ level. Pearson product-moment correlations were run to examine the association between reports of residents and proxies on each PELI-NH item. Intraclass correlations (ICCs) were performed to observe the consistency between the ratings of residents and their family members on the PELI-NH items. Percent agreement scores were calculated to determine the percentage of perfect agreement between residents and relatives by item (i.e., item was endorsed as very important by both the resident and the family member) and the percentage of agreement based on a dichotomized important versus not important scale (i.e., resident endorsed an item as very or somewhat important and the family member also reported the item as very or somewhat important *or* if both parties said the preference was not very or not important at all this was considered concordant; see Van Haitsma, Abbott et al., 2014).

Dyadic-based Domain Analysis—However, known limitations exist in relying solely on group level differences when analyzing data of individuals embedded in a shared context,

such as a family unit (Maguire, 1999). Non-independence of dyad members can result in too many or too few type 1 errors (Kenny, Kashy, & Cook, 2006). To account for this dependency in the data that one family may be more apt to respond in a given way because those individuals are a part of that given family, as compared to another family, we used multilevel modeling (MLM; SAS PROC MIXED; Littell, Milliken, Stroup, & Wolfinger, 1996) to investigate dyadic level concordance in understanding the importance of residents' preferences grouped into the four domains (growth activity, leisure/diversionary activity, self-dominion, and social preferences; *Note*: enlisting others in care was dropped from analyses due to low internal reliability in this sample). We then explored what factors were associated with discrepancy. MLM accounted for the interdependence of individuals within each dyad. This technique enabled prediction at both the level of the outcome, that is the importance of preferences within a domain as reported by the dyad overall, and direction of differences in reports of the outcome within pairs, or concordance between dyad members (Maguire, 1999). *Relation* was treated as a fixed effect repeated measures factor with two levels (resident/family proxy) At Level 1 (within dyad), we used observations from each individual reporter to implicitly fit a regression with two parameters—intercept and slope—on the factor, *Relation*. By scaling *Relation* as *resident* = -0.5 or *family proxy* = 0.5 we allowed the intercept to capture the mean level of preference importance reported by the dyad. The slope then captured the degree of discrepancy of reported importance between the dyad members. A significant negative fixed effect coefficient for discrepancy indicated that, on the average, residents reported a higher level of importance than family proxies; a significant positive coefficient for discrepancy indicated that family proxies reported a higher level of importance than residents. We modeled the individual value score (Y_{ij}) for j th member in the i th dyad as

$$Y_{ij} = \pi_{i0} + \pi_{i1}(\textit{Relation})_{ij} + \varepsilon_{ij}$$

Where the intercept (π_{0j}) and the slope (π_{1j}) were the individual regression coefficients. The residual (ε_{ij}), represented the deviations of the prediction around each resident's observed data.

The Level 2 equations then allowed the variability in the individual intercepts and slopes to be accounted for by variables of interest. For the variable, W , the Level 2 equations were as follows:

$$\begin{aligned}\pi_{i0} &= \beta_{00} + \beta_{10}W_{i0} + v_{i0} \\ \pi_{i1} &= \beta_{01} + \beta_{11}W_{i0}\end{aligned}$$

where β_{00} , β_{10} , β_{01} , and β_{11} were the fixed effect regression coefficients and v_{i0} was the random effect for the intercept. We estimated the model using an unstructured covariance matrix for the random effects and determined whether the variance components were significant and necessary. We used information criteria (AIC, -2 Log likelihood) to determine the best error structure model for these data. Additional covariates were added at either Level 1 or Level 2 (Bryk & Raudenbush, 1992). We included only the individual and relationship-based variables that showed a significant relationship with the difference or

average reports of residents and proxies on preference importance (Rovine, von Eye, & Wood, 1988) and trimmed models to only retain significant variables to take a parsimonious approach in analyses. Assumptions of normality and the criterion for at least 50 groups to allow for valid variance and standard error estimates were met (Maas & Hox, 2004).

Results

Results indicated that family members of individuals living in nursing homes were more accurate in reporting on the importance of some preferences than others for their elder relative (Table 3). T-tests revealed significant mean differences at the $p < .001$ level between proxies and residents at the group level on 12 of the 72 preferences (proxies reported higher importance for 1 item; residents reported higher importance than proxies on 11 items). When considering correlations and estimates of consistency, correlations and ICC estimates were low for all items (range: $r = .02$ to $.66$ and $ICC = -0.18$ to 0.64), indicating that there was a lack of consistency in the pattern of responses by residents and proxies. Percentage agreement estimates further indicated an overall low level of congruence in reports between proxies and residents when conceptualizing congruence as the perfect agreement between residents and proxies on the report of importance of preferences for the resident (e.g., very important = very important; $m = 44.25\%$, $sd = 11.28$; range: $23.6 - 79.8\%$). Concordance increased when dichotomizing responses of both parties into “Important” versus “Not Important” response scale (e.g., very important or somewhat important = very important or somewhat important; $m = 73.35\%$, $sd = 11.71$; range: $48.3 - 96.6\%$).

Multi-level modeling results further revealed that when examining concordance at the level of the dyad with 4 domains of preferences there was no significant discrepancy in reports of importance of leisure and diversionary activities ($\beta = 0.002$, $SE = 0.58$, $p = .99$), self-dominion ($\beta = 1.14$, $SE = 1.33$, $p = .40$) or social contact ($\beta = -0.69$, $SE = 0.74$, $p = .36$) for residents and proxies. However, there was a significant discrepancy in reports of the importance of growth activities for residents; residents reporting higher levels of importance of growth activities than proxies reported (see Table 4). This discrepancy was significantly related to proxies reports of residents’ personality trait of *openness* (when proxies reported greater perceived resident openness, proxies reported higher levels of importance of growth activities than residents self-reported; $\beta = 0.52$, $SE = 0.16$) and resident *hearing impairment* (hearing impairment was linked to greater reports of importance of growth activities by residents than by proxies; $\beta = -7.08$, $SE = 2.35$). Reports of the level of importance as rated by families were further linked to *race* (higher reports of importance by the dyad for African American families; $\beta = 4.14$, $SE = 1.93$), reports of residents’ *openness* (greater resident openness, higher reports of importance by the dyad; $\beta = 0.17$, $SE = 0.11$), and residents’ *positive affect* (greater resident positive affect, higher reports of importance by the dyad; $\beta = 0.32$, $SE = 0.09$).

Discussion

This study sought to investigate how well family members of individuals living in nursing homes understand their older relatives’ everyday preferences. Results demonstrate that family members understand some preferences better than others and that use of a

dichotomous answer choice (important vs. not important) increases concordance across reporters. These findings carry important implications for research and practice.

Findings of these exploratory analyses with a nursing home population are consistent with work by Carpenter et al. (2006) who found that child caregivers underestimate their parents' desire for enrichment and personal growth activities in the home setting. Clinical practice may draw on these results in particular by not asking family members to report on the importance of growth activities, such as keeping up with the news, learning about new topics, sports, or religious activities, for residents. Instead, it appears critical to ask residents themselves about the importance of growth activities, or in the case of limited cognitive ability to use observational methodologies to learn from the resident directly such as watching and recording indicators of engagement (e.g., smiling, alertness) during activity participation. It may be that as residents lose capabilities, particularly hearing ability, that family members see the resident as no longer able to participate in growth activities. This association may cause family members to perceive growth activities as less important. Or, it may be that growth activities do not appear to be adaptive to those with hearing impairments or allow for participant engagement (Solheim, Kværner, & Falkenberg, 2011), again leading to a perceived lack of importance by family members. Qualitative research demonstrates that residents see sensory impairment as both a barrier and situational dependency of preference fulfillment (Heid et al., 2014). Given the large number of nursing home residents affected by hearing loss (Garahan, Waller, Houghton, Tisdale, & Runge, 1992), further work is needed to explore how sensory deficits affect preference importance and what interventions can be implemented to address the impact of hearing loss on engagement in growth activities (Pronk et al., 2011). Family members' perceptions of their relatives' personality traits may also influence how they ascribe importance of growth activities to their relatives. For those residents that are perceived as more open, families may think residents would like to do more growth activities than they do. It may also be that family members have a biased perception of their relatives' personality traits or that this evaluation is based on past experiences when the resident was more active. Prior work also demonstrates that the family members' perceptions are linked to discrepancies (Reamy et al., 2011). Given this finding, families may benefit from an opportunity for dyad based discussions of residents' preferences to improve understanding (Whitlatch et al., 2006).

Results further indicate that some families may simply see growth activities as more important overall. African American families and families where residents are seen as more open or report more positive affect may value growth activities more. Identifying as African American may be linked to cultural differences regarding the value placed on growth activities for an older person. While race and resident affect were not linked to discrepancy, these family level differences may indicate a need to communicate/discuss values around growth differently for non-African American families or those where the resident is not reporting high levels of positive affect.

In regard to social, leisure/diversionary, and self-dominion preferences, results indicate that family members may be more readily called upon to report on their relatives' preferences, as no dyadic level discrepancies in preferences were found. However, prior findings of discordance (Reamy et al., 2011) and other estimates of mean difference and association in

this study indicate that we should proceed with caution. Results indicate that the use of a dichotomous response scale of *important* versus *not important* instead of a four choice Likert scale improves ratings of concordance. Although this may simply represent an arithmetic exercise with the data, we did not find that the majority of residents reported one side of the scale (e.g., very or somewhat important) while the relative reported on the other (e.g., not very or not at all important). Therefore, it may be that families can generally report on the valence of a preference for a relative (important versus not), but the more nuanced distinction of the degree of importance is harder to make. In fact, prior work demonstrates that residents themselves are also more reliable in the short-term with use of a dichotomous answer choice (Van Haitsma, Abbott, et al., 2014). The lack of ability to track degree of importance may be due to several interacting factors. Residents' preferences may change or be situationally dependent and family members may be thinking of a past version of residents' preferences. Work indicates that although values and preferences are relatively stable over a few weeks (Carpenter, Kissel, & Lee, 2007; Feinberg & Whitlatch, 2001; Whitlatch et al., 2005a), situational experiences *within the person* (e.g., functional ability, personal schedule), *facility environment* (e.g., facility schedule, facility policy), *social environment* (e.g., quality and type of interactions), and *global environment* (e.g., weather, current events), can impact the report of importance of a preference at a given point in time (Heid et al., 2014). Alternately, family members could be allowing their perceptions in care or sense of well-being to affect how they see residents' preferences, such as perceptions of how involved they see their family member in care and/or reports of their own quality of life as found regarding reports of older adults' values over time (Reamy et al., 2011; 2012). Or, families that "get it right" may be engaging in conversation and support that allows for a better understanding of preferences; measures in this study were limited in scope regarding assessment of involvement and further understanding may be key.

Future work can explore family members' understanding of residents' preferences over time, ways family members learn about their relatives' preferences, and the effects of within family dynamics on preference understanding. It may be that within families there are unique roles that individuals play in supporting a relative in the nursing home with some family members having a better understanding of some types of preferences such as self-dominion, while other family members can be called upon for knowledge on other preferences such as growth activities. There is also a need to understand temporal contextual factors associated with family members' reports of residents' preferences—are family members determining the importance of resident preferences based on the *past* experiences of the resident or on the resident's *current* interests and circumstances?

The study presented here is not without limitations. The generalization of findings is limited by the use of a small convenience sample of nursing home residents and their relatives that residents were willing to refer. It may be that referrals collected in this manner bias our findings to families that have strong family ties and positive relationships—factors that could not be explored here without a comparative sample or more extensive measure of family relationships—and that families not referred have a lower level of understanding of residents' preferences. Further exploration within a larger more diverse sample may provide additional insight into family understanding of nursing home residents' preferences. Second, reports of residents' personality traits are proxy reports and the personality traits in the

analyses can only be interpreted as family members' perceptions of their relatives' personality. Researchers have documented differences in self and proxy reports of personality (Carlson, Vazire, & Oltmanns, 2012; Oltmanns & Turkheimer, 2009); as a result, further work would benefit from the inclusion of self-reported personality to determine if it is in fact openness of the resident or the perception of openness by the family proxy that impacts understanding of preferences. Third, domain construction of preferences was informed by empirical concept-mapping work in home care (Carpenter et al., 2000); however, these domains may differ in a nursing home population, particularly in regard to our understanding of "enlisting others in care" preferences. The low inter-item reliability for this scale (.22) may be a reflection of the small number of items in this subscale or the need to reclassify these items in a different domain for a nursing home population. Additional examination with factor analysis may indicate alternative ways of empirically grouping preference items and shed further light on understanding of preferences by domain. Fourth, further development of scales that improve internal reliability estimates on constructs of depression and family involvement may improve our ability to see their impact on concordance.

Overall, these findings are strengthened by both their group-based and dyadic-based examination of family members' understanding of nursing home residents' preferences. Findings support the potential ability to call upon family members in reporting on some preferences of nursing home residents. However, clinical practice would benefit from further work that confirms these exploratory findings and garners perspectives on how families learn of residents' preferences and what reference point in time they are considering when reporting. In the end, this work is vital to advancing the mission of person-centered care. As individuals experience biological declines that may inhibit abilities to report on preferences, the role of family may prove critical in continuing to honor the person in care.

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Table 1

Demographic characteristics

Variable	Family Proxy <i>M(SD)</i>	Resident <i>M(SD)</i>
Age	61.33 (11.63)	83.32 (10.47)
Gender (Female = 1)	74% (63)	72% (61)
Race (AA = 1)	14% (12)	14% (12)
Marital Status		
Never married	9% (8)	17% (14)
Married	69% (59)	24% (20)
Widowed	6% (5)	50% (43)
Separated	5% (4)	1% (1)
Divorced	8% (7)	8% (7)
Education Status		
8th grade or less	0 % (0)	4% (3)
9th to 11th grade	1% (1)	14% (12)
High School	19% (16)	51% (43)
Technical School	1% (1)	4% (3)
Some College	18% (15)	8% (7)
Bachelor's Degree	28% (24)	7% (6)
Graduate Degree	31% (26)	8% (7)
Relation (Child = 1)	68% (58)	--

Note. *N* = 85 dyads of a resident and family proxy.

Table 2

Facility characteristics of recruited residents

Facility	Residents in Sample	Number of beds ^a	Ownership status
1	26	324	Non profit - Corporation
2	2	61	Non profit - Corporation
3	6	92	Non profit - Corporation
4	2	396	For profit - Partnership
5	3	180	For profit - Partnership
6	3	180	Non profit - Corporation
7	6	296	Non profit - Corporation
8	4	60	Non profit - Corporation
9	1	150	For profit - Corporation
10	1	170	For profit - Corporation
11	1	150	For profit - Corporation
12	5	180	For profit - Corporation
13	10	360	Government - County
14	4	73	Non profit - Corporation
15	1	120	Non profit - Corporation
16	2	180	Non profit - Corporation
17	3	120	Non profit - Corporation
18	3	96	Non profit - Corporation
19	4	273	Non profit - Corporation
20	1	120	Non profit - Corporation

Note. N = 85 dyads of a resident and family proxy.

^aData for number of beds and ownership derived from www.medicare.gov/nursinghomecompare

Table 3

The Association between Family members' and Nursing Home Residents' reports of Nursing Home Residents' Everyday Preferences by Domain

Preference [:"How important is it to you to..."] ^a	Resident Mean (SD)	Family Mean (SD)	t(p)	r(p)	IOC (p)	% Perfect Agree. ^b	% I/NI Agree. ^c
Self-Dominion Preferences							
Choose what to eat	3.66(0.59)	3.71(0.48)	-0.80(.43)	.20(.07) [†]	0.20(.04) [*]	64.3	95.2
Do what helps you feel better when you are upset	3.70(0.51)	3.78(0.48)	-0.90(.37)	-.13(.25)	-0.13(.88)	59.0	94.9
Choose what clothes to wear	3.20(0.86)	3.41(0.70)	-1.91(.06) [†]	.14(.20)	0.08(.10) [†]	45.9	92.9
Have privacy	3.55(0.68)	3.59(0.54)	-0.39(.70)	.07(.53)	0.06(.30)	55.4	91.6
Keep your room at a certain temperature	3.53(0.63)	3.56(0.59)	-0.25(.80)	-.04(.73)	-0.25(.64)	41.7	90.5
Choose how to care for your mouth	3.75(0.58)	3.50(0.70)	3.10(.003) ^{**}	.09(.41)	0.09(.21)	57.8	89.2
Choose your own bedtime	3.58(0.64)	3.53(0.59)	0.37(.71)	-.03(.79)	-0.24(.60)	49.4	89.2
Set up your bed for comfort	3.62(0.60)	3.56(0.60)	0.58(.57)	.05(.65)	0.06(.32)	49.3	88.7
Choose how often to bathe	3.57(0.56)	3.34(0.67)	3.02(.000) ^{***}	.24(.03) [*]	0.23(.02) [*]	52.4	87.8
Choose what time to get up	3.33(0.75)	3.58(0.52)	-2.73(.008) ^{**}	.25(.02) [*]	0.23(.02) [*]	56.0	86.9
Choose your roommate	3.34(0.85)	3.41(0.83)	-0.44(.66)	.30(.04) [*]	0.30(.02) [*]	47.9	85.4
Know your needs when going to the bathroom	3.46(0.80)	3.71(0.58)	-2.13(.04) [*]	-.11(.35)	-0.11(.82)	50.6	84.4
Choose how to care for your hair	3.57(0.78)	3.45(0.70)	1.80(.08) [†]	.27(.01) ^{**}	0.27(.006) ^{**}	60.2	84.3
Take care of your personal belongings or things	3.59(.70)	3.54(0.73)	0.42(.68)	-.07(.52)	-0.07(.74)	51.8	83.5
Set up your room the way you want	3.51(0.65)	3.38(0.76)	1.15(.25)	.10(.38)	0.10(.19)	45.2	82.1
Adjust the lighting in your room	3.45(0.59)	3.30(0.79)	1.47(.15)	.04(.70)	0.04(.35)	44.0	79.8
Choose how often to care for your nails	3.20(0.78)	3.21(0.84)	-0.11(.91)	.26(.02) [*]	0.26(.008) ^{**}	47.6	77.4
Follow a routine when you go to bed	3.30(0.86)	3.36(0.69)	-0.51(.61)	.03(.79)	0.19(.40)	44.4	76.5
Lock things up to keep them safe	3.39(0.89)	3.42(0.81)	-0.39(.70)	.15(.18)	0.15(.09) [†]	51.8	75.9
Choose what name to be called	3.14(0.89)	3.31(0.73)	-1.38(0.17)	.08(.47)	0.08(.24)	38.1	75.0
Follow a routine in the morning	3.21(0.86)	3.43(0.65)	-2.18(.03) [*]	.13(.23)	0.13(.12)	39.8	74.7
Choose between a tub bath, a shower a bed bath or a sponge bath	3.49(0.73)	3.27(0.82)	1.87(.07) [†]	.03(.78)	0.03(.39)	38.5	74.4
Choose what time of day to bathe	3.19(0.78)	3.25(0.70)	-0.67(.51)	.10(.37)	0.10(.18)	47.5	73.8

Preference [“How important is it to you to...”] ^a	Resident Mean (SD)	Family Mean (SD)	t(p)	r(p)	ICC (p)	% Perfect Agree. ^b	% I/NI Agree. ^c
Choose where to eat	3.17(0.92)	3.29(0.74)	-0.91(.37)	-.05(.67)	-0.05(.66)	32.1	69.5
Order take-out food	2.33(1.07)	2.40(1.05)	-0.49(.63)	.39(.000)***	0.39(.000)***	35.1	66.2
Choose when to eat	2.93(0.94)	3.17(0.77)	-1.85(.07) [†]	.07(.55)	0.07(.28)	33.3	63.1
Take a nap when you wish	2.94(1.02)	3.42(0.75)	-3.71(.000)***	.09(.43)	0.13(.22)	32.1	60.7
Enlisting Others in Care Preferences							
Choose who is involved in discussions about your care	3.75(0.46)	3.73(0.52)	0.49(.63)	.08(.49)	0.08(.24)	70.2	95.2
Choose your medical care professional	3.73(0.56)	3.29(0.75)	3.94(.000)***	-.10(.40)	-0.09(.79)	39.0	84.1
Talk to a mental health professional when you are sad or worried	2.66(1.12)	2.87(1.02)	-1.56(.12)	.34(.003)**	0.34(.001)***	32.1	61.5
Choose whether your daily caregiver is male or female	2.66(1.10)	2.72(0.93)	-0.67(.51)	.16(.14)	0.06(.07) [†]	31.3	51.8
Leisure & Diversiary Activity Preferences							
Drink alcohol on occasion	1.61(0.80)	1.65(0.99)	-0.37(.71)	.51(.000)***	0.50(.000)***	56.1	82.9
Watch or listen to TV	3.46(0.67)	3.56(0.72)	-0.88(.38)	.21(.06) [†]	0.21(.03)*	56.1	81.7
Take care of the place you live	3.63(0.58)	3.11(0.89)	4.87(.000)***	.14(.20)	0.13(.12)	45.8	72.3
Play games	2.98(1.02)	2.92(0.92)	0.52(.61)	.35(.002)**	0.35(.001)***	33.8	71.4
Go shopping	2.78(1.07)	2.60(1.04)	1.57(.12)	.36(.001)***	-0.14(.90)	81.5	66.7
Have snacks available between meals	2.78(1.08)	3.22(0.80)	-3.45(.001)**	.36(.001)***	0.35(.001)***	41.0	66.3
Eat at restaurants	2.76(1.11)	2.89(0.97)	-0.75(.45)	.34(.002)**	0.34(.001)***	38.0	63.3
Watch movies with other people	2.68(1.03)	2.93(0.93)	-1.69(.10) [†]	.11(.33)	0.11(.16)	30.5	62.2
Do outdoor tasks	2.64(1.06)	2.15(1.04)	3.70(.000)***	.20(.10)	0.20(.05) [†]	33.3	56.9
Use tobacco products ^d	4.00	3.00	--	--	--	--	--
Social Contact Preferences							
Spend time with family	3.89(0.31)	3.91(0.29)	0.30(.77)	.19(.09) [†]	0.19(.05)*	86.1	100.0
Have staff show they care about you	3.73(0.52)	3.84(0.37)	-1.53(.13)	-.03(.76)	-0.03(.61)	66.7	98.8
Have staff show you respect	3.79(0.49)	3.91(0.29)	-1.92(.06) [†]	.03(.82)	0.02(.44)	77.6	96.5
Spend time with friends	3.46(0.52)	3.51(0.67)	-0.50(.62)	-.09(.44)	-0.08(.77)	36.6	91.5
Spend time one-on-one with someone	3.44(0.82)	3.41(0.66)	0.60(.55)	.19(.08) [†]	0.19(.04)*	49.4	83.1

Preference [“How important is it to you to...?”] ^a	Resident Mean (SD)	Family Mean (SD)	t(p)	r(p)	ICC (p)	% Perfect Agree. ^b	% I/NI Agree. ^c
Be able to use the phone in private	3.33(0.94)	3.44(0.72)	-0.84(.40)	.20(.07) †	0.19(.04) *	51.2	80.5
Do things with groups of people	3.07(0.94)	3.35(0.80)	-1.91(.06) †	.25(.03) *	0.25(.01) *	43.8	73.8
Give gifts	3.38(0.83)	3.11(0.81)	2.02(.05) *	.11(.35)	0.11(.17)	48.8	71.3
Meet new people	3.06(0.84)	3.21(0.85)	-0.87(.39)	.23(.04) *	0.23(.02) *	35.8	69.1
Be around children	3.27(0.94)	2.65(0.92)	5.41(.000) ***	.28(.01) **	0.28(.006) **	33.3	67.9
Spend time by yourself	3.25(0.82)	3.08(0.83)	1.55(.13)	.14(.22)	0.08(.11)	38.0	65.8
Be a member of a club	2.62(1.00)	2.64(1.01)	0.38(.70)	.29(.008) **	0.28(.006) **	33.8	63.6
Volunteer your time	3.26(0.87)	2.42(1.07)	6.08(.000) ***	.15(.19)	0.15(.10)	26.3	51.3
Growth Activity Preferences							
Go outside to get fresh air when the weather is good	3.48(0.78)	3.44(0.77)	0.75(.46)	.32(.003) **	0.32(.002) **	57.8	85.5
Do your favorite hobbies	3.63(0.56)	3.39(0.92)	2.08(.04) *	.03(.78)	0.03(.40)	47.3	85.1
Attend entertainment events	3.39(0.80)	3.35(0.72)	0.58(.56)	.24(.03) *	0.24(.02) *	45.2	83.3
Do your favorite activities	3.56(0.64)	3.44(0.83)	0.94(.35)	-.04(.76)	-0.03(.62)	49.4	82.3
Learn about topics that interest you	3.50(0.70)	3.34(0.75)	1.67(.10)	.21(.06) †	0.21(.03) *	48.8	81.0
Have reading materials available	3.56(0.71)	3.39(0.84)	1.99(.05) *	.42(.000) ***	0.41(.000) ***	54.5	80.8
Keep up with the news	3.55(0.70)	3.30(0.75)	2.50(.01) *	.18(.12)	0.18(.06) †	50.0	80.0
Reminisce about the past	3.33(0.84)	3.28(0.76)	0.59(.56)	.29(.01) **	0.28(.005) **	45.7	77.8
Use the computer	2.21(1.25)	1.96(1.13)	2.41(.02) *	.66(.000) ***	0.65(.000) ***	61.0	76.6
Do things away from here	3.26(0.82)	3.14(0.91)	0.94(.35)	.24(.03) *	0.24(.02) *	45.0	76.3
Listen to music you like	3.51(0.69)	3.07(0.89)	3.92(.000) ***	.13(.24)	0.13(.13)	37.0	75.3
Participate in religious services or practices	3.28(0.91)	3.08(1.01)	1.77(.08) †	.47(.000) ***	0.47(.000) ***	50.6	72.3
Sports	2.95(1.03)	2.30(1.06)	6.65(.000) ***	.61(.000) ***	0.61(.000) ***	38.3	71.6
Exercise	3.25(0.89)	2.80(0.96)	3.94(.000) ***	.32(.003) **	0.32(.002) **	40.5	66.7
Take care of plants	2.70(1.17)	2.06(1.02)	4.53(.000) ***	.44(.000) ***	0.43(.000) ***	36.4	66.2
Participate in your cultural traditions	2.85(0.97)	2.90(1.01)	-0.55(.59)	.23(.05) *	0.23(.02) *	39.7	64.1

Preference [“How important is it to you to...?”] ^a	Resident Mean (SD)	Family Mean (SD)	t(p)	r(p)	ICC (p)	% Perfect Agree. ^b	% I/NI Agree. ^c
Be around animals such as pets	2.76(1.15)	2.34(1.07)	2.95(.004)**	.38(.000)***	0.38(.000)***	40.7	60.5
Be involved in cooking	2.70(1.17)	2.06(1.01)	4.83(.000)***	.41(.000)***	0.41(.000)***	34.6	60.5

Note. N = 85 dyads of a resident and family proxy.

[†] $p < .10$.

* $p < .05$

** $p < .01$

*** $p < .001$.

^a Importance ratings were recoded to a 4-point scale from 1 (*not important at all*) to 4 (*very important*).

^b Percent perfect agreement calculated based on responses by resident and family that were perfectly concordant (e.g., very important = very important).

^c Percent Important versus Not Important concordance calculated based on responses by residents and family members that indicate the same side of the importance scale (e.g., very important and somewhat important = important).

^d Analyses were not performed on this item given the low endorsement of smoking within the sample ($n = 2$)

Table 4
 Factors associated with Discrepancy in Reports of Importance of Growth Activities for Nursing Home Residents between Residents and their Family Members

	MODEL 1		MODEL 2		MODEL 3	
	B	SE	B	SE	B	SE
Fixed effect						
Intercept (mean)	55.12***	0.72	54.45***	0.76	40.13***	3.42
Slope (discrepancy) ^a	-4.62***	1.05	-4.92***	1.16	-9.42 [†]	5.24
Predictors of mean						
<i>Family Characteristics</i>						
Family Race	--	--	5.69**	1.99	4.14*	1.93
Family Involvement	--	--	--	--	0.47 [†]	0.25
<i>Resident Characteristics</i>						
Resident hearing	--	--	--	--	1.88	1.54
Resident Personality: Conscientiousness	--	--	--	--	--	--
Resident Personality: Openness	--	--	--	--	0.17*	0.11
Resident Positive Affect	--	--	--	--	0.32***	0.09
Predictors of discrepancy						
<i>Family Characteristics</i>						
Family Race	--	--	2.70	3.04	0.56	2.95
Family Involvement	--	--	--	--	0.75 [†]	0.39
<i>Resident Characteristics</i>						
Resident hearing	--	--	--	--	-7.08**	2.35
Resident Personality: Conscientiousness	--	--	--	--	--	--
Resident Personality: Openness	--	--	--	--	0.52***	0.16
Resident Positive Affect	--	--	--	--	-0.25 [†]	0.14
Random effect						
Variance (mean)	20.97**	7.70	16.80*	7.39	13.46*	6.20
Residual	46.45***	7.17	47.47***	7.47	38.16***	6.27

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	MODEL 1		MODEL 2		MODEL 3	
	B	SE	B	SE	B	SE
-2 Log Likelihood	1184.6		1142.0		1062.4	
AIC	1188.6		1146.1		1066.4	

Note. N = 85 dyads of a resident and family/friend proxy.

† $p < .10$

* $p < .05$.

** $p < .01$.

*** $p < .001$.