



Person-Oriented Research Ethics and Dementia

The Lack of Consensus

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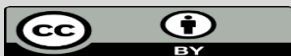
Abstract

Research ethics extends beyond obtaining initial approval from research ethics boards. The previously established person-oriented research ethics framework provides guidelines for understanding ongoing ethics throughout the tasks of a research project, in a variety of research contexts. It focuses primarily on the relational and experiential aspects of research ethics, organized around five guideposts: (1) focus on researcher-participant relationships; (2) respect for holistic personhood; (3) acknowledgment of lived world; (4) individualization; and (5) empowerment in decision-making. Given the widespread impact of dementia and the ethical challenges dementia research presents, conducting meaningful, ethical research is of high importance. This review explores this person-oriented framework in the context of dementia by examining existing literature on ethics practices in dementia research. We use a critical interpretive literature review to examine publications from 2013 to 2017 for content related to the five guideposts of person-oriented research ethics. While there is much literature addressing the relational and experiential aspects of research ethics, there is a lack of unanimous conclusions and concrete suggestions for implementation. We compiled practical recommendations from the literature, highlighting tensions and suggesting furthering evidence-based ethics research fieldwork to construct an accessible, easy-to-use set of guidelines for researchers that will assist in putting person-oriented research ethics into practice in dementia research.

Keywords: research ethics; bioethics; dementia; selfhood; empowerment; autonomy

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The experiences of people with dementia has garnered significant academic attention in both the health sciences and social sciences. However, conducting research with participants with dementia, who may be a particularly vulnerable population, can be difficult from an ethical perspective. In this context, “vulnerable” typically refers to having an impaired ability to advocate for oneself (Dempsey *et al.* 2016). Research ethics, with respect to vulnerable populations and more broadly, is centered around protecting potential and actual participants and regarding them as agents with the right to self-determination. Creating and conducting ethical studies is crucial for respecting participants’ wellbeing, autonomy, and rights; as well as collecting meaningful data. Ethical research does not begin or end with an ethics board review. Taking a broader review of everyday ethics, the framework of “person-oriented research ethics” (American Anthropological Association 2012; Cascio and Racine 2018) provides guideposts for understanding experiential and relational aspects of research ethics. This existing framework is applicable in diverse social fields. The purpose of this article is to use and expand the theory in the context of dementia research ethics through a purposive review of the current state of research ethics literature regarding studies that may involve participants with dementia.

Background

According to the World Health Organization, approximately 50 million people have dementia, with 10 million new cases occurring each year (World Health Organization 2018). Dementia is one of the leading causes of disability in older people, seriously affecting those with the diagnosis and their surrounding social networks (World Health Organization 2018). Its degenerative symptomology and widespread impact have garnered significant academic attention and resources. During the 2017 fiscal year, the US National Institutes of Health spent approximately \$1.4 billion on research in Alzheimer’s disease and related dementias (US National Institutes of Health 2017). Despite the considerable financial resources, conducting research on dementia is still logistically challenging. Two of the most salient barriers to completing timely, meaningful research are low enrollment and high attrition (Grill and Karlawish 2010). In reviewing recent commentary on ethical practices in dementia research, we hope to understand the bases for these barriers and potential solutions to overcome them.

Currently, there is no biological diagnostic test for dementia. The syndrome is progressive in nature (Mayo Clinic 2018; World Health Organization 2018). Although many people assume older adults generally develop dementia, the term is used to specify an experience that is not a normal part of aging. Understanding how people delineate and qualify boundaries between “normal” and not has long been a central topic of study in anthropology (Benedict 1934), including the anthropology of aging (Cohen 1998;

Lock 1993). Dementia specifically has been and continues to be (e.g., Antelius and Plejert 2016, Fetterolf 2015, Young 2015) an important topic in the anthropology of aging. The expectations and milestones of aging are inseparable from their sociocultural contexts. Although some may have biological bases, such as menopause, the expected experience is largely derived from both medical and social aging commentary (Lock and Kaufert 2001). Historically, defining the boundary between normal cognitive aging and dementia has been a significant point of contention (George et al. 2011; Lock 2013). The “entanglement of dementia and aging” (Lock 2013, 9) challenges social categorization and the culture of diagnostic medicine developing discrete, reliable categories for degrees of age-related and pathological cognitive impairment has been an ongoing challenge largely because of its subjectivity and questionable correlation with biomarkers (Lock 2013). Frail older adults who show no symptoms of dementia can be subject to paternalistic healthcare because of the assumption that they necessarily have a lesser cognitive capacity (McNally and Lahey 2015). While we focus on literature specifically addressing participants with dementia, we do not exclude studies based on how the researchers defined dementia, and we recognize that other adults may be subject to similar considerations or stereotypes by researchers and research ethics committees (RECs). We also acknowledge the variability of experiences included under the label of dementia, and the fact that participants with a diagnosis may also be subject to stereotypes based on ideas about dementia. Indeed, stereotypes about diagnoses and implications about capacity are a problem across studies including participants with many types of cognitive disabilities or differences (Cascio and Racine 2018).

Like a large portion of society, RECs can have biases. The purpose of RECs is to ensure that research methodologies are ethical to protect the welfare of the participants (Pachana *et al.* 2015). However, if RECs operate under the ageist stereotype that older people generally have a lower cognitive capacity, they will be over-protecting a large portion of the population (Forlini 2017). Under this assumption, older people are unable to participate in research safely and ethically. This assumption can result in the rejection of these studies by RECs, further limiting the opportunities for discovery and participation in research (Pachana *et al.* 2015). It also discourages researchers from engaging in studies involving this population because of the bureaucratic hassle (Holland and Kydd 2015). Despite there being a large population of older people and people with dementia who may wish to participate in research, they do not have the opportunity without accessible studies available (Murray 2013). However, the impact of dementia symptoms on a person’s cognition can impair their ability to self-advocate, thus resulting in further exclusion from research on the basis of protection, paralleling for example social exclusion of people with dementia who do not “still recognize” loved ones (Taylor 2008). RECs are in a position where they can reduce this discrimination by understanding the value of research participation in older populations and questioning researchers who exclude this population (Wood *et al.* 2013). They can also encourage researchers to shift away from viewing research ethics as only a regulatory requirement.

Reducing research ethics to a bureaucratic burden does not acknowledge the values that ethics guidelines promote (Cascio and Racine 2018). Ethical research practices go beyond fulfilling regulations and receiving REC approval (Lichtner 2014). They ensure that participants can have a safe and positive experience participating in the study, even in interactions that do not directly pertain to data collection such as recruitment, waiting periods, data analysis, and dissemination of the results. Scholars have suggested ethical practices for implementation in addition to regulatory requirements, promoting the positive engagement of society in research (Cascio and Racine 2018). These practices promote the inclusion, and thus discourage discrimination against, participants who are vulnerable (*ibid.*).

Person-oriented research ethics embraces a view of ethical practices as complementary to regulatory requirements. It is inspired by principles of person-centeredness and patient-centered care as applied to a research context (Cascio and Racine 2018), and draws from anthropological theories and

methods including person-centered ethnography (Hollan 1997; LeVine 1982) and relational ethics (Meloni *et al.* 2015). In their recent work, Cascio and Racine have outlined five practical guideposts for implementing person-oriented research ethics (see Figure 1): (1) focus on researcher-participant relationships; (2) respect for holistic personhood; (3) acknowledgment of lived world; (4) individualization; and (5) empowerment in decision-making (2018). Focusing on the researcher-participant relationship is an effort to minimize the power imbalance inherent to this relationship. Having respect for holistic personhood highlights that research participants are entitled to make their own decisions regarding research enrollment. Acknowledging the participant's lived world focuses on understanding factors external to the study that can impact the research process, as well as the unique trajectories the research can take with each participant. Individualization emphasizes adjusting the research methodology according to each participant's abilities and needs without compromising the integrity of the design. Empowerment in decision-making maximizes the participant's decision-making ability throughout the research process. The five guideposts are illustrated in Figure 1 and further described and contextualized in the Results and Discussion section of this paper.

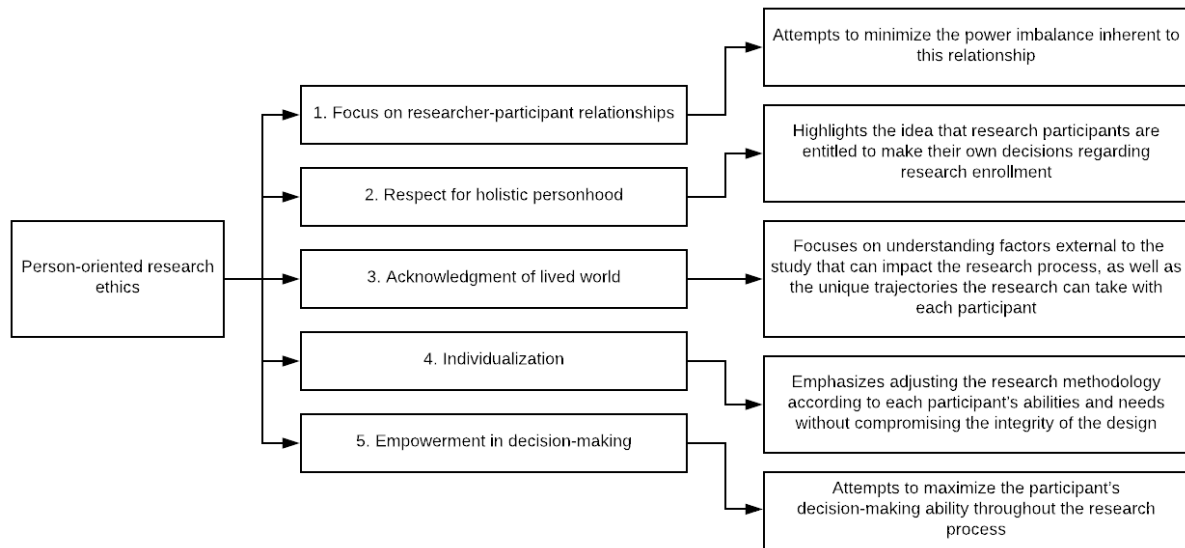


Figure 1: Five guideposts of person-oriented research ethics (adapted from Cascio and Racine 2018)

Guiding research by the guideposts of person-oriented research ethics in studies involving people with dementia requires consideration of both the participant and their caregiver, who may also be their research partner or proxy. In dementia research, the research partner oversees the study, acting as an informant for the researcher and an advocate for the participant (Cary *et al.* 2015). The caregiver, research partner, or proxy will likely have their own set of values, abilities, and needs during the process (Black *et al.* 2014). Having a caregiver present can be necessary for more vulnerable participants; however, the presence of a caregiver does not necessarily remove all ethics quandaries.

Methods

This study employs a critical interpretive literature review using systematic sample searching methods (McDougall 2015). The purpose of this review is to examine the key themes of recent literature on ethical practices in dementia research and relate them to the five guideposts of the person-oriented research ethics framework. It aims to elucidate potential challenges that underlie difficulties in conducting research with participants with dementia. It also identifies tensions and suggestions regarding designing ethical studies that acknowledge the specific needs of older persons (>65 years of age) with dementia and their caregivers. The review is limited to articles published between 2013 and 2017. This five-year range thus represented an exploratory investigation into the cutting edge of dementia research ethics.

Our review is descriptive, not evaluative. We identify literature purposively, to define the contours of the person-oriented research ethics framework in the context of dementia research, not to evaluate the presence or absence of ethics discussions in the literature, although we do identify tensions within these discussions. Our search strategy aims at finding sources that address research ethics and excluded others. Our refinement and enrichment of the person-oriented research ethics framework in this context uses a bottom-up approach, building from existing discussions in the literature, and not a top-down approach that judges these discussions against a pre-existing standard. Indeed, person-oriented research ethics is intentionally open-ended and amenable to this approach.

Selection of Databases

We selected Ovid Medline, Web of Science, and ProQuest Philosopher's Index databases for the sample search. Ovid Medline is a database specifically for biomedicine, which allowed us to gather data on clinical research and practice. Web of Science is an interdisciplinary database that covers articles in both the medical sciences and social sciences. This database was useful to avoid potential biases of focusing on clinical literature and examine the social science research on relevant topics, such as meaningfulness, ageism, and lived experiences. ProQuest Philosopher's Index is a database that covers philosophical and interdisciplinary research, which allowed us to gather literature from a philosophical perspective including philosophical ethics.

Proposed Keywords

For our study, an initial list of keywords was constructed based on preliminary searches on ethics and aging studies. The keywords were then divided into two main categories: ethics and target population. Different combinations of the keywords were searched, including sometimes in conjunction with "research," and the number of hits was recorded for each of the three databases. The quality of the results was evaluated vis-à-vis the purpose of this research. From there, the keywords were narrowed down based upon the number and quality of hits. For example, every query using "cognitive impairment" resulted in fewer hits than using "dementia," but using "dementia" resulted in more articles relevant to our review. Thus, "cognitive impairment" was eliminated from the final list of keywords. All possible combinations of terms were included in the final query.

Ovid Medline	ethic* AND dementia AND research
	bioethic* AND dementia AND research
	neuroethic* AND dementia AND research
	ethic* AND ag*ing AND research
	bioethic* AND ag*ing AND research
	neuroethic* AND ag*ing AND research
Web of Science ²	*ethic* AND dementia AND research
	ethic AND ag*ing AND research
ProQuest Philosopher's Index	ethic* AND dementia AND research
	bioethic* AND dementia AND research
	neuroethic* AND dementia AND research
	ethic* AND ag*ing AND research
	bioethic* AND ag*ing AND research
	neuroethic* AND ag*ing AND research

Table 1: Search Queries, October 17, 2017

* = truncation

Title and Abstract Review

The title and abstract of each article from the initial query (n=1,836) were screened for relevance to ethical practices in dementia research. An article was included if it discussed the ethics of research in older people and end-of-life patients with dementia, a cultural perspective of autonomy in older people, or legal protocol regarding research consent in older patients with dementia. Other topics that fell under the domains of person-oriented research ethics specifically and of research ethics more broadly were also included, for example an article that discusses optimizing patient-centered outcomes research (Wadekar, Sharma, and Battaglia 2015) and an article that discusses sensitive interviewing (Dempsey et al. 2016). The search was not limited to studies conducted in a specific geographic region. All titles of included articles were imported into a spreadsheet in preparation for data extraction. A source was excluded if it did not pertain to research participants with dementia or focused on patients that are under 65 years of age. All sources not involving human subjects or written in a language other than English were also excluded. From the primary search, 143 articles were questionable, and 256 articles were included from the original 1,836 articles. Both questionable and included articles progressed to the full review (n=399).

Full Review and Data Extraction

After reading the full article, an article was excluded (n=341/399) if it did not fit the initial inclusion criteria, as discussed above (i.e., if it was not about research ethics or regarding the population of interest). If an article that discussed ethics of medical care did not involve discussion of the ethics of a research method, it was also excluded.³ An article was also excluded if it discussed ethics of research topics but did not discuss research participants themselves or ethical practices in methodologies.⁴ Additionally, if an article did not discuss research ethics and did not address any ideas that are applicable to the person-oriented research ethics framework, the article was excluded. The literature was reviewed for relevance to

the five guideposts of the person-oriented research ethics framework (Cascio and Racine 2018). Content was extracted and copied into a spreadsheet as quotes if they pertained to any of the five guideposts.

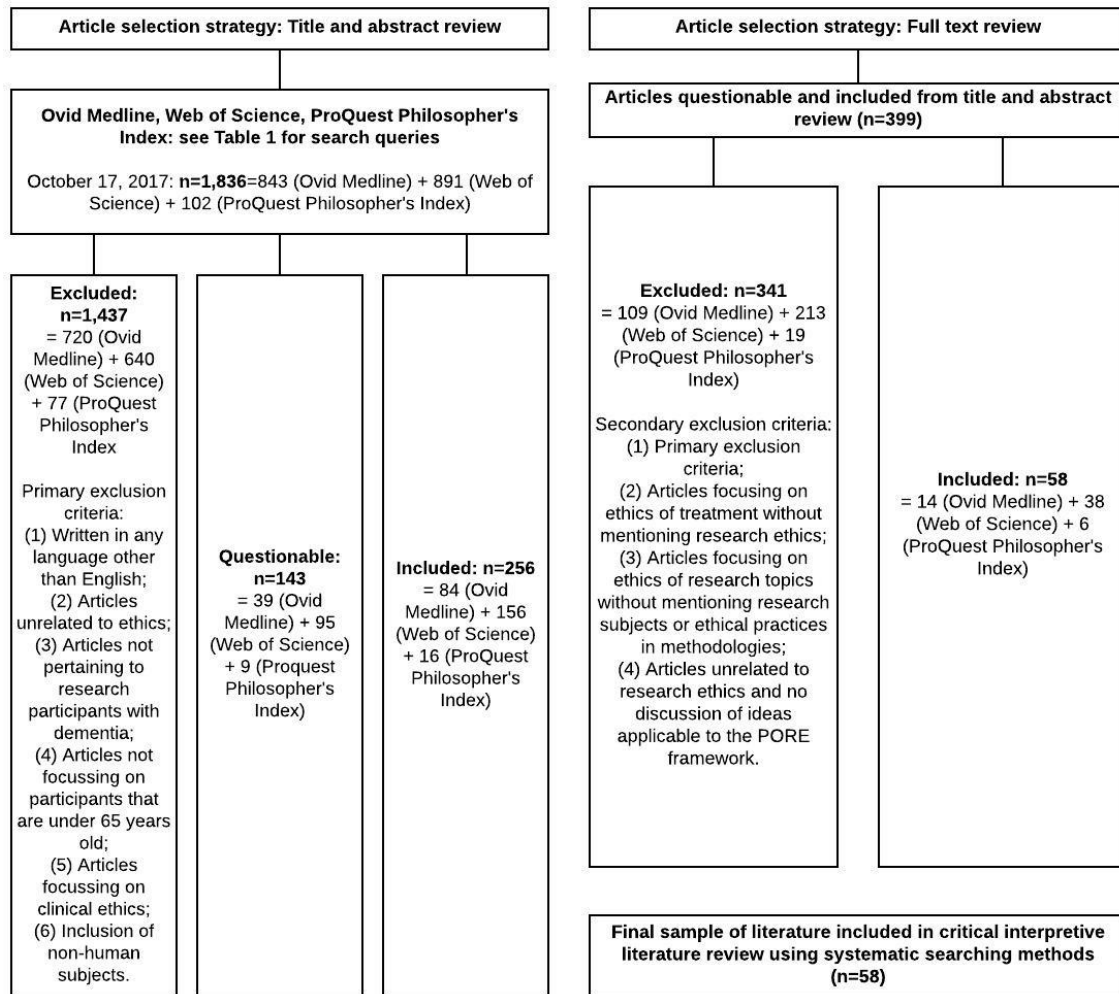


Figure 2: Review Flow Chart

Results and Discussion

The search yielded 1,836 individual papers. After the primary and secondary content reviews, 58 papers were included for data extraction (see Figure 2). The following sections highlight common themes found in the literature that are relevant within the participant-oriented research ethics framework. Each of the five guideposts of the framework are summarized under the context of dementia research and discussed using the search findings. A short discussion is included at the end of each of the five sections. Table 2 summarizes practical guidance found in the reviewed literature.

Focus on researcher-participant relationships	<ul style="list-style-type: none"> • Be aware of and respond to distress cues using a participant-specific predetermined distress protocol • Maintain positive relationships with gatekeepers • Provide gatekeepers with accessible information in advance • Express concern for caregiver’s wellbeing and provide them with resources (e.g., social networks, accessible information) • Establish positive closure between the researcher and participant at the end of the study • Be mindful of language in communicating with the participant and publishing the study (i.e., the complexity of language used, how the participant labels and identifies their cognitive condition) • For interview-based research, schedule time and location according to participants’ preferences, use a conversational tone, and use engaging active listening skills
Respect for holistic personhood	<ul style="list-style-type: none"> • Refrain from implicitly and explicitly excluding participants with dementia in research unrelated to dementia • Adjust communication techniques according to individual participant's needs, grounded in knowledge of dementia
Acknowledgment of lived world	<ul style="list-style-type: none"> • Identify relevant other parties (e.g., gatekeeper, caregivers, and proxy decision-makers) and engage with them as needed, following suggestions in “focus on research-participant relationships” above and “empowerment in decision-making” below • Tailor messaging about study to balance the avoidance of stigma with valuing transparency
Individualization	<ul style="list-style-type: none"> • Adjust research schedules according to each participant's level of lucidity at different times of day • Ask for consent during moments of peak lucidity
Empowerment in decision making	<ul style="list-style-type: none"> • Use ongoing consent • Recognize the participant's agency to make a decision outside of their "best interest" • Consider proxy consent, but use with caution • Consider advance directives, but use with caution • Adjust communication techniques to prioritize obtaining consent from the participant before resorting to a proxy or advance directive <ul style="list-style-type: none"> ○ Present information in an accessible format to each participant ○ Allow for participants to consent to some parts of a study and not others • Allow the participant to leave the study at any point, even if a proxy gave consent

Table 2: Practical Suggestions Extracted from Literature

Focus on Researcher-Participant Relationships

Researchers have power over their participants due to the social structure surrounding recruitment in studies, and the potential for cognitive impairment in participants with dementia to heighten power disparities. Focusing on the researcher-participant relationship is an effort to minimize this difference in power to ultimately help the participant feel at ease, comfortable, and safe throughout the study (Cascio and Racine 2018). Being aware of the researcher-participant relationship is particularly important when the participants have dementia because they may be unable to communicate discomfort, may feel like they do not have the ability to do so, or may be structurally disadvantaged in doing so. Researchers may have to rely on their awareness of the researcher-participant relationship to understand the participant's comfort level and experience. Additionally, the researcher-participant relationship in dementia studies requires an awareness of the experiences of both the participant and their research partner (who advocates for the participant), if they have one.

In recent literature, researchers have discussed the researcher-participant relationship in detail particularly as it relates to interview-based studies. They have suggested numerous strategies for conducting interviews that are mindful of the participant (Dempsey *et al.* 2016). For example, the location and environment of the interview seems to impact how the participant feels during the interview. Scheduling the interview according to the participant's schedule and location preferences diminishes the burden for the participant and caregivers. It gives the participant control of their environment, giving them a sense of security and safety (Dempsey *et al.* 2016). Allowing participants to be active agents in the research process can reduce the power disparity between the researcher and participant. For example, the researcher can allow the participant to direct the conversation instead of adhering to an interview schedule (Novek and Wilkinson 2017). Conducting the interview in a private space may increase the participant's comfort especially if the conversation may become more sensitive. Providing refreshments and tissues may also contribute to the comfort of the participant when discussing difficult topics (Dempsey *et al.* 2016).

In addition to the setting, the manner in which the researcher conducts the interview can impact the participant's experience. Conducting the interview in a conversational tone can support the participant in maintaining their train of thought (Murray 2013). Similarly, engaging in the conversation with active listening skills may help the participant feel at ease, allowing the conversation to flow naturally (Dempsey *et al.* 2016). Both of these strategies can give the impression that the interviewer has an interest in the participant as a person, rather than just a source for data (Dempsey *et al.* 2016; Hughes and Romero 2015). Being mindful of these strategies during interviews that contain sensitive talking points may be beneficial because it is ethical for the researcher to avoid causing any excess psychological harm (Novek and Wilkinson 2017). Providing comforting human touch and maintaining empathetic discourse can also be useful in more emotionally difficult interviews (Swarbrick, Sampson, and Keady 2017).

Interviews require the participant to disclose information about the self, which may cause emotional vulnerability and turmoil that results in the participant experiencing some distress during the study (Dempsey *et al.* 2016). Distress cues can have a subtle or sudden onset, so being attentive to the participant may aid in addressing the participant's distress (Novek and Wilkinson 2017). Being reflexive during the study and adjusting the research protocol to the participant's needs may help mitigate distress (West *et al.* 2017). This can include taking breaks as needed and potentially ending the interview prematurely for the day if the participant wishes (Novek and Wilkinson 2017). To more easily adjust to the wide range of emotions a participant may experience during an interview, researchers can prepare for these adaptations in advance. Developing a distress protocol can take place before beginning interviews so interviewers can remain grounded if distress occurs (Dempsey *et al.* 2016). Asking research partners and

caregivers which topics may be more sensitive for each participant allows researchers to feel more prepared and mindful before entering the interview (Novek and Wilkinson 2017).

The relationship between researchers and gatekeepers is a contributing factor for maintaining a positive researcher-participant relationship. In a research context, gatekeepers are anyone who can limit access to a potential participant, including caregivers and family members. Thus, maintaining a positive relationship with the gatekeeper is crucial because gatekeepers can mediate the researcher-participant relationship. Meeting the gatekeeper in person can initiate a trusting relationship, setting the groundwork for a smooth experience for all parties (Dempsey et al. 2016). Providing gatekeepers and participants with accessible information they can take home to read in advance can also encourage a positive relationship (Holland and Kydd 2015).

Caregivers can play an important role in the participant's life and affect their research experience. Facilitating participation in research can add burden to the already physically and emotionally taxing task of caring for another person (Prusaczyk et al. 2017). Expressing concern for the caregiver's wellbeing may generate a more positive research experience for all parties. Some caregivers' motivation for enrolling participants in research stems from a need for information, especially if they do not have much experience caring for people with dementia. Participating in research can provide them with a network of people who can empathize with their experiences (Black et al. 2014). Providing caregivers with resources and checking in on them can positively impact the relationships between all parties (Assari and Lankarani 2016; Black et al. 2014).

The research process can blur the boundaries between the researcher and caregiver roles (Lichtner 2014). The researcher may care for the participant's emotions during the interview session, and this can create a caregiver-like bond between the researcher and participant. Thus, some have suggested that it is imperative that both the researcher and participant have positive closure at the end of the study. Instead of a harsh end to the relationship, gradually withdrawing from the participant can take place (Dempsey et al. 2016). Asking the participant clarifying questions, following up with the final publication, and sending cards for birthdays are appropriate after the study concludes (Poscia et al. 2017).

Being mindful of language choice when interacting with participants and their caregivers can enhance the researcher-participant relationship. In general, avoiding stigmatizing language can de-emphasize the participant's vulnerability and lack of power in the situation (Novek and Wilkinson 2017). For example, the term "dementia" can be stigmatizing for some participants, especially if the participants have forgotten or are unaware of their diagnosis (Heggstad, Nortvedt, and Slettebo 2013; Higgins 2013; Novek and Wilkinson 2017). Thus, some have suggested using the term "memory problems" until the participant labels their difficulties as "dementia" (Higgins 2013). This raises critical questions regarding consent and data dissemination. Asking a participant to consent to a study on memory problems and later publishing the data as a study on dementia can be misleading and paternalistic, potentially causing psychological harm to the participant. Therefore, researchers being mindful that the language they use to obtain consent requires reflection on how they would like to publish or promote their findings (Novek and Wilkinson 2017).

Focusing on the researcher-participant relationship can be beneficial for both the participant and the researcher. Participants having positive experiences in research may lower attrition rates, thereby allowing the researchers to collect more meaningful data (Poscia et al. 2017). Yet, maintaining a positive relationship via some of the aforementioned strategies, such as following up with the participants after the completion of the study, requires both time and money auxiliary to the resource requirement of data collection. Factors such as study design and methods could moderate the degree of caretaking the

researcher experiences during their interactions with participants. It also may be difficult to avoid blurring the boundaries between researcher and caregiver, if at all possible, making the research termination more difficult to navigate because of the additional emotional connection. Thus, researchers could anticipate adopting a caregiver-like role and prepare to compassionately navigate this responsibility. The higher quality data may outweigh the costs of maintaining such a positive relationship. Additionally, RECs may be more inclined to approve of a study that positively impacts its participants by means of additional emotional support.

Respect for Holistic Personhood

Respect for holistic personhood recognizes the importance of including vulnerable participants in research and creating dementia-friendly accommodations to facilitate participation. In the context of research involving older participants, respecting holistic personhood values the enrollment of people with dementia and considers their needs throughout the research process. This includes allowing people with dementia to have access to research and not excluding them, while also acknowledging the selfhood of people with dementia despite having potential impairments in decision-making (Cascio and Racine 2018). In anthropology, “selfhood” is the idea that each person has individuality. It relies on the idea that people have a self, or a constant, permanent stream of consciousness throughout their lives (Scheper-Hughes and Lock 1987). Thus, a person contextualizes their continuous self within a temporal construct of their past, present, and future (Cohen 1998). Because dementia can compromise a person’s memory and cognition, and therefore impact their conscious continuous self, it can complicate decision-making (Buller 2015b). A dementia diagnosis can divide the continuous self into pre-diagnosis and post-diagnosis selves (Cohen 1998). Navigating this duality can be difficult from a researcher’s perspective, especially if there is conflict between the past and present selves. However, respect for holistic personhood values the research contributions of people with dementia and recognizes their personhood by considering the appropriate accommodations to facilitate their participation (Cascio and Racine 2018).

The articles that related to respect for holistic personhood typically fell into two main categories: medical research and social research. For research in either category, including people with dementia in studies can be beneficial for both the researcher and the participant, but the articles contextualized the benefits of research participation differently. By choosing to safely and ethically include this population, researchers are advocating for the population’s wellbeing.

Researchers have noted that because dementia symptoms vary drastically between people, there is also variation of communication abilities (Murray 2013; Novek and Wilkinson 2017). To accommodate the specific needs of participants with dementia and to make research more accessible, communication techniques can be adjusted, ideally by providing supplemental media to aid in the individual’s understanding. This can be particularly useful during consent processes and the giving of instructions (Hughes and Romero 2015; Murray 2013). An inability to communicate in a certain modality does not imply a lack of understanding or cognitive ability (Murray 2013). Adjusting communication according to the participant’s preferred modality can make the exchange of information easier (Murray 2013; Novek and Wilkinson 2017). Additionally, it helps in maintaining the person’s autonomy by inviting them to communicate their own decisions (Murray 2013).

Communication barriers can lead researchers to underestimate a person’s cognitive capacity and sense of self (Witham, Beddow, and Haigh 2015). Having dementia presents challenges to a person’s selfhood because it limits the ability to express individuality (Buller 2015b; Oneill 2013). However, if a person cannot communicate in a manner that others acknowledge, they may not properly recognize that person’s selfhood or holistic personhood (Oneill 2013). A person with dementia can still have a sense of

identity despite having bouts of confusion (Witham, Beddow, and Haigh 2015). Challenges to communication do not erase their selfhood, even if researchers are unable to fully comprehend it (Novek and Wilkinson 2017).

People with dementia typically experience significant exclusion from both social and medical research (Dowson, Doyle, and Rayner 2013; Onyemelukwe 2013; Prusaczyk *et al.* 2017; Wood *et al.* 2013). There are several factors contributing to this exclusion, including administrative limitations, a lack of accommodation, comorbidities, and gatekeepers (Prusaczyk *et al.* 2017). Meeting the administrative requirements, such as obtaining REC approval and adhering to deadlines, is more challenging because of this population's vulnerability. Researchers cite having a negative experience passing RECs and recruiting enough participants in a reasonable amount of time. Additionally, some researchers incorrectly assume that including people with dementia is prohibited (Henwood, Baguley, and Neville 2015). There is some uncertainty in conducting studies with vulnerable populations, creating additional challenges that researchers may not feel able to address.

In the medical literature, there is a focus on the implications of exclusion for knowledge production. Performing research with participants who have dementia can lead to discoveries of new treatments and therapies. Inclusion of these participants would actively contribute to the treatment of future generations by producing new information through research (Gilbert *et al.* 2017). Many people who have dementia also have comorbidities, and including them in studies not focusing on dementia will increase external validity (Prusaczyk *et al.* 2017). They may wish to participate in research pertaining to these other aspects of their life; however, the dementia diagnosis is a common exclusion criterion (Gilbert *et al.* 2017; Onyemelukwe 2013). Researchers who do not typically conduct studies that focus on dementia may not want to engage in the uncertainty and challenges that come with including participants with dementia (Onyemelukwe 2013). However, such exclusion from research can increase this population's vulnerability (Heggstad, Nortvedt, and Slettebo 2013). Additionally, the participants' caregivers may not wish to accept the burden of facilitating access to a study that does not focus on dementia if having dementia is the participants' most significant health issue (Dowson, Doyle, and Rayner 2013).

In social research, both knowledge production and the personal significance of participating in research were discussed. Involving participants with dementia in social research can reduce stigma and help advocate for this population. Participating in research gives people with dementia a voice and recognizes them as active members of society. If the general population gains a more accurate and valid understanding of dementia, there may be a reduction of stigma. Thus, including people with dementia in social research is a means of advocacy because higher inclusion rates lead to more information production and dissemination (Heggstad, Nortvedt, and Slettebo 2013).

In both social and medical research, scholars have largely cited navigating gatekeepers as a significant challenge to accessing people who have dementia. Because this population is vulnerable, as defined by the World Health Organization, they typically have several gatekeepers that attempt to protect them from the potential burden or harm of participating in studies (World Health Organization 2015; Hughes and Romero 2015). Several researchers have reported difficulties in recruiting participants with dementia because a gatekeeper denied access or asked for a specific participant to be excluded (Dowson, Doyle, and Rayner 2013). Gatekeepers also may be more likely to grant access if the potential participant is only in the early stages of dementia, which can result in a selection bias in the study (Hughes and Romero 2015).

Articles identified in this part of the review also paid significant attention to the ethics of exclusion. Although the grounds for excluding people with dementia suggest that inclusion would be unethical,

excluding this population on the basis of their diagnosis can also be unethical in certain circumstances (Dowson, Doyle, and Rayner 2013; Monroe et al. 2013). Denying this population the opportunity to participate in research solely because of the challenges their diagnosis presents, and not for the genuine safety of the participants, actively perpetuates discriminatory, ageist beliefs (Hughes and Romero 2015). Additionally, participating in research can be a valuable way to be active in society, and automatic exclusion from research denies this experience (Thorogood, Deschenes St-Pierre, and Knoppers 2017).

We found some disagreement in the literature regarding respect for holistic personhood. One of the primary issues is difficulty in navigating research administration. While researchers may wish to be inclusive of people with dementia, RECs may reject the proposal and thereby devalue their participation. This can demotivate researchers to include a significant portion of the older population. A 2012 review examined the exclusion rate of those with dementia-related cognitive impairment, revealing a 29% explicit exclusion rate in the sample of studies (Taylor *et al.* 2012). Other studies included in the review employed recruitment strategies that likely reduced the participation of those with cognitive impairment (*ibid.*). However, having respect for holistic personhood in both medical and social research can have significant benefits. In medical research, including participants who have dementia in research that does not centrally focus on dementia can make the data more generalizable to the older population. For example, in studies regarding treatment efficacy, inclusion of people with dementia can highlight whether a treatment is accessible and therefore effective for people who may have memory difficulties. In social research, inclusion of people with dementia can allow their voices to be heard, thus raising awareness, which can be a valuable and empowering experience for the participants.

Acknowledgment of Lived World

Acknowledging the lived world of a participant with dementia involves understanding the implications of both the diagnosis and the research study on the person's day-to-day life. The lived world encompasses participants' social experiences of illness (following Kleinman 1988) or disability (following Oliver 1983), and specifically the effect that participants' experiences in a world outside the research context may have on their present needs and overall experience within the research context (Cascio and Racine 2018). Likewise, participating in research can affect how they experience living with dementia. Acknowledging the lived world of someone with dementia involves understanding how their own and their community's beliefs and values can play a role in the research process.

As several researchers have noted, participating in both social and medical dementia research could impose a significant social risk (West et al. 2017). Society stigmatizes dementia, so those who begin to openly identify (or are identified by others) as having dementia may experience changes in how others treat them (Novek and Wilkinson 2017; Witham, Beddow, and Haigh 2015). These changes can include making assumptions about the person's cognitive ability, safety, and judgment, calling into question their identity as an autonomous adult (Reed, Carson, and Gibb 2017). Concepts such as relational autonomy, important in research ethics generally and person-oriented research ethics specifically, helpfully parallel long-standing anthropological skepticism towards the notion of a bounded, individual, egocentric self that underlies many discussions of autonomy in bioethics (see e.g., Buchbinder, Frank). Additionally, these social risks can cause people to feel less inclined to participate in research, especially if they have friends, family, or employers who can become aware of their participation (West *et al.* 2017). Identifying as a person who has dementia can negatively impact any and all relationships, including the relationship between the person and their self through internalized stigma. Participating in a dementia-related research study asks the participant to confront and acknowledge their identity as a person with dementia, which may be stigmatizing to the extent of deterring them from participating in research. A similar concept exists among some of the HIV+ population who choose to not receive antiretroviral therapy because of the emotional

burden of having a daily reminder of their HIV status (Persson *et al.* 2016). Acknowledgement of lived world requires understanding that these risks can impact the participation experience and participating in research can validate a person's status as a member of a stigmatized population.

Participating in a study may increase the daily challenges of having dementia, such as remembering additional appointments and following directions (Black *et al.* 2014). People and organizations that support people with dementia in their daily lives are also involved in everyday issues of research. These significant other people include family members, caregivers, and assisted living staff. If the person with dementia has a caregiver, the caregiver needs to accommodate the research requirements in their routine (*ibid.*). This can be difficult and thereby discourage participation in studies because even if the person with dementia wishes to participate, they might not have access due to their caregiver's schedule. Long-term care facilities may be less willing to accommodate individual patients' research schedules, and family members may live too far or may be unable to be free to facilitate these appointments (Wood *et al.* 2013). The caregiver may also have differing views on whether the person with dementia should be engaging in research, so they could simply be noncompliant in providing access (Dunn *et al.* 2013). However, it is worth noting that although most articles that discussed caregiver burden suggested it can inhibit participant enrollment, but Cary *et al.* (2015) argue there is no association between willingness to participate in research and caregiver burden.

The notable lack of articles in comparison to other guideposts could indicate a gap in research, an oversight by researchers, or a need for better strategies to discuss such an individualized topic. The major area in which a participants' lived world is discussed in the literature is through discussions of gatekeepers, caregivers, and proxies which overlap significantly with content in the guideposts of researcher-participant relationships (researchers must also build relationships with third parties) and empowerment in decision-making (when researchers consider proxy decision-makers). Although not discussed in the research ethics literature, there are also other significant persons who may have an impact on the research process. Notably, people with dementia may frequently talk about deceased or absent loved ones who continue to have a profound influence on the daily lives of participants.⁵ Observing the influence of absent or dead others in the lives of a person with dementia—whether the person with dementia experiences those others as dead or not—would be fully in line with longstanding anthropological engagement with the agential power and relational influence of the dead as ancestors, ghosts, memories, and so on.

Acknowledging the lived world of the participant is not always something that researchers can easily describe in their methods because it can simply be an empathetic attitude implicit in researcher-participant interactions. It is also largely participant-specific, so addressing this guidepost explicitly in their methods would be difficult in studies with numerous participants. For example, some participants may go through periods where they forget the focus of the study or their dementia diagnosis, thus using the term “dementia” may be disturbing (Bunn *et al.* 2012). Entirely avoiding the term could also be dishonest and unethical. Detailing these situations within the context of a methodology would be arduous but perhaps necessary, considering the current lack of resources in navigating dementia labels in research. Similar to focusing on the researcher-participant relationship, acknowledging the lived world and exercising empathy can decrease attrition by making research more accessible and comfortable (Poscia *et al.* 2017). Understanding the social and lived implications of participating in research can allow the researcher to adjust the protocol to make it more accessible to a larger population and increase enrollment.

Individualization

The guidepost of individualization in dementia research recognizes that even within culturally patterned social contexts, there are important individual differences in how each person may experience

their diagnosis, with both symptom presentation and day-to-day living. It considers these experiences throughout the research process and accommodates them as much as possible. Individualization goes hand-in-hand with acknowledging the person's lived world in that they both recognize how much variation there is within the dementia population. Literature pertaining to individualization in dementia research largely focuses on the implications of the variety in symptom presentation.

Scholars have suggested that researchers, health care practitioners, and anyone in a position of power over a person with dementia may automatically infantilize them on the basis of their diagnosis. A dementia diagnosis does not imply the incapacity to make decisions, nor should it be the basis for assumptions regarding the person's cognitive ability (McNally and Lahey 2015). In general, dementia is a progressive illness, but symptoms can vary from person to person. The progression is not necessarily linear, either, so knowing a person's typical symptom presentation does not allow for a sweeping generalization of their cognitive deficit. There can be high variation day-to-day and even hour-by-hour, with some people experiencing sporadic bouts of confusion or lucidity (West *et al.* 2017). Scholars have suggested it is up to the researcher to adjust their schedule accordingly. If a participant is typically more confused during a certain time of the day, the researcher can avoid performing the study at that time (Prusaczyk *et al.* 2017). Likewise, the researcher can ask for consent when the participant is most lucid, giving the participant maximal agency in the process (Prusaczyk *et al.* 2017; West *et al.* 2017).

Similar to acknowledgment of lived world, there were notably few articles pertaining to individualization. Per its title, this guidepost is participant-specific and difficult to discuss within an article that is not expressly discussing individualization. Additionally, the progression of dementia may cause a participant's needs to change throughout the study. We acknowledge that these details may be difficult to document within the confines of a research article.

Adjusting to each participant's schedule and abilities can be especially difficult when dementia symptoms vary day-to-day (Dempsey *et al.* 2016). However, these adjustments could make a formerly ineligible participant eligible for enrollment. Accommodating individual participant's needs allows more people to participate in research and can give participants a more positive experience throughout the process. Additionally, adjusting a medical study that does not focus on dementia to the specific needs each participant with dementia, and thus allowing them to participate, generates a more representative sample of the older population. This can increase the external validity and make the data more meaningful (Prusaczyk *et al.* 2017).

Empowerment in Decision-Making

Empowering a person with dementia in decision-making processes is an effort to retain their autonomy, and it allows them to act as their own agent as much as possible. Specifically, in dementia research, empowerment in decision-making allows participants to make any decision they are cognitively able to and provides participants with assistance in the decision-making processes if they need it. In the literature pertaining to this guidepost, the discussion primarily focuses on consent practices.

One strategy for empowering decision-making is the notion of ongoing consent already well-recognized by anthropologists and established in the American Anthropological Association Code of Ethics (American Anthropological Association 2012; Heggstad, Nortvedt, and Slettebo 2013; Overton *et al.* 2013; Thorogood, St-Pierre, and Knoppers 2017). It is a process where researchers continually ask for consent throughout the research project, thereby establishing a trusting relationship and providing many opportunities for dissent. Likewise, it provides several opportunities for the participant to make informed decisions and renegotiate the terms of consent (Heggstad, Nortvedt, and Slettebo 2013). These decisions

can be adjusted to the participant's cognitive abilities (Heggestad, Nortvedt, and Slettebo 2013; Monroe *et al.* 2013).

Some scholars suggested that proxy consent is sufficient if the participant has decisional impairment, provided that the researcher allows the participant to leave the study if they wish (West *et al.* 2017). However, this is a point of contention. On the one hand, participant's wishes are of primary importance even with proxies and assisted decisions (Hughes and Romero 2015; Monroe *et al.* 2013). A participant's decision-making capacity largely depends on the decision in question and the participant may not always need assistance (Dowson, Doyle, and Rayner 2013). Yet, on the other hand, other scholars suggest that advance research directives (a legal document written while a potential participant has consent capacity that allows the participant to express their preferences regarding research enrollment should they later not have consent capacity) more effectively preserve autonomy because it is still unclear why a proxy would be in a better position to determine the best interest for the participant over the participant's previous wishes (Jongsma and van de Vathorst 2015a).

Participants in dementia research have the right to make informed decisions, despite their status as members of a vulnerable population (Pachana *et al.* 2015). Participants with dementia even have the right to make decisions that are not in their "best interest" (Jongsma and van de Vathorst 2015a). For example, it may not be in the "best interest" of the participant to enroll in a biomedical study that does not suggest the potential for treatment. The participant may wish to enroll in a randomized controlled trial out of altruistic motivation, despite its burden and lack of medical benefit. Thus, a participant making a decision not in their "best interest" is not a sufficient basis to reject the decision (Jongsma and van de Vathorst 2015a). Similarly, scholars have denied its validity as an argument for assuming that the participant has low decision-making capacity (*ibid.*).

Advance research directives are another strategy to empower the decision-making of a person with dementia. They preserve the person's autonomy by allowing them to express their future wishes and desires before they become symptomatic (Jongsma and van de Vathorst 2015a; Onyemelukwe 2013). Although a person may not be able to explicitly reaffirm their previous decisions at the time of research enrollment, this does not indicate a change in preferences (*ibid.*). The wishes they outline in their advance directive are expressions of selfhood, and allowing them to make decisions about their future maintains their role as their own agent (Buller 2015b). However, outlining future research decisions in an advance directive is relatively uncommon because advance directives are traditionally for healthcare (Dowson, Doyle, and Rayner 2013). If a person with dementia does not have an advance research directive and is too symptomatic to consent, scholars suggest allowing them to appoint a proxy is another strategy for empowering their decision-making (Black, Wechsler, and Fogarty 2013).

It is the researcher's responsibility to enable the participant to take part in decision-making to the best of their ability (Heggestad, Nortvedt, and Slettebo 2013). Additionally, caregivers can underestimate the abilities and strengths that a person with dementia retains; thus, presenting research information personally to the participant may reveal their higher decisional abilities (Gilbert *et al.* 2017). Participants with dementia who are unable to consent to the entire study may still be able to make other, smaller decisions in the study. For example, they may be able to understand and consent to parts of the project, exercising some agency in the consent process (Dowson, Doyle, and Rayner 2013).

Empowerment in decision making is the guidepost that is most discussed in current literature, possibly because of its legal relevance in navigating the issue of the decision-making capacities of participants with dementia. Although legal regulation is a significant component of ethics, it does not encompass the entirety of ethics practices. Person-oriented research ethics focusses on everyday ethics,

which often exists outside of the legal realm. Thus, in keeping with the person-oriented research ethics framework, the data extracted specifically focused on everyday ethics.

We found contention about empowerment in decision-making, especially regarding the validity of proxies and advance directives. Some scholars suggest that obtaining consent from proxies is a good strategy when the participant is unable to make decisions, but others have argued that proxies might not necessarily make the decision that the participant would have made prior to experiencing dementia symptoms. Similarly, advance directives preserve autonomy, but the participant's opinions may have changed since creating the advance directive. Both of these strategies supersede obtaining consent from the participant, which may be paternalistic and unethical if they are still able to consent to any aspects of the research.

Documenting the consent process in publications would be a prudent step forward for dementia researchers. We found significant uncertainty in the literature regarding consent largely because researchers in the health sciences rarely describe their strategies or experiences in their final publications. Beginning to record how they assessed their participants for capacity to consent and how they obtained consent could help the process in future studies. It could also improve the experience for both the researcher and the participants because the researcher will be more confident in the process.

Empowerment in decision-making for dementia research is complex from an anthropological perspective. The emphasis on facilitating the participant to make decisions and provide consent is deeply rooted in the notion that dependency is a loss of self and identity (Cohen 1998; Leibing and Cohen 2006; Taylor 2008). Dividing the continuous self into pre-diagnosis and post-diagnosis selves is dubious because of the "entanglements" Lock (2013) identifies between dementia and normal cognitive aging (Lock 2013). Additionally, advance directives challenge the post-diagnosis self and have the potential to invalidate it (Bunn *et al.* 2012). This is problematic because, much like normal aging, dementia is irreversible (Cohen 1998; Leibing and Cohen 2006). However, some individuals experience moments of lucidity, which complicate the progression from pre-diagnosis to post-diagnosis self.

Conclusion

Handling more conventional research ethics issues as well as more relational and experiential aspects of research ethics is of high importance considering the prevalence of dementia and the amount of resources allocated to research on dementia. The person-oriented research ethics framework offers five guideposts which help think about these relational and experiential aspects and tackle them. In our extensive review of ethics and dementia literature, we extracted significant content pertaining to these guideposts which demonstrates their relevance in both clinical and social research and the enrichment brought by a purposive literature review. We address not only the ethical issues involved in research about dementia, but also the desirability of including people with dementia in research on other topics that interest them. Broadening the conversation in this way respects that people with dementia are not reducible to their diagnosis, but live full and complex lives that might involve research participation.

Despite the wealth of information on dementia research ethics, there is a distinct lack of explicit and consolidated dementia-specific guidelines available to researchers beyond the more conventional regulatory requirements about topics such as consent and confidentiality. Person-oriented research ethics requires attention to ethics beyond the regulatory. Dementia-specific guidelines in a person-oriented research ethics framework would provide details on day to day interactions between researchers, participants, and caregivers, research partners, or proxies. The literature also reveals that there are still significant barriers to conducting ethical, person-oriented, research with participants with dementia. The

systematic exclusion of participants with dementia is largely rooted in ageist conceptions of cognition in older people and a lack of accommodations for those with dementia. By delving into the existing literature, we have extracted some guidance, summarized in Table 2. However, these recommendations derive only from recent literature on research ethics, understood within the context of various tensions described in the narrative above. More targeted work needs to be done on the ground, to understand the everyday ethical issues that affect participants with dementia in research. Such work would contribute to the empirical study of human research ethics and frameworks of evidence-based research ethics (Kalichman 2009), which benefits immensely from anthropological work describing inter- and intracultural variations in the definitions, meanings, and experiences of ethics concepts. Such further work would inform a stronger set of accessible, easy-to-use dementia-specific guidelines for researchers, informed by lived experience and ethnographic expertise, which will assist in operationalizing person-oriented research ethics in a variety of situations.⁵

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Notes

- ¹ The work described in this paper was carried out at the Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal.
- ² Web of science allows truncation at the beginning of words so this database required fewer queries.
- ³ Examples include an article that discusses the ethics of using monitoring devices for patients with dementia (Hall *et al.* 2017) and an article that discusses the ethics of providing palliative care to patients with dementia (Mahin-Babaei, Hilal, and Hughes 2016).
- ⁴ Examples include an article discussing the ethics of growth hormone replacement research (Juengst 2002) and an article discussing the ethics of extending the human life span (Partridge *et al.* 2009).
- ⁵ We are grateful to Christine Verbruggen for this observation.

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