

University of Nevada, Reno

**Finding Pesa Soaname:
Using Documentary Film to Explore Selfhood and Personhood
Within the Context of Dementia at the Pyramid Lake Paiute Tribe**

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Arts in Journalism

by

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ABSTRACT

Increasingly, academics are exploring selfhood and personhood among people living with dementia with intent to inform care practices and community development efforts. Yet very little is understood about dementia in indigenous populations, and nearly no information is available regarding selfhood and personhood within the context of dementia for Native people, despite their increased risk of developing dementia. This study—conducted in partnership with the Pyramid Lake Paiute Tribe—utilizes Video-Based Dialogical Analysis to unpack how tribal elders living with dementia are supported in preserving selfhood and personhood. The analysis employs a dialogical research framework, which rejects the tendency to finalize participants as is typical in traditional, monological research. Rather, participants are engaged in genuine conversation that helps them chart their path of perpetual becoming, expanding complexity through generative questions instead of reducing it through fundamental truth claims. Participants described selfhood for tribal members as inextricably linked to land, family, culture, and community. Identity was so interwoven with notions of service that selfhood and personhood appeared to operate as a single construct. Tensions between Western and traditional ideologies related to these pillars of selfhood and personhood threaten the well-being of tribal elders living with dementia, yet participants believe that intentional conversation surrounding dementia will help navigate those tensions. Throughout such conversations, one phrase rings with particular resonance: “*pesa sooname*.” Meaning “good thought” or “good think” in Northern Paiute, “*pesa sooname*” denotes the power of positivity and strengths-based perspectives. At Pyramid Lake, tribal members are using *pesa sooname* to make positive change, and hope to find *pesa sooname* on the other side of that important work.

DEDICATION

This study is dedicated to the man most influential in my life: my grandfather, Frank Lionel. I grew up with my mother and her parents, so my grandfather was a core part of my life since my earliest days. He was diagnosed with Lewy body dementia when I was 13 years old. My family had no idea what to do, so what we did was focus on his dementia. We treated him as if he was his disease, and in doing so we lost sight of his humanity. When it made most sense from a disease-centered perspective to move my grandfather into a nursing home, we did that. My grandfather died just a few weeks later, perhaps from his disease, but perhaps too because he no longer had anyone treating him like a full human being. He no longer felt connected to others.

Now, through the connections I have been privileged to make with people living with dementia across the world, I know that not only is it possible to live well with dementia, but people are doing just that. I've come to know the power of a supportive community, and the importance of maintaining connections between communities and people living with dementia in a manner that fosters both individual and collective well-being. I may no longer be in a position to make a positive impact in my grandfather's life, but his memory fuels me every single day as I work alongside people living with dementia to tell a different story of dementia—the real story of dementia—that honors people living with dementia as not only fellow community members, but elders to be revered.

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I also want to thank the Pyramid Lake Paiute Tribe, and specifically the Pyramid Lake Paiute Tribal Council, for their enthusiasm for this project and their commitment to mobilizing the stories of elders, family members, and people living with dementia at Pyramid Lake. It is my enduring honor to work with all of you in support of this mission.

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Within our conversations, participants recounted these creation stories of Pyramid Lake, quoted verbatim as the stories were told.

A long time ago, there was a council that was sent to the ocean for a meeting, and they went to the ocean, and they traveled to get there. And when they were there, there was a young man who wasn't interested in what they were talking about. So, he wandered, just to go see what he could see. While exploring, he met a woman and fell in love. So, when it was time for them to come back, he said, "I met somebody, and I would like to take her home with me." And they said, "No, she's different," and "No, you can't take her back.," and they decided to come back. And on the trip, it kept raining on them all the way on their trip. It rained and rained and rained and rained. And they came along, and water would kind of puddle around them. And they got up on the top of the mountain and they decided they were gonna camp out there, but then water just really started accumulating. So, they came down the mountain, kept coming and kept coming. And they got here, to this valley where we are now. And he said, "I brought her home. I told her to follow us." And they said, "Because you disobeyed us, you need to take her and go to live all the way at the end of the valley. Go and live there with this woman that you brought home that we told you, 'Don't bring home.'" And water accumulated around them. And it turns out she was a mermaid. That's why she needed the water. On the trip up, the waterways are clear liquid, clear water. Lake Tahoe was the lake that formed on the mountain, which is clear. They didn't stay there long enough. The Truckee River flows through Reno, through Nixon, to here. And that's freshwater. But Pyramid Lake is salty because she needed the salt water, because she was a mermaid.

There was a mother and a father, and they had children. And out of the children, you know, when they were small, they listened to the parents, they behaved, but as they got older, they started to misbehave, become naughty and not listen to the parents. And as a result of that, the parents decided that the only thing that they could really do is to separate the children and have them be away from each other. And so, two of the children—a boy and a girl—were sent south, and a boy and a girl were sent north, and they were instructed by the mother that they were to build a fire each evening so the mother would know that they got to the place that they needed to be. So, they were to do that, to build a fire for four nights in a row. And the mother was able to see the smoke from the fire for the children that went south, but she wasn't able to see the smoke from the fire of the children that went north. And with that she became very sad and distraught, and she cried and cried and cried. And so, it's her tears that formed Pyramid Lake, and she still sits there to this day on the east side of the lake. And the water is salty here at Pyramid Lake, so just as our tears are salty so is our water.

INTRODUCTION

The Truth about Dementia

To define the term, “dementia” refers not to any single disease but instead to a collection of symptoms that can be brought about through a variety of different diseases of and injuries to the brain. In this fashion, dementia is most accurately described as a syndrome (Breitner, 2006). Alzheimer’s disease is the most common cause of the dementia syndrome amongst the population at large, representing approximately two-thirds of cases, however there are currently over 100 different distinct forms of dementia that have been identified (Alzheimer’s Association, 2023). Many individuals—perhaps even a majority—are living with more than one type of dementia at the same time, a condition called “mixed dementia” (Zekry et al., 2002). While each form of dementia involves its own typical symptoms and progression, and everyone’s experience of dementia is unique, in most instances dementia entails a shift in thinking skills significant enough to disrupt daily life and that is progressive, meaning it gets worse over time. Memory is the most well-discussed of these thinking skills, but dementia can also affect planning, judgement, vision, emotion, and one’s sense of time and place (Alzheimer’s Association, 2019).

Approximately one in nine Americans aged 65 and older are living with dementia or will go on to develop dementia, and the total number of people living with dementia is set to reach 12.7 million by 2050, a near tripling of the current statistic (Alzheimer’s Association, 2023). Just within United States, there are approximately 6.7 million people living with dementia as of 2023. Dementia is not an uncommon condition, so why do so many of us still remain so woefully unaware of its realities, to the extent that the average citizen likely would be unable to describe the difference between dementia and

Alzheimer's disease? The answer lies squarely in the lack of public amplification of the voices of people living with dementia and family care partners. It isn't that people living with dementia aren't sharing their stories; time and time again, people living with dementia raise their voices in self-advocacy on national and international stages. Rather, the authentic lived experience of people living with dementia is not showcased in popular media.

Portrayals of Dementia

Some analysis has been conducted on the portrayal of dementia and people living with dementia in both fictional and factual manners throughout popular culture. Within journalism in the United States and United Kingdom, dementia has been overwhelmingly presented through a biomedical lens (Bailey et al., 2021; Zeilig, 2015). This way of understanding dementia explains the experiences, words, and actions of people living with dementia as products of a biomedical condition generated entirely within the person living with dementia. A social/relational lens, conversely, explains the things people living with dementia feel, do, and say as products of an interaction between the person living with dementia and their environment. A biomedical perspective isolates a person living with dementia and ascribes them no agency; a social/relational perspective emphasizes connectivity and assumes that people living with dementia speak and act with meaning (Davis, 2004). The biomedical paradigm of discussing dementia threatens the well-being of people living with dementia, while the social/relational paradigm supports that well-being. To further emphasize this point, one review of dementia portrayals within popular culture described the systematically biomedical nature of those portrayals as equating

dementia itself with a “natural disaster” and people living with dementia with “the living dead” (Low & Purwaningrum, 2020, p. 10). Another found the portrayals of dementia to be exemplary of inter-relational violence (Mitchell et al., 2013).

When high-quality content that highlights the lives of people living with dementia in a social/relational manner is indeed created, it is often left to languish in niche corners of society, reaching people who already are connected with the dementia activism space but not finding its way to the general public on any notable scale (Cohen-Shalev & Marcus, 2013). However, this is not the case in all cultures. Dementia within Japanese journalistic and creative content almost never alludes to the “loss of self” so intricately connected to a biomedical contextualization of dementia (Drott, 2018), and fictional stories involving characters living with dementia in Germany focus on the enduring self and are typically quite positive (Kessler & Schwender, 2012).

If there are societies across the globe that are successfully discussing dementia differently and embracing a social/relational lens, why is that not happening in the United States? When considered closely, the lack of enlightened portrayals of dementia is not surprising. Perhaps no group of people experiences the compounding influences of intersectional oppression more than people living with dementia, who bear the brunt of both ageist and ableist stereotypes. Western ideologies of intellectualism and cognitivism—particularly rampant in the United States—have all but equated human value with what one *does* rather than who one *is* (Descombes, 2021), and an associated paradigm of individualism has exalted those of us who go it alone and “pull ourselves up by our bootstraps” (Vandello & Cohen, 1999). This way of thinking relegates people living with dementia—who by nature of their condition cannot *do* as much and who rely on systems

of interdependent support for their well-being—to the bottom of a value-based stratification of personhood, with all the stigma that is furnished by such a designation (Hanssen & Tran, 2019). It is assumed that a life with dementia must necessarily be a life of suffering, an existence to be resented by the person living with dementia and pitied by everyone around them. This narrative has been termed the “tragedy discourse” of dementia (Reed et al., 2017). Yet, when considered through a social/relational lens, the tragedy is redefined; nothing inherent to the changes in thinking skills associated with dementia produces such suffering. Rather, it is in fact society’s response to dementia—the complete dehumanization of people living with dementia—that causes much of the suffering typically ascribed to a life with dementia. If we can reorient society’s default modes of reacting to and interacting with people living with dementia, the tragedy itself might dissipate; people living with dementia who exist in a manner outside of traditional social norms would be freed to explore the possibilities of their realities, and dementia would become as much an emancipatory space as it is a pathology (Foth & Leibing, 2022). Simply put, the way we discuss people living with dementia has a direct impact on their ability to live well (Cahill, 2021).

Selfhood and Personhood

Academia, for its part, is increasingly striving to unpack the complexities of living with dementia and to detail empirical and theoretical groundings for continued selfhood and personhood among people living with dementia. To clarify the difference between these two concepts, selfhood is a reflexive capacity and is connected to one’s sense of oneself, whereas personhood is a sociopolitical capacity that is expanded and retracted as

one's place in society is negotiated between oneself and others. The popular framework of "person-centered care" is founded on the understanding that the identity of people living with dementia does not diminish as dementia progresses but remains for as long as the people around the person living with dementia continue to grant that person their personhood and offer opportunities for their engagement in their selfhood (Kitwood, 1997).

It is a reasonable question to ask whether someone living with dementia continues to retain a sense of self throughout their disease progression. After all, people living with dementia are often considered to be detached from their surroundings, unable to engage in conversation, and unable to attend to their basic needs of daily living (Low & Purwaningrum, 2020). A biomedical perspective on dementia would label this the inevitable result of the brain disease causing the dementia in the first place. However, a social/relational lens allows the realization that the perceived loss of self is in fact not a result of the dementia but of the ways others view and treat the person living with dementia (Sabat & Harré, 1992). Some even consider the state of living with dementia to be one in which a person living with dementia can confront their internal life—their selfhood—with greater clarity and continuity, even if they cannot as easily express those internal explorations as cogently (Hutmacher, 2021). In addition, scholars are now extending the notion of selfhood to existing not solely in the realm of the sociocultural but also in the body itself, an embodied selfhood that comprises physical movements made by the body (Kontos, 2005). Such movements can be powerful, containing knowledge that can assist in direct care and support just as much as it can assist in interpersonal communication (Katz, 2013; Kontos & Naglie, 2007). Some scholars have even gone as far as to posit that the self is in fact more *dividual* than *individual* and exists in an inter-embodied fashion

amongst a person living with dementia and the people and places supporting their care (Jenkins, 2014; Kovan & Soled, 2022). In these ways and others, the description of selfhood for people living with dementia is being continually elaborated in qualitative research circles, with the resounding conclusion that selfhood is not extinguished even in the most progressed cases of dementia.

Yet for selfhood to translate into well-being, a person must also be granted personhood and be considered as a genuine member of their family, community, and society. Despite the proven nature of retained selfhood for people living with dementia, adequately supported personhood is far less reliable. First, it involves the simultaneous interaction between the person living with dementia and a multitude of external actors all of whom might have differing assumptions about even the very selfhood of the person living with dementia (Hennelly & O’Shea, 2021). Second, effectively upholding personhood requires thinking beyond the dominant philosophical frameworks—such as Cartesian mind-body dualism—that undergird Western cognitive life (Dewing, 2008). Some scholars purport that due to these complexities, personhood itself is too ethereal a concept to be useful for guiding actions to support the well-being of people living with dementia, instead urging a focus on “supporting people’s existing capacities, while minimizing the harmful consequences of their incapacities” (Higgs & Gilleard, 2016, p. 773). Yet if we can successfully uphold personhood for people living with dementia in a manner that is systematic and institutionalized, we can re-integrate people living with dementia into the political and social systems as full citizens (Swinton, 2021), a necessary measure for a truly inclusive society.

The Role of Care Partners

Contrary to popular notions, most people living with dementia do not in fact live in institutional care setting like nursing homes or memory care communities. Rather, they live in their own homes, in their own communities, without direct daily support from the healthcare workforce (Chi et al., 2019). This positions family members as the primary care partners for most people living with dementia, and therefore an essential variable in the personhood equation that each person living with dementia and the people around them must balance. Given the sheer number of unpaid family care partners for people living with dementia in the United States—over 11 million as of 2021 (Alzheimer’s Association, 2023)—significant effort has been dedicated to understanding what makes for a beneficial and rewarding care partnership.

Care partners that experience positive outcomes of care partnership—such as stronger relationships or personal meaning—enjoy increased well-being and report higher self-efficacy (Quinn & Toms, 2018), which is important considering that a sense of purpose in life for both care partners and people living with dementia contributes to more positive outcomes for both parties (Polenick et al., 2018). Conversely, decreased well-being has been connected to lowered care partner competence (Quinn et al., 2019). Care partner well-being is clearly an important factor in supporting the well-being of people living with dementia, and culture itself can have great bearing on such well-being; the average well-being of care partners has been shown to differ greatly between care partners of different racial backgrounds (Liu et al., 2020). In summary, just as a person living with dementia cannot be granted personhood in isolation, it is fundamentally incomplete to consider the

well-being of people living with dementia without also considering the well-being of their care partners (Miller et al., 2019).

Dementia in Indian Country

Most of the research cited in this thesis so far—and all the work pertaining to selfhood and personhood—was conducted with populations of European descent. In a search of the “Academic Search Premiere” database, the keyword combination “Indigenous AND Dementia AND Selfhood” returned no results. The keyword combination “Indigenous AND Dementia AND Personhood” returned only two results (Hulko et al., 2010; Yip et al., 2022), neither of which discussed personhood within the context of dementia amongst American Indian people. This gap in the academic literature is striking for two reasons. First, Native people are at a three-fold higher risk of developing dementia than members of the general population, and therefore American Indian and Alaska Native communities will be those most highly impacted by dementia and those which could most benefit from a robust understanding of how to support people living with dementia in preserving their personhood (Alzheimer’s Association & Centers for Disease Control and Prevention, 2019). Second, the core concepts of selfhood and personhood among American Indian and Alaska Native people already hinge on relationality and inter-embodiment (Bacigalupo, 2004; Krupat, 1991; Schwarz, 1997; Tinker, 1992), which represents a marked alignment with research-based portraits of selfhood within dementia. As such, American Indian and Alaska Native communities may be particularly suited to supporting the well-being of their members living with dementia.

Given that we already know that the concept of dementia and the experiences of people living with dementia and family care partners are influenced by cultural notions of health and wellness (Henderson & Henderson, 2002; Henderson & Traphagan, 2005), it is reasonable to hypothesize that American Indian people have come to different conclusions regarding dementia from those often encountered in Western cultures, and have been supporting the well-being of people living with dementia more capably because of that shift in understanding. Indeed, this hypothesis is supported by existing research that has explored perspectives on aging and memory loss amongst First Nations elders in Canada that identified the very notion of dementia itself as a culturally foreign label that interferes with traditional manners of supporting elders through age-related memory changes (Hulko et al., 2010).

The Power of Film

To summarize the above paragraphs, three things are clear. First, it is essential that we create opportunities for the general public to connect with the true identities of people living with dementia if disabling stigma is ever to be dismantled. Second, those identities comprise more than just the person living with dementia, but manifest as inter-embodied selves that are encapsulated within body movements and relationships with people and places as much as they are defined by personal histories, preferences, and goals. Third, it is of particular importance to expand our understanding of selfhood and personhood within dementia among Native people. Documentary film is the perfect tool for expanding our conceptions of dementia according to the needs at hand for three reasons: it can be readily

disseminated and encountered publicly, can serve as the foundation for rigorous qualitative analysis, and honors the wisdom and full identities of indigenous people.

Documentary film is being increasingly employed to educate the public about dementia, however many films perpetuate the very dehumanizing narratives that need to be transformed (Zeilig, 2014). The films that do approach dementia from a more enlightened angle tend to highlight specific therapeutic approaches that might benefit the health and well-being of people living with dementia rather than unpacking the question of how to support their selfhood and personhood (Mills, 2018, 2021; Rossato-Bennett, 2014) or focus predominantly on the experience of care partners without exploring the experience of people living with dementia themselves (Mills, 2016). There is one film—titled *Mum*—that prompts in-depth consideration of how people living with dementia and their care partners might work together to all live well throughout the course of dementia, however the film is quite theatrical and abstract, potentially leaving viewers without any resolution to their considerations (Swinnen, 2013). It is also important to note that none of the aforementioned films discuss dementia within an American Indian context. A compelling and easy-to-follow documentary that foregrounds the conversation about selfhood and personhood among American Indian people living with dementia and their care partners is desperately needed.

Documentary film has the potential to be utilized academically in addition to popularly. Recent work has demonstrated the power of documentary film to serve not only as the output of qualitative research (Brandt et al., 2016; Petrarca & Hughes, 2014) but as the basis for qualitative analysis as well (Borish et al., 2021). Borish et. al. developed a new method of qualitative investigation they titled Video-Based Qualitative Analysis that

combines the processes of qualitative data analysis and documentary film construction. Additionally, the method considers not only the transcripts of research interviews but also the physical expressions of interviewees and the locational context in which interviews take place. This opens the door for the examination of embodied aspects of selfhood in a manner that more traditional qualitative analysis does not, and recent explorations of personhood within dementia identify this sort of analysis as a needed contribution to the existing literature (Hennelly & O'Shea, 2021).

Lastly, documentary film is uniquely situated to authentically communicate knowledge held by indigenous individuals and communities in a manner that upholds their identities, preserves cultural and artistic modes of expression, and contributes to broader global conversations about indigenous sovereignty (Aufderheide, 2008; Bonny & Berkes, 2007; Rice et al., 2020).

The Pyramid Lake Paiute Tribe

The Pyramid Lake Paiute Tribe has approximately 3,000 enrolled members, approximately 1800 of which live on the tribe's 750-square-mile reservation 35 miles northeast of Reno, Nevada. The tribe joined the statewide Dementia Friendly Nevada initiative in 2018 and is among the first tribes in the country to begin considering dementia as a public health priority (Alzheimer's Association & Centers for Disease Control and Prevention, 2019). They named their Dementia Friendly Nevada Community Group "the Pesa Soaname Advisory Group." In Northern Paiute, "Pesa Soaname" means "Good Thought" or "Good Think," and their intentions for the group were to promote good thoughts toward people living with dementia and also to protect their own good thinking

through proactive measures to support brain health. Through my work with Dementia Friendly Nevada, I had the opportunity to build strong relationships with key tribal leaders. Given their preexisting interest in dementia and the already established working relationships I had cultivated, the Pyramid Lake Paiute Tribe represented an ideal population with which to partner for this study.

Purpose of the Study

The purposes for this study are twofold. First, this study fills a gap in existing knowledge, building on scholarship surrounding selfhood, personhood, and dementia and investigating the concepts within an American Indian population—the Pyramid Lake Paiute Tribe—for the first time. The knowledge gleaned from this work has the potential to expand our current notions of how selfhood evolves throughout someone’s life with dementia and how someone’s personhood can be best supported regardless of their living with dementia. It also lays a foundation for further exploration of these topics within American Indian communities: an essential step forward toward appropriate representation and equity in research.

Second, the execution of the aforementioned academic components of this study was accomplished through the production of a documentary film exploring supporters of well-being amongst people living with dementia and family care partners at the Pyramid Lake Paiute Tribe. This film can be mobilized broadly and therefore can steward the wisdom of Pyramid Lake Paiute Tribe members to achieve impact amongst the population at large. Were it not for the production of this film in association with the academic

research, the insights gleaned would not be translated into a medium of actual utility to people living with dementia and family care partners globally.

Theoretical Framework

Qualitative research typically involves the selection and utilization of a central theoretical framework that guides the development of research questions, the analysis of qualitative data, and the synthesis of themes and/or theories that add to existing knowledge about the study population (Denzin & Lincoln, 2017). Qualitative approaches such as Grounded Theory utilize inductive reasoning to generate theory that is “grounded” in the data to foster the emergence of understandings that might otherwise have been occluded by researchers’ pre-existing assumptions, but even Grounded Theory strives to surface some measure of truth that can be compiled into humans’ collective foundation of knowledge (Charmaz, 2014). This paradigm of conducting research on populations of interest for the benefit of humanity more broadly is problematic for two reasons. First, it presumes the capacity to fully capture and define the identities and characters of research participants. Since humans are constantly evolving and since no research methodology—no matter how rigorous—could ever elucidate all there is to know about an individual, it is erroneous to make fundamental truth claims as the result of qualitative research. Second, such endeavors do little to benefit the research participants themselves, and thus represent a form of exploitation that can be criticized on both moral and practical fronts; the alienation of research participants from the goals of research efforts can jeopardize the success of future academic work with the study population. Arthur Frank (2005), paraphrasing and quoting Bakhtin (1984), summarizes the above points as follows:

Academic interrogation holds researchers responsible for rendering those whom they have studied “as something totally quantified, measured, and defined to the last detail.” Dissertation committees, journal referees, and grant adjudication committees expect a research report to be able to claim of its subjects, “all of you is here, there is nothing more in you, and nothing more to be said about you.” Those expectations, Bakhtin argues, are wrong. They are wrong both as an empirically adequate description of the human condition, and they are ethically wrong. (p. 965)

Research of this sort has been a hallmark of colonization amongst indigenous communities globally, and Native people have partnered with researchers committed to improving their discipline to suggest practices that must be upheld for research with indigenous communities to be both just and productive (Cochran et al., 2008; Jacklin & Kinoshameg, 2008; Warry, 2009), actively supporting decolonization in addition to simply doing no additional harm (Jones & Jenkins, 2008; Watson, 2022). Decolonization is defined as “the process of identifying and taking apart the institutions, policies and practices that the colonizers erected in order to diminish and/or destroy Indigenous cultures and traditional ways of life” (Hulko et al., 2010, p. 320). Accomplishing decolonization necessitates shifting perspectives away from extracting information *about* indigenous communities and considering them as the exotic “other”—research *on*—to instead seeking to foster reciprocal knowledge sharing and mutual growth (Jones & Jenkins, 2008)—research *with*. The goal of decolonization should always be the self-determination of Indigenous people and communities (Simpson, 2008; Warry, 2009). This mandate of decolonization requires a dramatically different approach to research: one that prioritizes benefit to the research participant themselves and to the communities of which they are a part, and that does so without attempts at typification from outside academics.

Accordingly, this study is grounded firmly in a dialogical research paradigm. As described by Frank (2005), dialogical research resists the tendency to define and finalize

research participants according to any specific typologies, and instead understands people to be ever-evolving and fundamentally interconnected. Instead of yielding claims of capital-T “Truth,” dialogical research evokes the life stories of research participants and offers an opportunity for participants to themselves interact with those very stories on their journeys of perpetual becoming. Michelle Tracy Berger’s (2004) ethnography of women with HIV/AIDS who have engaged in political advocacy and activism presents an excellent example of dialogical research, and Frank (2005) describes her work as follows:

Dialogue *interrupts* monologue (Frank, 2000) and Berger presents women’s perception of their experiences in order “to try to interrupt traditional assumptions about ‘these’ women” (p.79)... Berger’s (2004) objective is not to institute a new typification, which would only substitute her finalization for the old one. She seeks, instead, to leave the reader with “as many unsettling questions as I can” (p. 79). Her report does not offer the monological assurance of knowing what certain lives consist of and what can be expected of them. She challenges and unsettles any finalization. As Berger depicts the lives of the women she studied, disease is their opening to an unfinalized new possibility of being. (p. 969-970)

In alignment with these principles, while this study does elucidate key themes about selfhood and personhood within the context of dementia for members of the Pyramid Lake Paiute Tribe, the primary goal was always to partner with the Tribe—and in particular the research participants themselves—in an effort to increase their own understanding of their lives and their communities and to disrupt dominant assumptions about Native people, elderhood, and dementia through the prompting of unsettling questions, positioning disease as an “opening to an unfinalized new possibility of being” (Frank, 2005, p. 970).

An important element in this endeavor is the abdication of moral neutrality. In dialogical research,

The researcher can seek to affect the participant’s future—analysis is in no sense morally neutral about good and bad future directions—but the basic recognition is

that this future is open. In existential terms, the claim of unfinalizability is a claim of freedom. (Frank, 2005, p. 967)

As such, this study's analysis draws judgements of participant responses, but does so in a fashion that unwaveringly respects their open and free future. This study seeks only to support participants—and their broader communities—in further exploring their struggles as themselves moral. Frank (2005) draws particular attention to this inherent component of dialogical research:

As the researcher necessarily offers or withholds recognition of people's struggles, she or he participates in the struggle to determine what the relevant standards of moral worth are among people whose lives can never fit the moral expectations of mainstream, middle-class society. The researcher is necessarily more than an observer of people's lives. She or he becomes an engaged witness whose recognition people seek as confirmation that their struggles are moral, at least in intent. The relevant standard of moral worth is neither relativist, situating moral worth solely within the conditions of one individual life, nor absolute, emanating from a space of no specific life. Dialogue is the space between those extremes. (p. 972)

Ultimately, this study purposely does not yield any finalities; it uncovers unseen complexities and informs further consideration and conversation.

METHODOLOGY

Partnership with the Pyramid Lake Paiute Tribe

Though the initial idea for this study was my own, it rested on my well-informed yet incomplete understanding of the Pyramid Lake Paiute Tribe's goals related to knowledge gathering and storytelling on the topics of elderhood and dementia. I had worked with the tribe for nearly four years at the time, and I had come to realize their desire for mobilizing individual wisdom for the benefit of their community more broadly. For example, in 2019 the Tribe convened the first of a series of talking circles to discuss how they might best implement public health strategies toward brain health and dementia outlined in the CDC Healthy Brain Initiative Road Map for Indian Country (2019). They did not want a sterile analysis of community needs and opportunities for action; they wanted their own people—elders, family members, and tribal staff—to share personal stories of how they support their own brain health so that existing strengths based in traditional practices might be leveraged to improve their health and well-being. For this study, I wanted to honor that intention and connect with tribal members to externalize their accrued wisdom surrounding the support of continued selfhood and personhood for people living with dementia, adding to their existing conversations about community development.

From the outset, this study was conducted in full partnership with the tribe. Hulko et al. (2010) specifically detail the importance of participatory research within an indigenous context:

Incorporating and respecting Indigenous worldviews and attending to research ethics or 'doing it in a good way' (Ball and Janyst 2008) requires that researchers locate themselves (Absolon and Willett 2005) and consult with First Nation

communities from the outset, that the roles and responsibilities of researchers with respect to the participating communities be negotiated and agreed upon in advance of data collection, and that the research be of benefit to the community (see Cochran et al. 2008; Jacklin and Kinoshameg 2008). (p. 321)

The project was presented to the Pyramid Lake Paiute Tribal Council for a discussion of how they would like to see the study unfold. In particular, honest and extended conversation was needed to explore my role in interviewing tribal elders, given that I am neither a tribal member nor Native. It was decided that my interviews with elders be conducted in collaboration with a tribal member. The Council also requested involvement in reviewing, finalizing, and disseminating the documentary film produced as a result of this project. They did not, however, express a desire to form an Advisory Team of tribal members to guide the work, as has been suggested as a best practice for research within indigenous communities (Borish et al., 2021; Hulko et al., 2010).

Study Populations and Participant Recruitment

It is without doubt that the true experts in the experience of living with dementia are people living with dementia themselves, and therefore it was a primary intention that the study population include people living with dementia. Based on available population data (United States Census, 2020) and dementia prevalence statistics (Alzheimer's Association, 2023), approximately 30 individuals are currently living with dementia at Pyramid Lake. However, to the best knowledge of key tribal research partners, no members of the Pyramid Lake Paiute Tribe are currently diagnosed with dementia; the nearest diagnostic infrastructure is located an hour away in Reno, and neuropsychiatric assessments are often considered less important than treatment to manage comorbid cardiovascular and metabolic conditions. Without formal diagnosis, changes in memory

that could signify dementia might be disregarded, especially considering memory loss might be understood as a natural component of the life cycle, as demonstrated by Hulko et al. (2010) and reproduced in this study. Additionally, as mentioned later in this thesis, historical trauma and dementia stigma combine to produce conditions in which elders and family members are hesitant to publicly acknowledge they are living with memory loss that might be dementia. As a result, no people living with dementia or severe memory loss were engaged as participants in this study. However, a robust consideration of dementia at the Pyramid Lake Paiute Tribe was still possible through the collation of diverse perspectives, including elders, family care partners, and tribal staff who support the well-being of elders.

A total of nine participants from these target populations were interviewed for this study: five of whom were elders, three of whom self-reported memory changes due to age or injury, six of whom were present or former care partners for someone living with dementia, and eight of whom were tribal staff with a role in supporting the well-being of tribal elders. Eleven total interviews were conducted, ranging in length from 26 minutes to 73 minutes and averaging 51 minutes. Participants were recruited through convenience sampling, identifying individuals who might be interested in sharing their stories in connection to dementia and contacting those individuals to invite their participation. An email was also sent to all Tribal staff with a flyer advertising the opportunity to participate (flyer and email included Appendix A). No formal criteria were employed to determine prospective participants' eligibility. If an individual self-reported any involvement in supporting the well-being of elders in any way—personal or professional—that individual was welcomed to participate. No participation incentives were provided to participants of

this study, other than the ability to receive unedited versions of all visual media in which they are featured.

Research Ethics

Approval for this study was sought and obtained through the University of Nevada, Reno Institutional Review Board. Special attention was given to ensuring the informed consent of participants living with dementia, whose cognitive capacity might be diminished. Given that no participants living with dementia participated in this study, the matter did not end up being relevant. For the benefit of future qualitative research with people living with dementia, the specifics of the decided arrangement for engaging participants living with dementia are pertinent to report here.

No standardized assessment is used to determine a participant's capacity to consent, as no such single tool exists. Additionally, from a legal standpoint, people living with dementia are presumed to retain their capacity to consent unless formally proven otherwise in a court of law. From the American Bar Association's and American Psychological Association's *Assessment of Older Adults with Diminished Capacity* handbook,

Capacity to provide informed consent for research participation depends on the complexity of the study in question. That is, a person may have capacity to make an informed decision about a simple low-risk study, such as one that requires a paper and pencil interview, but not have sufficient capacity to make an informed decision about a study involving more complex procedures, such as surgery. (p. 132)

Given this study's low-risk nature, the vast majority of people living with early to moderate dementia would retain capacity to consent. As an extra measure to ensure ethical research standards, any individuals with either financial or medical durable powers-of-attorney would not have been engaged as research participants in this study, given the potential that

those individuals would be experiencing diminished decision-making capacity. However, it is important to note that individuals with powers-of-attorney are legally capable of deciding to participate in research, and ought to be offered the opportunity to do so. Decisions about participation in research can be made only by the individual participant in questions or by a court-appointed guardian, not by their powers-of-attorney.

Participants were provided a letter of informed consent (included in Appendix B) at the time of their first interview and were engaged in discussion about the contents of the letter to confirm full understanding of their rights as research participants and the details of their participation. Because this project entailed video-recorded interviews that would be utilized within a publicly disseminated media product, an additional form (included in Appendix B) was provided to research participants outlining ways in which their likeness might be utilized and requesting informed consent for each specific channel. Given the film component of the project, participants were not ensured of confidentiality. All participants consented to having their name, likeness, and other personal information discussed in the interviews shared publicly through both academic and popular channels.

Interview Structure

Dialogical research aims to support participants and their communities in confronting and externalizing their internal conversations in the hopes of expanding those conversations and developing them into a well-considered future. It would therefore be counterproductive to approach interviews with research participants as solely information gathering endeavors, as such interactions would offer no mechanism for participants themselves to engage *in dialogue* with the researcher and with themselves, positioning

them to accomplish the growth central to the purpose of dialogical research. As such, interviews for this study were intentionally designed to avoid feelings of formality and sterility; the more comfortable participants could be, the more likely they would engage with the interaction as they would genuine conversation. The location and timing of interviews was decided entirely by research participants, with participants being encouraged to choose a setting in which they felt most themselves and that meant something to them. For some participants this was at home or at work, while for others it was the shores of Pyramid Lake or a meaningful community gathering place.

A select number of interview questions were prepared in advance and were organically incorporated into the conversation. For all participants, conversations extended beyond the boundaries defined by these questions, however the questions provided a framework to ensure some continuity between the topics of discussion from one interview to the next. The minimum questions asked of each participant were as follows:

- Please introduce yourself however you would like to do so.
- What role have elders played in your life?
- What does it mean to be an “elder?”
- What is your connection to dementia?
- What do elders living with dementia still have to contribute to their communities?
- What does it mean to live well?
- What are your hopes for your community for the future?
- What are your hopes for yourself for the future?
- When you hear the words “Pesa Soaname,” what does that mean to you?

Following the “sit-down” conversations, participants who were not limited by time constraints were asked if they would like to continue the interview in a walking fashion, touring the interview location and unpacking their connection with that place. Four participants agreed to this second, dynamic interview component. All participants were

interviewed at least once. Two participants were contacted for follow-up interviews, and both agreed.

Video-Based Dialogical Analysis

Throughout data collection, the documentary film and qualitative research components of this project were inextricably linked; interviews served the simultaneous purposes of soliciting participant testimony, opening a space for the conversation component central to dialogical research, and filming of a visually compelling scene to be incorporated into a feature-length documentary film. This complete overlap between the creative and academic project elements did not end after data collection; it permeated data analysis as well. Qualitative research typically entails the coding of transcribed interviews to uncover and construct an underlying theoretical structure that offers some degree of unifying explanatory power. Documentary film production entails the separation of recorded content by theme and the careful development of a narrative arc connecting those themes in a manner that offers viewers a lens through which they perhaps have not seen before and therefore an opportunity for new understanding about an important topic. These two endeavors, while rarely utilized in tandem, are indeed perfectly analogous. David Borish et al. (2021) developed an approach called “Video-Based Qualitative Analysis” that leverages the process of editing a documentary film as the manner through which qualitative data is analyzed. This new method of qualitative investigation considers not only the transcripts of research interviews but also the physical expressions of interviewees and the locational context in which interviews take place, both dimensions of interaction easily captured and considered through a visual medium, opening the door for the

examination of embodied and inter-embodied aspects of selfhood in a manner that more traditional qualitative analysis does not.

Video-Based Qualitative Analysis holds great potential for diversifying the way in which we conduct qualitative research, yet it is undeniably grounded in a traditional, *monological* research paradigm that strives to finalize and typify. The method is well positioned for such research, as coding documentary video data is relatively straightforward using only existing features offered through popular documentary film editing software. Dialogical research, however, involves no such formal coding; broad thematic consideration is as definitive as dialogical research ever should be. As such, this study utilizes and documents an adapted “Video-Based Dialogical Analysis” approach that remains in alignment with dialogical research principles. Within the process of coding the data, this adaptation entailed the decision to code entire participant responses rather than separating those responses into more discrete, topically specific segments. Such a decision honored the intention of dialogical research to avoid parsing and finalizing elements of participant identities. Following coding and the delineation of primary and sub-themes, the adapted approach required an additional analytical step. Once identified, themes were collected and organized according to their role in participants’ exploration of a series of empirically generated questions guiding participants’ perpetual becoming and that of the Pyramid Lake Paiute Tribe more broadly. Those questions were then utilized to generate a narrative representing the story of dementia at pyramid lake, and the reported results below represent that story.

RESULTS

This study's results are reported in a manner that reproduces whole participant responses—and sometimes even more extended conversations with participants—rather than quoted excerpts. Retaining the full context surrounding evocative quotes allows for themes to be observed as they occur in tandem with each other and still presents the opportunity to trace a narrative thread through those themes. There is good precedent for such an approach to reporting results in other dialogical research publications. Frank (2005) describes the research of Paul Draus (2004) as an example of such a report:

In Draus's shared space, the participants genuinely participate. Notably, their stories are not edited to fit the analytic needs of the report. Draus's dialogical relation of researcher to participant requires allowing people's stories to continue well beyond what would be required to provide an illustration. Draus makes no pretense at presenting an analytic framework—whether explanatory or descriptive—that contains every aspect of the stories he presents. On the contrary, the stories, in both length and scope of content, exceed whatever he is able or willing say about them. The effect of reading Draus, which is difficult to render in a description of his writing, is to experience people who unpredictably exceed what can be said about them. Draus never romanticizes these people's lives; he shows them in all their brutality and self-destructiveness. But he also allows them the dignity of making choices that cannot be reduced to social scientific explanations. (p. 970-971)

The conversations had with participants as part of this study opened the doors to a collective story of identity, community, and dementia that is being actively lived and elaborated by members of the Pyramid Lake Paiute Tribe.

Identity and Community at Pyramid Lake

The word "identity" conjures notions of the individual, and indeed participants communicated strong personal selves through their responses. Identity is by definition unique to each person, however common themes emerged as participants discussed the

foundational elements of their identity and the aspects of self they hoped to support in others: land, family, service, and health.

Participants expressed a strong connection to the land of the Pyramid Lake Reservation itself, with Pyramid Lake as a place and the Pyramid Lake Paiute Tribe as a people being inextricably linked. In reflecting on our conversation together, one participant—an elder woman who works as the Tribal Museum and Cultural Center—mentioned:

It was an enjoyable little session that we had here and, you know, like listening, just listening to the waves and the little-- the little things that's going on around us, you know. It's-- That's what it is. That's why I like being here, you know. It's just all the stuff that we have, you know, that makes us who we are and how you feel, makes you feel good in your heart, makes your heart, you know, skip a beat. It's just how-- how the land is, you know, to be as a people. That makes this, you know.

Later, as we walked together along the beach, she added that Pyramid Lake as a place helps her stay connected to herself through being connected to her memories.

And that's what I like doing out here, and the thing that drives me, is this. Is doing this. Like this. It takes my heart away when I see all these beautiful rocks and this-- the ice. You know, the ice formations and stuff like that. It makes it. It brings back memories of when I used to play on the river. Of being with the ice and stuff. As a little girl I used to play along the river with my brother in the ice. It used to be really, really cold.

In addition to supporting one's connection with oneself, a strong connection with the land also fosters important connections with family for people at Pyramid Lake. In an unfolding conversation with one participant—who serves as the Director of Senior Services for the tribe—it became clear that a continued connection with the land was the vehicle through which she received support from her family growing up, through which she now offers that same support to her younger family members and her broader community, and

through which she hopes her children will be able to support her as she transitions to elderhood in the coming years.

Participant: *When I lived in Southern California, I had a friend that-- she used to tell me, "I'm a houseplant. You're a tree." And I used to think, "She's a librarian. She's got a really big, good imagination. Houseplant versus tree." So, one day I finally asked her, "What are you talking about? You're a houseplant and I'm a tree?" She says, "Well, I'm a houseplant. You know how houseplants live in a pot in one spot? You move it from here to there. The roots just go round and round. It only gets so big. And then eventually it dies. You throw it out. Just get rid of it." She says, "I'm a houseplant. I have no roots." Because, where she lived in downtown LA is now a parking garage. She says, "I can never go home." She says, "You, on the other hand, you're a tree." She says, "You know what your roots are. You know who your family is. Your roots can go on forever because you're a tree. You can keep growing and have lots of family around you." She says, "You probably even know where you're going to be buried when you die." And I went, "Well, yeah." She says, "I don't know. What do you do with a houseplant when it dies? You throw it out." She says, "You probably have a place already." And I said, "Actually, I do. You know, I know where I'm going." She says, "So you're a tree and I'm a houseplant." Sad.*

Interviewer: *So, let's think about-- take this metaphor one step further. What do you feel have been the aspects of living here at Pyramid Lake that have helped your tree to grow? Like, how have you-- What have been your nutrients throughout your life? What has helped you to grow?*

Participant: *I guess to help me to grow as I was growing up was family. You know, we had-- I knew my great grandma, my mother's mother. I knew my grandmother's sisters. I knew how people were related. I guess having other trees around me because we all knew who we were and where we came from. So, I wasn't a lonely tree. You know, I always had family around. Grandparents. Great grandparents. Community, you know, because everybody just kind of looked out for each other. And I guess that helped me to be a good straight tree.*

Interviewer: *And on the other side of things, what do you feel like-- What fruit have you produced to feed the community? What has your tree given back?*

Participant: *What have I given back? I think being raised to take care of people. I'll give you an example. My grandma had eight children and raised eight others. She took in and helped raise eight others. So that was kind of like my role model, was to take care of people. You know, she was very important to me, very significant. And giving back is not-- I don't know what you would call it, like being service minded. Giving back, sharing what I know, you know. A lot of times I believe that, like old stories-- We used to have an elder come in to tell us stories when we*

were in like first and second grade. So, just giving back, because it's not my story. It's-- it was his story, and somebody gave it to him. So, giving back is always really important to me. My kids used to hate going anywhere with me where I volunteered because I would like be one of the last ones that are making sure everything was getting put away. You know, it's like I just-- they would-- now they go in separate cars because yeah, I'm going to stay and I'm going to help. That's just what I do. It's the way I was raised and say it's giving back, you know. Someday I won't be able to, you know, so right now I am. So, I do. I hope for myself to be healthy enough to be able to take care of myself. You know, I don't want to have to be a burden on my kids and I think many of our elders don't want to be a burden on their children. So, I worry about that. You know, when my son got sick recently, I thought, "He's always there for me. Who's going to take care of me?" You know. He's better, and I just-- I just hope that that he'll always be there for me, you know. I used to joke with him and I said to him, "You bury me or I bury you." Yeah. So, you know, I'd love to see my grandkids grow up and be healthy and happy.

So, a strong connection to the land fosters a strong connection to family. The importance of family was something shared by every participant in some fashion, and frequently the lines between oneself and one's family were fluid. Commonly, participants introduced themselves by also sharing information about their close family. One participant, an elder who serves as a Councilwoman on the Pyramid Lake Paiute Tribal Council, introduced herself as follows:

"My name is Harriet Brady. I'm a tribal citizen of Pyramid Lake. My grandmother is Nona Garcia and my grandfather is Roy Garcia and my mom is Elaine Joan Garcia."

I followed her introduction with a question about the practice of incorporating family members into one's introduction, asking her why she felt it was important to include her family members in this way. Sitting in her home, surrounded by family photos, she responded:

Mainly because you show who you are, because a lot of times people don't know who you are if you're not embedded in a community. But then, like my grandpa, he worked for the Bureau of Indian Affairs on the roads department. He traveled around a lot and all the tribes are interconnected in one way or another, but he also sat on the Tribal Council. So, for me, it's easier to identify like that and to

honor and acknowledge who your people are, that lineage, because a lot of times the older people will say, "Oh, I know who you are." Which is funny because as an older person that I am now, I do that even with my own students. "I know who you are." But you do make those connections. It's those family ties, and it's important that you know that background. So, that's one of the strongest points that seemed to be-- that was always there. You just always do that...

I think that is a cultural practice, because rather than saying "me, me, me," that you acknowledge the other people. I know people on the outside basically wanna-- "Who are you?" basically. And it is all about you. Whereas when you're in Native communities, indigenous communities, it's like, "Who are you?" And then you acknowledge all your family, because it's just not you. It's a community, basically.

As seen in this response, just as self flows into family, family also flows into community.

Each participant was asked about their hopes for themselves for the future, as a way to support participants in imaging the person they hope to continually become. Repeatedly those hopes pertained to service to family and to the broader community. Sometimes, this service was described as simply helping one another in daily life. Other times, service was something more institutional, to be achieved through continued vocational work.

According to the Councilwoman, her sense of service entailed both of these ideals:

[I hope] that I can be as healthy as I can to continue. I try my best to volunteer, you know, like I try to help out with the powwow, like serving the elders. I want to continue to be able-bodied enough to do stuff like that. I don't want to become feeble, you know. If there's anything that I fear, it's being feeble and not being able to do the things that I want to do. I like to take care of my yard and help out my family and my community as much as I can. A lot of times, you know-- There's a lot of people who do stuff. I mean, it's just not me. There's a lot of people who do stuff for the community, and they don't have to boast about it. And even though I did kind of talk about it, it's still kind of uncomfortable because you're really not there for yourself. You're doing it for the betterment of the community, even if it's picking up trash, even if it's, you know, like cleaning up the post office. Doing little things like that can help out. But my thing is just to be healthy enough to keep on doing those kind of things, to always be there to help out. And I know sometimes my students will ask me, you know, like, "When are you going to retire?" And I was like, "There's no thought of that." As long as I can, you know, keep managing my classroom and teaching, I just, you know, I don't think about it. You just keep going, because that's what my grandma did. I mean, she worked all the way up until she did retire, and

it seemed like she kind of went downhill after she retired because, you know, she wasn't getting up early. She still got up early, I mean, but, you know, as far as going to work and stuff. I think that sense of worth kind of went away a little bit, even though she had her house and her yard was really good and things like that. That sense of helping other people, you know, like work-wise-- Because she used to be a housekeeper, and so she was always on the go, going upstairs, going downstairs, making sure people cleaned rooms properly, things like that. I think that does, you know, fall within that range of feeling good about yourself, because you're doing something, making something look nice.

This participant's vocation happened to be teaching, however notions of service across participants were specifically connected to teaching younger generations essential components of Pyramid Lake Paiute Tribe culture in both formal and informal ways, while still continuing to engage in those cultural traditions oneself. The Director of the Tribal Museum and Cultural Center, herself an elder, described her desire for service in this fashion:

Well, I continually have hopes for myself and I would say probably on the top of that list, I want my grandchildren to know who they are, where they come from, that they know, you know, their spirituality, teachings, that they know ceremony, that they know how to pray, that they can incorporate their culture and language as much as possible. So, continue to learn our Paiute language, our native language. And with that comes other aspects, with prayer and learning traditional arts, whatever it may be. And that's probably my most important hope, because I want our people to continue to survive, and it's up to our young people to maintain that and keep it going, and I have full faith in that.

My other hopes are health-wise, you know, to continue to be healthy as I can and to continue working as long as I can, but in between having fun, which means traveling and doing-- attending ceremonies or meeting new people. Sometimes it may be a conference, it might be a powwow. I recently started dancing again, and I love to, you know, go to powwows and dance. That makes me feel good and it makes me feel like I'm honoring our ancestors.

As evidenced by nearly all participant responses regarding service, including the two above, remaining in good health was considered necessary in order for participants to manifest their desired future selves.

Identity for study participants, then, seems to arise from and be enabled by a strong connection with place and history that positions participants to further that history through their own family and to become their full selves through being of service to their broader community in a variety of ways. Therefore, for research participants, being oneself necessitates active citizenship, and thus their selfhood and personhood are in fact entwined.

A Confluence of Ideologies at Pyramid Lake

The unbreakable relationship between selfhood and personhood described above was further expounded by research participants throughout their discussion of a single, central tension that bears on the well-being of both individuals and community: the negotiation of traditional and Western ideologies. Participants discussed three examples of this tension as particularly pertinent for supporting the selfhood and personhood of elders and people living with dementia, relating to service, care, and dementia itself.

To Serve or Be Served?

Historically, elders at Pyramid Lake have been among the most active members of the community, occupying positions of leadership and accepting the responsibility of guiding their community toward the future. Participants' descriptions of this service-oriented conceptualization of elderhood were at times quite grand in their connection to community survival, as demonstrated by the Senior Services Director's portrayal of many of her family members:

I think that going back generations, we've always had people that have always been of service to the people. I have a, probably about a fourth great grandpa, who his Indian name was Numana... "father of the people." When they were going to create the reservation—the Pyramid Lake Reservation—he outlined it. He went mountain top to mountain top and said, "If you're going to force our people to live here, then

this is what we want.” And he went, because he said the mountains will never change. So, from mountain top to mountain top to mountain top, he went all the way around Pyramid Lake. And through those high mountains around the lake, he identified this as our point. “If you're going to make us live on a reservation, this is what we want.” My grandma used to say that in her lifetime, those mountains disappeared, and I never understood what she meant, because they're still there. And she said, “No, they disappeared. In my lifetime, they disappeared.” And I finally figured that what she meant was the boundary line of the reservation kept creeping in. As the government saw that we didn't need-- that people were leaving because they were migratory people, people would come and go. So, the government would come in and see that there weren't a lot of people here at certain times of the year. So, they'd decrease the size of the reservation, and the reservation boundary line is on this side of the mountain, the mountain that she said disappeared.

Yeah, but we've always had people in the family on Tribal Council. We've always had people on committees. My grandma, who wasn't real-- she would never run for Council. And maybe it was because back in those days, women didn't sit on Council. But she was active with the Election Committee because she wanted it to be done right and done fair. So, she was always-- as far back as I can remember, she's been on the Election Committee for the tribe. And I have uncles who've sat on Council. My mom has sat on Council. I've sat on Council, been on School Board, just of service to our community.

The service elders provide to the community was described at a more interpersonal scale, too, in addition to a sociopolitical one. The same participant also said this of her grandmother:

You know, I think back-- I'm not an elder yet, but I think back at-- Our elders probably didn't think they were elders either. They were living their lives helping, because they were always helping. Teaching, sharing, but that's just the way life was. They probably never saw themselves as elder, because I know my grandma didn't slow down. She was always busy. I don't think she thought of herself as an elder. It's kind of a new-- I guess-- or a different mentality. I know my grandma and them didn't like to be served. She would rather be up doing the serving. You know, at funerals or gatherings, family gatherings. She wouldn't sit and wait to be fed. She would make sure everybody ate. And I know that's one thing that I know that I've seen in my lifetime. That it changed. And maybe it's another culture's thought that you have to cater to your elders. But it was different. It was just different. She didn't like that. She wanted to be the one serving people. And it just kind of changed somewhere. But I guess that's just life. We've adapted. Things have changed.

What it means to be an elder at Pyramid Lake, then, is being re-evaluated and redefined. Participants associated elderhood in a traditional sense with being of service to family and community, but now elderhood is beginning to be associated with a need to be served, following more widespread adoption of Western ideologies toward aging and care. Often, the two competing understandings of elderhood were juggled by individual participants, even within single responses such as this one from an elder who serves as the Director of the tribe's Social Services program:

Elderhood could be, like, a noble status in your community, when the community places the elders in high esteem and when the community takes extra measures to protect them and to provide for their emergent needs, immediate needs. It's important that our elderly people are revered with honor despite a lifetime of what could be viewed as not so good. But our people are still valuable. I have a very close friend who is 71, and he is starting to have, like, a little bit of memory loss. But when we are together, he talks Paiute to me. He'll remember some old dance songs that the Pyramid Lake Pageant Group singers used to sing, because his father was one of their performers, and he would talk about those kind of things, the cultural values that we have. I'm really grateful that he is still with us in our community because he shares quite a bit of things and I think that's what elderhood is, when our elders are able to recall historical knowledge and oral traditions and are willing to share those things with our younger people.

Participants also revealed some degree of sense-making within the apparent juxtaposition between these two ways of thinking. One young participant in his twenties, who works in the tribe's Language and Culture Program, described how he felt the best way to be in service to elders involves letting them be in service to him:

I know one thing that you see happen a lot now is elders being told to go first. And it-- I guess in a large like community setting that's normal, but it's like, in a smaller setting, it's like-- We grew up and the older people were served. And I think that's one way of showing respect, is you, you know, you acknowledge that they have done a lot and it's kind of hard for them to move around so you go and get them their food for them... I think that just being willing to help them when they ask for help is the main thing, like just the way you interact with someone. I know there's a lot of times we've just turned around and-- We had plans for a day, and then those plans get completely shaken up because someone says, "Well, can you help me with

this?" and they're older. "Yeah, we'll be right over." And then we'll be rushing around to get our other plans done afterwards, but it's like, you kind of take your time out of the day just to make sure something's done. Or like, when you go to someone's house, you don't go empty-handed. I think that's something we try not to do is, if we're going to someone's house and make sure we bring something with us. And at the same time, it's like-- it's also awkward because then they'll say "Well stay and eat," or "Stay and do this," and you know you kind of have to. You don't just turn around and say, "Okay, I'm leaving, bye." You know, you stay, and you listen to them with whatever they have to say.

Where to Care?

Just as Western society has influenced what it means to be an elder at Pyramid Lake, it has also impacted conceptions of where elders—particularly elders living with dementia—should spend their final years to experience the care they need and be their full selves. Participants perceived that Western modes of thought surrounding elderhood promote long-term residential care as a primary option, resulting from deeper cultural undertones of individualism. Some participants, including the Councilwoman, were adamant that Pyramid Lake be insulated from such an ideology:

I think it is fully ingrained in our community to where, because of that identification of who we belong to, who's connected with us-- I think that's what makes it harder to let go. Whereas in the outside society—and you can never stereotype or just say it's across the board—but it just seems to be prevalent of their self-centeredness. You know, like, "Nobody's gonna intrude upon my life. I'm not gonna deal with that. And I'll just-- I have the means. I'll just shove 'em away and shelf 'em." We don't like to do that. We still-- I mean, I remember one of the community members, she was always brought to things, even though, you know, she wasn't the person that she was. She had started her transition to where she didn't recognize her family or, you know, it was just different. But the family hung on. The family took her places. So-- And then you'd see those little glimpses, you know, like where, whatever reason, then she recognizes something. And I think that's important because that can make somebody feel comfortable, like they recognize that, rather than shelving them and putting 'em with different people who have no connection. Their faces aren't familiar, you know, their-- the way they talk or, you know, just the setting is different. And so, it's just real sad when you see people being shelved. So, I think there is a difference. And I think that's why the family tries to make sure that the people are comfortable in their setting where they're at.

The communal core of Pyramid Lake Paiute Tribe culture was invoked as a potential strength to be leveraged in helping elders living with dementia continue to live with their families and in their communities. A participant—not yet an elder—who works as the police officer for the Tribal Health Clinic gave her thoughts on community.

I think community is a big thing, because the reservation-- and I see it here, is everyone's always willing to help everyone. And I think as a community, as a whole community, everyone comes together, you know, they come together for funerals, for the most part. And I think when someone's sick, you know, everyone knows and tries to do what they can to help that person. And even people who are homebound for whatever reason, and maybe they're homebound for dementia, I don't know-- I don't know who all has it. I think the community, you know, the Tribal Health Clinic, their neighbors, it's, you know, how they say, it takes a, what-- a community to raise, or whatever. It also is takes a community to help care for people that might have that. I think that's the big thing, is community. You know I- You don't see that in big cities really, because everyone's kind of, you know-- They're big cities. But here everyone kind of knows everyone. They know their families, they know their mom, they know their dad, their grandma, you know, and they might have known them since they were young. So, it's like, yeah, you care about them, and maybe not in a such a familial way, but you know what, you care what happens to them and you may want to help them. And I think that will help, you know, someone who has dementia or their family, may need support, you know, they may need cooking or something done, you know. So, community is a big thing. I think that's one aspect.

Participants did, however, acknowledge the potential necessity for long-term care for tribal elders living with dementia, while continuing to reinforce the immense benefits of keeping families together. The same participant noted:

There's a lot of people with dementia in homes, and yes we had to temporarily put [my dad] in a home, but I think-- and I know-- it's good and bad. Because, you know, [my stepmom] took care of my dad at home. She would, you know, do his diet and-- because he ate better, you know, he was always bathed, he was always clean, we always tried to include him in conversations as best we could, decisions. I think giving him that love and care kept him going for, what, another four more years. And a reason I believe that too is because when my little sister, their child-- She had muscular dystrophy, she was in a wheelchair, so she had to have that care, and when she was first diagnosed, when she was three or four or younger than that, actually, because she couldn't-- she wasn't crawling, they said she'd live till three or four. She was still alive. Next thing you know they said she'd live till eight, or

seven or eight. She lived to be 21, and I really think it was the love given at home and the care, and not being put in a home. And I'm not critical of that. People have their own lives, but that's what I think. [My stepmom] was able to do that because she's retired. A lot of people aren't so they have to do that, and I know that because my mom's in a home right now. But I think that's what helped him live longer, because he got his health back in check.

Gender roles motivated some discussions of the necessity of long-term residential within the Pyramid Lake Paiute Tribe, as outlined by the Director of Social Services.

Participant: I think that if I realized that I could no longer care for myself, then I would probably have to arrange for assisted living or a place where dementia care is available to me. I have two adult sons and they're living their lives, and the last thing they want to think about is having to take care of their mom. They've always been very independent and I'm proud of that for them. I think that now they're realizing that I am getting older. They ask me questions about how I'm doing and what's going on.

Interviewer: So, you wouldn't say that they feel like they would want to play the role that you and your mom played for your grandmother?

Participant: I don't think so.

Interviewer: What do you think creates that difference?

Participant: I think it's because it's the role of a man that it's not the man's place to be taking care of an elder female family member. But I do have a twelve-year-old granddaughter who says, "When you're old, Grandma, I'm going to come and live with you and take care of you." I told her that I'm not going to get old.

Yet those gender roles themselves are being actively reconsidered given their relationship with colonial ideologies. The Museum and Cultural Center Director provided context for these changes.

A matriarchal society, you know-- Traditionally the women always had a say, you know, as far as decisions, and when the, you know, when we were colonized, it put patriarch in into everything, like the man has the last word, the man has the say. So, it minimized the role of the women, and I think now in contemporary times people are realizing that, you know, the women do have a lot of strength and knowledge, courage, and, you know, they can make very good decisions, you know, on behalf of the people. Because as mothers, we have that instinct to, again, protect

our children and, you know, have that foresight to know what's going to be good for our children down the road.

Just as was the case for participants' consideration of the role of elders, within this societal conversation about long-term care, participants expressed efforts to make sense of the tension by integrating the two perspectives. The Director of Social Services discussed:

My hope for the Pyramid Lake Paiute Tribe is that our tribe will be able to manage a care facility for our people here. We have an increasing number of people who are becoming 60 years old and over. It's very hard to have to put our own people into a nursing home because-- A lot of times that's what my job includes, is having to prepare elders for end of life. That's really difficult for me because I come to a place where I revere these people that I have to provide assistance to, and then to be a place to have to help them decide end of life decisions. It would be my lifetime goal is to see that we had like an elder village here in Nixon, where our tribe and our housing authority can provide several alternative dwelling units, small little trailers where our elders can live independently. But I think that we need to have good accessible facilities for dementia care as well.

Dementia: Lost or Found?

The final cognitive dissonance seeded by the cooccurrence of Western and traditional ideologies at Pyramid Lake indicated by participants pertained directly to dementia. Participants discussed a deep-seated traditional understanding of memory changes associated with dementia that was contextualized within the expected progression of aging. According to the young participant working in the Language and Cultural Program:

So, growing up, we never really heard anything, talk about that. It was always just, "Oh, they're just being old." It was never a discussion. There was never a diagnosis. It wasn't noticed. And then working-- from the point when I started working, we worked with the clinic, under the clinic. And I guess you kind of hear diagnoses more, but you still didn't hear that. You never heard Alzheimer's, dementia. You never really heard any diagnosis or any of that kind of stuff. And it's only in the last few years when we started hearing about it, that you really start noticing it in elders or with people coming in. And it's just subtle things at first. And then you slowly watch it progress.

There is in fact no Northern Paiute word for dementia. When asked about this, the same participant mentioned:

I think a lot of them-- a lot of the normal thought is, "Well, you're getting older, you're gonna start, you know, losing your ability to do things." And I think it was just common knowledge that that was gonna, you know-- it was a progression at some point, that you weren't gonna be able to walk so good, you weren't able to remember as well, or you know, a lot of that kind of stuff. And again, there was a lot of ways that you took care of someone or, you know, a lot of ways that you eased their burden so that they didn't have to do as much anymore. You kind of limited their-- their-- you kind of just eased their burden, I guess.

Without a pathological narrative to mold cultural attitudes toward dementia, other manners of thinking about the condition were allowed to solidify. An elder who is versed in the traditional healing arts of the Pyramid Lake Paiute Tribe recounted the way his dad taught him to consider elders living with cognitive changes.

Dementia, you know, like we were saying, my dad said sometimes the spirit will leave for a little while and come back. But because the body's still alive, the spirit has to come back. But sometimes when that happens, people will forget, or they won't remember things, or they won't remember people. And sometimes they'll see maybe people that follow them, their family members that follow them back. And a lot of times, you know, in the old days they'd call a medicine man, a puhagum, to come and pray for them. They'd paint them. Sometimes they'd do his personal colors and put an abalone shell and tie it here, right on the forehead. This is like in our old way, another place where you can see, by closing your eyes, what you can see through this. You know, we got places, power places in your body. And they'll use those, you know, they'll use those points to pray with-- to put medicine on there and help you. And that's where they'll use that...

And that's how they would help them when the spirit kind of leaves or for whatever reason, it just goes and comes back. Maybe in a dream it'll take off and come back. Sometimes you dream and you're in another place or you'll see all the old people, your ancestors, that's gone or you'll see people that's long gone and they come to see you. And sometimes it's like traumatic for whatever reason, you know, it traumatizes you and you'll forget things. That's why they have to pray for them like that, use the medicines like that, you know, to take care of you.

As this participant mentioned, there are immense gifts to be found within the context of dementia, and there are also hardships experienced by people living with dementia as a result of their condition. Dementia, therefore, is more of a change than it is a loss. This approach to dementia as a change in perspective was echoed by the Councilwoman:

I think if you look at, like, their little hobbies-- I don't want to minimize it, their hobbies, you know, what they were doing before, trying to make sure that you're still offering something familiar to them. I think that that's beneficial. You know, that they are surrounded by love and care. I think that that gives them that sense of well-being, even though we may not recognize it. I think that we just have to try to be as supportive as we can, not yelling, not getting frustrated, even though it is frustrating. But just trying to help them out as much as, you know, whatever little thing that, you know, you can find. I mean, I've seen stuff on social media where people are doing things like that, and involving them in, you know, day-to-day activities.

Like, I just saw one recently with this little grandma sitting there, and then she was given a present. And it was cute watching her because, you know, just by that sense of what they had written, you know, that this wasn't the same person that they grew up knowing. But yet, it was almost like looking at a situation through a different pair of lenses. And I think if you look at it like that, that maybe it's more livable for yourself, you know, to understand. Almost like-- I don't want to diminish it by saying, "Oh, they're just like little kids." But if you remember how the lens is for a child, you know, this is something that's new to them. You can't expect them to know everything because they haven't learned it. They haven't experienced it. But then just to understand that perhaps that, you know, even though you know this, maybe that person, because of their transition, maybe they have a different lens to look through. And then that you have to be supportive of that and find that same joy like that little grandma was expressing joy of opening that present. You just have to try your best to understand that part of it.

Considering dementia in this way, as a “...different lens to look through...” creates opportunities for well-being among more than just people living with dementia themselves. The police officer for the Tribal Health Clinic reported the impact of a dementia-related shift in cognitive perspective on her personally as a care partner for her father.

But my dad, I mean he remembered stuff from being in the Air Force that I never heard. He would tell me stuff I didn't hear before, and I'm like-- and so there's a value there. I learned something new that I probably wouldn't have learned if he

didn't have dementia, because he remembered what happened in 61 or 62 and I'm like, "You did what? You were in Alaska?" you know. And you know, and I'm like, "I didn't know you went to Alaska," you know, or whatever. And so, I think there's probably some value there, and I don't think our community would devalue them. So, they would still be an elder and still be important. It's just they would need more care, you know.

Acknowledging dementia as a natural part of existence and withholding value judgement regarding the changes associated with dementia informed participants on how best to approach care and support for people living with dementia. Dementia need not, and in fact should not, be “fixed,” even while acknowledging immense challenge and heartbreak; instead, people living with dementia ought to be supported in their experience. The elder Museum and Cultural Center staff member told a story illustrating this outlook.

You know, it was sad too because, you know, I'd bring my kids to visit and he wouldn't know them. We talked to him and told him, "Hey, this is Dominic. This is Leanna. This is Penny," you know. He would look at them and he said, "I don't know them," you know, and it was hard. Because you couldn't, um-- He couldn't relate to us, you know. And it's, you know, it's sad because, you know, it took my grandpa's life. You know, my grandpa passed away from that, from dementia. So that's why, you know, I-- when I see elders that are having difficulty, you know, I always try to help them. I'm always trying to help people, you know, because that's where I came from, you know. I've seen that, and dementia is-- It's a terrible thing. It's a terrible thing to deal with with your family. They fight with you. You try not to fight back with them because you know they're-- it's not their fault, of what they're going through. And you just try to be there for them and help them as best as you can, and just try to steer them. You know, take their meds or get up in the morning, you know. Grandpa used to always put his shirt on backwards and he'd say, "Don't put it on right," you know, "I gotta put it on backwards," you know, he'd always be shirt on backwards. But we just button it and just leave him be, you know, because if you would fight with him and try to put it on right, you know, you-- You don't want to fight with him. Just leave him alone and let them be. Let them go to that stage. You know, my kids were always around their grandpa, you know, they'd sit around him and stuff. Like, he'd know them one minute and not know them the next. But then he cared, you know, they still played around him. They'd feed him. Yeah, and they just took care of him.

From a care partner perspective, embracing a supportive approach rather than a judgmental one opened the opportunity for participants to find a great deal of value within care

partnership. One participant, Director of the Tribal Museum and Cultural Center, stated directly that she felt she had changed positively as a person as a result of her experience as a care partner:

The dementia experience affected me personally as far as having that compassion, that we all go through things as we get older, and having the patience and understanding of what that's like. Because I see it's becoming more common. And my mom was a registered nurse. So obviously, she had awareness of things that changed within her body and her mind. And so, I think it just created more of an understanding to have more patience, taking more time. But I really valued those last years and took my mom as many places as I could for her to enjoy life and appreciate it.

Later, that same participant described the act of being a care partner as something genuinely beautiful:

I really couldn't speak on behalf of anybody else. I just know through my own personal experience. But I do see people in the community with, say, their mother. And I can picture somebody right now, that the care and attention that they gave their mom in their final days, it's really, really awesome that it's like, they just really-- It's like carrying something so precious and knowing that they're in the end stages of life.

Predominantly, even when participants expressed negative emotions in connection to dementia, there was always a balance of experience gained and experience lost. Western, biomedical notions of dementia as uncompromisingly tragic were not often employed by participants in an unqualified fashion within a single response, and if full conversations are explored for alternative perspectives, the incidence of a participant sharing about dementia through only a biomedical lens drops to zero. However, such perspectives are indeed present at Pyramid Lake. The youngest participant interviewed—the Language and Culture Program staff member—shared to that end.

I think it kind of makes them a shell. It's sad to see, because even now, I see certain people in our community with behaviors that could be identified as, I guess, risk behaviors, or as unconscious behaviors, and it's hard to watch, you know. You try

to talk to someone, you see them, you know, you get excited to see someone, and you hear the same thing. "Oh, I'm gonna do this on this day." See them the next week at the same time, "Oh yeah, I'm gonna go do this this day," you know. And it's hard not to sit there and say, "You didn't-- You already did that." Or you know, you see certain people getting skinnier because they may be forgetting to eat, and it's hard to watch.

The elder healer mentioned that such biomedical framing of dementia might be expanding at Pyramid Lake, while traditional thought on dementia wanes.

I think some of the older people will ask for help like [traditional healing]. But nowadays we're so lost, we've lost so much culture and tradition. We'll go with what the doctor says or what they think. A lot of times that's not the right way, but it kind of helps people. But I think we-- When you really need help, maybe go to somebody that will pray for you, smudge you off or use a feather, span you off, maybe even sing for you, make you feel better. And sometimes that'll send that other side back and they'll leave you alone. You'll slowly start remembering again... We've gotten so far away from it. We don't, we no longer practice those ways.

Surviving and Thriving at Pyramid Lake

In every conversation with participants, it was clear that members of the Pyramid Lake Paiute Tribe are actively considering how to support the survival and wellbeing of their people and their culture. Multiple possible pathways forward were illuminated through our conversations.

Preserving Land and Culture

Given the central role that land itself plays in the selfhood and personhood of tribal members, it was unsurprising to find that environmental conservation arose as a primary concern for the future in nearly all conversations with participants. When asked specifically about her hopes for the future of her community, the Museum and Cultural Center Director responded specifically that continuation of cultural identity is predicated on preservation of Pyramid Lake.

My hopes for the community mostly would involve unity. I think we really need to come together to support one another and to have a common vision, which is to maintain our identity and our culture, fight for our water. You know, that's really important to me because as Kooyooe Tukadu [Fish Eaters], if we didn't have the lake, if we didn't have the fish, we would not be who we say we are. And so we need to continue what represents our culture, and it has to do with the land, the water, the resources that are here, and we have to be able to maintain it as pristine as we can. And it's a real struggle, because we have challenges before us with mining and with other social issues. And so, it's a distraction, but we've got to keep in mind who we are.

As we sat together on the shores of Pyramid Lake, another participant—the Director of Senior Services—shared similar sentiments:

I think looking into the future, I would love for our children, our grandchildren, great grandchildren, to be able to enjoy Pyramid Lake as much as we all have growing up. One time my son, he was seeing all of his buddies at Christmas had gotten money from their reservation. He says, "How come we're so poor we don't get money?" I think he was like, maybe a sophomore. And he said that-- we happened to be riding through here and I go, "Look at Pyramid Lake. It's our lake, that belongs to us." I said, "The tribe spends a lot of money protecting it, fighting for it, making sure that we have water coming to it." I said, "And it's been-- Pyramid Lake has been here since-- for thousands of years. And it's shrunk and shrunk and shrunk and shrunk. But this is where we come from. This is where we live. This is our lake." I said, "You're a tribal member. This is your lake." And I said, "We're not poor. We have this beautiful, awesome resource that is ours." And I just hope that the future generations will be able to come here and enjoy it just as we have. And I hope it never changes. I know it's got a 12% annual evaporation rate, but hopefully on good years like this year where we have snow on the mountains, that we'll always have water coming. Preserve Pyramid Lake.

Alongside land, traditional culture and ideology is also critical for supporting selfhood and personhood, particular for people living with dementia. This importance was also reflected in participants' hopes for the future, which hinged on the preservation of traditional cultural practices and perspectives. The elder healer described his view of the current situation facing the Pyramid Lake Paiute Tribe:

It's more than me saying-- It's those, our people that want-- they're going to have to want to bring it back. A lot of our young people, they look at it like, "Oh, that's old fashioned." That's primitive to them. So, a lot of our young people will say, "I

don't want to do that. That's old fashioned." So our people is going to have to want to bring all these back, like the language, culture, tradition. A few of them are wanting to learn, but the majority of our people are lost. They've gone over the edge and maybe will never come back. That's sad. We're in a sad state nowadays with our Indian people. We're really pitiful. Our people are just pitiful nowadays because we put aside all of our teachings, traditions, culture, language. We lost all that. We have to want to bring it back. Our people are going to have to want to bring it back. Our people are going to have to change to bring it all back. They say it's all waiting. Everything's just waiting for people to want to bring it back and pick it up. Everything, even the songs are out there. You just got to go out and get the songs, bring them back. The old round dance songs, the healing songs, the blessing song. Everything's still out there. The food's still out there. Every year it comes, nobody goes out and harvests the food. The Creator, Mother Earth, they're all sad because we're destroying our Mother Earth. We're putting everything aside, our teachings, culture, ourselves, our people, putting our people's minds aside. In time we'll be taibo thinking people. We'll be brown-skinned taibo, white people. That's what the government wants. Then they'll say, "Oh, you're not Indians no more." They'll take our land, our reservation. "Oh, you people ain't Indian no more. No. Terminate all the reservations. You're just brown-skinned white people." That's what sadly we have pretty much become, because we let ourselves do that by turning our backs on our culture, tradition, language, all of that.

It wasn't just elders who noted a dearth of motivation among tribal members to preserve traditional culture. The youngest participant interviewed reinforced this reality:

I think a large part of it is because a lot of people have lost who they are. They don't know who they are as a person. You see a lot of people trying to be something else, be something that they aren't. You see them trying to be... Western. You see them trying to be gangsters, you see them trying to be something that isn't culturally relevant to us. You always hear the phrase "warrior up" or "you need to be a warrior" from people that don't necessarily know what it actually entails. They don't know what that would mean for us, because when it comes down to it, yeah, you would do anything for your people. You would do anything in your power to ensure that the future generations are able to continue, and when you go back to Paiute philosophy, our people always acknowledge the children and our old people as important to us. They were the ones that ensured that things kept going. And I think we kind of see that people are more worried about themselves than they are about those that are around them.

Yet this young participant remains hopeful that tribal members can reconnect with traditional mindsets and preserve communities and culture in the process.

I think part of my hopes for the future is that we kind of take the teachings that we have and actually utilize them and, you know, put our money where our mouth is, I guess. You always hear people complaining about respect, respect, respect, but you don't really see as many people actually showing it. You always hear people saying, "You need to respect this person, you need to do this," but you don't see it. You don't see people doing things the way that our old people would, and you don't hear about our people being as close as we were. Because you really think about it, in our area there's only a certain number of families when it comes to lineage, and it all comes back to very few people that started it. And it's like, you hear about that, and you would think that we would act more as family then. You would think that we would be able to all sit in a room and not have as much bad blood as we do now. I think that's one of my hopes, is that we don't keep carrying that on and that we don't keep allowing behaviors like that to be affecting our community as bad as they are.

It is important to acknowledge a significant barrier to cultural preservation: historical trauma. Only one participant—the Tribal Museum and Cultural Center Director—shared specifically about the negative impacts of historical trauma, but those impacts she detailed are profound enough to merit consideration as a potent factor in cultural preservation efforts at Pyramid Lake. In describing historical trauma, she said:

I think with historical trauma that pretty much all Native peoples, you know, experience that, because it's passed down generation to generation, and a lot of unresolved issues that result from that. Whether, you know-- You could go way back historically as far as, you know, the Pyramid Lake Wars of 1860. You could go back to, you know, other times when the reservation was created. That was traumatic for our people here, especially at Pyramid Lake, because establishing a reservation was more like a prison camp where people could no longer hunt and gather, which was their normal way of life. And they were restricted to stay within the reservation. And if they left, they were killed. And so that is historical trauma in itself. With a lot of the oppression from the government and policies, say, with the boarding schools. That was traumatic as well, where young children were basically kidnapped from their homes, taken far away and put in a school and then punished if they spoke the language or if they practiced any of the cultural ways. And that was very traumatic. So, through historical trauma, we have a number of incidents that, you know, don't get resolved and then parents pass it on to their children and it continues on generationally.

When asked how such historical trauma obfuscates the preservation of traditional culture, she responded:

Well, historical trauma has affected culture in many, many ways. So, like I said, with boarding schools, the main intent was to beat the Indian out of children, you know, so that they wouldn't speak the language, that they would forget about their culture. And so, we have a lot of tribes that don't carry on the language to this day, including the tribe here. We have very few fluent speakers because parents didn't want their children to be punished for speaking the language. Therefore, they quit teaching it.

She believed, too, that historical trauma has a direct negative effect on the well-being of people living with dementia.

So, I see that there's a connection between historical trauma and dementia, because as long as we have a trauma and it's unresolved, it's not been dealt with, people choose to forget and they may not want to deal with it throughout their lifetime. And then as we get older, the dementia sets in which compounds with the historical trauma issues as well. And I think that at least for what I see with Native people, it really compounds that dementia and may progress to other stronger forms or serious forms of forgetfulness.

Yet even with the challenges imposed by historical trauma, she was optimistic about pathways to healing for the tribe.

With healing historical trauma, I think there's various ways that that can be accomplished. So, you know, we work on wellness. Wellness is a concept of being holistically healthy, you know, mind, body, spirit, and heart. That, you know, when you do wellness work, you're looking within yourself to look at what do you need to improve on, whether, you know, health-wise, physically, mentally, spiritually, how does that work. And I think it's got to start individually to create that movement. And from there, it catches on, you know, with parents that teach their children, you know, how to be well, how to be healthy.

Altogether, participants conveyed that supporting selfhood and personhood for all people at Pyramid Lake, including people living with dementia, requires special attention to conservation of the land of the Pyramid Lake Reservation, preservation of the tribe's traditional cultural practices, and collective healing of longstanding historical traumas.

Dementia Awareness

Another avenue of action for Pyramid Lake communities, in the eyes of participants, is increased awareness and conversation about dementia. Extreme uncertainty about all aspects of dementia was expressed by almost every participant in relation to the topic, and they were not hesitant to admit their lack of knowledge, given its striking magnitude. The police officer for the Tribal Health Clinic expressed her own lack of awareness about dementia.

You know, I don't know. I don't know about that, because-- I don't know-- I don't know anyone else who has dementia. I just know what I dealt with with my dad. And I mean, I could make an assumption of what people think, but I don't know. I don't know. I don't know anyone else who, you know-- I don't know anyone who's-- I don't know. I don't know anyone who's been officially diagnosed. I know people will say, "Oh yeah, he's got, you know, maybe dementia or something." I don't think we treat them any different, but I don't know, you know. I mean-- And I wouldn't respect them less, you know. If anything, I would help them more, as, you know, valuing them because they're an elder. They can't help, you know, what happened to them. But I would think they would still be valued as, you know, important. You know, they might not be able to think the same way they used to or-- Who knows, you know, I've never sat down with them and done something like that, you know.

As a result of this lack of awareness, participants—including the Director of Senior Services—unanimously agreed that tribal members ought to further consider what a growing incidence of dementia means for Pyramid Lake.

It's a reality. It's not something that we could pick and choose to not have. You know, it's-- with the high risk factors, it's very real. And I think we just need to know about it. We need to learn about it. We need to talk about it. We don't talk about it. Like a lot of things that happened to Native people, you know, throughout history, we don't talk about it. But how do we heal if we don't talk about it? How do we grow if we don't talk about it? We need to talk about it. Yeah. You know, yeah. Awareness, education... It can happen in Indian country. It just takes a spark. Somebody to say, hey, light it. You know, light that spark because it's not happening.

According to participants, having these conversations is important for improving access to supportive services on the community level. The same participant detailed the tendency among Native families to “...*just deal with it...*” when an elder is struggling, and how that practice—while laudable—might prevent dementia from being discussed on any notable scale at Pyramid Lake.

I see it happening with different families, with different elders here. Actually, across Indian country, not just from Pyramid Lake, but from other places, I see families struggling with not knowing. See families struggling with loved ones that they have that have dementia. It's not talked about. As families, we deal with it. Whenever we have any kind of illness going on in our families with our elders, we just deal with it... It's like, the more that I learn about dementia, the more I want to share with people because it's something that isn't talked about. When families, like I said, have a member that might be ill with anything, we just deal with it. But it's like, the more I learn about dementia, the more questions I have, I think. Because, where's the data? We don't have any data. Where's the services? We don't have any services. Where's-- it wasn't until just recently that we've got grants that are now going to try to help Native people address dementia. It's not something that's talked about. And we need to change that because it does happen. And with Native people being at that higher rate, higher risk of getting it, why aren't we talking about it? We should be talking about it.

Participants also indicated that they are working to navigate the complexities of such conversations about dementia, given that they are essential to supporting the well-being of people living with dementia. However, those conversations are far from easy. The youngest participant shared his insights:

I think they're-- the most they can really do is have the discussion, because although they might have the best intentions, it can be taken the wrong way very easily and cause a lot of issues. So, it's a sticky situation, because you don't want to be that one that kind of makes the decision for someone, and you don't want to be the person that kind of hurts feelings in the process, but you do have to have the discussion. You do have to talk with them and say, you know, "This is what we've noticed," or, you know, "Do you want to get help? Do you want to, you know, have it-- the information? You know, the information is that easy to get, we can go talk to so and so and we can have an answer. Or do you want to just stay in the dark?" Because ultimately if they say no, then there's not really much you can do until it's

already progressed. So, I think that's a hard-- the hard talk that people actually have to have and a lot of them aren't willing to.

Finding Pesa Sooname

When considering their hopes for of their tribe, one of the most profound ways that participants felt tribal members could manifest a shared future of prosperity was also one of the simplest: staying positive. All participants were asked how they relate to the phrase “pesa sooname,” which translates to “good thought” or “good think” in Northern Paiute.

The Councilwoman responded:

Um, like, you're supposed to be in a good way. Like, the good thoughts, that you can't have negative thoughts, like go to the bad right away, you know. You have to be open for the good, basically. And that you try to keep that balance of-- And it's not to overlook the negative, I don't think, but just again remember, because like that situation where my grandpa, you know, that I talked about, he would always be kind, he would always be nice to people, even though they were like saying ugly things to him, he just went along. And I know when I was a teenager, I didn't understand that because it's like, if somebody's talking smack to you, you know, you've got to stop them, you've got to make them stop. But I think that having good thoughts, then it'll make you feel better inside. That goes along with it. It's just like, you know, that saying about, you know, it takes more muscles to frown than it does to smile. And then the fact that you're smiling releases those endorphins to make you feel better. It's like that. To me it's along the same lines as that.

When asked specifically about his thoughts on Pesa Sooname, and how they relate to his work on Tribal Council, the Tribal Chairman—who is not yet an elder—shared:

Pesa Sooname to me, it means, you know, everything's a good thing. You have a good approach to everything. And it's really your choice to choose whether you want to have that approach or not. And a lot of times it's not always that way. I get it. But we have to reframe our way of thinking so that we're approaching life and situations like that. And I have to go back to my experience as a police, that I had to approach each and every call like that. You know, I have to go in with a good thing. I have to try to figure this one out. And rather than going with preconceived notions and have a bad attitude, you know. So, I always give thanks every day to the Creator for that. And I try to pray like that every day. And that's how I really sincerely feel. And that's what I do. You know, so I just want you to know that's from the heart. And I pray like that all the time.

Positivity and positive interactions with family and community members goes beyond being a moral aim for participants; it infiltrates how they think of themselves as people.

The Tribal Museum and Cultural Center Director recounted the story of her Indian name:

Participant: I've done quite a bit in my life, and I would say-- Well, I've had a lot of reflection, you know. I was looking and talking to my niece about, you know, just within the last year, of a lot of things that had happened and it was all very positive. You know, there were some things that were sad, but for the most part I think-- you know, living life in a in a positive way and being able to help other people, I would say. I have an Indian name, which is "Many Relatives Woman," and that was given to me through ceremony and so for me it represents that's how I have to live my life, is that the people that I encounter on a daily basis I have to treat as my relative. And so I value my relatives very, very much, and, like I said, you know, through dancing or through ceremony, that's how I live my life, is to be a helper. And also as a sun dancer, that I've made that commitment to pray and to help my people as much as possible.

Interviewer: I actually would love to follow up on that. Your name, "Many Relatives Woman." I wonder if you wouldn't mind sharing what that name is in Northern Paiute and also, what does it mean to you to treat someone as a relative?

Participant: So with the name "Many Relatives," many relatives, "Ewa'yoo Nanumu," is part of that. "Mago'ne" is, you know, what we call the woman. And what does it represent, what does it mean? You know, in treating relatives well. It's, you know-- I envision through a design that I made many, many years ago of how is this pictured, you know. And so within this design-- and it's beaded, it's on a purse, and I use that in my dance regalia. So for the center of that is the Stone Mother, and here at Pyramid Lake, the Stone Mother they say represents our creation story of how the lake was created, through the mother's tears as she was crying for her children because they had been sent to different directions. And I feel like that's the center of who we are, you know, that we all have mothers and as children we're not to fight amongst each other for-- Being with my grandmother, that was the worst thing anybody could ever do is, you know, to allow the children to fight with each other. And you know, through the years I came to understand why. And so, in that design the Stone Mother is in the middle and then you've got the water, there's eagle feathers, and then there's a place-- there's a circle around that. And part of this design represents all the people, and it's in each of the four directions. So, kind of an explanation, you know, how I see it visually. And that's to me how it looks, is that it's in a circle, the prayers-- or the feathers represent prayers, so we come to life through prayer and we're here because of prayers of our ancestors and our relatives.

“Pesa sooname”—“good thought”—is therefore both an end to achieve in and of itself—to live well and live positively—and also a means through which self, family, community, and culture can all be supported and preserved.

DISCUSSION

This study explored selfhood and personhood within the context of dementia for members of the Pyramid Lake Paiute Tribe. The general aim of this study was to shed light on ways of thinking about dementia informed by the Pyramid Lake Paiute Tribe's culture that help support the well-being of people living with dementia, with a specific focus on the continued support of personal identity—selfhood—and active citizenship—personhood—for those individuals. Given this study's grounding in a dialogical research approach, an additional and still primary aim was to offer research participants the opportunity to further explore their own thoughts on selfhood, personhood, and dementia in a way that might inform their continual process of self-becoming. Video-Based Dialogical Analysis, and the development of a research-informed documentary film as a core component of this study, were key to accomplishing both of these aims. The documentary film produced will provide an easy mechanism for participants to continue engaging in conversations with both themselves and their fellow community members on the subjects of this research in the sort of iterative research-participant dialogue required by a dialogical research approach and by decolonizing research efforts (Hulko et al., 2010). As directed by the intentions of dialogical research, the discussion below considers and proposes ways in which study results might be of use to study participants individually and to their communities more broadly as they continue along their journey of perpetual becoming.

Following a total of eleven conversations with nine participants, this study identified a number of key themes that frame a story of identity, community, and dementia at Pyramid Lake that is being actively constructed and lived by tribal members. Of primary

importance to understanding that story and supporting its continuance is the linkage of selfhood and personhood that participants expressed. Identity for people at Pyramid Lake is not an individual experience; rather, identity is generated from a single person's connection to the land of the Pyramid Lake Reservation itself, to other members of one's family and tribe, and to the very idea of a unified tribal community. Participants repeatedly expressed that they would not be who they are without Pyramid Lake and its surrounding geography, just as they would not be who they are without the traditions and practices that have been passed down from generation to generation for millennia. The place of Pyramid Lake and the culture of the tribe support selfhood both through a person's direct involvement and also through a fostering of connection between tribal members; the notion of service to one's community—in particular supporting the continuation of cultural knowledge—lays at the core of participants' identity. It is therefore senseless for participants to consider notions of selfhood without invoking components of personhood, and vice versa.

This interweaving of selfhood and personhood yields both risks and opportunities for people at Pyramid Lake. As participants and their communities more broadly continue to chart a future that supports the well-being of all tribal members, including people living with dementia, avenues that sacrifice community cohesion for the sake of individual growth may render a great deal of damage even if they are well-intentioned, as individual and community are in fact not able to be parsed so cleanly. Conversely, strategies to bolster community will also likely reinforce tribal members' senses of self and identity, and thus even small investments on that front might yield disproportionately large impacts. Participants were united in their calls for greater focus on community at Pyramid Lake

moving forward, so it appears that the Pyramid Lake Paiute Tribe is well-positioned to leverage the selfhood-personhood bond.

While such a strong connection between self and community is not as ubiquitous a component of Western life as it is for members of the tribe, understanding this aspect of life at Pyramid Lake—and how participants' single greatest hope for the future is a stronger community—can help non-Native people remember the potential critical role that community can play for people living with dementia. Depending on the individual, community might extend beyond providing a means through which people living with dementia can connect with others socially and connect with a meaningful purpose; it might be the best enabler of them connecting with their very selves. As communities across the world consider what it means for them to better support people living with dementia in living well, community itself should not be overlooked as a powerful pathway to positive change. Dementia-friendly efforts must be about more than building and delivering programs, services, and resources *for* people living with dementia. Steps must be taken to ensure that communities are genuinely inclusive *of* people living with dementia, since it is very possible that personal well-being cannot be fully maintained without authentic participation in community. This is supported by existing research exploring factors contributing to the well-being of people living with dementia, in which domains connected primarily to selfhood, such as “Being Me” and “Growing and Developing”, were seen to work in tandem with domains connected primarily to personhood, such as “Being With” and “Making a Difference” (Dupuis et al., 2012).

Participants in this study expressed that the primary tension orchestrating their collective community-level conversations about the future—especially in relation to

elderhood and dementia—was that between Western and traditional ideologies. Existing research has demonstrated the significant extent to which Western ways of thinking about health and well-being have negatively impacted the lives of Native people (MacDonald & Steenbeek, 2015), and participant responses indicated the very same phenomenon is unfolding at Pyramid Lake. In three different ways, a departure from traditional perspectives at Pyramid Lake threatens to disenfranchise people living with dementia from their communities, and—given the fundamental connection between community and self described above—from their selves as well. First, elders with dementia are being averted from opportunities to be of service to their families and communities, as Western ways of thinking about elderhood perpetuate a narrative of elders needing help from their communities rather than communities needing the help of elders. Second, the Western tendency of families choosing to move family members living with dementia into long-term residential care is creating chasms between family members at Pyramid Lake and interfering with the roles that elders and their family members traditionally play in each other's lives. Third, Western biomedical descriptions of dementia are leading people at Pyramid Lake to increasingly consider dementia itself as a problem, label it a medical condition through formal diagnosis, and view it as something causing great loss both at the individual and community levels, supplanting more strengths-based, social/relational perspectives that are deeply seated within traditional modes of thought.

In all three of these cases, participants simultaneously expressed a reverence for traditional ideology and practice while acknowledging the need to strike a balance with influences coming from outside of traditional culture. Based on those responses, it seems that in fact the Pyramid Lake Paiute Tribe's traditional culture is the main driver guiding

them in setting both individual- and community-level goals for the future, and the tribe is struggling to determine how best to utilize the tools offered through Western culture to achieve that future without being redirected by foreign ideology. For example, participants considered how to be of service *to* elders by supporting them in being *of* service to others, they noted the benefits that might arise from creating long-term residential care options on the reservation, and they spoke of using Western medicine for specific people and specific cases, in concert with and in support of traditional healing practices. Explicitly underlining such intentions appears to be helping tribal members find all possible benefits from Western approaches without losing their identity and becoming Western. However, such a balance is difficult to maintain, and participants did express concern that the Pyramid Lake Paiute Tribe is on a track toward excessive engagement with Western culture that might impede their communities' future thriving.

This model outlined by the Pyramid Lake Paiute Tribe—of envisioning the desired future and leveraging the various strengths and tools available to achieve that future—is one that might also achieve success in non-Native communities seeking to become more dementia-friendly and inclusive. Most Western community planning discussions center on the identification of problems and the development of solutions to those problems (De Sio & Lachat, 2021). Though problem-solving might be expedient, it risks losing focus of a primary future objective; indeed, as previously mentioned, people at Pyramid Lake are now finding themselves in such a dilemma. Bringing more strengths-based, future-oriented planning processes to the table in community conversation can help circumvent the pitfalls of pure problem-solving, and methods exist for doing this very thing. For example, Appreciative Inquiry utilizes a structured, four-phase approach that guides community

members toward identifying aspirations for their shared work as a community, and then taking action toward realizing those aspirations (Loty, 2014). Adapting approaches like Appreciative Inquiry for use at the individual and family levels would even further mobilize the wisdom demonstrated by the Pyramid Lake Paiute Tribe in relation to supporting the well-being of people living with dementia by focusing on what matters most to them from selfhood and personhood angles.

Participants did note some additional essential actions that must be taken at Pyramid Lake to ensure a successful future: the conservation of Pyramid Lake and its surrounding land, and a dedication to spreading awareness of dementia within a Native context. These actions do not necessarily lie outside the tension between traditional and Western ideologies described above. Indeed, environmental conservation is firmly rooted in the negotiation of individual monetary interests against collective, qualitative benefits gleaned from unadulterated environmental resources. Similarly, conversations about dementia must navigate the diverse and sometimes contradictory cultural narratives about dementia presented in traditional and Western spheres. However, these two actions represent prime targets for partnership between the Pyramid Lake Paiute Tribe and non-Native groups seeking to support the tribe's well-being and success. When discussing these actions, participants delineated clear next steps in a manner that seemed difficult to do for broader and more cognitively dissonant conversations surrounding the role of traditional culture in supporting the well-being of tribal members. These clear steps are prime targets for outside, non-indigenous people and organizations who are interested in genuine partnership with the tribe and who are committed to a decolonizing approach to supporting the tribe's flourishing, as their importance and urgency are coming not from any outside

analysis but from tribal members themselves. For work between tribes and non-Native groups more widely, it is essential that the needed time be spent to open genuine conversations—such as the ones had through the course of this study—so as to surface clear steps for action and avoid further harm caused by well-meaning but paternalistic aid (Baaz, 2005).

Throughout all of the needed collective community work described by participants and outlined above, a central attention was given to the importance of approaching that work with an appreciation for what is, what has been, and what is to come. “Pesa sooname,” meaning “good thought” in Northern Paiute, lays a foundation on which self, community, and systems of care for people living with dementia can be built. Conversations with participants about *pesa sooname* summoned portraits of a community in which all community members are treated with dignity and respect, connected with meaningful opportunities for active citizenship, and supported through care that honors who they are as a person along with their continued role in the community. This positive mindset was sometimes considered as a goal in and of itself, but often participants treated a commitment to *pesa sooname* as a necessary means through which to achieve broader goals and actualize the shared future for which they hope. In this manner, participants prioritized process alongside outcomes, signaling that focus need be given to both. Continually reflecting on this intention will help people at Pyramid Lake remain working along their desired path, and it is a lesson that non-Native dementia-friendly efforts globally can incorporate into their operations. A focus on good process, through good thought, will yield good outcomes.

STUDY LIMITATIONS

This study yielded strong results that will hopefully be of utility to research participants, the Pyramid Lake Paiute Tribe, and both indigenous and non-Native communities more broadly. However, there are some limitations that are important to recognize, and which will help to guide future research on selfhood and personhood within the context of dementia among Native populations.

First, this study engaged only nine participants. Those participants represented diverse perspectives, including care partners and tribal staff contributing to the well-being of people living with dementia at Pyramid Lake. As such, robust themes and ample complexity was highlighted through the course of participant conversations, however future research could be further strengthened through the inclusion of additional research participants. Of particular note, no people living with dementia participated in this study. Multiple participants reported feeling changes in their memory or other thinking skills, and one participant had the experience of living with a traumatic brain injury that produced memory symptoms, however no participants had ever received a formal diagnosis of dementia or had experienced symptoms that were severe enough to be considered dementia. This limitation is significant on both practical and ethical grounds. First, any attempts at unpacking the experience of living with dementia and identifying supporters of well-being for people living with dementia are grossly incomplete without the perspectives of people living with dementia themselves. In fact, people living with dementia are the only true experts of what it means to live with dementia and what supports might help them to live well. Second, researching, writing, and creating a film about the topic of dementia without the active participation of people living with dementia presents an undeniable

problem of representation. People living with dementia are already systematically marginalized; to perpetuate such marginalization through even the most well-intended research efforts is difficult to justify.

A great deal of effort was devoted to recruiting participants living with dementia for this study, yet those efforts were met with no success. This is informative in-and-of-itself, as it provides an example of the downstream effects of phenomena being described by research participants. Recruitment attempts were conducted via word-of-mouth, but contacted individuals seldom could identify someone who they personally knew who was living with even probable, undiagnosed dementia. When they did have a connection to someone living with dementia, they often felt uncomfortable reaching out to that individual on the subject of their dementia, signifying that dementia is indeed quite stigmatized among tribal members. The lack of discussion about dementia at Pyramid Lake is striking, and recruitment efforts for this study highlighted that reality. Without ample community conversation about dementia, a true understanding of dementia's prevalence at Pyramid Lake will continue to stagnate, and stigma surrounding dementia will continue to grow.

Other notable limitations of this study all pertain to interview design. Former research has suggested that best practices for research with Native populations include knowledge-gathering formats such as talking circles and photo elicitation to further decolonize research practice and maximize the degree to which research participants can share in the manner that feels most comfortable for them (Hulko et al., 2010). This study did not incorporate any such alternative knowledge-gathering channels. This decision reflected an attempt to produce material that would lend itself well to inclusion in the documentary film produced in conjunction with the study, under the assumption that direct,

interrogative interviews would be most suitable in that regard. Upon reflection, that assumption was rooted solely in familiarity; one-on-one interviews are pervasive throughout the documentary film genre, and therefore it was falsely determined that such a format would be most desirable for the film product of this research. There is no reason to believe this is true. Creative and innovative approaches to writing and editing the film could have made content gleaned from talking circles, photo elicitation sessions, and other alternative knowledge-gathering channels both informative and engaging to film viewers.

Also related to participant interviews, all participants in this study were asked directly about their relationship to dementia, and were asked numerous questions either about their experience of being a care partner for someone living with dementia or about their thoughts on how best to support the well-being of people living with dementia. In this way, dementia itself was an explicitly outlined topic within all participant conversations. Past research on the subject of memory loss among Native people suggests that such a direct approach to questioning about dementia might obscure more nuanced understandings of memory loss among participants (Hulko et al., 2010). As found, too, in this study, dementia is in fact foreign concept for many Native people, and is associated with Western notions of health, elderhood, and care. Approaching the subject of dementia more delicately—perhaps asking about thinking changes or memory loss first before broaching the concept of dementia per se—might have uncovered hidden complexity that this study in its current form failed to expose.

Lastly, Video-Based Dialogical Analysis holds yet untapped potentials within the study of selfhood, personhood, and dementia. The capacity of Video-Based Dialogical Analysis to capture data nonverbally is one feature that makes it so compelling for use in

research that engages people living with dementia, since people living with dementia tend to communicate less and less verbally over time, are inappropriately judged to be less and less adept at communicating, and are therefore frequently excluded from research efforts. Employing Video-Based Dialogical Analysis invites the researcher to reject this narrative of diminution and receive communication from people living with dementia in the manner most comfortable for them, which is often nonverbally. As mentioned previously, no people living with dementia participated in this study, and so the intended nonverbal analysis of participant data was foregone. Even so, Video-Based Dialogical Analysis was central to this study at every phase, given that it served as the unifying pipeline through which participant interviews were simultaneously digested and incorporated into two connected products: a research product targeted toward academia, and a film product targeted toward the broader public. The process of analyzing participant data for the research and the process of topically categorizing interview content for the film were one and the same.

Future research that employs Video-Based Dialogical Analysis would benefit from intentional interview design that solicits ample non-verbal contributions from participants so as to provide fertile ground for leveraging the methodology's full capability. In this study, the interview set-up during participant conversations—along with the questioning structure—likely conveyed to participants that they were taking part in a traditional, video-recorded interview, and so participants may have felt compelled to remain still and focus on their verbal responses. Additionally, for all but two participants, only one conversation was convened, meaning that there may not have been ample time to build researcher-participant relationships to the point that participants felt comfortable being themselves in

a physical, embodied fashion. As such, future research might consider engaging in repeated interviews with the same participants over time, along with interviews during which participants are physically conducting a task.

CONCLUSION

In a world in which people living with dementia are frequently deemed to be shells of their former selves, this study set forth to explore the realities of how selfhood and personhood are sustained, lost, or grown among member of the Pyramid Lake Paiute Tribe living with dementia. Until now, little to no research had considered selfhood and personhood within the context of dementia in indigenous populations, despite strong evidence for the presence of social/relational, strengths-based perspectives on dementia among Native people. With intentions to decolonize research practices and to honor research participants' full, ever-becoming selves, this research utilized Video-Based Qualitative Analysis situated within a dialogical research framework. This analysis resulted in the above written report—telling the story of identity, community, and dementia at Pyramid Lake—and also a documentary film to be released in partnership with the tribe following further collaborative review and participatory editing with research participants.

Members of the Pyramid Lake Paiute Tribe are motivated and well-situated to leverage cultural identity and traditional practices to support people living with dementia in living a life full of well-being, strongly connected to their selfhood and personhood. Land, family, and service represent three primary pillars of identity for people at Pyramid Lake, and form bridges between oneself and one's community in a manner that generates an interdependence between selfhood and personhood. Pronounced tensions were discussed surrounding the sometime discordant convergence of traditional and Western ideologies in relationship to these core components of identity and citizenship, and elders—including people living with dementia—are at risk of becoming trapped in that turbulence if dementia continues to remain undiscussed on any meaningful scale amongst tribal

members. Yet a resounding commitment to community at Pyramid Lake, and a long history of supporting each individual as they are and appreciating them for their unique strengths, provide robust reason for hope. Indeed, the generative struggles underway for members of the Pyramid Lake Paiute Tribe, and the community-level conversations they are employing toward resolution, offer an example not just for other indigenous groups but for both Native and non-Native communities globally.

Central to those conversations is one standout enabler of individual and community well-being, and a catalyst for progress toward community goals: *pesa sooname*. Meaning “good thought” or “good think” in Northern Paiute, this simple but powerful phrase depicts how members of the tribe approach all efforts and all people with notions of positivity and possibility. *Pesa sooname* is the instrument of choice for community members to wield as they work together toward their shared future, and *pesa sooname* is what they hope to find on the other side of that important work.

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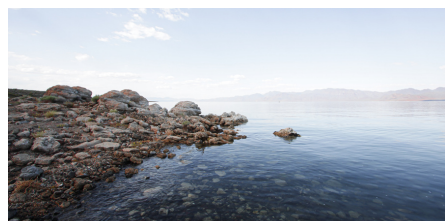
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APPENDIX A

Recruitment Flyer

ARE YOU EXPERIENCING COGNITIVE DECLINE, OR KNOW SOMEONE WHO IS?

**Tell your story as part of
a research project and
documentary film!**



REQUIREMENTS

**You or someone you know is experiencing
cognitive decline that could be dementia.**

Your story will help explore the experience of living with dementia for members of the Pyramid Lake Paiute Tribe, and will be archived as part of the Tribe's oral history!

**Participation is as simple as having a
video-recorded conversation,
and is 100% voluntary.**

**This project is led by the Numaga Senior Services Program,
in collaboration with a graduate student from UNR.**

**Interested in participating?
Email: cacklin@unr.edu or call: (775) 857-7818**

Recruitment Email

Hello everyone,

I am working with a graduate student at UNR, Casey Acklin, to create a film about elderhood and dementia at Pyramid Lake. We are talking to elders, family members, and tribal staff to hear their stories and perspectives about elderhood, dementia, and caregiving.

We are also doing a research project along with the film, to understand what aspects of culture here at Pyramid Lake support the well-being of elders. This film and project has been fully approved by Tribal Council.

We have talked to 7 people so far, but our goal is 15 people, so we need your help! I've attached a flyer with contact information for Casey; his email is cacklin@unr.edu and his phone number is (775) 857-7818. Reach out to him if you are interested; we would love to talk with you!

We are trying to finish interviews by the end of January. Even if you aren't interested, if you know someone who might be, we would so appreciate you passing along this information.

Thank you so much, and we look forward to hearing your stories,

Carla Eben
Numaga Senior Services Director
Pyramid Lake Paiute Tribe

APPENDIX B

Letter of Informed Consent

University of Nevada, Reno
Consent Form Template, Social Behavioral or Educational Research

Title of Study: Using Documentary Film to Explore Selfhood and Personhood within the Context of Dementia at the Pyramid Lake Paiute Tribe

Principal Investigator: Laura Crosswell, PhD

Co-Investigators / Study Contact: Casey Acklin

Study ID Number: 1943045-1

Introduction

You are being invited to participate in a research study. Before you agree to be in the study, read this form carefully. It explains why we are doing the study; and the procedures, risks, discomforts, benefits, and precautions involved.

At any time, you may ask one of the researchers to explain anything about the study that you do not understand.

You do not have to be in this study. Your participation is voluntary. If you do not agree to participate, you will still have the opportunity to share your story if you wish to do so.

Take as much time as you need to decide. If you agree now but change your mind, you may quit the study at any time. Just let one of the researchers know you do not want to continue.

Why are we doing this study?

We are doing this study to learn more about the experience of living with cognitive changes caused by a probable dementia-related condition at the Pyramid Lake Paiute Tribe, both from the perspectives of elders and also from their family, friends, and other community members that support them in living well.

Benefits of research cannot be guaranteed, but we hope to both collect and tell stories of Pyramid Lake Paiute Tribe members in a way that can be recorded for future generations while also understanding more about dementia within an American Indian context.

Why are we asking you to be in this study?

We are asking you to be in this study because you, or someone you know, is living with cognitive changes that may be dementia, and we want to learn more about your perspectives and experiences as either a person living with dementia or a family or professional care partner.

How many people will be in this study?

We expect to enroll approximately 15 participants from within the Tribe.

What will you be asked to do if you agree to be in the study?

If you agree to be in this study you will be asked to engage in a conversational video-recorded interview in which we will talk about your history, your present experiences, and your vision for the future.

How long will you be in the study?

The study will last until Spring 2023, and you will have the opportunity to participate as much or as little as you would like until that time.

What are your choices if you do not volunteer to be in this research study?

If you decide not to be in the study, you may still be involved in the creation of a documentary film in which you would have the chance to share your story, if you wish to do so.

What if you agree to be in the study now, but change your mind later?

You do not have to stay in the study. You may withdraw from the study at any time. If you do withdraw, you can remain in the film being produced alongside the study, or you can ask that you not be featured in the film, however you will not be able to request withdrawal from being featured in the film once the film has already been released.

What if the study changes while you are in it?

If anything about the study changes or if we want to use your information in a different way, we will tell you and ask if you want to stay in the study. We will also tell you about any important new information that may affect your willingness to stay in the study.

Is there any way being in this study could be bad for you?

If you participate in this study, you may find our conversations very positive or rewarding. However, you may also find yourself having some difficult and/or emotional conversations during interviews. If this occurs, you will always have the opportunity to

end those conversations and either re-commence at a later time or withdraw from the study. You also have the option to ask that the recordings of the conversations be deleted after the fact, although you will not have this option once the documentary film has been released.

Will being in this study help you in any way?

We cannot promise you will benefit from being in this study, but we do aim to offer you an opportunity to tell your story in a manner that helps you better understand the role of cognitive changes within your own life, whether you are living with dementia or are a care partner for someone living with dementia.

Who will pay for the costs of your participation in this research study?

No costs are associated with participation in this study.

Will you be paid for being in this study?

You will not receive any payment for being in this study, but you will receive all raw video-recorded interviews and a copy of any media produced during this project.

Who will know that you are in this study and who will have access to the information we collect about you?

The researchers, and the University of Nevada, Reno Institutional Review Board will have access to your study records. Additionally, participating in this study entails being featured in a documentary film being produced alongside this study. However, you may request that you be anonymized (changing your name, hiding your face, or both) if you choose. That being said, even in cases where you request anonymity, it is possible that other community members who are familiar with your story might still be able to determine who you are.

How will we protect your private information and the information we collect about you?

We will not use your name or other information that could identify you in any reports or publications that result from this study unless you explicitly tell us that we have permission to do so. You may withdraw this permission at any time, up to the point that the documentary film is released. Your information will not be used or distributed for future research studies even if identifiers are removed.

Do the researchers have monetary interests tied to this study?

The researchers and/or their families have no monetary interests tied to this study.

Whom can you contact if you have questions about the study or want to report an injury?

At any time, if you have questions about this study or wish to report harm to yourself that may be related to your participation in this study, contact Casey Acklin at cacklin@unr.edu or (775) 857-7818.

Whom can you contact if you want to discuss a problem or complaint about the research or ask about your rights as a research participant?

You may discuss a problem or complaint or ask about your rights as a research participant by calling the University of Nevada, Reno Research Integrity Office at (775) 327-2368. You may also use the online *Contact the Research Integrity Office* form available from the [Contact Us page](#) of the University's Research Integrity Office website.

Agreement to be in study

If you agree to participate in this study, you must sign this consent form. We will give you a copy of the form to keep.

Participant's Name Printed

Signature of Participant or Legal Guardian

Date

Signature of Person Obtaining Consent

Date

Photo/Video Release Form

University of Nevada, Reno
Photo/Video Release Form for Research

Title of Study: Using Documentary Film to Explore Selfhood and Personhood within the Context of Dementia at the Pyramid Lake Paiute Tribe

Principal Investigator: Laura Crosswell, PhD

Co-Investigators: Casey Acklin

IRB Number: 1943045-1

Photographs will be taken and video recordings will be made of you during your participation in this research project. Please indicate below how we may use your images. Agreeing to allow your images to be used for research is completely voluntary and up to you. In any use of your images, your name will not be disclosed.

For all uses to which you agree, please initial in the spaces provided in the following table:

Initials	Uses
	1. The images may be studied by the research team for this research project.
	2. The images may be used for scientific publications.
	3. The images may be used at meetings of scientists interested in the study of dementia and American Indian communities.
	4. The images may be used in classrooms to teach students about dementia and American Indian communities.
	5. The images may be used in public presentations to non-scientific groups.
	6. The audio recording may be used on television and radio.

You have the right to request that the recording be stopped or erased at any time.

By signing below, you are agreeing that you have read the above description and give your consent for the uses of your images as indicated by your initials.

 Participant's Name Printed

 Signature of Participant

 Date

 Signature of Person Obtaining Consent

 Date