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Review Article

Person-Centered Assessment and Care Planning

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Abstract

The quality of dementia care rendered to individuals and families is contingent upon the quality of assessment and care planning, and the degree to which those processes are person-centered. This paper provides recommendations for assessment and care planning derived from a review of the research literature. These guidelines build upon previous recommendations published by the Alzheimer's Association, and apply to all settings, types, and stages of dementia. The target audience for these guidelines includes professionals, paraprofessionals, and direct care workers, depending on their scope of practice and training.

Keywords: Dementia, Evaluation, Interdisciplinary, Person-centered care, Quality of life

This paper provides practice-oriented guidelines for person-centered assessment of persons living with dementia, their family members, and care partners. It is one in a series of articles in this supplement issue and is intended to complement these other papers by building on the definition of person-centeredness provided by Fazio, Pace, Flinner, and Kallmeyer (2018) and providing recommendations for assessments that support the practices described in the subsequent papers.

Part one of this paper begins with the core concepts of person-centeredness informed by the philosophies of Kitwood (1997) and Brooker (2005). Two additional approaches are then introduced to provide a clear philosophical and practical foundation for comprehensive, person-centered assessment: Mast's (2011) approach to whole person assessment and Molony's (2010) work on at-homeness. These perspectives view assessment as an ongoing, dynamic approach to care.

Part two of this paper provides recommendations for assessment based on a review of literature published since the 2009 Alzheimer's Association (Alz Assoc). Recommendations for assessment and care planning are supported by national and international dementia care guidelines; published quality indicators; literature related to the process and/or outcomes of person-centered care; literature written by persons living with dementia and care partners; and literature published in core journals relating to specific domains of dementia assessment.

Part three discusses the evidence-based recommendations for care planning and transforming assessment data into action. Taken together, the assessment guidelines in this paper provide a foundation for the interventions described in the subsequent papers in this supplement issue.

Overview of Person-Centered Assessment

In his seminal work on dementia, Kitwood (1997) highlights three core elements of personhood: relationship, uniqueness and embodiment. According to Kitwood, relationship implies recognition, trust, and respect, and prioritizes the experience of the person. Kitwood references Martin Buber's concept of I-Thou relationships to convey true meetings with another in a spirit of openness, full acceptance, presence, and sense of new possibility. Kitwood (1997) points out that unfortunately:

> …a man or woman could be given the most accurate diagnosis, subjected to the most thorough assessment, provided with a highly detailed care plan and given a place in the most pleasant surroundings – without any meeting of the I-Thou kind ever having taken place"(p. 12).

This statement highlights the fact that assessment and care planning are processes that are informed not only by published research and clinical expertise, but also by the possibilities that emerge *in the moment*, during authentic human encounters with individuals living with dementia and their families. Person-centered assessment must therefore incorporate openness to the experience and relationship unfolding in the present moment. The word assessment often conveys a goal-oriented, task-centric set of activities, but in a person-centered context, assessment begins with valuing the experience of being present with another human being, trying to understand that person's experience, and coming to know the uniqueness of the person.

The purpose of assessment and care planning is to support the individual and family to live the best possible life, with dementia. The key components of person-centered dementia care described by Fazio and colleagues in this issue (p. 10) correspond to assessment modalities. *Personhood and relationship-based care* align with assessment approaches that convey respect and seek to understand the subjective experience of the individual living with dementia. I*ndividualized care and meaningful engagement* is practiced during assessment by prioritizing information about individual preferences, needs, values, routines, sources of joy and personal meaning. *Relationship-based care and positive social environments* are supported by identifying care partners and assessing their needs for support, information and resources. In residential care settings, this includes assessing staff needs, resources, satisfaction, and person-centered communication skills.

Mast (2011) describes an approach to whole person dementia assessment that combines nomothetic and idiographic perspectives. Nomothetic approaches utilize empirical studies with groups of people living with dementia to identify general principles and evidence-based strategies that may apply broadly to other persons in similar situations. The assessment recommendations found in the research literature and reviewed in this paper typify the nomothetic approach. Idiographic approaches rely on in-depth assessment of the individual in the context of his/her experiential, autobiographical and social world. Using this approach, assessment includes gathering information about life history; accomplishments, losses, significant experiences, hopes, dreams, preferences, important roles, and ways of dealing with previous challenges or stressful situations (Mast, 2011). The assessment also includes information about the significant people in the person's life, including the primary care partner and others. Mast points out that this information may not be obtained in one sitting, but is gathered across multiple encounters over time. In order to make the information useful for planning care, it must be documented, shared with other care providers, and periodically revisited and updated.

Molony (2010) conducted a metasynthesis of studies on the meaning of home that included papers focusing specifically on persons living with dementia (Wiersma, 2008; Zingmark, Norberg, & Sandman, 1993, as cited by Molony, 2010). Molony describes home as an experiential place of empowerment, refuge (comfort, warmth, and ontological safety), lived relationship (with persons, animals, meaningful places, cherished possessions, time, and ideas), and self-reconciliation (maintaining selfhood in the context of transition or loss). Understanding and assessing personalized meanings of home, and the processes by which home is experienced, built, shared, sustained, or lost, extends the concept of person-centered care more broadly into physical, social, and environmental domains. At-homeness is potentially threatened by medical crises and thus Kitwood's focus on embodiment, Molony's discussion of the lived body and traditional medical approaches to health and physical assessment are consistent with person-centered assessment.

Taken together, the core components of person-centered care as informed by Kitwood, Brooker, Fazio et al., Mast and Molony, call for an intentional preassessment phase to prepare the assessor to enter *the experience of the person* living with dementia and their care partner(s) by asking three self-reflective questions: (a) How will I demonstrate empathy and respect this person's uniqueness and wholeness while inquiring about the challenges of the disease/diagnosis? (b) How will I demonstrate that I value therapeutic alliance and partnership with this person and care partner(s)? (c) How will I demonstrate therapeutic optimism (for quality of living, if not for cure) and foster hope?

Qualitative studies examining the experience of persons living with dementia draw attention to the role of the care provider's attitude in shaping the person's outlook on dementia (Frank & Forbes, 2017). Simple strategies of therapeutic communication should not be undervalued in the assessment process. It is important to recognize that internalized stigma or therapeutic pessimism may adversely affect assessment process and outcomes (Wolverson, Clarke, & Moniz-Cook, 2016).

Recommendations for Assessment and Care Planning

A review of practice guidelines published after 2009 was conducted to update evidence-based recommendations related to assessment content, frequency, methods, measures, and outcomes. Wiener, Gould, Shuman, Kaur, and Ignaczak (2016) conducted a detailed analysis of 37 practice guidelines that included medical and psychiatric guidelines from diverse national and international sources including the American Medical Directors Association, the American Psychiatric Association, the American Psychological Association, the British Columbia Ministry of Health, the European Federation of Neurological Sciences and many others. Global reviews and panel summaries such as those by Callahan et al. (2014) and Mitchell and Coleman (2015) as cited by Wiener et al. (2016) were also reviewed. Some of these guidelines were setting-specific, discipline-specific, or domain-specific. Six primary assessment domains were uniformly identified as essential to assessment: cognitive status, functional abilities, behavioral symptoms, medical status, living environment, and safety. There is consensus in the literature that dementia must be distinguished from delirium and depression, and that reliable and valid instruments must be used that are designed to detect changes in cognition, function and behavior. Many guidelines recommend integrating systematic pain assessment tools that are appropriate for seniors and/or persons living with dementia. Wiener and colleagues (2016) also recommend assessment for indicators of abuse, neglect or inability to live alone including repeated hospitalizations, medication misuse, malnutrition, wandering from home. Recommendations specific to home and community settings highlight the need to assess caregiver health and signs of strain or stress, and to identify family member needs for education, support and services.

Guidelines for frequency of assessment are based on setting, with primary care assessment recommended at a minimum every 6–12 months and more often if changes in behavior, cognition, or function occur. Frequency of assessment in residential long-term care is guided by regulation, including key times such as: upon admission, after return from a hospital stay, and with significant changes in condition, function or behavior. Direct caregivers provide important assessment data in these settings, in addition to professional assessments using the MDS 3.0. All evidence-based guidelines stress the need for ad hoc assessment whenever behavioral changes occur, including an in-depth investigation of antecedents and contributors to behavioral and psychological symptoms of dementia (BPSD). Behavioral changes necessitate inquiry into unmet needs, stressors in the physical and social environment (including loneliness, boredom and isolation), and most importantly, underlying physical or psychiatric comorbidities. In these scenarios, referral to a health professional for comprehensive health assessment is recommended (Wiener et al. 2016).

A few of the guidelines reviewed by Wiener and colleagues (2016) recommend system-level incentives and supports needed to promote documentation and tracking of cognition, function and symptoms, provide training for caregivers, and establish standardized protocols for pain assessment and management. In acute care settings, the National Institute for Health and Clinical Excellence (2007), as cited by Wiener and colleagues (2016) recommend referral to a liaison service that specializes in assessment and treatment of dementia.

Ngo and Holroyd-Leduc (2015) conducted a systematic review of 39 practice guidelines published from 2008 to 2013. There is significant overlap with the recommendations provided by Wiener et al., with increased emphasis on regular, serial assessment of activities of activities of daily living and cognition to evaluate and document changes over time. Serial assessment for BPSD is recommended every 3 months, and medication changes, adherence and effects are to be assessed during every visit. Assessment for vascular risk factors is also recommended.

Additional published guidelines were obtained through the AHRQ and ClinicalKey databases. Multiple authors suggest that care plans should incorporate individual values, cultures, and needs, and should promote the maintenance of function and independence to the greatest degree possible. Specific assessment domains not already highlighted include the living environment, physical exercise, recreational activities, signs of abuse or neglect, caregiver needs, advanced directives, decision making, and plans for end-of-life care. While it is beyond the scope of this review to provide detailed recommendations for each of these facets of assessment, guidance is available for individualized assessment and management related to bathing, driving, mealtime difficulties, oral hygiene, nursing care (all settings), and care planning (National Guideline Clearinghouse, 2013; Clinical Key, 2017). The Gerontological Society of America (GSA) recently published a guideline outlining a four-step process for earlier detection and diagnosis called the KAER toolkit (GSA, 2017). The toolkit is primarily intended for primary care providers, but the associated appendices and tools provide efficient, valid, recommended tools for professional assessment in multiple settings.

Callahan and colleagues (2014) reviewed evidence-based models of dementia care and identified key components for assessment and care planning. Assessment domains not already highlighted include goals of care, driving, home safety, and use of substances. The review also highlights the importance of using each assessment opportunity to evaluate the outcomes of previous therapeutic interventions. The authors recommend consideration of referral to a specialty memory care practice for ongoing evaluation and management. Additional recommendations include educating the individual and family about diagnosis, care options, and community resources. This implies that pre-existing knowledge has been assessed.

Two performance measure sets for dementia care were included in this review. The American Academy of Neurology (AAN), American Geriatrics Society (AGS), American Medical Directors Association (AMDA), American Psychiatric Association (APA), and Physician Consortium for Performance Improvement® (PCPI™)

published quality measures to improve outcomes for persons with dementia (AMA, 2011). The International Consortium for Health Outcomes Measurement (ICHOM, 2017) brought together patient representatives, clinician leaders and registry leaders from all over the world to identify a comprehensive set of outcomes and case-mix variables for all providers to track. These standards are applicable to all types and stages of dementia. Table 1 depicts a comparison of the domains and topics recommended in these documents. These sources provide strong support for regular comprehensive assessment, with an emphasis on health, function, clinical, caregiver and safety domains. While there is some focus on the person living with dementia and care partner, the *experience of the person* living with dementia has not been a central focus in most research-based guidelines and quality measures.

To provide additional data for this review, evidence from individual research studies was gathered by searching in PubMed, CINAHL, SocINDEX, PsychINFO, and Social Work Abstracts for articles published since 2000, using various combinations of search terms including: dementia, assessment, whole person, strengths, strengths-based, needs assessment, person-centered or person centred care, nutrition assessment, symptom assessment, risk assessment, health assessment, health impact, quality of life, self-assessment, and geriatric assessment. This search yielded additional search terms that were then included in a PubMed search. After eliminating duplicates, non-English language papers and articles that were not research-based, a total 885 abstracts were reviewed. Since the goal of this paper was not to conduct a systematic review, the 108 papers selected for full text review and data extraction were prioritized based on the quantity and quality of evidence that included person-centered care or quality of life and/or experiential data from persons living with dementia or care partners, and/or publication in a core clinical, nursing or gerontological journal. Research-based articles were also included that provided elaboration of assessment recommendations given less detail in other works.

This scoping search revealed that BPSD, pain, quality of life, safety, and risk are more frequent topics for study in the professional literature than the process or outcomes of

Table 1. Assessment Data Needed to Support Quality Measures[a]

Assessment focus	PCPI	ICHOM (Specific instruments or measures are in bold)
Demographics		*Baseline*—Age, sex, level of education; Annually - living status and location, smoking status, alcohol use, BMI
Clinical status	Dementia severity	*Baseline*—Type of dementia (**ICD classification**), *Annually*—Level of dementia (**Clinical Dementia Rating Scale**)
Associated clinical history	Depressive symptoms	*Baseline*—history of head injury; Annually—cardiovascular event incidence, comorbidities (including hypertension, diabetes, high cholesterol, depression)
Medication variables		Total number of medications prescribed, documentation of any prescribed acetyl-cholinesterase inhibitors, N-methyl-D-aspartate (NMDA) receptor antagonists, antipsychotic drugs, antidepressants, anticonvulsants, or hypnotics
Symptoms	Neuropsychiatric symptom assessment; identification of potential triggers/precipitants and consequences; search for treatable, contributory causes	Neuropsychiatric symptoms (**Neuropsychiatric Inventory [NPI]**)
Function—cognitive	Cognitive assessment (using reliable and valid instrument or formal neuropsychological evaluation)	Cognitive function (**Montreal Cognitive Assessment [MOCA]**)
Function—daily living	Social function, Activities of Daily Living (using reliable and valid scale)	
Quality of life		*Baseline and 6-monthly* - Overall quality of life and wellbeing (**Quality of Life-AD [QOL-AD]** and **Quality of Wellbeing Scale-Self-Administered [QOLWS-SA]**)
Care partner/caregiver	Caregiver health assessment	Carer quality of life (**EuroQoL-5D or SF-12 or VR-12**)
Care provision		Need for 24-hr care
Safety	Home safety evaluation; driving risk	Falls
Other	Advance care plan, identification of surrogate decision-maker	Hospital admissions

Note: BMI = Body mass index; ICHOM = International Consortium for Health Outcomes Measurement; PCPI = Physician Consortium for Performance Improvement.

[a] Assessed annually unless otherwise stated.

person-centered assessment and care. The search for evidence was therefore extended to include texts and audiovisual media written or hosted by persons/families living with dementia. These sources provided insight into the process of assessment and underscored the importance of supporting dignity, autonomy and the voice of the person living with dementia. A synthesis of key assessment topics is provided in Table 2, and a summary of updated recommendations for assessment and care planning are included at the end of this paper.

Assessment Process

Feasibility and Scope

Regular, comprehensive assessment is recommended at baseline and interim reassessments are recommended in all settings at least every 6 months (Wiener et al., 2016). Time-pressed clinical environments require prioritization and the use of toolkits to increase efficiency. The first priority is to detect issues that detract from quality of life or prevent the person from living fully with dementia. This includes detection of hidden medical illness or pain or sources of excess disability and assessment of the degree of engagement in enjoyable activities. The presence of caregiver challenges should also be assessed as these may increase risk for institutionalization. More frequent reassessment is indicated in the context of recent medication changes, changes in health or behavior, living alone, driving, unstable or multiple comorbid conditions, bothersome symptoms, care partner stress, individual or care partner health concerns, recent hospitalization, or emergency department visits (Kales, Gitlin, & Lyketsos, 2014). There is considerable variability in cognitive and physical function in persons with Alzheimer's disease and other forms of dementia have different patterns of progression that would warrant more frequent assessment. The care partner's wellbeing and ability to provide support commensurate with the person's needs, may also change over time. A person-centered approach will tailor the frequency of assessment to the individual and family situation.

Persons living with dementia may become fatigued by cognitive and functional demands throughout the day and experts, including persons living with dementia, recommend that when possible, assessments be conducted during times of day when the person is at peak performance, in an environment free from distractions and competing demands.

Table 2. Comprehensive Person-Centered Assessment

Experience of the person/care partner
- Strengths/factors that support wellbeing including experiences of at-homeness
- Challenges/unmet needs
- Living situation and care needs
- Advance planning and awareness of resources (including education, support, palliative care)
- Caregiver health, unmet needs, stress
- Care dyad's knowledge about diagnosis, care options, and community resources

Function and Behavior
- Neurocognitive function
- Decisional capacity
- Physical function (including activities of daily living [ADL], instrumental activities of daily living [IADL])
- Psychological, social and spiritual activity and wellbeing
- Everyday routines, activities (including personal care, exercise, recreational activity, sleep)
- Behavioral changes, symptoms

Health Status and Risk Reduction
- Comorbidities (medical/psychiatric)
- Health indicators (e.g., pain, nutritional status, oral health)
- Medications (over-the-counter, prescription, supplements)
- Safety and risk reduction

Outcomes of Therapeutic Interventions

Sources of Information

Sources of information for the assessment include interviews with the person living with dementia, interviews with the care partner (and/or health care proxy if applicable), clinical records, prior assessments and observations. Observation, functional measurement and physical assessment provide objective data. The perspective of the person living with dementia should be prioritized in all assessments (de Medeiros & Doyle, 2013). Individuals living with dementia often report being ignored or infantilized (Bryden, 2016; Ellenbogen, 2012; Specht, Taylor, & Bossen, 2009). Using a life review approach, and asking about strengths and abilities before focusing on losses and disabilities, recognizes the person as someone who is a whole person. This forms a basis for a therapeutic partnership between the professional and the person living with dementia (Mast, 2011). Research has shown that even in late stages of dementia when people tend to "live in the moment," responses to simple questions about their well-being and feelings are possible (Kolanowski, Litaker, Catalano, Higgins, & Heineken, 2002). When the caregiver or other person is serving as a health care proxy, the viewpoint of the person living with dementia should still be sought, and preferences noted, including those expressed through verbal and nonverbal means (Bangerter, Abbott, Heid, Klumpp, & Van Haitsma, 2016). Repeat observations over time and/or behavior and symptom diaries are particularly useful for this purpose.

The majority of nonpharmacological treatments and care practices that have demonstrated efficacy in randomized controlled trials have targeted the person/care partner dyad and/or family caregivers (Maslow, 2012). It is therefore essential that family members also be included in the assessment process. In residential or institutional settings, direct caregivers who spend a great deal of time with the person are essential informants to collect data about usual routines, preferences, sources of joy, and sources of discomfort or frustration. Caution should be used when relying exclusively on proxy report (family or staff) for subjective experiences such as pain or quality of life, which covary with caregiver variables and may not always agree with ratings from the person living with dementia (Conde-Sala et al., 2013; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Reliable and valid observational measures and consultation with multiple informants may be of greatest benefit in these situations.

Preparation for the Assessment

Comprehensive assessment is supported by having reliable and valid assessment instruments (e.g., the Montreal Cognitive Assessment, the Neuropsychiatric Inventory), algorithms and toolkits (e.g., Medicare Annual Wellness Visit Algorithm and Toolkit for Assessment of Cognition; Cordell et al., 2013, KAER Toolkit; GSA, 2017), and resources regarding issues of frequent concern (e.g., Alzheimer's Association materials regarding wandering and driving safety). Print and on-line resources assist the individual and family in understanding the disease, planning for the future, dealing with situational challenges, anticipating and mitigating risks, enhancing meaningful engagement, and promoting healthful practices. Table 3 contains links to resources that support person-centered assessment.

Assessment Content

The goal of systematic assessment is to identify opportunities to support personhood, reduce health risks, optimize function, and identify comorbidities that may be impacting health, function and quality of life. Priority assessment topics that support positive person-centered care include factors that are relevant to living well with dementia, such as maintaining a sense of identity, agency, belonging, purpose, and positive emotional expression (Wolverson et al., 2016). This would include asking explicit questions about sources of joy, personally meaningful experiences of at-homeness and exploring the activities, environments, care practices and relationships that support the person's strengths and/or minimize distress.

Assessment of the Experience of the Person/Care Partner

Living with dementia is dynamic and situational and therefore what "matters" at any particular time in the course of the person's experience will change as the disease progresses, the person's perspective changes, and challenges occur that may threaten equilibrium and/or provide opportunities for growth (Taylor, 2007). The person living with dementia and care partners exist in a world of shifting salience where some things show up in the foreground as more important at a given time, and other things take the background. This means that person-centered assessment and care planning is an ongoing process, and not a one-time, finite task. A focus on the experience of the person will also guide setting-specific differences in assessment. The experience of living in the community poses challenges to autonomy, self-care, instrumental activities of daily living, and positive engagement with the social world. The experience of the person/care-partner dyad is particularly salient in this setting. This calls for proactive, systematic assessment from home, and community-based service providers. The experience of discomfort or disability related to undetected or undertreated physical and mental health conditions calls for the use of high-quality relational skills, listening, and strategic use of screening tools to identify these issues in primary care settings. In residential long-term care settings, the experience of the person living with dementia is often overwhelmed by organizational, staff, regulatory, and task-driven processes. In order to prioritize experiential assessment in these settings, leadership practices, organizational policies, culture building efforts, person-centered assessment tools, staff development activities, and quality improvement processes must all be aligned with the philosophy, goals, and practices described later in this paper.

Strengths and Facilitators of Wellbeing

In routine assessment, it is preferable to inquire about strengths, abilities, and successful self-care and caregiving approaches prior to assessing deficits and/or inquiring about alterations in personality, cognition or behavior (Judge, Yarry, & Orsulic-Jeras, 2010; Specht et al., 2009). While periodic symptom and behavioral inventories are useful to identify triggers for more in-depth assessment and care planning, they may also foster internalized stigma and fear. Using an assessment approach that focuses on the individual's experience conveys that the person living with dementia and their family are partners whose input is solicited, valued, and used in the plan of care.

Assessment of psychosocial and emotional health includes inquiry into overall positive and negative mood and affect, preferences for daily activities, pleasant events, quantity of social interactions, and the quality of relationships with significant people and animals (Mast, 2011). Assessment tools such as the Preferences for Everyday Living Inventory (PELI) (Van Haitsma et al., 2013) and the Pleasant Events Schedule (Logsdon & Teri, 1997) may be used to identify opportunities to enhance autonomy, meaningful engagement and psychosocial wellbeing. Persons living with dementia share the needs of all people to express emotions, fears and opinions, play or have fun, satisfy curiosity, give and receive affection, feel a sense of accomplishment, and engage in spiritually meaningful and faith-based activities. Wolverson and colleagues (2016) provide an overview of assessment tools related to these constructs of positive well-being.

Table 3. Resources for Person-Centered Assessment

Type	Source (All sites Accessed 26 October 2017)
Comprehensive resources (including all topics below)	http://www.alz.org; https://www.nia.nih.gov/health/alzheimers
Legal and financial planning and financial capacity	
Hospice and palliative care	http://www.nhpco.org/
Family care	https://www.caregiver.org/
Dementia subtypes and young-onset dementia information	http://www.theaftd.org/; https://www.lbda.org/; http://www.alz.org/i-have-alz/if-you-have-younger-onset-alzheimers.asp)
Living fully with dementia	http://daanow.org/
Primary care providers—system-level resources	https://www.thepcpi.org/pcpi/media/PCPI-Maintained-Measures/Dementia-Cognitive-Assessment-Updated-meas-wksht-FINAL.pdf; http://www.alz.org/careplanning/downloads/cms-consensus.pdf; https://www.geron.org/images/gsa/kaer/gsa-kaer-toolkit.pdf
Advance planning and serious illness conversations	http://theconversationproject.org/
Behavioral measures and resources for care planning	The Commonwealth Fund and The John A. Hartford Foundation Nursing Home Toolkit: www.nursinghometoolkit.com Rothschild Person-centered Care Planning Task Force *Guideline*: http://www.ideasinstitute.org/PDFs/Process_for_Care_Planning_for_Residnet_Choice.pdf; Support Health Activities Resources Education (SHARE) model: http://www.benrose.org/Research/share.cfm; WeCareAdvisor™ online interactive tool (Kales et al., 2017): http://ummentalhealth.info/2015/08/10/new-web-based-tool-called-wecareadvisor-aims-to-provide-support-for-caregivers-of-those-with-dementia/; Alzheimer's Navigator: https://www.alzheimersnavigator.org/; Care to Plan (CtP) online tool (Gaugler, Reese, & Tanler, 2016)
Safety and risk reduction (falls, driving, home safety)	https://www.alz.org/national/documents/brochure_stayingsafe.pdf; https://www.patientsafety.va.gov/professionals/onthejob/falls.asp; https://www.cdc.gov/steadi/; http://alz.org/care/alzheimers-dementia-and-driving.asp; https://www.thehartford.com/resources/mature-market-excellence/publications-on-aging)
Pain assessment	http://www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/ Chan, Hadjistavropoulos, Williams, & Lints-Martindale, 2014; Warden, Hurley, & Volicer, 2003

The wellbeing of care partners and caregivers strongly influences wellbeing and behavioral function of persons living with dementia. Therefore, caregiver wellbeing, self-efficacy, and perception of unmet needs should be a component of every assessment (Jennings et al., 2016). Assessment tools have been developed to explore caregiver values and preferences, caregiver relationships, consequences and rewards of giving care, caregiver skills, abilities, and the motivation to provide needed care (Whitlatch, Judge, Zarit, & Femia, 2006).

Challenges and Unmet Needs

Asking about current challenges and unmet needs (person living with dementia and care partner) facilitates empathy, enables tailored interventions, and informs the care planning process. Unmet needs commonly reported in the literature include: home maintenance, food, daytime activity, socialization, psychological distress, vision/hearing, self-care, and accidental self-harm. Persons living alone have more unmet needs than others (Miranda-Castillo, Woods, & Orrell, 2010).

Designing person-centered approaches requires a detailed assessment of environmental and caregiving features that either support or detract from function, independence, and safety (Gitlin, Marx, Stanley, & Hodgson, 2015). For community dwellers, an in-home assessment is recommended to identify safety concerns, environmental barriers to function and additional assessment data that may not be shared in more formal clinical settings (e.g., over-the-counter medications and supplements, pet-related concerns and living conditions). For persons living in residential care settings, the ability to observe the person's usual activity within their residence offers a great deal of information about abilities, preferences, social interactions, stressors, and person–environment fit (Brooker, 2005; Gaugler, Hobday, & Savik, 2013).

Reports of caregiver distress during any assessment occasion warrant referral to a team member with dementia-specific expertise in order to conduct a more in-depth assessment of needs, dyadic interaction, home environments, and opportunities to enhance function and safety. As the disease progresses and caregiving support needs are increased, the assessment of caregiver wellbeing and the balance of care provision between informal supporters and family caregivers versus formal/paid care providers become increasingly salient. The literature recommends assessment for neglect and abuse (physical, financial, emotional, or sexual), particularly in high-risk situations including aggressive behaviors and BPSD and caregiver variables including anxiety, depression, social isolation, low education, and emotional problems (Wiglesworth et al., 2010).

The evidence supports the need to assess and address caregivers' personal needs, including physical and psychological health, and the need to manage their own lives (McCabe, You, & Tatangelo, 2016). Assessing caregiver needs and awareness of community and on-line resources is particularly important for minority populations who experience disparities in diagnosis and follow-up care (Cooper, Tandy, Balamurali, & Livingston, 2010).

Cognitive Function and Decisional Capacity

Sudden or unexpected declines in cognition or function warrant referral to a health care provider to identify physical and mental health conditions that if undetected, may result in excess disability and cognitive dysfunction. Delirium (acute, potentially reversible cognitive impairment) is more common in persons with dementia (Morandi et al., 2012) and a high index of suspicion is recommended for this life-threatening condition (Inouye, Westendorp, Saczynski, Kimchi, & Cleinman, 2014). Serial assessment using reliable and valid cognitive assessment tools (by professionals with appropriate training and scope of practice) is recommended to identify potential acute changes in cognition or function. (Wiener et al., 2016). Two recent systematic reviews of instruments to detect delirium may be useful to clinicians trained in their administration (Morandi et al., 2012; Wong, Holroyd-Leduc, Simel, & Straus, 2010) and some researchers recommend that family members be educated to recognize delirium (Paulson, Monroe, Mcdougall, & Fick, 2016).

Cognitive function should be assessed in a manner that optimizes success and preserves dignity (Bryden, 2016). The assessor needs to understand not only the presence of cognitive and functional changes, but also the impact on the person living with dementia and care partners, and the implications for the goals, relationships, daily living, and engagement (Brooker, 2008). It is important to recognize different cultural views of cognitive impairment and the acceptance of dementia as a diagnosis, and to use cognitive assessment tools that have been validated in populations for whom English is not the first language (Wiener et al., 2016).

Cognitive assessment also supports person-centered care planning by guiding recommendations for activities and setting up appropriate expectations tailored to the person's function (Agostinelli, Demers, Garrigan, & Waszynski, 1994). For example, deficits in executive function may warrant task simplification, cueing, and activity-specific strategies. Deficits in language and communication may benefit from demonstration, hand-over-hand techniques, and specific strategies recommended by speech and occupational therapists (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). Tailoring activities to the person's neurocognitive abilities and strengths may preserve dignity, prevent excessive stress-inducing demands, and prevent excess dependency, boredom, and learned helplessness.

Cognitive function includes the capacity to make decisions. Assessment of decisional capacity is most frequently discussed in the research literature in relation to medical treatment decisions. Decisional capacity (a clinical assessment) is distinct from competence (a legal determination) and is decision-specific. Involvement in everyday decision making is associated with quality of life and may include choices about living environments, types, and amount of support for daily activities and planning for a future of diminished capacity or function. (Menne, Judge, & Whitlatch, 2009). Capacity assessment tools have been developed for treatment-related decisions Grisso, Appelbaum, & Hill-Fotouhi. (1997) and everyday decisions (Lai et al., 2008). A specialized case of capacity assessment involves capacity for sexual decision making (Wilkins, 2015). Illness may temporarily alter capacity and reassessment is indicated after appropriate treatment. Even in situations of diminished capacity, a person-centered approach supports that the values and wishes of the person living with dementia be sought, and included in the consideration of options (Mezey, 2016).

Physical Function

Functional independence is a component of health-related quality of life (Barbe et al., 2017) and is associated with care partner wellbeing and caregiving time (Razani et al., 2014). Functional assessment includes both basic (bathing, dressing, grooming, mobility, toileting, feeding) and instrumental activities of daily living (managing finances, shopping, cooking, managing medications, housework, using transportation). Performance-based measures are recommended, in addition to obtaining data from multiple sources (e.g., person, care partner, direct observation, and measurement).

Functional assessment includes inquiry into any changes in day-to-day social, occupational, recreational, or physical function. Financial capacity and driving ability are sensitive but particularly important domains in the early phases of the disease, and it is recommended that these be discussed candidly with the person living with dementia and the care partner (Frank & Forbes, 2017; Sudo & Laks, 2017).

Psychosocial Assessment

Whereas neurocognitive and functional assessments are often focused on detecting deficits or sources of illness and disability, assessment of psychosocial and emotional health focuses more on aspects of life that contribute to wellbeing. Qualitative studies emphasize two important themes related to quality of life: connectedness and agency (O'Rourke, Duggleby, Fraser, & Jerke, 2015). Relationships with family, friends, long-term care staff, and other residents all contribute to the sense of connectedness in addition to harmonious relationships with place. Individualized meanings of home may be assessed and used as a basis for planning discrete experiences to improve quality of living (Molony, 2010). Assessment of the person's ability to experience autonomy and control, to set and meet achievable goals, and to maintain spiritual connections are essential to inform person-centered care planning (Frank & Forbes, 2017).

Everyday Routines

Part of assessing day-to-day function and planning person-centered care includes reviewing daily habits, preferences, routines, and responses to various personal care activities. Evidence-based guidelines are available for assessment and care planning related to person-centered bathing, dressing, and oral care. (Crandall, White, Schuldheis, & Talerico, 2007; Zimmerman, Sloane, Cohen, & Barrick, 2014).

Behavioral Symptoms

Behavioral symptoms have been conceptualized as a form of communication and expressions of unmet needs (Algase et al., 1996) and/or a reflection of lower tolerance for stressors in the physical and psychosocial environment (Hall & Buckwalter, 1987). A recent framework proposed by Kales and colleagues (2015) includes the quality of interaction between the caregiver and person living with dementia.

Behavior is universally acknowledged by researchers and families living with dementia as an essential component of assessment. Behavioral symptoms increase the burden of care for family and formal caregivers, often precipitate institutionalization and account for one-third of all dementia-related costs (Herrmann et al., 2006; Toot, Swinson, Devine, Challis, & Orrell, 2017). Common behavioral symptoms include aggression, agitation, and apathy (Kales et al., 2015). A whole-person assessment of behavior is the first step in understanding what these symptoms may signify so that the response is appropriate and person-centered. Careful assessment may identify triggering conditions or contexts that can be modified to reduce the likelihood of distress. In addition, assessing what aspect of the symptom is most distressing for the individual and caregiver will support individually tailored treatment strategies. This type of assessment is incorporated into successful models of care (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010).

Once the behavior is well-characterized and untreated medical conditions are excluded as a possible cause, the second step is to assess for modifiable causes of the symptom. These precipitants then become targets for intervention. The investigation of these triggers involves astute observation of behavioral patterns. Behavioral logs can assist in identifying triggers that commonly include medications, pain, comorbidities, lost functional abilities, boredom, poor communication, task-focused care, and environmental characteristics such as noise, lighting, temperature, and crowding (Gilmore-Bykovskyi, Roberts, Bowers, & Brown, 2015). The WeCare™ web-based application provides individually tailored guidance for caregivers and families assessing and managing behavioral symptoms (Kales et al., 2017).

Kolanowski Boltz and Galick (2016) conducted a recent scoping review of causes or determinants of behavioral symptoms. A number of causes were common across several behavioral symptoms: neurodegeneration, type of dementia, severity of cognitive impairments, declining functional abilities, caregiver burden, poor communication, and boredom. These findings have implications for further assessment and care planning to support functional independence, improve communication, and prevent boredom.

Health Status and Risk Reduction

Comorbidities

Co-occurring health conditions such as heart failure, diabetes or lung disease may amplify cognitive, functional, and behavioral challenges in persons living with dementia. Thorough investigation for co-occurring conditions may prevent disability and distress (Wiener, 2016). These investigations include assessment of vision, hearing, oral health, communication, swallowing, nutrition, hydration, substance use, sleep, oxygenation, skin integrity, sexuality, continence, bowel function, and mobility and signs of infection or pain.

Older age, more chronic health conditions, polypharmacy, reduced mobility, advanced dementia, and/or communication impairments warrant a more comprehensive approach to physical assessment to identify undetected sources of illness or distress. There is a gap in the literature regarding the best methods to conduct a sensitive physical assessment in persons with dementia. The first author's clinical experience suggests that a person-centered approach includes modification of the usual head to toe, palpation-before auscultation approach. Using less intrusive assessment techniques first (e.g., observation, resting auscultation), providing simple instructions and explanations, using a calm reassuring tone of voice and nonverbal communication strategies, are helpful in completing the assessment, particularly for persons in advanced phases of dementia. Referral to interdisciplinary colleagues for vision, hearing, and nutritional assessment is helpful when these team members are available. Vision loss may contribute to visual misinterpretation, nonrecognition and hallucinations. Vision screening has been shown to be feasible even in moderate to advanced dementia (Chriqui, Kergoat, Champoux, Leclerc, & Kergoat, 2013). Inspection for wax impaction is part of routine geriatric assessment and is particularly important to prevent avoidable hearing loss in persons living with dementia.

Depression is common in early-stage Alzheimer's disease. A recent meta-analysis found a pooled prevalence of major depression of 30.3% (Goodarzi, Mele, Roberts, & Holroyd-Leduc, 2017) with a higher prevalence when criteria specifically developed for depression in dementia were used. While screening tools such as the PHQ-2 may be used mild stages of the disease, Goodarzi and colleagues (2017) found that the Cornell Scale for Depression in Dementia (CSDD) and Hamilton Depression Rating Scale (HDRS) had higher sensitivity and discriminatory ability than other instruments. Both of these scales include interview with persons with dementia and their caregivers. If a more in-depth assessment for depression is indicated, referral to a provider with mental health, geriatric, and/or dementia expertise is recommended.

Medications

Medications are a frequent contributor to cognitive dysfunction and a careful medication review is universally endorsed in the literature. Assessment includes identification of high alert medications and potentially inappropriate medications, as well as any medication usage or medication management challenges (American Geriatrics Society [AGS], 2015; Johnell, 2015). While additional studies are needed to support predictive validity, the Mini-cog and Medi-cog screening assessments have demonstrated clinical utility in identifying the need for more assessment and support related to medication management and may be used by well-trained assessors (Anderson et al., 2014).

Safety and Risk Reduction

One of the most valuable types of support for persons and care partners is planning for risk reduction. Persons living with dementia in early to middle phases are at increased risk for harm related to financial mismanagement (Dong, Chen, & Simon, 2014), medication-related adverse events (Wucherer et al., 2016), driving (Rapoport, Cameron, Sanford, & Naglie, 2017), falls (deRuiter et al., 2017), wandering, elopement, and getting lost (Ali et al., 2016). Recommendations for community-based care include providing a referral to the Alzheimer's Association and providing information about resources such as MediAlert® and the Safe Return® program, and the Alzheimer's Navigator (an individually tailored assessment and management program available from the Alzheimer's Association. Tools are available in the literature to support home safety assessment to identify opportunities to reduce the likelihood of avoidable injury (Tomita, Sumandeep, Rajendran, Nochaiski, & Schweitzer, 2014).

Table 4 identifies safety issues cited in the literature that need to be periodically assessed to provide anticipatory guidance and reduce risk (Amjad, Roth, Samus, Yasar, & Wolff, 2016). Persons living with dementia point out that skillful, empathetic communication strategies are needed to prevent these assessments from being conveyed as prophecies of a feared future, acknowledging that each person's disease and trajectory are unique (Taylor, 2007).

A person-centered approach requires that safety not be narrowly constructed to mean only physical safety. The person's integrity may be threatened by risk-averse approaches that discount threats to personhood and dignity (ontological safety). Frank discussions about risk tolerance and risk mitigation are essential. The Alzheimer's Association website has tools and resources to assist professionals in assessing and promoting safety while optimizing autonomy, including strategies to promote restraint-free care. Another excellent resource is the Rothschild Foundation guide for care planning processes (Calkins & Brush, 2016) which was designed for nursing home settings and provides numerous clinical examples, quality improvement tools and templates to support care planning around risk-related activities while honoring individual preferences.

The range of safety-related topics illustrate the need for situational flexibility between wide-ranging, scoping assessment and in-depth, targeted assessment. In addition to driving safety, areas that are frequently in need of more detailed assessment include: nutrition (Abdelhamid et al., 2016), pain (Beer et al., 2010), oral care (Delwel et al., 2017), falls (de Ruiter, de Jonghe, Germans, Ruiter, & Jansen, 2017) and planning for restraint-free care (Kopke et al., 2012). Restraint-free care is supported by all of the assessment practices recommended in this paper. Learning each person's life history, values, habits, and preferences and conducting skillful assessment of contributors to wandering,

Table 4. Safety and Risk Reduction

Community dwellers

- Driving problems
- Money management or financial exploitation
- Medication management problems
- Wandering or getting lost
- Cooking, appliance or power equipment problems
- Spoiled food or non-food
- Attending medical visits alone
- Difficulty responding to crisis/emergency
- Unsafe storage/use of firearms

Persons living with dementia in all settings

- Care partner/caregiver stress/strain
- Smoking problems or use of alcohol or other substances
- Behavioral symptoms (suspicious or accusative behavior; verbal or physical aggression)
- Threats to hurt oneself or suicidality
- Falls
- Mistreatment or neglect
- Risk for restraints

behavioral symptoms, delirium, and falls, may reduce the need for restraints. System-wide policies for restraint-free care are recommended to guide this assessment and to raise awareness of preventable risk factors.

Advance Planning

While systematic reviews confirm that early attention to advance planning maximizes autonomy and increases the likelihood that the person living with dementia will have individual preferences and wishes honored, there is a gap in translating this knowledge into practice (Robinson et al., 2010). The Institute for Healthcare Improvement and The Conversation Project have developed supportive materials for serious illness conversations tailored to the particulars of Alzheimer's disease (Bernacki & Block, 2014). Assessment of the individual and family's knowledge and attitudes related to palliative care and symptom management (distinct from hospice care), inform the care planning process and may prompt referral to interdisciplinary team members for ongoing education and support (e.g., social worker, care manager, Alzheimer's Association, and/or palliative care team).

Advanced dementia poses particular challenges for assessment. If the disease has affected the individual's ability to communicate, care providers must have a high index of suspicion and vigilance in detecting delirium, illness, discomfort, hunger, constipation, impaction, urinary retention, infection, fear, grief, loneliness, and boredom. Skin breakdown, dehydration, swallowing difficulties, and aspiration are common threats to wellbeing that require timely detection and management. The more advanced the disease and/or the greater the number of comorbidities, the more frequent assessment should occur to identify potentially remediable causes of suffering (Mitchell et al., 2009).

The Alzheimer's Association End-of-Life Care Practice Guidelines (2007) contain detailed information and recommendations about decision making, planning, symptom management, and end-of-life care. Researchers have identified essential components of family-centered care at end of life and intensive individualized comfort care (Lopez, Mazor, Mitchell, & Givens, 2013; Lopez & Amella, 2012).

Turning Assessment into Action

A new Medicare Cognitive Assessment and Care Planning billing code (G0505) took effect in January of 2017 that provides reimbursement to practitioners for a clinical visit that results in a comprehensive care plan for persons with a documented cognitive impairment. The rules require a multidimensional assessment that includes cognition, function, safety, neuropsychiatric and behavioral symptoms, medication reconciliation, and assessment of caregiver needs. Transdisciplinary, collaborative care approaches are increasingly being recommended and evaluated (Galvin, Valois, & Zweig, 2014). Collaborative assessment and care management may be particularly useful in reducing disparities in dementia care quality among caregivers with lower educational attainment (Brown, Vassar, Connor, & Vickery, 2013). In any team-based approach, there needs to be agreement on who is accountable for coordinating and documenting assessment findings and follow-up actions.

Team care planning includes medical, nursing, direct care/personal care providers, care partners and other family, social workers, occupational therapists, physical therapists, speech therapists, registered dieticians, and pharmacists (Wiener et al., 2016). This may require use of technologies to facilitate team collaboration, use of asynchronous written or electronic input and/or a care coordinator accountable for linking with all other team members, sharing and integrating all perspectives. If not already done, a list of strategies, approaches, therapies, and joy-enhancing activities should be gathered from family members, care providers, and all members of the team. This list must be frequently re-evaluated, revised, and used with sufficient flexibility to accommodate situational changes in the individual's health, preferences and needs.

The person living with dementia should be involved in the care planning process and may need support in having their "voice" (including verbal and nonverbal communication) heard. The information obtained during whole-person assessment is used to plan care that meets the goals of the person living with dementia and their caregivers. Unfortunately, information contained in care plans does not always get shared with care providers in a systematic way. This is a barrier to person-centered care because many of the preferences and needs of residents are known to direct care workers as a result of their daily contact (Abbott, Heid, & Van Haitsma, 2016). All staff must be included in the care planning process, particularly those who spend the most time with the person. This includes personal care assistants in community-based settings. Care plan implementation requires the use of tools to capture and distribute person-centered information to workers at the point of care (Van Haitsma et al., 2014).

Others involved in the process include persons who care about, care with and/or care for the person with dementia. Using person-centered conceptual models to guide care and person-centered language in all documentation are two strategies that will increase the likelihood of person-centered planning. A number of outstanding resources are available to assist with care planning (see Table 3). The Dementia Action Alliance, a grassroots advocacy organization, provides white papers to support these practices (available at: http://daanow.org/).

Experiential, functional, behavioral, and health assessment provide the basis for ongoing care and referrals to other members of the interdisciplinary team. The outcome of comprehensive assessment is an interdisciplinary plan for function-focused care, rehabilitation, modification of tasks and environment, and activity-specific recommendations to improve engagement, enhance function, optimize choice, autonomy and comfort during personal care and decrease person/care partner stress (Galik, Resnick, Hammersla, & Brightwater, 2014; Gitlin et al., 2015). Published guidelines recommend that care plans specifically address family well-being and the needs of caregivers and incorporate the person's choices about the goals of care and end-of-life wishes.

Specific goals included in the plan include strategies to build on strengths, promote success, honor personhood, and support function (physical, cognitive, psychosocial, and spiritual). A quality assurance and performance improvement (QAPI) audit may be used to review whether plans of care respect the person's unique preferences, consider the experience of the person and family, and focus on what really matters to the person and those who care deeply about them. The care planning process implies frequent reassessment about whether previous goals and preferences are being met and if not, what revisions need to be made (Van Haitsma et al., 2015). Lack of goal achievement or behavioral challenges indicate a need for more comprehensive assessment and problem-solving leading to small individually-tailored trials with frequent checks to evaluate success. Consultation with advanced practice clinicians or dementia care experts may be sought if they have not previously been included in the process. It is particularly important to evaluate whether pharmacologic interventions are having the intended effect and providing benefits that outweigh the risks.

The time spent performing a comprehensive assessment and creating a holistic, person-centered plan will be wasted if that plan is not documented and shared in a manner that guides day-to-day care and experiences for the person and care partners. A study by Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak (2015) found that certified nursing assistants in the nursing home setting did not have access to written information and/or the information that was available was out of date or too time-consuming to read.

Person-centered care interventions have demonstrated effectiveness in clinical trials (Brooker et al., 2016; Kim & Park, 2017) but organizational barriers frequently prevent the implementation of these strategies. Future work is needed to create and sustain supportive environments that enable implementation of these practices.

Summary

As discussed throughout this manuscript, person-centered assessment and care planning focus on the unique needs and characteristics of the person. At present, many persons living with dementia do not receive person-centered assessment and care planning because of programmatic, organizational, and regulatory requirements and professional and provider practices that reflect the needs of staff and settings, more than the needs of the person with dementia. The following recommendations are intended to increase the use of assessment and care planning practices that focus on the needs of the person in a wide array of care settings, across types and stages of dementia, and conducted by professionals, paraprofessionals, and direct care workers, depending on their scope of practice and training.

1. Perform regular, comprehensive person-centered assessments and timely interim assessments.

   Assessments, conducted at least every 6 months, should prioritize issues that help the person with dementia to live fully. These include assessments of the individual and care partner's relationships and subjective experience and assessment of cognition, behavior, and function, using reliable and valid tools. Assessment is ongoing and dynamic, combining nomothetic (norm-based) and idiographic (individualized) approaches.

2. Use assessment as an opportunity for information gathering, relationship-building, education, and support.

   Assessment provides an opportunity to promote mutual understanding of dementia and the specific situation of the individual and care partners, and to enhance the quality of the therapeutic partnership. Assessment should reduce fear and stigma and result in referrals to community resources for education, information and support. Assessment includes an intentional preassessment phase to prepare the assessor to enter the experience of the person living with dementia and their care partner(s).

3. Approach assessment and care planning with a collaborative, team approach.

   Multidisciplinary assessment and care planning are needed to address the whole-person impact of dementia. The person living with dementia, care partners and caregivers are integral members of the care planning team. A coordinator should be identified to integrate, document and share relevant information and to avoid redundancy and conflicting advice from multiple providers.

4. Use documentation and communication systems to facilitate the delivery of person-centered information between all care providers.

   Comprehensive, high-quality assessment is of benefit only if it is documented and shared with care providers for use in planning and evaluating care. Information must be current, accessible, and utilized.

5. Encourage advance planning to optimize physical, psychosocial and fiscal wellbeing and to increase awareness of all care options, including palliative care and hospice.

   Early and ongoing discussion of what matters, including values, quality of life and goals for care, are essential for person-centered care. The person living with dementia's preferences and wishes should be honored in all phases of the disease, even when proxy decision making is required. The individual and family should be referred to health care team members to provide ongoing education and support about symptom management and palliative care.

Further research is needed to inform the assessment process. Models of care are needed that balance the nomothetic and idiographic approaches to assessment in a person-centered, yet cost-effective manner. Future research is needed to investigate contributors to wellbeing and positive relationships in care partner dyads. Additional research is also needed to validate strategies for ensuring that best practices in person-centered assessment and planning are carried over to implementation at the point of care in both community-based and residential settings. The National Health Service Quality Outcome Framework in the United Kingdom explicitly lists "Ensuring that people have a positive experience of care" as a quality standard (National Institute for Health and Care Excellence, 2013). This places the experience of the person living with dementia in the center of quality improvement efforts. A future challenge will be to integrate and measure outcomes of the relational processes needed to establish and sustain an "I-Thou" relationship, and support personhood, as envisioned by Kitwood.

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