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Dementia in Work Place: A Theoretical Examination of the Risk Factors

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Abstract - Culture determines how members of society think and feel: it directs their actions and defines their outlook on life. Not much is known about the dementia perceptions and care giving workers experiences in Nigeria amidst cultural misgivings of their heritage. To seek solution to this gap in knowledge, this study explores a qualitative method to understand the dementia perceptions of some Nigerian social work students who were fulfilling their internship scheme as well as workers working as paid dementia caregivers in some private homes and missionary owned old people's homes in Benin City, Edo State, Nigeria and to determine the potential for continued employment post-diagnosis. Ten case studies focused on persons with dementia who were still in employment or had left in the previous 5 years were examined. Each involved interview with the person with dementia, and a workplace representative. This data triangulation endorsed precision, permitting the experiences to be seen via a variation of opinions to build a clear image of each circumstance. The inferences of this study are multi-layered and require to be measured in terms of the individuals' wellbeing, organizational support, and the wider theoretical, economic and societal consequences of supporting employees as well as persons with dementia.

Key Words: dementia, Alzheimer's disease, employment, workplace.

INTRODUCTION

Dementia, also known as brain failure or loss of mind, is a clinical condition characterized by impairment in cognitive abilities (remembering things, orientation, language use, judgment, problem-solving abilities, abstraction etc.) that is enough to disturb activities of daily living in the conscious and alert state. It is the most common degenerative disease of the nervous system and a leading cause of death and disability. Among neurological disorders, it ranked second after stroke as a leading cause of disability in human adjusted life years. Dementia is an age associated disorder, and with its rising proportion in adults and the aged, is referred to as the "greying revolution". All forms of dementia, including the two most frequent which are Alzheimer's and vascular dementia, involve loss in significant areas such as memory, language, reasoning, spatial awareness, and even physical movement. Dementia can also be associated with mental symptoms, such as delusions, anxiety, depression, and even alterations to an individual's personality.

As regards mental fatalities, cognitive behavioural therapy can be used to a reputable effect, enabling the patient to concentrate on the current and absorb coping aids that will support the position they find themselves. An example would be the posting of reminders such as the milk is in the fridge and so forth, and the use of a large calendar/diary in which to note tasks for the week ahead. Memory loss is usually related to issues of short-term memory, such as what did you eat for breakfast this morning, whereas long term memory, such as where did you take shelter during the war to have remarkably survive. Psychoanalytical techniques of taking the patient back in time, by the use of photographs, music, even sounds and smells, can help to bring the patient 'back to life' and

provide a sense of connection for them. Such psychoanalytical approaches can be facilitated either on a one to one basis or within a group.

However, not all care givers of the persons/elderly suffering from dementia employ such techniques, and there is a strong case to be made for better qualifications for those tasked with either the medical or social care of this group in order to achieve a far better quality of life. It can be very depressing to the caregiver to see persons suffering from such illnesses slumped in a chair in their own home or sat in a circle in a Care Home. We need to do far more than keep such people clean, fed, and medicated. Freud's approach with talking therapies provides us with one important way into this problem.

Conceptualization of the risk of dementia in workplace

Risk is ultimately delineated by cultural insights and meanings, which transform over time. Even within cultures, risk holds varied implication to diverse people, and can be altered in various situations over the years. Besides, persons with dementia, careers and health workers are heterogeneous groups. As such, all persons situate concepts such as risk in the framework of their cultural, individual, and proficient involvements. Consequently, no two persons are probable to have identical standpoint on what constitute risk, in spite of being in the same 'group'. Furthermore, risk has turn out to be a universal and prevalent occurrence within modern-day life therefore, a component of growth into adulthood in contemporary society encompasses learning to identify, reply to and be able to address risk in a society that has become "increasingly preoccupied with the future, which generates the notion of risk" (Giddens, 1998, 27).

What happens, however, when one's ability to identify, reply to or be able to address risk is brought under uncertainty, or considered as diminished? This is the experience persons with dementia suffer incessantly from the point at which their ability is probed via diagnosis to the point at which such individual is scheduled to be managed. Dementia is a mounting worry globally. Although many individuals may equate dementia to a loss of memory, yet the truth is that dementia is a condition that can distress not one but several mental areas. These areas comprise memory, nevertheless, correspondingly consist of behaviour, thinking, judgment, language, and personality (Australian Institute of Health and Welfare, 2017; World Health Organization, 2016).

Statement of Problem

As the world population ages, Alzheimer's disease (AD) and dementia are becoming global health priorities due to their increasing incidence and prevalence (Prince, 2013, World Health Organization (WHO), 2011). This global demographic situation is resulting in an increased demand for formal dementia caregivers in countries like the United Kingdom (UK), which has been met through hiring migrants from countries such as Nigeria to work as dementia caregivers. However, research from the perspective of Nigerian migrant caregivers on dementia-related topics is rare, and little is known about their perceptions of dementia, which may influence dementia caregiving practices in the new cultural context of Nigeria. To address this gap, this pilot qualitative study of the theoretical examination of the risk of dementia in work place was explored. It is on this premise that this study also seeks to examine the dynamics of some of the culturally grounded perceptions of dementia and some Nigerians experiences as dementia caregivers as well as its effect on organizational effectiveness.

Scope of the study

This study covers the relative theoretical examination of the risk of dementia in work place in Nigeria from the period of 2019 to 2021

Objective of The Study

The specific objective of this study includes;

- 1) To unveil an in-depth understanding of dementia perceptions.
- 2) To identify the effect of dementia on industrial organization success.

- 3) To ascertain the significance of age on the outcome of dementia

Empirical Literature Review

Dementia as a universal problem amongst various cultures

Dementia cognizance is a worldwide matter because its signs are not well understood, and people often wrongly assess the disorder as an ordinary fragment of aging (Alzheimer's Disease International, 2012). The idea of seeing dementia signs as a fragment of aging has been labeled in an ethnographic study of family dementia caregivers in India (Brijnath, 2011), and among African and Caribbean participants living in the UK (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016). In rural South Africa, a qualitative study by Gurayah (2015) found that confusion attributed to dementia is understood as a part of the aging process. Another study described that health workers in the Republic of Congo are aware of dementia, but others viewed dementia symptoms as a non-medical condition (Faure-Delage, 2012). In many cultural settings, stigmatization related to dementia is a social problem that exceeds provincial borders (Alzheimer's Disease International, 2012). A study found people in the UK and the US expressed worries over screening because of fear of being socially marginalized because of having dementia (Justiss, 2009).

Additionally, immigrants living in the UK from African and Caribbean descent reported that they would rather keep dementia a secret and seek help from religious practices and other self-remedies to avoid the stigma (Berwald, 2016). The fear of having dementia is described in some African countries where dementia is believed to be caused by evil spirits (Ogunniyi, 2005) or seen as a punishment from God or other mystical powers that can be cured by traditional healers (Khonje, 2015). Understandably, Khonje and colleagues (2015) recommend that researchers frame interview questions about dementia with sensitivity to minimize the risk of biases related to social desirability. To better understand dementia perceptions of Nigerian workers, it may be important to view dementia awareness sternly in the Nigerian context. Poor dementia awareness in the country may be linked to its low average life expectancy (55 years) from birth (World Health Organization, 2014) as older age increases dementia risk. Its lack of long-term care policies also means poor dementia awareness, and care is usually done by family members even in severe cases (Awosika, 2003, Ogunniyi, 2005).

Other risk factors for dementia in Sub Saharan Africa include rural living (Lekoubou, 2014, Russ, 2012), older age (Yusuf, Baiyewu, Sheikh, & Shehu, 2011), and other socio-demographic characteristics such as female gender, illiteracy, and low educational status (Lekoubou, 2014). This may differ slightly from the situation in developed regions like the UK where rural living, gender, and illiteracy are not identified as risk factors for dementia; although, similarly, advancing age and low education are identified as risk factors for dementia in the UK (Alzheimer's Association, 2019). However, providing specialized care for people with dementia in Nigeria is limited by a shortage of health workers (Kasper & Bajunirwe, 2012), poverty (Berwald, 2016), medical co-morbidities, and psycho-geriatric care specialists (Ogunniyi et, 2005). Since primary care settings are where the majority of older Nigerians receive care (Schubert, 2006), primary care providers would rather attend to acute illnesses instead of dementia needs which are often times regarded as mild or easy illness even though it can be quite complex (Nilsson, Rasmussen, & Edvardsson, 2013).

Social Determinants of Dementia

The circumstances in places as well as the nature or structure of the family people are born into, lived in, learn from, worked in, and play in are called social determinants of their behavioural disposition. These conditions can have a profound effect on a person's health, including their risk dementia. Variations in social determinants of health contribute tremendously to the disease. While public health predicaments and economic ambiguity may focus on discrepancies, how health inequities have persisted across generations perhaps because policies and practices have logically restricted access to health care and further prospects. An increasing body of work exists around social and economic factors that may contribute to a person's health status, including a person's risk for dementia. Although more work needs to be done to ascertain the exact relationship between these factors and dementia, here are a few areas that could be considered:

Education

Studies show an association between a higher level of education and better brain health. For example, among adults aged 45 years or older, the proportion experiencing subjective cognitive decline was lowest for college graduates and nearly three times greater for those without a high school diploma. One theory being considered by researchers as to why education levels may affect the risk of developing dementia has to do with cognitive reserve. Cognitive reserve refers to the level of knowledge and education “banked” in early years that may protect and compensate for a decline in cognitive health in later years.

Access to Health Care

Access to health care touches various aspects of a person’s physical and brain health. Dependable access to health care services gives people the chance for consistent preventive health services and often allow them to enjoy early detection of many other health situations, such as diabetes, blood pressure, heart disease, and dementia. Easy access to health care can also help prevent hospitalizations through the successful management of chronic health conditions. People with dementia often have one or more other chronic health conditions, and care coordination with providers and family care partners is essential to better care and improves health outcomes.

Built Environment

The built environment is the physical environment around us. It includes the spaces where we live, learn, work, and play—our homes, schools, businesses, streets and sidewalks, open spaces, and the options people have for transportation. Built environments can influence overall community health and individual behaviors, such as physical activity and healthy eating. Built environments can affect health both positively and negatively. Healthy community design such as the construction of well secured Estates can improve opportunities for exercise, access to services, and community supports—all of which have a positive impact on brain and physical health.

Loneliness and Social Isolation

Studies shows that keeping strong social associates and being mentally active as one grow older could reduce the risk of cognitive decline and dementia. Experts are not certain about the reason for this association, perhaps it is due to a strengthening of connections between nerve cells in the brain as people reminisce or engage in active social activity. Even though it is difficult to accurately ascertain social isolation and loneliness, there is a robust indication that numerous adults aged 50 and above are socially isolated or lonely in manners that place their health at risk. Current studies found that Social isolation meaningfully amplified an individual’s risk of untimely death from all other causes, a risk that can compete with those of smoking, obesity, and physical inactivity. Givensocial isolation was associated with about 50% percent increased risk of dementia. While a single poor social affiliation was associated with 29% increased risk of heart disease and 32% increased risk of stroke. One loneliness was associated with higher rates of depression, anxiety, and suicide.

The influence of sociology on dementia.

Sociologists have been criticized for not engaging with the needs and concerns of older people with mental health issues (Pilgrim and Rogers, 1999). Indeed Sayce (2000) identifies older people with mental health problems as those among the unheard voices that we need to actively seek out and suggests that mental health groups should build alliances with older people’s groups in order to increase their strength as social movements. Although there is indeed little evidence of sociological theorizing on dementia, however, sociological theories have been applied to the study of dementia (Bond and Corner, 2001) and this connection has not continuously been taken into cognizance. The influence of work that has applied sociological viewpoint to dementia has been philosophical in terms of our understanding of the social construction of Alzheimer’s disease (Gubrium, 1986; Harding and Palfrey, 1997) and the purpose it has served for the “Alzheimer’s Enterprise”(Binney and Swan, 1991), the bio medicalization of dementia (Bond, 1992; Lyman, 1989; Robertson, 1990) and the emphasis on lived experiences of

dementia (Froggatt, 1988; Lyman, 1989; Lyman, 1998; Bond 1992; Bond and Corner, 2001; Robertson, 1991; Vittoria, 1998).

Dementia as a subject matter seems to have” tumbled through the cracks between social gerontology and medical gerontology, with neither specialty paying much attention to the social forces that affect the conceptualization and understanding of the disease” (Lyman, 1989, p 599). This in turn has led to a lack of social theories of dementia. For example, Kitwood’s (1990) account of malignant social psychology draws on the sociology of deviance, namely labeling theory (Becker, 1963; Lemert, 1972), and Goffman’s (1963) work on stigma; Sabat and Harré’s (1992) and Sabat’s (1998 & 2000 & 2001) work on selfhood is grounded in social constructionist theory (Berger and Luckmann, 1966). In line with the inquiry of normalcy in relation to the brain disease theory and the bio medicalization of dementia, social constructionists view normalcy as a socially negotiated designation (Harding and Palfrey, 1997; Pilgrim and Rogers, 1999) based on social constructions of unwanted or deviant behavior.

This theorizing is derivative of Thomas Szasz’s 1961 thesis *The Myth of Mental Illness* (Szasz, 1994) and Berger and Luckmann’s (1966) influential work “*The Social Construction of Reality*” in which they state that “questions of psychological status cannot be decided without identifying the reality-definitions that are taken for granted in the social-cultural situation of the person’s emotional position in comparative analysis to the social descriptions of reality in general and is itself socially distinct” (p 196). Rather than biology or physiology, it is society that is seen to create mental illness through its explanation of normative behavior. The resultant definition of abnormal is used differentially and it has a variable outcome on those to whom it is applied based on features such as their race”, ethnicity, class, gender and age (Cohen, 1995). This further aligns with Harding and Palfrey (1997) question “to what extent dementia is a tag used for people who resist oppression through an assertion of their eccentricity and their freedom”.

Pilgrim and Rogers (1999) claim that “it is the roles and context of individuals’ circumstances that impact the kind and degree of psychological suffering they experience in life” (p 40). They were precisely signifying the social construction of senility. While Traphagan (2000) on the other hand states that it is a” matter of human identities as they change and are negotiated between and among people over their lives” (p 186) and stresses that this social construction is not universal, it is culturally mediated. For this reason, anthropologists, such as Traphagan (2000) and Cohen (1998), refer to senility as culturally, rather than socially constructed. Therefore, viewing dementia as a social construction is supportive in that it speaks to the political economy of dementia - the interaction of the political, the economic and the social structures, and their impact on human experience. It runs the risk, however, of opposing the very real experience of disorientation, memory loss, diminished judgment, and other symptoms endured by people with dementia.

Further, it does not adequately explain the role of intersecting identities, nor does it place people in a socio-cultural context that differentially supports or disables them based on where they lie on the dual axes of privilege and oppression. For older people with dementia who are experiencing the intersectionality of age and disability, without even factoring in other dimensions of their identities, there is a need for theory that is grounded in their lived experiences and that further develops our understanding of the intersecting nature of oppression.

Alienation Contributes to Dementia

One of the layers of argument this study discovers is the relationship between alienation and dementia. The argument is that if there is a growing social alienation in workplace and at the onset of unprepared retirement, this increases the risk of pathology at the individual level. That is, the social alienation contributes to dementia. I try to elucidate this relationship thus: Individuals feel they are losing their supports as the social constants they have been used to (such as loss of job, positions of power, economic status, loved ones, retirement and so on) are collapsing. That is, the person feels that the familiar social structures are gradually lost. As a result, and because of fear of

exposure to something new, person recoils, closes him/her into withdrawal, depression and does not participate equally in social life, and retreats. This social isolation creates the foundation on which the epidemiological risk factors for dementia are more likely to increase. We need to exercise caution here: social isolation is not a direct risk factor for dementia. However, we can consider it an indirect factor. In conclusion, alienation contributes to dementia.

Nevertheless, detailed analysis of the diagnoses of dementia globally shows that the increase of cases of dementia is not due simply to increased biological risk factors. Research proposes that in addition we should take into consideration the socio-cultural background that affects these risk factors. (Prince et al, 2003). Therefore, we can conclude that social alienation begins to increasingly affect economically developing societies. This can happen because of the easy and continuous propagation of so-called "Western lifestyle" with all the advantages and all its consequences. Alienation, as a consequence of social change happens in an increased rate not only in the richest societies but also in developing societies like Nigeria.

Dementia theorizing

Some ontological theories concerning dementia have been put forward. However, phenomenological perspectives remain a major, acknowledged gap in the literature. Given the lack of experiential theories, the focus here will be on theories that address the nature of dementia. It is noted, however, that in order to begin to understand dementia, we need to ask the people who are labelled as such about their experiences and then generate theory from these answers, rather than imposing a meta-theory on observed /described phenomena. Current theories on dementia may be loosely classified as: (1) dementia as a brain disease, (2) dementia as a normal part of the aging process, (3) dementia as a psycho-neurological condition, (4) dementia as a disability, (5) dementia as a mental health problem, and (6) dementia as a social construction.

This current proliferation in the number of theories, or other perception of this issues we call dementia, is methodically connected to displeasure with the capability of the medical model to adequately account for the inconsistency and multiplicity of indications and behaviours found in people with dementia. The random way in which dementia was demarcated as a brain disease assists us in understanding the disappointment with this model as an explanatory theory and will be briefly reviewed below.

Dementia as a brain disease

The medical model sees dementia as a brain disease and has been the leading example in this field since Kraepelin named an amalgam of symptoms and associated behaviours Alzheimer Disease (AD) in 1910 and tagged it as a discrete subsection of senile dementia (Cheston and Bender, 2000; Dillmann, 2000; Fox, 1989; Gubrium, 1986; Herskovits, 1995; Holstein, 2000; 1998; Leibing 2001; Robertson, 1990). This tagging helped to distinguish Alzheimer Disease (AD) from senile dementia, a verdict which Alois Alzheimer himself disputed at the time as he held that what he had observed clinically was not the outcome of a diverse disease process, but rather an irregular kind of senile dementia. Similarly, an associated debate as to whether any distinction could be made between senile dementia and normal ageing was earlier put up before this assertion of Alzheimer Disease (AD). These systematic debates were undeveloped up until the early 1970s when Alzheimer Disease (AD) was revived by medicine and psychiatry and treaty was incorporated to treat Alzheimer Disease (AD) as an organic disorder that is associated with and distinct from senile dementia.

This occasioned the reinstatement of the overall grouping of dementia in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994. As Cheston and Bender (2000) state, this "re-creation of Alzheimer's disease has served to place people with Alzheimer's disease within a narrowing descriptive framework in which they incline to be viewed as persons with brain disease rather than as social beings with dynamic mental lives" (p 44). There is irrefutably a connotation amid dementia and ageing in that occurrence and frequency rates rise with age however, this does not align with the credence that dementia is a normal part of the

aging process. Modern-day theorists see dementia as a pathological ailment that principally attack people arbitrarily. Furthermore, the brain disease theory is similar to the personal tragedy theory profoundly criticized in disability studies (Bond and Corner, 2001; Oliver, 1996) which sees disability (dementia) as a tragic coincidence of fate that leaves the affected person subject to the pity of others.

Theoretical framework

Dementia' suggests that the person is out of his or her mind. This is stigmatizing, especially given that, even into severe dementia, there is evidence that the person living with dementia remains minded. But this leads us on to consider different theories relating to the nature of the mind. In each case two questions are posed: First, does philosophy of mind give us insights into the nature of dementia? Secondly, what can we learn about mind from the perspective of any particular theory by studying people with dementia? The deductions are that we need to have a comprehensive knowledge of what constitutes mind and that, for people with dementia, it is significant to understand them holistically as individuals. The intent of this study is to introduce a new area of social science inquiry into the field of dementia - intersectionality/interlocking oppressions - and to apply this to an analysis of the literature to date on subjective experiences of dementia. This particular investigation is sociological in nature, however, critical theorists, practitioners and educators have been talking intersectionality" across numerous disciplines for over a decade. The concept is rooted in Freire's (2001) depiction of oppression as a structure of domination in which all humans participate, both as oppressors and as the oppressed. In the past 30 years since the first publication of Freire's seminal text on oppression, terms like multiple, simultaneous, interdependent and interlocking have been affixed to the root word "oppressions" in an attempt to broaden the theory to include systems of inequality other than class and to do so in a way that consciously avoids the "add and stir approach" (Dressel, 1991).

Freire himself was engaged in this work as noted by Macedo (2001) in his introduction to the 30th anniversary edition of *Pedagogy of the Oppressed*. "Freire's later works make it clear that what is important is to approach the analysis of oppression through a convergent theoretical framework where the object of oppression is cut across by such factors as race, class, gender, culture, language and ethnicity". Intersectionality/interlocking oppressions as a theoretical concept and level of analysis resides in a decidedly critical terrain that seems not to be marked by disciplinary boundaries and positioning, but by a shared sense of the emancipatory potential of theory that is derived from lived 232 experiences and subjugated knowledges. The introduction of this way of thinking about identity and difference is attributed to critical legal theorists (Crenshaw, 1994;1989; Delgado 1995), although it surfaced in broader feminist and anti-racist writings of the same period (Andersen and Collins, 1995; Bannerji, 1995; Bishop, 1994; Stasiulis, 1990).

Since then it has been adopted by social work (Carniol, 2000; Dominelli, 1997; Mullaly, 1997; Oliver, 1996; Thompson, 2001) and eventually made incursions into critical gerontology (Dressel, Minkler and Yen, 1997; Estes, 2001; Vincent, 1995). A distinction was made between the micro-sociological concept of intersectionality and the macro-sociological concept of interlocking oppressions by Collins in 1995: First, the notion of interlocking oppressions refers to the macro level connections linking systems of oppression such as race, class, and gender. This is the model describing the social structures that create social positions. Second, the notion of intersectionality describes micro level processes - namely, how each individual and group occupies a social position with interlocking structures of oppression described by the metaphor of intersectionality.

Together they shape oppression (Dressel, Minkler and Yen, 1997, p 583-584). Intersectionality is used to point to the ways in which multiple and complex identity categories such as gender, "race", ethnicity, class, age, able-bodiedness, sexual orientation and faith/religion interact to shape individual life experiences. We cannot compartmentalize people and investigate, for example, how either race or class contributes to individual experiences of a particular social phenomenon, as we are all "racialized" and classed interact with the world as holistic beings.

Moreover, it should remain an important focus of sociological analysis as long as the values ascribed to this term and the resulting hierarchies remain in existence, shaping all our experiences of privilege and oppression.

Rio de Janeiro, Brazil. *Doctoral student in the Department of Applied Social Science, University of Stirling, Scotland, identifies the experiences of people with dementia as they try to make meaning of their lives as intersectional beings. The application of this analytical lens to dementia represents a progression from the preoccupation with the self/person that has categorized much dementia theorizing and research since the groundbreaking work of Kitwood (1990) and Sabat and Harré (1992). It is also a move towards the concept of identities - as intersecting, fluid and problematized - and an attempt to excavate and accord central importance to subjugated knowledges (Foucault, 1994) regarding identities and lived experiences of dementia. Emergent interest in identity follows a decade of heavy criticism of the predominance of biomedicine in the field of dementia (Binney and Swan, 1991; Bond, 1992; Downs, 2000; Herskovits, 1995; Holstein, 2000; Lyman, 1989; Robertson, 1990).

Social scientists and others have been arguing for alternative approaches to dementia that focus on the person, not only the disease/disability, and many have contested the belief that dementia is an organic condition, seeing it instead as a social construction (see Harding and Palfrey, 1997). Although there is this aforementioned trend in dementia concerned with personhood (Kitwood, 1997; Kitwood and Bredin, 1992) and selves (Sabat, 2001; Sabat and Harré, 1992), this has not been approached with an understanding of identities as multiple and intersecting. Rather, „identity“ is used interchangeably with „selves“ and „person“ and is constructed as both universal, in that we all are presumed to have one, and particular, in that we each have a unique, personalized one. The way in which identity categories interact with one another and the broader socio-cultural context of dementia is essentially ignored in these largely psychologically-oriented approaches to understanding dementia.

These approaches do, however, represent progression from bio-medical models that see pathology as central and exclude both psychological and socio-cultural factors. If one ascribes to the belief that dementia is a disability, it is relatively easy to see that dementia represents an intersectional state of being, as it resides most often at the intersection of age and able-bodiedness with prevalence increasing as it does with age. Add to this gender, „race“, ethnicity and class and the picture no longer lends itself to individualistic theories that appear to view people as homogeneous beings apart from their biology and/or psychology. As there is a lack of theorizing and research in dementia on how older people with dementia conceptualize their experiences in relation to intersectionality, literature must be drawn together from fields that are often disconnected: critical gerontology, mental health and illness, disability studies, critical race studies, women’s studies, social work, cultural anthropology and legal/human rights theory.

Making these links enables connections to be made across different experiences of intersectionality and interlocking oppressions. This study will apply the foregoing analytical discussion to the literature to date on subjective experiences of dementia. Prior to embarking on this however, a few theoretical distinctions are necessary in order to substantiate the position that we do not yet have an adequate explanation for this particular realm of human experience.

Symbolic Interactionism theory

Symbolic interactionism on the other hand is a micro-level theory in sociology that focuses on the relationships among individuals within a society. Its basic assumption is that Communication which is the exchange of meaning through language and symbols is believed to be the way in which people make sense of their social worlds. According to symbolic interactionism, an individual's personality is formed within society, that is, a human community. A dominant distinctive feature of human communities is interaction, among other things with the help of symbols. By constantly acting and interacting, social norms and values are created. The three assumptions frame of symbolic interactionism is that Individuals construct meaning through the communication process. Self-concept is a motivation for behavior. A unique relationship exists between the individual and society.

The symbolic interactionism (SI) used in this paper stems from Blumer's (1969) theoretical tenets and Goffman's (1963) empirical work. The theory rests upon three principles: people act based on the subjective meanings that things hold for them; these meanings are produced in interaction with others; meanings are negotiated in an interpretative process (Blumer 1969, p. 2). Every person inhabits a world of objects. These objects are anything that can be referred to, from a physical item like a chair to an abstract concept such as freedom. Interaction with others reveals the meanings which they assign to objects, allowing a person to negotiate others' meanings alongside their own, in an interpretative process similar to self-interaction, whilst facilitating shared meaning. Objects are defined by people's actions towards them; depending upon use, a chair may be a seat, a weapon or a door stop.

Most importantly, a person has a self because he or she is an object to himself or herself. The self is defined in interaction, allowing each individual to view themselves through the eyes of others. This looking glass self is interpreted alongside the individual's existing self-object to renegotiate the self. This study relies on an object-based understanding of the self as self-aware (although not solely consciously) because one interprets oneself as an object (Mead 1934, p. 136). People act upon their world of objects, interpreting meanings as the basis for an appropriate line of action. Based upon their self-objects, people enact roles framed by consensual meanings, indicating which actions befit which roles (Blumer 1969, pp. 12–13). Frames establish guiding boundaries, but are advisory rather than formative, allowing variation in action, even when actors share similar worlds of objects. Overall, SI puts interaction and interpretation within worlds of objects at the heart of human existence. Existing dementia and mental illness literatures are now combined and situated within the outlined framework. The result is a novel theoretical account, providing a basis for the refinement of a holistic sociological understanding of dementia. A symbolic interactionism of dementia is now outlined, charting a process whereby the selves of people with dementia and those around them are transformed under the influence of the dementia object.

First, it is argued that the dementia object has transformative potency as a known and feared condition. Second, this transformative quality is explored in terms of continuity and change, and agency and determinism. Third, the necessity of interpretive interaction in negotiating these competing tendencies is considered regarding language, embodiment and space. Finally, the trajectory of becoming symptomatic is discussed. This is presented in terms of malignant social psychology and the moral career. Social theory is applied to lived experiences within a narrative of the overall illness process. This is an account of excess disability whereby social processes render impairment disabling. Such an understanding suggests potential social approaches to minimizing disability in interaction. In the concluding remarks, the SI of dementia is repositioned within entanglement and broader repercussions for dementia.

The discovery of stigma Dementia can exert substantial influence over the interactionist processes of meaning negotiation via interaction and interpretation. Participants in Beard and Fox's (2008, p. 1516) study of social disenfranchisement in Alzheimer Disease experienced immediate changes in interpersonal interactions following diagnosis. The dementia object arrives in a pre-existing social context, introducing instability into existing relationships and challenging existing worlds of objects. This arrival threatens both existing meanings and the negotiation of new ones (Snyder 2006). Labelling a person as having dementia is potent, particularly in light of media alarmism sensationalizing the condition, reinforcing negative stereotypes. This extends beyond dementia to wider ageism. Ageism constitutes "stereotyping of and discrimination against people because they are old" (Butler 1975, p. 12).

Functionalist theory

This study also makes use of the functionalist theory of sociology to proffer a social understanding of dementia. Through its founder, Emile Durkheim, it argues that any change in a social system causes chain reactions in the form of dysfunctions. The argument can be formulated as follows;





We live in a period categorized by huge and unforeseen variations. The variations in social institutions and social structure are experienced directly by more people. One could say that this always happened. The difference is that we believe that these variations are more massive and faster. We react precisely because we are just in the middle of all the changes and we have not thought out yet how to adapt. Beginning with the social institution of the family, we experience changes that tend to relax previous rigid structures. The definition of 'family' is ever changing, including new, non-standard structures. Examples are single parent families, families of single persons, same sex parents and so on.

As perceived by Talcott Parsons (1951), the functionalist perspective emphasizes that good health and effective medical care are essential for a society's ability to function. Ill health or disorder impairs our ability to perform our roles in society, and if too many people are unhealthy, society's functioning and stability suffer. This was especially true for premature death, said Parsons, because it prevents individuals from fully carrying out all their social roles and thus represents a "poor return" to society for the various costs of pregnancy, birth, child care, and socialization of the individual who ends up dying early. dementia is likewise dysfunctional for society, as people who are afflicted by it face greater difficulty in becoming healthy and people who are healthy care-givers are more probable to become ill over the years and be unproductive to themselves and the society at large.

Talcott Parson asserted that for a person to be considered *legitimately* sick, several expectations must be met. He referred to these expectations as the sick role. First, sick people should not be perceived as having caused their own health problem. If we eat high-fat food, become obese, and have a heart attack, we arouse less sympathy than if we had practiced good nutrition and maintained a proper weight. If someone is driving drunk and smashes into a tree, there is much less sympathy than if the driver had been sober and skidded off the road in icy weather. Second, sick people must want to get well. If they do not want to get well or, worse yet, are perceived as faking their illness or malingering after becoming healthier, they are no longer considered legitimately ill by the people who know them or, more generally, their employers and the society at large. Third, sick people are expected to have their illness confirmed by a physician or other health-care professional and to follow the professional's instructions in order to become well. If a sick person fails to do so, she or he again loses the right to perform the sick role. This assertion of Parson buttresses the importance of dementia diagnosis while in employment and the need for employers' support for proper health care to address the issues early enough in order to prevent its consequential effects to achieving the organizational goal and recording healthy workforce as well as retired brand ambassadors of the organization.

If all these expectations are met, sick people are treated as sick by their family, employers, their friends, and other people they know, and they become exempt from their normal obligations to all these people. Sometimes they are even told to stay in bed when they want to remain active and or given an active cognitive stimulation if that is the prescribed therapy to get well. To Parson, Physicians also have a role to perform. First and foremost, they have to diagnose the person's illness, decide how to treat it, and help the person become well. To do so, they need the cooperation of the patient, who must answer the physician's questions accurately and follow the physician's instructions. Parsons thus viewed the physician-patient relationship as hierarchical: the physician gives the orders (or, more accurately, provides advice and instructions), and the patient follows them.

Parsons was positively right in accenting the importance of people's good health for society's health, but his viewpoint has been criticized for several reasons. First, his idea of the sick role applies more to acute (short-term) illness than to chronic (long-term) illness. As much of his argument infers a person briefly enters a sick role and leaves it soon after following adequate medical care, whereas people with chronic illnesses can be locked into a sick

role for a very long time or even permanently. Second, Parsons's argument overlooks the fact, mentioned earlier, that our social backgrounds affect the likelihood of becoming ill and the quality of medical care we receive. Third, Parsons wrote favorably of the pyramid contained in the physician-patient relationship. Many experts say today that patients need to reduce this order by asking more questions of their physicians and by taking a more dynamic role in maintaining their health hence in today's world specifically in developing country like Nigeria, physicians do not always provide the best medical care, the hierarchy that Parsons favored is at least partly to blame for this.

The Conflict Approach

The conflict approach stresses inequality in the quality of health and of health-care delivery (Weitz, 2013). As noted earlier, the quality of health and health care differs greatly around the world and within Nigeria. To Karl Max, Society's inequities along social class, race and ethnicity, and gender lines are reproduced in our health and health care. People from disadvantaged social backgrounds are more likely to become ill, and once they do become ill, inadequate health care makes it more difficult for them to become well. The conflict approach also critiques efforts by physicians over the decades to regulate the practice of medicine and to describe several social problems as medical ones. Physicians' inspiration for doing so has been both good and bad. On the good side, they have believed they are the most qualified professionals to diagnose problems and to treat people who have these problems. On the negative side, they have also recognized that their financial status will improve if they succeed in portraying social problems as medical problems and in monopolizing the treatment of these problems. Once these problems become "medicalized," their possible social roots and thus potential solutions are neglected.

Several examples illustrate conflict theory's criticism. Alternative medicine is becoming increasingly popular, but so has criticism of it by the medical establishment. Physicians may honestly feel that medical alternatives are inadequate, ineffective, or even dangerous, but they also recognize that the use of these alternatives is financially harmful to their own practices. Eating disorders also illustrate conflict theory's criticism. Many of the women and girls who have eating disorders receive help from a physician, a psychiatrist, a psychologist, or another health-care professional. Although this care is often very supportive, the classification of eating disorders as a medical problem however offers a good source of income for the professionals who treat it and confuses its cultural roots in society's standard of beauty for women (Whitehead & Kurz, 2008). Obstetrical care offers another example. In most of human history, midwives or their equivalent were the people who helped pregnant women deliver their babies. In the nineteenth century, physicians claimed they were better trained than midwives and won legislation giving them authority to deliver babies. They may have honestly felt that midwives were inadequately trained, but they also fully recognized that obstetrical care would be quite lucrative (Ehrenreich & English, 2005).

Furthermore, to conflict theory, physicians have often sought to define various social problems as medical problems. An example is the development of the diagnosis of ADHD, or attention deficit/hyperactivity disorder. In a final example, many hyperactive children are now diagnosed with ADHD, or attention deficit/hyperactivity disorder. A generation or more ago, they would have been considered merely as overly active. After Ritalin, a drug that reduces hyperactivity, was developed, their behavior came to be considered a medical problem and the ADHD diagnosis was increasingly applied, and tens of thousands of children went to physicians' offices and were given Ritalin or similar drugs. The definition of their behavior as a medical problem was very lucrative for physicians and for the company that developed Ritalin, and it also concealed the conceivable roots of their behavior in inadequate parenting, boring schools, or even gender socialization, as most hyperactive kids are boys (Conrad, 2008; Rao & Seaton, 2010).

Critics say that the conflict approach's valuation of health and medicine is exaggeratedly punitive and its criticism of physicians' motivation far too pessimistic. Scientific medicine has significantly upgraded the health of people globally. Although physicians are definitely inspired, as many people are, by economic considerations, utilizing their efforts to extend their scope into previously nonmedical areas. Definitely, there is some fact in this criticism of the conflict approach, nonetheless the indication of disparity in health and medicine and of the negative aspects of the medical establishment's motivation for extending its reach remains compelling.

Basic Sociological Theory on dementia at a glance

Theoretical perspective	Major assumptions
Symbolic interactionism	Health and illness are <i>social constructions</i> : Physical and mental conditions have little or no objective reality but instead are considered healthy or ill conditions only if they are defined as such by a society. Physicians “manage the situation” to display their authority and medical knowledge.
Functionalism	Good health and effective medical care are essential for the smooth functioning of society. Patients must perform the “sick role” in order to be perceived as legitimately ill and to be exempt from their normal obligations. The physician-patient relationship is hierarchical: The physician provides instructions, and the patient needs to follow them.
Conflict theory	Social inequality characterizes the quality of health and the quality of health care. People from disadvantaged social backgrounds are more likely to become ill and to receive inadequate health care. Partly to increase their incomes, physicians have tried to control the practice of medicine and to define social problems as medical problems.

Disengagement Theory

The disengagement theory of aging claims that it is natural and acceptable for older adults to withdraw from society and personal relationships as they age. The theory further suggests that society responds to the elder's disengagement with a sort of mutual recognition that the elder will soon pass and society must prepare to function in their absence. As such, the theory argues that it is natural and acceptable for older adults to withdraw from society. Disengagement theory was the first theory of aging developed by social scientists. It was originally formulated by Elaine Cumming and Warren Earl Henry in their 1961 book *Growing Old*. In *Growing Old*, Cumming and Henry develop a logical argument for why older adults would naturally disengage from society. They formulate their argument along nine postulates to explain why it is rational for individuals who know that death is approaching and who have seen friends of their age pass to begin to anticipate their own deaths and disengage.

The postulates are as follows:

1. Everyone expects death, and one's abilities will likely deteriorate over time. As a result, every person will lose ties to others in his or her society.
2. Because interactions between people strengthen norms, an individual who has fewer varieties of interactions has greater freedom from the norms imposed by interaction. Consequently, this form of disengagement becomes a circular or self-perpetuating process.
3. Because men have a centrally instrumental role, and women a socio emotional one, disengagement differs between men and women.
4. The individual's life is punctuated by ego changes. For example, aging is seen as a form of ego change which causes knowledge and skill to deteriorate. However, success in an industrialized society demands certain knowledge and skill. To satisfy these demands, age-grading ensures that the young possess sufficient knowledge and skill to assume authority and that the old retire before they lose their skills. This kind of disengagement is affected by the individual, prompted by either ego changes or the organization, which is bound to organizational imperatives, or both.

5. When both the individual and society are ready for disengagement, complete disengagement results. When neither is ready, continuing engagement results. When the individual is ready and society is not, a disjointedness between the expectations of the individual and of the members of this social systems results, but engagement usually continues. When society is ready and the individual is not, the result of the disjointedness is usually disengagement.
6. Man's dominant role is work, and woman's is marriage and family. If individuals abandon their dominant roles, they radically lose social life space, and so suffer crisis and discouragement which may trigger dementia unless they adopt the different roles required by the disengaged state.
7. Willingness for disengagement happens if the person is mindful of the shortness of life and scarcity of time, the individual perceives his or her life space decreasing, and loses ego energy.
8. Fewer interactions and disengagement from dominant roles lead to the relationships in the remaining roles changing. In turn, relational rewards become more varied, and vertical solidarities are transformed to horizontal ones.
9. Disengagement theory is independent of culture, but the form it takes is bound by culture.

Disengagement theory is suffering from lack of empirical support as such has mainly been dismissed by social scientists and gerontologists.

Activity Theory

Activity theory proposes that successful aging occurs when older adults stay active and maintain social interactions. The theory was developed by Robert J. Havighurst as a response to the disengagement theory of aging. The activity theory of aging proposes that older adults are happiest and successful aging occurs when they stay active and maintain social interactions. These activities, especially when meaningful, help the elderly to replace lost life roles after retirement and, therefore, resist the social pressures that limit an older person's world. The theory assumes a positive relationship between activity and life satisfaction. Activity theory reflects the functionalist perspective that the equilibrium, that an individual develops in middle age, should be maintained in later years. The theory predicts that older adults that face role loss will substitute former roles with other alternatives.

The theory was developed by gerontologist, or, scholar of aging, Robert J. Havighurst in 1961, and was originally conceived as a response to the recently published disengagement theory of aging. The disengagement model suggests that it is natural for the elderly to disengage from society as they realize that they are ever nearer to death. However, withdrawing from their central societal roles—working, marriage, raising a family —means they drastically lose social life space and so suffer crisis and demoralization which may likely result in dementia. Havighurst's activity theory is at deliberate odds with what some perceive as the pessimism of disengagement theory. However, critics of activity theory state that it overlooks inequalities in health and economics that hinders the ability for older people to engage in such activities. Also, some older adults do not desire to engage in new challenges. Five decades of gerontological research, however, suggest that the activity model is more accurate than the disengagement model. Not only is activity beneficial for the community, but it engages older adults (both physically and mentally) and allows them to socialize with others. This increases feelings of self-worth and pleasure, which are important for happiness and longevity.

Methodology

The qualitative descriptive method was embedded in several sociological perspective which views meaning as that which is developed from social interaction (Charmaz, 2014). Qualitative descriptive method uses restricted levels of interpretation to provide an honest description of the phenomenon and it allows the use of various philosophical assumptions such as symbolic interactionism, functionalist, conflict amongst others (Colorafi& Evans 2016). This

method focuses on capturing the who, what, and where of events, and in the process, gains more knowledge about a poorly understood phenomenon such as dementia in a Nigerian context. The cultural similarities shared by the lead researcher and the participants allowed for better probing to gain an in-depth understanding of meanings derived during the data collection process. The participants recruited for the study work as caregivers. Purposive sampling was used and included the following criteria to recruit participants: age 18 years and above, dementia caregiver in Nigeria for at least 12 months and retirees who had suffer dementia while on employment and had retire within the past five years. Physical meetings were conducted with those who responded to explain more about the study and ensure they fit the inclusion criteria.

Study location and sampling

The study was conducted in Benin City, Nigeria. The region has industrial organizations, residential homes and missionary owned health care facilities for old people. Eight participants agreed to participate in the study and they were enrolled after providing informed consent. A total of eight participants were in the study (two male and six female Nigerians) and their ages ranged from 28 to 34 years. Among the eight participants, 4 are auxiliary nurses in Benin City working as healthcare/nursing assistants. The participants are all Christians, 3 are from the Bini tribe, one is from Ibibio, two from the Itsekiri tribe and two are from Yoruba. The first author is able to interpret and describe meanings in the study because he is from the Bini tribe and has lived among the people of the other tribes in Southern Nigeria. The participants' names were changed to ensure confidentiality.

Data collection

The data collection was conducted from December 2020 to September 2021, and the study was completed in September of the same year. Using semi-structured interviews, these Nigerian healthcare assistants were asked questions about dementia, with particular emphasis on:

- 1) how dementia is perceived in Nigeria and how common they perceive it to be in Nigeria
- 2) what did they perceive that caring for a person with dementia entailed?
- 3) whether their perceptions of caring for a person with dementia changed since working as care givers
- 4) how they perceived their ability to explain the severity of dementia with their current level of knowledge.

Two out of the eight participants have experience of working in both Nigeria and UK healthcare settings. The interview questions were not rigid to allow for probing into relevant emerging concepts. Six interviews were conducted and the interview times ranged from 30 min to 50 min. As recommended by Charmaz (2014), memo writing was undertaken concurrently to consolidate the audio-recordings; this process ensured that codes and ideas worthy of further exploration in the emerging categories could be noted down during the interviews. For example, memo writing was used during each interview to note observations ranging from specific words and phrases to physical and emotional expressions of a participant while answering a particular question, as this provided cues on the significance of such questions or area of discussion. The interviews and memo taking were done by the first author, and the interviews were transcribed verbatim.

Data analysis

Thematic analysis is used to interpret and summarize qualitative data. This captures element of the data that represents the participants' responses that are equally important to the research question (Braun & Clarke, 2006). This iterative process involved line-by-line coding of the transcribed interviews; the codes were assigned themes. The frequently recurring themes were identified and the research team agreed on which ones were relevant to the research objectives. The interview audio recordings were transcribed, coded, and compared to the themes to see how they fit into the emergent themes. As the key components emerged, coding continued and the main themes were adjusted to include relevant codes. Where necessary, a new theme was developed to group relevant codes that did not fit into the main themes.

Exploring dementia perceptions and experiences of the participants underpinned by symbolic interactionism generated themes that encompass what the participants think about dementia. Symbolic interactionism helps us make sense of how views influenced by one's culture are sustained by social interactions (Charmaz, 2014). Field notes such as memo writing helped the research team stay on track with some emerging concepts that helped to answer the research question (Denzin & Lincoln, 2018). Also, peculiar or significant areas during the data collection were noted and plans were devised on how to probe further. All these were possible using the field notes. For example, the first participant's account contained concepts relating to prayer and indigenous religion and with the field notes, the next participant interviewed was asked their views on prayer and religion as they relate to dementia.

The rigor of the research was maintained by discussing emergent themes, concepts and analytical ideas with team members. The main themes developed from the collected data were discussed with the participants to ensure the findings were linked to their responses. This process, known as member checking, is to ensure the study's trustworthiness is upheld. Since the first author undertaking the data collection is from Benin and lived in Abuja, it was possible to ensure that questions were structurally framed in ways that are relatable to the participants. Also, having a similar cultural background with the participants was a valuable tool for the interpretation of meanings conveyed in the interviews. Data saturation was achieved after the fifth interview as it establishes a clear explanation of the relationship between dementia perception and care giving among the participants.

Results

Through participants' descriptions of their cultural views or actions relating to dementia, we are able to see that these healthcare workers are still influenced by dementia meanings from the society they come from and still feel connected to. The resulting themes were grouped into cultural specificity, dementia awareness, and empathic witnessing. This section also includes sub-themes and illustrative quotes.

Table 1. Dementia perception of participants

Themes	Sub-Themes
Cultural specificity	Praying for someone or something Indigenous religious beliefs Ancestral connections Going with the flow
Dementia awareness	Longevity and life expectancy Dementia is secondary to other-co-morbidities Using aging as an excuse Appreciation of the importance of dementia
Empathic witnessing	They are people's relatives Putting yourself in their shoes Emotional involvement over time

Field survey 2021

Cultural specificity

Cultural specificity refers to those explanations and meanings, actions and thoughts that are connected to dementia and care giving pertaining to a particular society and the people that are part of it. According to the study, symptoms of dementia are often times mistaken and confused for other things that are permissible within the socio-cultural premise of that society (Nigeria). Regarding the issue addressed by the study, some of the themes that predominantly were encompassed by "cultural specificity" are: praying for someone, indigenous religious beliefs, ancestral connections, and going with the flow.

Praying for someone

Praying for someone who is suffering or in need may be linked to people's culture. In this sense, it may not matter the type of religion. When someone is perceived as undergoing too much health-related suffering without a foreseeable solution, the likely thing to do according to some of the participants is to pray for the affected person amongst other things. For example, participant B was asked how she would handle a typical dementia case with family members in Nigeria and she said this:

"Although I stand that I will tell the person to prayerfully back it up since we all believe in God, joined with any medication from the hospitals or Traditional caregiver. Prayerfully back it up and provide mechanisms that support."

Another participant (D) also mentioned that in Benin, Edo State, being old and having dementia is viewed as approaching 'the end of life' which is why praying for the person with dementia is the only way you can assist in addition to home management. *"The only thing you could do is assist the person with prayers and home management."*

Indigenous religious beliefs

This concept refers to irrational beliefs about aging and dementia symptoms that originate from indigenous, tribal cultures but have been integrated into formal religion in Nigeria. Although Nigeria's population is made up of about 50% Muslims and 50% Christians, indigenous religious beliefs are still combined with these popular religions (United States Department of State 2015). Amongst poorly educated people in Nigeria, some of these indigenous beliefs may go without question and are likely shared in families from one generation to the next. Although they are usually devoid of empirical evidence or proof, they are believed by some members of the society as an appropriate description or explanation of a phenomenon. For example, participant D stated that in Benin City, dementia symptoms may be linked to an older person getting retribution for his/her evil deeds or he/she is simply a witch or wizard hearing voices or saying happenings from a hidden coven which is inconsistent with present reality. The quote given was:

"They believe most people that are elderly (with dementia) are not good people, witches or something...it is a myth to some while to some it is real." These beliefs sometimes lead to stigmatization and in some cases negatively affects the type of attention that should be given to someone with dementia. This is evident in participant C's comment that: *"Some people, because they are not educated, will dismiss them as old, aged or possessed."*

Ancestral connections

Participants explained how in African traditional settings like Nigeria, it may sometimes be assumed that a person can have some sort of communication link to their dead relatives as they become very old. This belief that older adults can communicate with the dead is used to explain an episode of hallucination or confusion in an older adult with dementia especially if he/she mentions the name of a dead relative and such behavioural disposition can earn such person his or her job even if he/she is still within the working age limit (specifically in private owned organizations and most times in some public organization, if such individual is on the junior or middle cadre may be sent to a redundant unit such as training institute of some establishment where activities are minimized and to occupy such an inconsequential position. As participant A said:

"They feel like those elderly people are closer to their ancestors than the younger ones and they can hear things."

Similarly, participant F had a similar comment to the above quote but wanted it to be clear that it is not what he believes. Hence, he acknowledged that such meanings exist in his society but he does not subscribe to them. He stated thus: *"They could think the gods are at work or maybe he saw spirits of the ancestors of which I don't buy that because for something to keep happening often and on then there is definitely something wrong. For me that's what I think."*

Going with the flow

Some of the participants expressed that in Nigeria (even in healthcare practice), it is difficult to change the minds of people about meanings they hold about a condition like dementia regardless of their level of knowledge. In such situations, “if you can’t beat them, you join them”, hence the concept “going with the flow”. For example, participant A stated thus: *“Since I am back in Nigeria, I am going with the flow and sometimes say oh yeah you people probably need to go call her pastor because she is now seeing things.”*

The above quote shows that regardless of the participant’s adequate level of knowledge and awareness on dementia, cultural beliefs influence the health-related recommendation provided. Even when the participant understands that those views are superstitious, he/she would rather go along with the views of the family affected by dementia by affirming their irrational ideas. Participant F, G and I all gave a similar more succinct response when asked how they could debunk traditional beliefs about dementia. His comments were: *“...well if you can’t beat them you join them. If you keep explaining to them and they don’t seem to buy your explanation, you just do two things. You either walk away or see if you can change their minds or hopefully one day, they will come to realize what you were saying was real.”*

Dementia awareness

The attention and importance given to dementia as a health condition with serious implications may depend on dementia awareness in work place as well as in Nigeria generally. The study found that participants attributed their previous low dementia awareness to three themes, which include the low rate of longevity and life expectancy in Nigeria, dementia is secondary to other pressing co-morbidities in the country, and the use of aging as an excuse for dementia. In addition to the themes mentioned, another concept that is under this theme is “appreciation of the importance of dementia.” The three themes presented below provide an insight into the experiences of these participants in relation to their changing knowledge of dementia.

Longevity and life expectancy

Participants mentioned that the reason they had seen very few people with dementia in Nigeria is because of the very low average life expectancy and longevity in the country. It is estimated that its 65+ age group makes up about 3.12% of its 186 million population (Agency, 2017); and these older adults mostly reside in rural areas. This could be why participants had seen only a handful of people with dementia and the assumption that dementia awareness is low. After Participant A was asked if she has seen people with dementia in Nigeria, she explained: *I would say yes but not compared to what I saw in UK because from here in Nigeria, we usually don’t see dementia patients may be because of the life expectancy or because of the onset of the disease or the fact that they are usually hidden and cared for by relatives for fear of stigmatization.*

Another participant (E) who also has experience practicing as a registered nurse in Benin City had a contrasting view about longevity and dementia but went ahead to acknowledge that there is low average life expectancy and longevity in Nigeria. Her comment was: *“Though people do not live that long in Nigeria, but maybe it is age related but I think it is because people in Nigeria have immunity from it.”*

Dementia is secondary to other co-morbidities

According to the participants, dementia is given lesser attention in healthcare settings in Nigeria and other co-morbidities are prioritized. Co-morbidities could be communicable diseases like HIV, polio, and malaria; and non-communicable (chronic) diseases such as heart diseases, and diabetes. More so, it is assumed that a person with dementia would not visit the hospital because of dementia. According to participant A: *“...that’s not why they are in the hospital anyway. They have other co-morbidities that you know, bring them to the hospital but alongside it could be said of this person has dementia.”*

Participant D mentioned how the presence of other diseases limits dementia awareness and response at a macro level. Also, the participant calling dementia a small case is an indication of how she views dementia in comparison

to other health burdens. She mentioned that: *In Nigeria, people are trying but not much attention is paid to dementia patients because we have other serious health-related diseases like HIV to concentrate on which affects a majority of the population. We have polio that the government is really trying to eradicate so the occurrence of these major cases does not leave room for consideration of smaller cases such as dementia in Nigeria.*

Using aging as an excuse

Just as culturally grounded meanings were associated to dementia during the course of data collection and analysis, it was also discovered that being old or saying someone is aged was the explanation given for dementia symptoms in an older adult in Nigeria. Participant C mentioned that: “When an older person is exhibiting forgetfulness, his colleagues, employers as well as family will dismiss it as because he or she is aging. As you often hear captions like Na old age dey worry you so or simply... Old age don dey come oohh”

Another participant (A) spoke of her experience in a healthcare setting in Abuja where a woman in her early 60s with dementia exhibited poor cognitive symptoms; she was dismissed from work as being too old to be productive which is an indication of poor dementia awareness. Her comment:

“...they just hiss then say leave her alone she is too old already. Exactly, especially when the person is elderly because they just see it as you know as part of being elderly as part of wanting to die.”

Appreciation of the importance of dementia

The study from its robust literature review and theoretical examination, unveil that base on the cultural background of the participants and their perception of dementia awareness in Nigeria, living and working with people with dementia in the UK resulted in an appreciation of the importance of dementia. Although these participants are educated, they are influenced by the culture of the society they come from and live in and their comments indicated that dementia could be accorded more attention than it is getting in Nigeria. According to participant A:

“I knew a bit about it but it was very new to me and the experience was life-changing because I’ve never seen it as a big deal because in my country (Nigeria) it is not a big deal but it was a big deal in UK.”

Participants also mentioned how experiences from living in the UK and working with people with dementia changed their knowledge and appreciation of dementia. Participant B who had no previous work experience in UK healthcare added that: *“I never knew something like dementia existed. The whole thing was just really (pause) what’s the word (longer pause), I was really shocked that something like this existed”.*

Empathic witnessing

The term empathic witnessing refers to participants’ experiences of compassion and deeper understanding that arose as they spent more time caring for persons with dementia. Some of the participants indicated that they started caring deeply for persons with dementia they cared for when they imagined them as people with friends and families and how much they mean to their relatives. Such assumptions triggered a feeling of deeper compassion for a person with dementia. Like participants A said: *“It is really a sad thing and it makes you reflect on your own self, your relatives and all that; putting them in the position of the people you care for”* More so, seeing a person with dementia as someone who could be your relative may induce a certain type of positive proactive response to their needs while caring for them. Just like participant F said: *“You have to still have the empathy as if they are your relatives; seeing them as a relative or possible relative help to carry out the service they need.”*

Putting yourself in their shoes

Similar to imagining people with dementia as people’s relatives or people that could be your relatives, participants imagined that they may also be in such a vulnerable condition when they are older. Assuming the position of people living with dementia puts a somewhat vivid understanding of their plight while caring for them and may raise the urge to do more for them regardless of unfavorable conditions. For example, participant F stated that staff to resident/client ratio is low in some residential homes especially when a significant number of the residents have dementia, and this makes care giving more difficult. To give his best, he added that: *“I think I have*

come to understand that it is quite a challenge to care for them and I expect one day I'm going to get older and may have dementia as well. So, I always put myself in their shoes."

Emotional involvement over time

Most of the older adults who were participants in this study care giving services to their patient/clients started out as strangers but as time went on, they developed some sort of personal relationship with the person for whom they provided care. This was what some of the participants described when talking about their experiences while providing care for people with dementia. More understanding of the challenges of dementia resulted from spending more time with a person with dementia which in turn caused more emotional involvement as stated by participant B: *"It was subsequently that everything started to fall in place and I understood how terrible this disease was and the effects."* Interestingly, the emotional involvement and compassion which has a positive influence on caring for a person with dementia may equally become a stressor on caregivers. The emotional stress of witnessing someone suffer may become so much that a caregiver might be relieved when the person with dementia dies. Participant B stated thus: *Some of us were frustrated because some situations may come up and you will be like this person should just die and go. There is an adage in Edo language that says, "Aimwenekpo mase nor fionuvun--- norwu mase nor ragbon nor marhenmwinnarhu" which means "it is better not to have a pocket at all, than have one with a hole in it"---- "Rather than be alive without memory, it is better if you were dead" or "better off dead than alive" situation. So, some situations like that mean trying your best but when the person dies you just shrug and say at least the burden has been lifted.* This traditional "Bini" (a major tribe in Edo State, Nigeria) quote is an expression of empathy towards a person who is going through a long-lasting, often terrible, traumatizing experience. A person or observer may become emotionally involved by spending time or observing someone going through severe hardships or struggle like dementia. As a result of this deepening empathy towards their struggle (vicarious feeling of the sufferer's pain), the person or caregiver may begin to think that death may be the best way to put the person suffering out of his/her misery.

Discussion

This pilot study's objective is to gain an in-depth understanding of dementia perceptions and experiences of Nigerian workers and formal dementia caregivers. The findings show that cultural specificity (praying for someone, indigenous religious beliefs, ancestral connections, and going with the flow), dementia awareness (longevity and life-expectancy, dementia is secondary to other co-morbidities, using aging as an excuse, appreciation of dementia importance), and empathic witnessing (they are people's relatives, putting yourself in their shoes, emotional involvement over time) help to explain dementia perceptions and experiences of the Nigerian healthcare workers in the study.

Similarly, reviewed literature shows that caregivers in developing countries may view dementia as mysterious and part of getting old (Brijnath, 2011, Gurayah, 2015, Berwald, 2016). Therefore, it is not surprising that culturally grounded meanings are given to symptoms similar to that of dementia, and the recommendation for religious interventions like prayers or calling for a pastor as the study found. Individuals from participants' communities may see dementia as beyond ordinary or beyond scientific intervention hence resorting to prayers to make the situation better. The problem with dementia care associated with offering only prayers as the main solution to dementia is that it may discredit the use of evidence-based practices to improve dementia care. In exploring the dementia perceptions of the participants, we found that these meanings attributed to dementia may have implications such as stigmatization and negative effect on help-seeking behavior.

The study revealed that sometimes people with dementia are perceived to be facing retribution or some sort of karma for evil deeds committed in the past. Older people perceived as witches/wizards are also viewed this way (Khonje, 2015, and Mkhonto, 2017), so to prevent stigmatization, family members or the affected person may rather keep the dementia status private (Justiss et al., 2009, Berwald et al., 2016). Indigenous religious beliefs surrounding

dementia may influence the way dementia care is assessed; they push relatives to cope with living with loved ones with dementia on their own rather than seeking for medical assistance.

Incidence and prevalence of dementia are dependent on several factors that may be genetic, biomedical, environmental and physical. Nigeria's low life expectancy (World Health Organization, 2014) may have added to why little is known about dementia as age is a major risk factor Yusu, (2011). The study found that regardless of the factors influencing dementia incidence and its prevalence, knowledge of dementia by members of any given community may be influenced by presence of co-morbidities (Ogunniyi, 2005) and the perception that symptoms of dementia are a normal part of the aging process (Brijnath, 2011, Gurayah, 2015, Berwald, 2016). This is evidenced in one of the participants' statement that Nigeria is burdened by health issues like HIV and polio eradication to bother about what she referred to as "small issues" like dementia.

In the study, participants became more empathetic about persons with dementia from imagining them as people's or their relatives. Although a close relationship may lead to positive outcomes for the care recipient and caregiver, it may also cause an adverse psychological effect on the caregiver (Fauth et al., 2012). Empathic witnessing explains how one of the participants who is frustrated by the working conditions in the institution he works, still does his best to provide care for persons with dementia because he expects to eventually become older too and may need help with activities of daily living. Spencer, (2010) pointed out that such a level of dedication and quality of dementia care by migrant workers may be because of their religious belief and cultural orientation towards older adults. More so, realizing that dementia is a major issue may create a kind of psychological burden. Sometimes, it is as a result of the emotional investment in the caregiver-care recipient relationship over time or in the question, "Is this what would become of me when I am old with dementia?"

Emotional stress from empathic witnessing was evident in the study which was why one of the participants mentioned how caregivers could get so emotionally stressed with the conditions of some persons with dementia that they wish him/her could die just to be done with the suffering. This kind of stressful feeling supports what Boyle (2011) referred to as caregivers' compassion fatigue which could lead to depression, anger, detachment, apathy, and physical exhaustion. Some of the participants in the study wished they could do more for people with dementia and they tried to in their own way. This increased compassion and willingness to do more for someone who used to be a stranger is in line with Bryon, Casterlé and Gastmans, 2012 study that showed that over time, nurses caring for persons with dementia in hospitals became more compassionate and offered more personalized care to these dementia patients as they became more like family to them (the nurses).

Generally, it can be said that sociocultural factors like prayer, ancestral connections, and indigenous religious practices and beliefs shape the meanings given to dementia in the participants' society. These meanings of dementia consequently determine the kind and level of care given to someone with the condition. Furthermore, perceived low longevity and life expectancy of Nigeria, presence of other pressing co-morbidities, and use of aging as a means of explaining dementia symptoms, are indications of low dementia awareness. This, in turn, results in little knowledge about dementia, hence affecting the level of importance given to dementia as a health condition.

Conclusion and recommendations

A qualitative descriptive methodological approach involving symbolic interactionism proved effective in achieving the study objective. The method established which socio cultural factors influenced dementia care and knowledge through illuminating perspectives on dementia and caregiving as perceived by the Nigerian healthcare workers. These are of direct relevance to the provision of dementia care giving. The study suggests that meanings given to dementia are influenced by socio cultural factors and these meanings may ultimately affect quality of care giving.

Additionally, when workers from communities with erroneously constructed meanings of dementia and little knowledge of the condition become caregivers in developing countries, there may potentially be new psychological burdens that emanate from the differing contextual significance of dementia care and minimal knowledge of dementia as a serious medical condition. To provide even greater contextual significance to the study findings, this study indicates the need for more extensive research on perceptions of dementia in the UK which includes the perceptions of both migrant healthcare workers and informal dementia caregivers from alternative global communities.

Finally, the study also highlights the need for healthcare institution and agency staff in Nigeria to remain conscious of the need to provide motivational support for healthcare workers. Many working as dementia caregivers may have different native cultural perceptions of dementia and the resultant psychological strain of caring for people with the condition. The holistic quality of their lives may also be affected by this process as they provide extensive support and care; and as such, continuing motivational support for dementia care giving staff is recommended.

References

- [1] Aluttis,C., Bishaw,T., & Frank, M.(2014). The workforce for health in a globalized context global shortages and international migration *Global Health Action*, 7 (2014), pp. 1-7, 10.3402/gha.v7.23611Scopus Google.
- [2] Alzheimer's Association (2019). Alzheimer's and dementia in the United Kingdom. Retrieved January 8, 2019, from <https://www.alz.org/uk/dementia-alzheimers-uk.asp#factors>.Google Scholar
- [3] Alzheimer's Disease International (2012). World Alzheimer report 2012: overcoming the stigma of dementia. Retrieved July 23, 2017 from <https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>.
- [4] Awosika, G., Odunbaku,S., Olley,B., & Baiyewu, O., (2003).Supporting caregivers of elderly Nigerans with dementia: The experience of the Ibadan dementia research project *IPA Bulletin* (2003), pp. 10-11
- [5] Berwald,S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016).Black African and Caribbean British communities' perceptions of memory problems: "we don't do dementia" *PLoS One*, 11 (4) (2016), Article e0151878, 10.1371/journal.pone.0151878 CrossRefView Record in ScopusGoogle Scholar
- [6] Boyle, D. (2011). Countering compassion fatigue: A requisite nursing agenda *Online Journal of Issues in Nursing*, 16 (1) (2011), p. 1, 10.3912/OJIN.Vol16No01Man02View Record in ScopusGoogle Scholar
- [7] Braun, V., Clarke, V., (2006). Using thematic analysis in psychology *Qualitative Research in Psychology*, 3 (2006),pp. 77-101, 10.1191/1478088706qp063oa
- [8] Brijnath, B. (2011).Appropriation and dementia in India *Culture, Medicine and Psychiatry*, 35 (4) (2011), pp. 501-518, 10.1007/s11013-011-9230-2 CrossRefView Record in ScopusGoogle Scholar
- [9] Bryon,E., Casterlé, D., Gastmans, B.(2012).Because we see them naked - nurses' experiences in caring for hospitalized patients with dementia: Considering artificial nutrition or hydration (ANH)*Bioethics*, 26 (6) (2012), pp. 285-295
- [10] Blumer H. *Symbolic Interactionism: Perspective and Method*. Prentice-Hall; Englewood Cliffs, NJ, USA: 1969. [Google Scholar]
- [11] National Academies of Sciences, Engineering, and Medicine. (2020). *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25663>external iconexternal icon
- [12] Spencer, S., Martin, S., Bourgeault, I., L. & O'Shea, E. (2010). The role of migrant care Workers in ageing societies: report on research findings in the United Kingdom, Ireland,
- [13] Canada and the United States. Retrieved January 27th, 2019, from https://www.library.nuigalway.ie/bitstream/handle/10379/3217/The_Role_of_Migrant_Care_Workers_in_Ageing_Societies.pdf?sequence=1&isAllowed=y
- [14] World Health Organization (WHO) (2011).Dementia: a public health priority. Geneva, Switzerland. Retrieved August 17, 2017, from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1



- [15] Yusuf, A., Baiyewu, O., Sheikh, T., Shehu, A. (2019). Prevalence of dementia and dementia subtypes among community-dwelling elderly people in northern Nigeria
- [16] International Psychogeriatrics, 23 (3) (2011), pp. 379-386, 10.1017/S1041610210001158 View Record in ScopusGoogle Scholar © 2019 The Authors. Published by Elsevier L
- [17] Podcast: Dr. Craig Thomas on the Serious Health Risks of Social Isolation and Loneliness in Older Adults before and during COVID-19, December 2020.
- [18] Podcast: Dr. Craig Thomas discusses a new report that shows social isolation in older adults was associated with a 50% increased risk of dementia, June 2020.

