# Perceived Unmet Need and Need-Related Distress of People Living With Dementia

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## Abstract

The unmet needs of people living with dementia have been shown to be multidimensional and impact well-being. However, there are a lack of studies examining variability of unmet needs and need-related distress from the person living with dementia's perspective. The current study (*n* = 12) examined the self-reported unmet needs and need-related distress of people with mild to moderate dementia. Seventy-five percent of participants (*n* = 9) identified at least one unmet need and 50% (*n* = 6) reported 10 or more unmet needs. "Finding and Arranging Services" and "Health Information" subscales had the highest reported average unmet needs. The most frequently reported unmet need-item was "*getting information about your memory problems?*" Participants reported variability in distress for both unmet and met needs. Continued research can provide beneficial information on the relationship between unmet needs, need-related distress, and outcomes of well-being for future interventions.

## Keywords

people living with dementia, unmet needs, need-related distress, self-report, illness experience

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People living with dementia are at increased risk of experiencing unmet needs due to communication, physical functioning, and cognitive difficulties associated with dementia (Cohen-Mansfield et al., 2015). Unmet needs constitute needs in a particular area of an individual's life in which insufficient or inadequate support is provided or unavailable (van der Roest et al., 2007). Unmet needs are multidimensional and show variability across disease severity, living location, and demographic characteristics (Black et al., 2012; Bossen et al., 2009; Zhang et al., 2020). Identifying and addressing unmet needs are essential as individuals with more dementia-related unmet needs are at greater risk of lower quality of life (Black et al., 2012; Hancock et al., 2006), nursing home placement (Gaugler et al., 2005), and behavioral expressions (Cohen-Mansfield et al., 2015; Hancock et al., 2006).

Research has documented the negative impacts of unmet needs; however, there is a lack of non-pharmacological interventions aimed at alleviating unmet needs for people with dementia. This could be due to limited research describing the self-reported unmet needs of people with dementia (Kerpershoek et al., 2017; Shiells et al., 2020) as well as a lack of research examining disease-specific stressors that may arise because of unmet needs. These stressors, in relation to unmet needs, can be conceptualized as need-related distress or the experience of physical, psychological, social, and/or emotional consequences that result from the cognitive, functional, and behavioral aspects of dementia (Pearlin et al., 1990; Judge et al., 2010). To the authors' knowledge, no studies to date have examined need-related distress in people with dementia, the potential relationship between unmet needs and need-related distress, or how these constructs may predict well-being outcomes.

Recent calls to examine the subjective illness experience of living with dementia through self-report methodologies (Gitlin et al., 2018; Zimmerman & Stone, 2020) have driven advancements in other constructs, such as illness representation (Clare et al., 2016), values and preferences (Whitlatch et al., 2006), and behavioral expressions (Minyo & Judge, 2021). Including people with dementia within data collection values the subjective world of the person and the continuity of personhood (Kitwood, 1997).

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Despite evidence that people with dementia can provide reliable and valid self-reported data (Clark et al., 2008; Trindade et al., 2019; Whitlatch et al., 2005), literature studies on self-reported unmet needs and need-related distress are underdeveloped.

Research thus far has focused on questions pertaining to correlates of unmet need (Black et al., 2012; Black et al., 2013) or the discrepancy between a person with dementia's self-report and a caregiver's proxy-report of needs (Kerpershoek et al., 2017; Orrell et al., 2008; van der Roest et al., 2009). Unmet needs have been measured differently based on the research question, which typically requires multiple data sources. Assessment tools such as the Camberwell Assessment of Needs for the Elderly (Reynolds et al., 2000) and The Johns Hopkins Dementia Care Needs Assessment (Black et al., 2008) have largely been used to examine the needs of people with dementia. These tools are administered by a trained professional who makes the final decision of "met" and/or "unmet" need, taking into consideration reports from the person with dementia and their caregiver.

Investigations utilizing these assessment tools highlight several important findings, including variability in needs depending on living location. Bossen and colleagues (2009) reported several unmet needs identified by community-dwelling individuals with early-stage Alzheimer's disease, including the need for early diagnosis and to be heard, the need for more information and knowledge, and the need for emotional and cognitive support. Comparatively, people with dementia in long-term care facilities often report management of behavioral problems, individualized daily activities and care (Cadieux et al., 2013), and psychological distress (Hancock et al., 2006; Orrell et al., 2008). Unmet needs have been shown to vary by level of cognitive impairment, functional abilities (Black et al., 2013), and neuropsychiatric symptoms (Hancock et al., 2006), such that increased levels of cognitive impairment, decreased functional abilities, and more neuropsychiatric symptoms are related to increased unmet needs.

Other investigations detail discrepancies found between self- and proxy-reported perspectives of unmet need (Kerpershoek et al., 2017; Orrell et al., 2008). Orrell and colleagues (2008) found that people with dementia rated significantly more unmet needs than residential staff and family caregivers across food, eyesight/hearing, physical health, and psychological distress domains. Poor agreement between family caregivers and people with dementia included memory, eyesight/hearing, continence, physical health, money, company, and daytime activities. Memory, daytime activities, continence, and psychological distress had poor agreement with residential staff and people with dementia. The authors' concluded that the person with dementia's view on needs should be sought, as reliance on assessments by staff and family may lead to under recognition of unmet needs (Orrell et al., 2008). Misalignments

between self- and proxy-reported perspectives have been consistently found within other unmet need studies (Kerpershoek et al., 2017; Schölzel-Dorenbos et al., 2010; van der Roest et al., 2009) as well as other constructs within illness experience research (Hongisto et al., 2018; Moon et al., 2016; Reamy et al., 2013).

Need-related distress is a related area of research that has not received adequate attention. Disease-related stressors, or the physical, psychological, social, and/or emotional consequences that result from the cognitive, functional, and behavioral aspects of dementia, have been found to impact well-being (Pearlin et al., 1990; Judge et al., 2010). For example, the disease-related stressors of increased duration of caregiving, behavioral symptoms, and functional dependency of the person with dementia have all been found to be related to higher subjective caregiver burden (Etters et al., 2008). Hughes and colleagues (2014) described how unmet need and the person with dementia's behavioral symptoms were independent predictors of caregiver burden. For people with dementia, self-reported data on disease-related stressors such as embarrassment about memory loss, physical health strain, and role captivity were found to uniquely predict psychosocial well-being outcomes (Dawson et al., 2012).

These studies provided initial empirical evidence that stressors specific to a dementia diagnosis can impact well-being for both the person with dementia and their caregiver. While studies have found the number of unmet needs to be related to well-being outcomes (Hancock et al., 2006; Martyr et al., 2018), to the authors' knowledge, no published studies to date have examined the relationship between self-reported unmet needs of people with dementia and subsequent need-related distress. For example, need-related distress could be directly or indirectly impacting well-being (e.g., depression or quality of life). It is unknown whether the number of unmet needs or the amount of need-related distress is more impactful on well-being and thus which construct is more effective for targeted interventions.

The current study's aims included: (a) examining the frequency of unmet needs reported by people with dementia and whether these reports were consistent with prior self-reported data in the literature and (b) exploring the need-related distress reported by people with dementia. To address these aims, an unmet need assessment tool previously utilized within a dementia caregiving evidence-based program (Bass et al., 2019) was selected as it offered a comprehensive, self-report assessment of need for a dementia population.

## Methods

### Participants

Self-reported illness experience data was collected through convenience sampling of people with mild to moderate dementia residing in an assisted living memory care
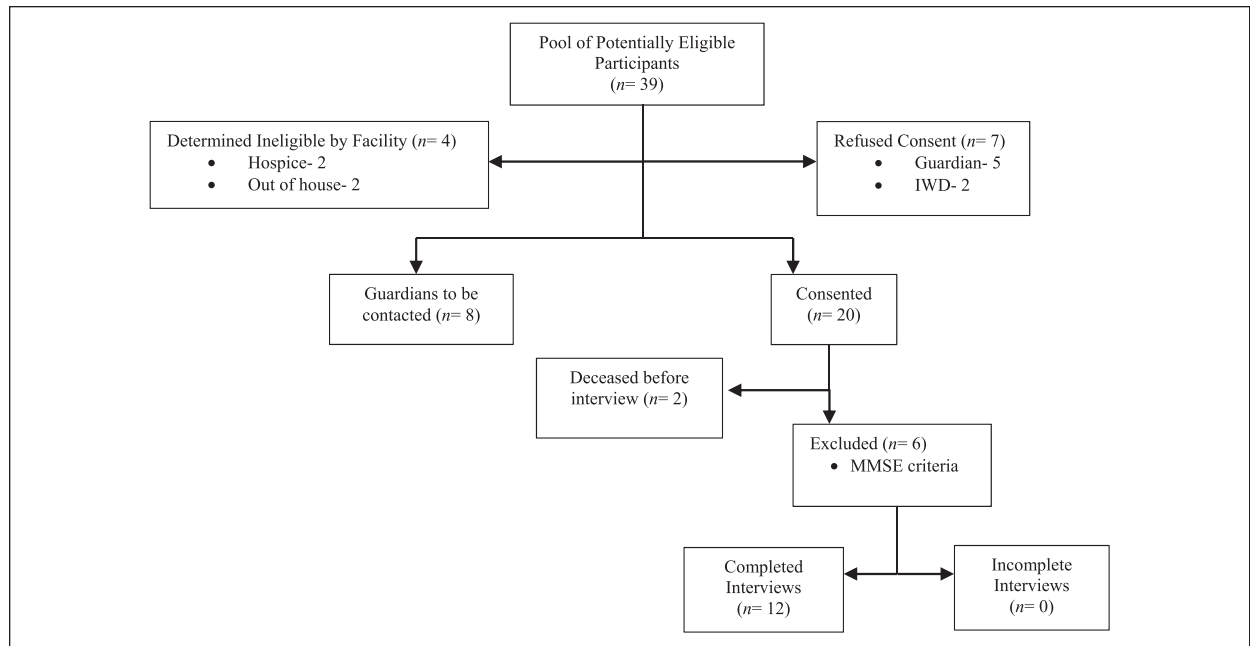
**Figure 1.** Recruitment Consort Diagram.

facility located in Northeast Ohio. This site was selected as it was part of an on-going research partnership between the authors and the assisted living facility. The study was designed to examine illness experience constructs before expanding to other residential sites and community-dwelling participants. Data collection began prior to the impact of the COVID-19 Pandemic. However, participant interviews were suspended mid-data collection per safety policies of the assisted living memory facility, limiting subsequent data collection. As a result, descriptive data analysis focused on the self-reported frequency of unmet need and need-related distress of the 12 completed interviews. Inclusion criteria included scoring an 11 or higher on the Mini-Mental State Examination (MMSE). Written consent was obtained from each participant or their legal guardian along with verbal assent prior to participating. Thirty-nine potential participants were identified (Figure 1). Seven declined participation (5 legal guardians, 2 participants), 2 participants died between obtaining consent forms and scheduling structured interviews, and 6 participants were excluded due to study inclusion criteria.

## Measures

Demographic information was assessed through a self-reported questionnaire read aloud to participants and included participant's age, birth date, gender, race, highest level of education, and current marital status. The MMSE was used to assess overall cognition, with lower scores indicative of greater cognitive impairment (Folstein et al., 1975).

Unmet need and need-related distress were examined through an adapted two-part measure, previously published and tested on populations of people with dementia and their caregivers (Bass et al., 2013; Bass et al., 2014). The two-part unmet need assessment tool included 43 dichotomous "yes/no" items examining the frequency of unmet needs in the first part of the measure, and the subsequent distress experienced from needs in the second part. Across the 43 items, participants were first asked, "Do you feel you need more information about . . .?" followed by the 43 need- items. Participants were then asked, "Does this cause you any distress?"

Higher summed scores indicated more perceived unmet need and more perceived need-related distress across the following subscales: (1) Family Concerns, (2) Health Information, (3) Daily Living Tasks, (4) Legal and Financial Issues, (5) Accessing Services, (6) Emotional Support and Counseling, and (7) Living Arrangements and Activity. Based on the literature, several questions were added to the measure such as socialization, meaningful activity, and psychological distress (Black et al., 2013; Cadieux et al., 2013; Hancock et al., 2006; Kerpershoek et al., 2017). Additionally, various need-items related to utilization of Veterans Affairs services, which were critical questions for the original studies of the developed measure, were deleted or modified within the current study.

Within the current sample, the two-part frequency and need-related distress assessment demonstrated good reliability with internal consistencies of 0.96 and 0.98, respectively. Additionally, all seven subscales demonstrated good reliability with the frequency of unmet needs ranging from 0.82 to 0.96. All but one subscale ($\propto$ = 0.52, Legal and Financial Issues) demonstrated good reliability ranging from 0.71 to 0.94 for need-related distress (Table 1).

## Procedure

The Cleveland State University Institutional Review Board approved this study. Once written consent from a legal guardian and written and/or verbal asset from the participant was obtained, participants completed the in-person structured interview. The following procedures were used based on recommendations for collecting self-reported data from people with dementia (Krestar et al., 2012). All interview questions and response choices were read aloud to participants by the interviewer. Interview techniques were aimed at engaging participants, including large print response cards with scale response choices in large, bold font. Response cards were provided to all participants during the interview to assist with the selection of answers. Participants were offered and reminded of the ability to take breaks and to finish the interview questions at a later date if the participant appeared and/or expressed fatigue. All participants in the current sample were able to finish the interview in one sitting and no participants became upset or frustrated during interviews.

## Results

Participants' ages ranged from 73 to 101 ($M$ = 86.83, $SD$ = 8.11), with 58.3% ($n$ = 7) being male. All participants were white, not of Hispanic origin (100%), with a large portion of participants stating they were widowed (41.7%), and the remaining identified as married (25.0%), single (16.7%), or other (16.7%). All participants completed high school, with 41.7% having graduated college (Table 1). MMSE scores ranged between 12 and 22 ($M$= 16.92, $SD$= 4.12). As seen in Table 1, participants had an average of 9.6 unmet needs. Seventy-five percent of participants ($n$ =9) identified at least one unmet need. Of the nine participants that reported at least one unmet need, six of these participants identified 10 or more unmet needs.

The "Finding or Arranging Services" subscale had the highest average reported unmet needs (33.3%), followed by "Health Information" (26.8%) and "Legal and Financial Issues" (20.8%). "Family Concerns" (10.7%), "Daily Living Task" (16.7%), and "Living Arrangements

**Table 1.** Sample Characteristics, Means, and Standard Deviations of Study Outcomes.

| Characteristics (n = 12) Value | ∝ | |
|---|---|---|
| *Demographics* | | |
| Age, mean ± SD | — | 86.8 ± 8.1 |
| Sex,% | | |
|   Male | — | 58.3% |
|   Female | — | 41.7% |
| Race, % | | |
|   White | — | 100.0% |
|   Non-white | — | 0.0% |
| Education, % | | |
|   Completed high school | — | 41.7% |
|   Attended college—did not graduate | — | 16.7% |
|   College graduate | — | 16.7% |
|   Master's degree | — | 16.7% |
|   Doctoral degree/ MD/ JD | — | 8.3% |
| Marital status, % | | |
|   Single | — | 16.7% |
|   Married | — | 25.0% |
|   Widowed | — | 41.7% |
|   Other | — | 16.7% |
|   MMSE, mean ± SD | — | 16.9 ± 4.2 |
| *Needs* | | |
| UN-frequency, mean ± SD | 0.96 | 9.6 ± 10.3 |
|   FC, mean ± SD | 0.86 | 1.4 ± 2.2 |
|   HI, mean ± SD | 0.87 | 3.8 ± 3.7 |
|   DLT, mean ± SD | 0.82 | 0.5 ± 1.2 |
|   LF, mean ± SD | 0.90 | 0.8 ± 1.4 |
|   ES, mean ± SD | 0.87 | 1.3 ± 1.9 |
|   FAS, mean ± SD | 0.85 | 1.0 ± 1.3 |
|   LAA, mean ± SD | 0.96 | 0.8 ± 1.5 |
| UN-distress, mean ± SD | 0.98 | 7.0 ± 10.2 |
|   FM, mean ± SD | 0.87 | 1.3 ± 2.2 |
|   HI, mean ± SD | 0.94 | 1.9 ± 3.5 |
|   DLT, mean ± SD | 0.71 | 0.3 ± 0.8 |
|   LF, mean ± SD | 0.52 | 0.3 ± 0.6 |
|   ES, mean ± SD | 0.89 | 1.3 ± 2.1 |
|   FAS, mean ± SD | 0.82 | 0.9 ± 1.2 |
|   LAA, mean ± SD | 0.92 | 1.1 ± 1.7 |

*Note.* SD = standard deviation; ∝ = Cronbach's alpha; UN = Unmet Need; FC = Family Concerns subscale; HI = Health Information subscale; DLT = Daily Living Tasks subscale; LF = Legal & Financial subscale; ES = Emotional Support subscale; FAS = Finding and Arranging Services subscale; LAA = Living Arrangements and Activities subscale.

**Table 2.** Number of Items, Average Percentage of Unmet Need, and Percentage of at Least One Unmet Need Per Subscale.

| Domain: | Number of Items | % Unmet Need | % At least 1 Unmet Need |
|---|---|---|---|
| Family Concerns | 8 | 10.7% | 41.7% |
| Health Information | 14 | 26.8% | 75.0% |
| Daily Living Tasks | 3 | 16.7% | 16.6% |
| Legal & Financial Issues | 4 | 20.8% | 33.3% |
| Emotional Support & Counseling | 6 | 21.6% | 41.6% |
| Finding or Arranging Services | 3 | 33.3% | 50.0% |
| Living Arrangements & Activities | 5 | 16.6% | 41.6% |

*Note.* n = 12.

**Table 3.** Item-Level Frequency of Unmet Needs and Need-Related Distress.

| Item *n* (%) | Unmet *n* (%) | Distressing |
| --- | --- | --- |
| **Family Concerns** | | |
| a. Getting family members or friends to help you because of your memory problems? | 1 (8.3%) | 3 (25.0%) |
| b. How to discuss your memory problems with other family members? | 2 (16.7%) | 3 (25.0%) |
| c. Who could provide your care? | 1 (8.3%) | 1 (8.3%) |
| d. Discussing who you prefer to provide your care? | 2 (16.7%) | 1 (8.3%) |
| e. Discussing the future course of your illness with family members? | 3 (25.0%) | 2 (16.7%) |
| f. How to get family members to cooperate in helping you? | 2 (16.7%) | 1 (8.3%) |
| g. Dealing with disagreements among family members about how to help you? | 2 (16.7%) | 2 (16.7%) |
| h. Getting family and friends to accept that you have a memory problem? | 4 (33.3%) | 2 (16.7%) |
| **Health Information** | | |
| i. Getting the treatment you need? | 2 (16.7%) | 1 (8.3%) |
| j. Trying things that may prevent your memory problems from getting worse? | 5 (41.7%) | 1 (8.3%) |
| k. Things to do to help you stay healthy? | 2 (16.7%) | 0 (0.0%) |
| l. Tests for diagnosing your memory problems? | 5 (41.7%) | 1 (8.3%) |
| m. Getting information about your memory problems? | 7 (58.3%) | 2 (16.7%) |
| n. Understanding the causes of your memory problems? | 2 (16.7%) | 2 (16.7%) |
| o. How to deal with other health conditions or problems you have? | 2 (16.7%) | 2 (16.7%) |
| p. Making plans for how to deal with future changes in your memory problems? | 4 (33.3%) | 1 (8.3%) |
| q. Taking your medications in the correct amounts and at the correct times? | 2 (16.7%) | 2 (16.7%) |
| r. The way medications are supposed to help? | 3 (25.0%) | 1 (8.3%) |
| s. the possible side effects of medications? | 2 (16.7%) | 3 (25.0%) |
| t. Knowing the future course of your memory problems? | 5 (41.7%) | 1 (8.3%) |
| u. How to keep written notes to use when talking with your doctors or other service providers? | 3 (25.0%) | 2 (16.7%) |
| v. Scheduling follow-up visits with your doctors? | 1 (8.3%) | 4 (33.3%) |
| **Daily Living Tasks** | | |
| w. How to best manage daily tasks such as eating and activities? | 2 (16.7%) | 1 (8.3%) |
| x. How to best manage your personal care such as bathing and dressing? | 2 (16.7%) | 1 (8.3%) |
| y. How to make the place you live safe? | 2 (16.7%) | 2 (16.7%) |
| **Legal and Financial Issues** | | |
| z. Letting others know what you want if you were unable to speak for yourself? | 2 (16.7%) | 0 (0.0%) |
| aa. Having a living will, advanced directives, or durable power of attorney for health care? | 3 (25.0%) | 0 (0.0%) |
| bb. Available help for legal issues? | 3 (25.0%) | 1 (8.3%) |
| cc. Paying for services not covered by insurance? | 2 (16.7%) | 2 (16.7%) |
| **Emotional Support or Counseling** | | |
| dd. Finding someone to talk to who understands your situation? | 1 (8.3%) | 2 (16.7%) |
| ee. Getting emotional support or counseling? | 4 (33.3%) | 3 (25.0%) |
| ff. How to manage your feelings when you feel confused or upset? | 3 (25.0%) | 4 (33.3%) |
| gg. What to do if you feel uncomfortable accepting help from others? | 3 (25.0%) | 2 (16.7%) |
| hh. What to do if you feel isolated from other people? | 3 (25.0%) | 3 (25.0%) |
| ii. How to stay happy with your social life? | 2 (16.7%) | 2 (16.7%) |

*(continued)*

Table 3. (continued)

| | | |
|---|---|---|
| **Finding or Arranging for Services** | | |
| jj. Knowing which service providers to ask for different types of help? | 4 (33.3%) | 4 (33.3%) |
| kk. Getting different service providers to work together? | 5 (41.7%) | 4 (33.3%) |
| ll. Finding services you need? | 2 (16.7%) | 2 (16.7%) |
| **Living Arrangements and Activities** | | |
| mm. Making yourself comfortable with your current living arrangement? | 1 (8.3%) | 2 (16.7%) |
| nn. Activities, games, and hobbies you can participate in? | 2 (16.7%) | 2 (16.7%) |
| oo. How to keep involved in everyday activities? | 1 (8.3%) | 2 (16.7%) |
| pp. How to keep doing the things that you always liked and enjoyed? | 4 (33.3%) | 4 (33.3%) |
| qq. How to stay as independent as possible? | 2 (16.7%) | 3 (25.0%) |

*Note.* $n$ = 12. Stem question for frequency question, "Do you feel you have enough information about . . .". Stem question for subsequent distress question, "Does this cause you any distress?"

and Activities" (16.6%) had the lowest average reported unmet needs (Table 2). It is interesting to note, when examining subscales with at least one unmet need reported, 75% ($n$ = 9) of participants reported at least one unmet need for "Health Information," 50.0% ($n$ = 6) reported at least one unmet need for "Finding and Arranging Services," and 41.7% ($n$ = 5) reported at least one unmet need for "Family Concerns". Only three participants (25%) reported no unmet needs.

Table 3 displays frequencies of unmet need and need-related distress at the item-level, which demonstrate variability of unmet need types and levels of need-related distress. Four of the top five reported unmet need items fell within the "Health Information" subscale, including "*getting information about your memory problems?*" ($n$ = 7), "*trying things that may prevent your memory problems from getting worse?*" ($n$ = 5), *"tests for diagnosing your memory problems?"* ($n$ = 5), and "*knowing the future course of your memory problems?*" ($n$ = 5). Other unmet need items frequently reported by participants fell within the "Finding or Arranging Services" subscale. Five participants reported having an unmet need for "*getting different service providers to work together?*"

In contrast, several need-items across subscales were reported less frequently. Both the "Daily Living Tasks" and "Living Arrangements and Activities" subscales had almost all or all need-items as being unmet for only one or two participants. "*How to best manage your daily tasks such as eating and activities?*", "*how to best manage your personal care such as bathing and dressing?*", and "*how to make the place you live safe?*" were reported as unmet by two participants. Similarly, "*making yourself comfortable with your current living arrangement?*" ($n$ = 1), "*activities, games, and hobbies you can participate in?*" ($n$ = 2), "*how to keep involved in everyday activities?*" ($n$ = 1), and "*how to stay as independent as possible?*" ($n$ = 2) had lower unmet need frequencies.

The distress portion of the unmet need assessment tool provides novel information on how needs, both met

and unmet, impacted participants' distress levels. Five need-items were reported as the most distressing to participants, with all of these need-items distressing four participants. These need-items included, "*scheduling follow-up visits with your doctors?*", "*how to manage your feelings when you feel confused or upset?*", "*knowing which service providers to ask for different types of help?*", "*getting different service providers to work together?*", and "*how to keep doing the things that you always liked and enjoyed?*" The need-items "*things to do to stay healthy?*", "*letting others know what you want if you were unable to speak for yourself?*", and "*having a living will, advanced directives, or durable power of attorney for health care?*" were not reported as distressing to any participants.

Examining the combination of unmet need and need-related distress responses, three patterns emerged. The first included need-items that were more likely to be reported as unmet but reported less need-related distress. These need-items mainly fell within the "Health Information" subscale. For instance, "*getting information about your memory problems?*" was the most frequently reported unmet need among participants ($n$ = 7). However, this need-item was only reported as distressing for two participants. Other need-items that followed this pattern included, "*tests for diagnosing your memory problems,*" "*trying things that may prevent your memory problems from getting worse,*" and "*knowing the future course of your memory problems*". These findings provide preliminary evidence suggesting a person with dementia can report having an unmet need that does not necessarily result in need-related distress.

The second pattern highlights when participants reported need-related distress for need-items reported as met needs. "*Scheduling follow-up visits with doctors?*" was reported as an unmet need for one participant (8.3%). However, this need-item was reported as distressing for four participants. "*Getting family members or friends to help you because of your memory problems?*" had only one participant report it as an unmet need, but three

participants identified this need-item as distressing. This pattern displays initial evidence that met needs can be distressing for people with dementia. The third pattern, which included a majority of need-items, reported alignment between unmet needs and need-related distress. "*Knowing which service providers to ask for different types of help?*" was reported as an unmet need by four participants and was also reported as distressing to four participants. "*Getting different service providers to work together*" was an unmet need reported by five participants and distressing for four participants. "*How to keep doing the things you always liked and enjoyed?*" was reported as an unmet need-item for four participants and distressing for four participants.

Although very preliminary and interpreted with caution, correlations were used to examine whether unmet needs and need-related distress were related, both for total summed scores as well as the seven unmet need domains. A positive relationship between unmet needs and need-related distress ($r = .67$, $p = .02$) suggested self-reporting more unmet needs was related to more self-reported need-related distress in the current sample. Across unmet need domains, "Health Information" ($r = .61$, $p = .04$), "Emotional Support" ($r = .64$, $p = .03$), "Finding and Arranging Services" ($r = .78$, $p = .01$), and "Living Arrangements and Activities" ($r = .93$, $p < .001$) had significant and positive relationships between unmet need frequency and subsequent need-related distress. The unmet need domains of "Family Concerns" ($r = .01$, $p = .97$), "Daily Living Tasks" ($r = .40, p = .20$), and "Legal & Financial Issues" ($r = .16$, $p = .63$), while all in the positive direction, were not significant. Given the small sample size of the study, these findings provide an interesting glimpse into how these constructs may be related and provide a rationale for future research.

## Discussion

This study examined the illness experience of unmet needs and need-related distress in people with mild to moderate dementia residing in a long-term memory care facility. Though the study had a small sample size ($n = 12$), there was variability in unmet needs and need-related distress across participants, which highlights several theoretically important and innovative findings. Seventy-five percent of participants ($n = 9$) identified at least one unmet need, with 50.0% ($n = 6$) reporting 10 or more unmet needs. "Finding and Arranging Services" and "Health Information" subscales had the highest reported average unmet needs across participants. All of the top five reported unmet need-items fell within these two subscales. The most frequently reported unmet need-item was "*getting information about your memory problems?*" In contrast, both the "Daily Living Tasks" and "Living Arrangements and Activities" subscales had almost all or all need-items reported as being met for participants.

The type and amount of unmet needs reported in the current study align in many ways with unmet needs identified in the literature. Getting adequate information and education on diagnosis and care support, general health, and care planning (Black et al., 2013; Bossen et al., 2009; van der Roest et al., 2007), which are topics included within the "Health Information" and "Finding and Arranging Services" subscale of the current study, along with psychological distress (Hancock et al., 2006; Orrell et al., 2008), which was included within the "Emotional Support and Counseling" subscale, have all been identified as unmet needs in the literature. Findings from dementia populations specifically living in long-term care settings report behavioral management and lack of daytime and/or meaningful activities as common unmet needs (Cadieux et al., 2013; Shiells et al., 2020). However, need-items related to meaningful activities were low for the current sample and the unmet need assessment tool that was used did not ask the person with dementia questions concerning their own behavioral expressions or symptom management. Only recently has the literature provided initial evidence that people with dementia can self-report behaviors and behavioral-related distress (Minyo & Judge, 2021).

Providing novel preliminary data on need-related distress, participants reported distress to both unmet and met needs. Needs that were frequently reported, at the item level, as distressing to participants, included "*scheduling follow-up visits with your doctors?*", "*how to manage your feeling when you feel confused or upset?*", "*knowing which service providers to ask for different types of help?*", "*getting different service providers to work together?*", and "*how to keep doing the things that you always liked and enjoyed?*" Need-items less frequently reported as distressing were "*things to do to stay healthy?*", "*letting others know what you want if you were unable to speak for yourself?*", and "*having a living will, advanced directives, or durable power of attorney for health care?*" Trends of a positive relationship between unmet needs and need-related distress also emerged suggesting participants who identified more unmet needs also identified feeling more need-related distress.

Interestingly, experiencing an unmet need did not always equate to reports of need-related distress. "*Trying things that may prevent your memory problems from getting worse?*", "*knowing the future course of your memory problems?*", and "*getting information about your memory problems?*" are all examples of need-items that were frequently reported as unmet needs but not frequently reported as instilling need-related distress within the sample. This is also supported by the lack of relationships found for some unmet need domains including "Family Concerns," "Daily Living Tasks," and "Legal & Financial Issues," which did not show a meaningful relationship with need-related distress. Conversely, need-items reported less frequently as an unmet need

were still reported as inciting distress for some participants. Need-items following this pattern included, "*scheduling follow-up visits with doctors?*", "*getting family members or friends to help you because of your memory problems?*", and "*how to discuss your memory problems with other family members?*"

To the authors' knowledge, this is the first published study to examine self-reported need-related distress of people with dementia. These initial findings align with previous literature reporting subjective distress as a result of the cognitive, functional, and behavioral aspects of a dementia diagnosis (Dawson et al., 2012; Hughes et al., 2014; Minyo & Judge, 2021). Similar to the frequency of unmet needs, the extent to which participants experience need-related distress varied across need-items. These results provide additional evidence: 1) that people with dementia can report their own unmet needs and need-related distress; 2) that unmet needs and need-related distress can vary across individuals; and 3) the importance of utilizing self-report methodology to understand the illness experience.

There are several important study limitations. The small, homogeneous sample of people with mild to moderate dementia living in a long-term care facility limits study generalizability. Future work with a larger, more diverse sample utilizing the two-part unmet needs assessment tool would help extend knowledge on various types of need domains that a people with dementia report and how needs may vary and adapt depending on disease severity, living location, and demographic characteristics. Recent work has provided empirical evidence that needs vary depending on demographic characteristics, such as ethnicity (Mazurek et al., 2019; Muñoz et al., 2019). Zhang and colleagues (2020) examined the pattern of self-reported needs of people with dementia residing in a community in China. Participants self-reported caring for someone else, looking after the home, self-care, and intimate relationships as frequent unmet needs.

Another limitation is the lack of questions assessing other domains of needs experienced by people with dementia, such as behavioral expressions (Minyo & Judge, 2021). There is a lack of person-centered measures that are specifically designed for a person with dementia to self-report, which is necessary to examine the lived experience. Future work should develop unmet need assessment tools designed specifically for people with dementia based on their subjective experiences. Methodologies such as focus groups that include stakeholders' perspectives may reveal novel areas of unmet need. Development of person-centered outcomes could lead to person-centered interventions that target the individualized unmet needs and need-related distress. Indeed, a recent systematic review found underrepresented need items for people with dementia, such as a lack of freedom or choice, insecurities about feeling "at home" or safe within their environment, feeling unimportant, lack of support for grief and loss, and a lack of

peace and comfort with end-of-life care (Shiells et al., 2020).

Continued research on the illness experience of unmet needs and need-related distress could elucidate connections with psychosocial constructs. For example, behavioral expressions have been shown to be associated with unmet needs (Cohen-Mansfield et al., 2015; Hancock et al., 2006; Martyr et al., 2018), such that behavioral expressions arise as an attempt to communicate an unmet need (Algase et al., 1996; Cohen-Mansfield et al., 2015). Typically, behavioral expressions are proxy-reported from the perspective of caregivers and unmet needs are examined through clinical assessments that require multiple informant ratings. Recent work has provided initial evidence that people with dementia are able to self-report their own perception of behavioral expressions and behavioral-related distress (Minyo & Judge, 2021).

An examination of the potential connection of unmet needs and behavioral expressions when both constructs are self-reported by the person with dementia could provide an empirical basis for the development of interventions that aim to alleviate behavioral expressions, which are associated with negative outcomes for both the person with dementia and their caregiver (McKeith & Cummings, 2005). Specifically, interventions targeting unmet needs could subsequently alleviate behavioral expressions. Additionally, addressing unmet needs may be a direct and feasible target for intervention protocols, as previous interventions have found beneficial outcomes for targeting the unmet needs of dementia caregivers (Bass et al., 2013) and people with dementia (Bass et al., 2014).

Further exploring the construct of need-related distress and the potential association with outcomes of well-being within a theoretical framework that incorporates the illness experience could further the development of person-centered interventions. For example, the Stress Process Model for Individuals with Dementia (Judge et al., 2010), an adaption of Pearlin and colleagues (1990) Stress Process Model for Caregivers, was developed to examine the experience of living with dementia from the person's perspective. The framework postulates that increased need-related distress, which is a primary subjective stressor from having a dementia illness, has a direct (or indirect) impact on outcomes of well-being, such as depression. Studies have found that more unmet needs, a secondary stressor, are related to more depressive symptoms (Hancock et al., 2006) and lower quality of life (Martyr et al., 2018). However, it is unclear if the number of unmet needs or the level of need-related distress, regardless if the need is met or unmet, is more predictive of well-being outcomes.

It could be theorized that an individual's subjective experiences of distress are more predictive of psychosocial outcomes than frequency or quantity defined unmet need reports. In fact, Dawson and colleagues (2012)

found empirical evidence that subjective stressors can predict well-being outcomes. Higher perceived difficulty with instrumental activities of daily living and higher perceptions of role captivity were related to lower quality of life and more depressive symptoms, respectively. If unmet need and need-related distress constructs follow similar patterns, interventions targeting the person with dementia's subjective perceptions of distress, regardless of objective measurement standards or proxy-reports, may prove more efficacious for positively impacting well-being.

This would require understanding not only the needs that are unmet for an individual but also the areas of care that are inciting distress and the reason behind the distress. For instance, in the current study need-items that were reported as distressing, but were not unmet needs, included "*scheduling follow-up visits with doctors?*", "*getting family members or friends to help you because of your memory problems?*", and "*how to discuss your memory problems with other family members?*". It is unclear if these items were distressing due to individualized feelings about having a dementia diagnosis (e.g., embarrassment about their memory problems), lack of information or care planning, or another disease-specific stressor. Such a relationship between met needs and distress could have major implications for how services are provided in order for people with dementia in both long-term care and community-based settings to feel as though their perceptions and concerns are being addressed.

This study has important key findings for future theoretical development on the illness experience and non-pharmacological interventions. Results provided further rationale and empirical evidence for the inclusion of people with dementia within the research process and understanding unmet needs and need-related distress through a person-centered lens. Continuing to understand the type of needs that people with dementia experience, the level of distress that can arise from both unmet and met needs, and how these constructs impact well-being are important future research avenues.

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## IRB Statement

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