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## **Living With/Out Dementia in Contemporary South Korea**

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### Abstract

While the debate on diagnostic disclosure is often based on the premise that knowing about one's condition (the diagnosis and its prognosis) is essential in securing the patient's autonomy, many people with dementia in Korea are not directly told about their diagnosis. This paper concerns the laborious and ethically contentious "post-diagnostic" living undertaken by the families of people with dementia, which I call "living with/out dementia". This is a paradoxical form of living that has emerged through the increasing biomedicalization of dementia, the socialization of elder care and an enduring fear of dependency in old age. Attending to how "living with/out dementia" comes to be initiated and maintained through efforts of care, I argue that nondisclosure entails a kind of ethical process through which dementia is un/done in the caregivers' struggle to truthfully engage with the person with dementia while actively hiding the diagnostic truth from them.

Keywords:

care, dementia, diagnostic disclosure, Korea, bioethics

My grandmother doesn't know she has dementia. So, every time I give her the medication, I say, as we decided following a long family discussion, it's a drug to "prevent" dementia. She then takes the pill pretty willingly and happily. She's now living with the goal that she will never get dementia until she dies. In the meantime, I feel we are *deceiving* her in some ways.

Jimin's grandmother was diagnosed with dementia in 2013, but she has never been told. Following the diagnosis, family members had a serious discussion about whether to tell her or not. Whereas Jimin believed her grandmother should be given a chance to prepare for her remaining years, other family members thought disclosure would ruin her remaining years, that she would be offended by the diagnosis, and become hostile to the person who delivered the news. They decided not to tell, and have kept it secret from her since then. Yet, the grandmother is taking medication to treat her symptoms, is taken care of as someone with dementia, and is taking part in the "study sessions" that Jimin and her mother created to work on her memory. Jimin, a thoughtful and considerate graduate student in her twenties, finds herself in the midst of ethical conundrums in her daily interactions with her grandmother. Is it "deceiving" her to withhold the diagnosis, while treating her as a patient with dementia?

This article concerns a specific form of living that I call "living with/out dementia". I use the term to describe a situation in which a person diagnosed with dementia is believed and expected to be living without knowing about the diagnosis, while being taken care of as a person with dementia. Here, one is living with dementia without explicitly identifying oneself as such. While it has been reported that the overwhelming majority of Koreans are willing to know about a dementia diagnosis (Jung

et al. 2017), it is not a matter of course to deliver the diagnosis directly to patients. As I learned from my encounters with family caregivers and medical professionals, it is often family members who are told about the diagnosis, and who decide (not) to disclose it to the patient, while still trying to get the person treated and cared for as someone with dementia. The caregivers act as though their family members had not been diagnosed with dementia, but on the premise that they should be treated as patients who do have the condition. Negotiating the discrepancy between living with and without dementia becomes a task for caregivers. Living with/out dementia involves caregivers' constant efforts to keep the diagnostic "truth" at bay—not only withholding the diagnosis from the patients, but also trying to engage with their family members "with" dementia while trying not to disclose the diagnosis, which entails further ethical questions and practices. This article focuses on how the process and practices of maintaining secrecy are at once a condition and practice of care.

In examining this post-diagnostic form of living, I shift attention from the *why* of nondisclosure (namely the cultural and structural contexts that make it favorable) to *how* it is done and maintained over time. The emphasis on truth-telling and its underlying assumption of the universal value of individual autonomy in formalistic bioethics have long been debated among ethicists, medical practitioners, and social scientists of medicine. Critiquing the hegemonic value of individual autonomy (Gammeltoft 2014; Adams et al. 2007) and a "disclosure ideology" that links transparency to a patient's interests (Brada 2013), medical anthropologists have argued that the question of "(non)disclosure" cannot be dissociated from cultural norms and values regarding life and death, health and illness, and care relations and personhood; therapeutic narratives

and the structure of health care; and language ideologies (Brada 2013; Bennett 1999; Carresse and Rhodes 1995; Feldman 1992; Good et al. 1990; Gordon 1990; Gordon and Paci 1997; Kaufert 1999). While bioethics debate tends to privilege the “acute” moment of revelation of truth and crisis (Manderson and Smith-Morris 2010), which is to be balanced with its long-term benefits (Carpenter and Dave 2004), ethnographic studies of living without full disclosure show that (non-)disclosure is a dynamic and heterogeneous process that is differently shaped in particular care relations (Clemente 2015; van Hollen 2018), and a “social act” in which social roles and responsibilities are negotiated over time (Bluebond-Langner 2005). Nondisclosure does not mean that patients will not know anything about the truth: they may know viscerally (Gordon 1990) and “soft truth” may be conveyed through the cues given by their carers (Bennett 1999). The diagnosis is only a “partial secret” that is “both endlessly concealed and perpetually exuded” (Squire 2015: S201), or is managed like a secret through the mutual pretense of carers and patients, who act as though the catastrophic future were not in their purview and make meticulous efforts to control information in order to protect one another from the effects of disclosure (Bluebond-Langner 1978, 1996). Care of the secret is simultaneously care of both people and relations.

I attend to what forms of living and caring emerge through practices of nondisclosure and what their ethical implications are. Nondisclosure of a dementia diagnosis is particularly troublesome, because it is overshadowed by anxieties about “deceiving” the person with dementia and dismissing his/her agency and subjectivity (Blum 1994; Schermer 2007; Seaman and Stone 2017). However, the efforts to keep the diagnosis secret, or rather not to utter it, may be seen as one way, although fraught with

ethical tensions, to grant the person with dementia a subject position that is different from what s/he might fear. If full disclosure involves an utterance that interpellates one as a “dementia patient”, nondisclosure leads carers to constantly tinker around language and gestures as they care for the person with dementia in order that he/she does not see him/herself as such. The continued efforts to keep a diagnosis secret entail an ethical commitment to maintaining, enacting, and achieving a certain aspect of that person, agency, and subjectivity in offering certain positions to him/her to live as someone with/out dementia (Driessen 2018; Svendsen et al. 2017; Taylor 2008). As a collective project of active concealment that must be maintained over time, nondisclosure further forces caregivers to deal with ethical and practical questions on a daily basis, concerning not only how to handle the situation with care, but also what kind of person someone with dementia is, and what it means to live a good life with/despite dementia. These questions arise and are addressed through caregivers’ acts to create and maintain a place for a person with dementia to live with/out dementia in everyday circumstances (Lambek 2010).

In the following, I discuss how the diagnostic naming of dementia and an ethical and practical commitment to keep it unnamed lead caregivers to reformulate repertoires of everyday interactions and invent intricate and creative ways of engaging with their family members with dementia. Living with/out dementia is initiated by the hope of slowing down dementia using biomedical means, and (anticipated) resistance to the diagnostic labeling on the part of the person with dementia in a context where dementia is increasingly medicalized, yet is seen as a condition that makes a person a disgraceful burden. Because secrecy needs to be maintained over time through the pretense of

caregivers, it begs more questions than simply why the decision is made. I ask: how does “living with/out dementia” begin? What form of living is it when a person is affected by dementia but is living without necessarily knowing, or assumed to be not cognizant of, the diagnosis? What kinds of work are done by family members and people with dementia to make this form of living possible? Finally, in what ways do the agency and subjectivity of the person with dementia come to matter differently to those surrounding him/her through the diagnosis? I consider the diagnosis to be a painful, yet generative, event that enacts different relational practices between the person with dementia and the people who care for him/her than those which existed before. It necessitates constant efforts on the part of caregivers to keep the diagnosis at bay while dealing with difficult practical puzzles and ethical questions. I argue that living with/out dementia entails a kind of ethical process through which dementia is un/done in the caregivers’ struggle to truthfully engage with the person with dementia, while actively hiding the diagnostic truth from them.

After a brief discussion on my research methods, I analyze the portrayal of dementia in popular media to contextualize what is at stake in (not) disclosing the diagnosis to the person with dementia in Korea. The three sections that follow describe the process through which the diagnosis and its nondisclosure reshape familial life into living with/out dementia. I start by discussing the use of tricks to initiate the diagnostic process and the subsequent withholding of the diagnosis from the patient as an effort to keep care ongoing. Then, I describe how post-diagnostic living poses ethical challenges to caregivers that necessitate the recalibration of relations and interactions, and a reconsideration of subjectivity and agency. The last section considers how dementia may

be un/done in the caregivers' efforts to keep the person with dementia from getting a sense that s/he has dementia.

### **Dementia Support Center without Dementia: Notes on Methods**

This article is based on a twelve-month period of ethnographic fieldwork in Seoul, Korea. I conducted participant observations between June 2017 and February 2018 in caregiver education sessions in two district Dementia Support Centers (DSCs) and carried out interviews with 14 family caregivers, most of whom I met through those sessions. I also conducted additional interviews with three medical professionals (a psychiatrist, a neurologist, and a professor of nursing), each of whom has designed family caregiver education programs, and five staff members of DSCs. I also collected popular media materials, policy reports, guidebooks, and online posts that address dementia in particular and the “elderly issue” in general to get a sense of popular understandings of dementia in Korea.

The DSCs, a key institution in the national dementia management initiative, were established on the basis of what might be called a biomedical model of dementia. Its main emphasis is on early diagnosis, therapeutic intervention, and the effective “management” of dementia. Its caregiver education programs, too, are designed by medical professionals. Given the virtual absence of grassroots dementia advocate groups in Korea, however, these education sessions are one of the rare places in which caregivers can learn about dementia. For example, caregivers are told that the “problem behaviors” they find frustrating are not inevitable consequences of brain impairment but potentially the responses of patients to hostile environments or relations and attempts at

communicating their unmet needs. Also, it is one of the few venues where caregivers of people with dementia, predominantly women (wives, daughters, and daughters-in-law), who differ in many aspects such as age, economic status, and educational level, can share common experiences that “others who haven’t done it never understand”—the difficulties of caring for someone with dementia at home, which often make them feel alone and lacking sympathy from others, even their own family members.

This study is limited and possibly flawed, as it considers post-diagnostic living without including the first-person accounts of people with dementia who have not been told about the diagnosis. This is in part due to the practical and ethical problems associated with recruiting and interviewing people with dementia who are diagnosed but have not been told about the diagnosis. Whether the person with dementia is aware that s/he has dementia or not, it is hardly justifiable to make it visible to them, which may cause the very troubles that caregivers are trying to avoid. This clearly highlights the problems that this paper is addressing and that family caregivers and health practitioners are grappling with: why it has to be concealed, and how one can take care of somebody as a person with dementia without making it explicit.

The issue of nondisclosure was not originally my focus. Originally, I had assumed that people with dementia had been informed because they are living as patients—taking medication, attending classes in the DSCs, or going to the adult day centers. Until I started hearing the same question among family caregivers—“does he know he has dementia?”—asked as though it would be an exceptional case, I had not been aware that some people with dementia whom I encountered at the DSCs had never been told about their diagnosis. Since it is called a “Dementia Support Center”, it appeared obvious that



they came to get help with (their) dementia. As I gradually learned that nondisclosure is not necessarily unusual, I started noticing that the staff would never talk about dementia around the persons with dementia—except when some activities are encouraged as “good for dementia prevention”. When the word needs to be used around people with dementia, the staff, mostly nurses, may say “dementia” in English. I also started learning about the various tactics that family members use to persuade them to attend the cognitive training classes in the DSCs or adult day-care centers. Indeed, even taking the person to get diagnosed is not a straightforward process. This strange absence of “dementia”, even in a place that is dedicated to the diagnosis and post-diagnostic support of dementia, is tied to how it is perceived and imagined in Korea, which makes the delivery of the diagnosis (“*you* have dementia”) very difficult. There may be anticipation and experiences of resistance from the person with dementia, who takes it not just as a painful truth, but also as a kind of accusation or attack on his/her self. Before moving to the narratives of family caregivers, let me briefly sketch out the popular imaginary of dementia in Korea today.

### **Faces and Feces**

“I killed your mother.” In 2017, Moon Jae-in, then a presidential candidate, opened his campaign commercial regarding dementia-related policy with the story of a caregiver who eventually killed his wife with dementia. Instead of addressing Korea’s aging/aged citizens, his promise was made to their families, who would “fall into the bottomless pit of misfortune because of dementia”. This theme was reiterated in a TV report about the family caregivers of people with dementia that was produced and aired in the same year by EBS (Educational Broadcasting System), “People Who Are Living with Dementia”,

which includes some starkly brutal and offensive images. In its first and bleakest episode, viewers are introduced to the everyday life of a middle-aged woman who lives with her mother with dementia. The camera records her not only as she feeds her mother with great care and works hard to earn a living, but also as she shows pictures from her smartphone album of her mother's feces lying here and there, and nags her mother to go for a pee. In the end, the woman confesses her outrageous thought of ending this life or lives with dementia—whether the mother's or her own. She concludes by stating that she has thought of committing suicide if she is ever diagnosed with dementia because she “doesn't want to burden her family,” “really, truly”.

Stories of caregiver homicide-suicide cases are, of course, not the only story told about dementia in Korea. Even in the same TV report, one can see a couple who are doing relatively well despite the wife's ongoing memory decline. Yet, the caregiver's confession of murderous/suicidal thoughts, amid the daily grind of care she tried to capture and convey in the images of feces, is still powerful. These images are constantly mobilized to call attention to the burden on family caregivers and the need for more extensive welfare support. Since state-subsidized formal elder-care services are recent establishments dating back only to 2008, responsibility for care of the elderly with dementia has been assumed by family members until the very late stages, and dealing with the elderly's soil has been part of the story about difficulty of at-home care, which appears easier for others to “understand” and potentially sympathize with. For the elderly, incontinence highlights disgrace in old age in which one loses awareness of one's own leakages (consider an age-old Korean insult, “you live long until you smear the wall with your own shit!”). The image of feces is one way for the caregiver to speak of the hard

work that is needed to discipline and contain soiling bodies. Her efforts to contain her mother's bodily leakages in order to preserve a sanitized home and the figure of a dignified mother (Brijnath and Manderson 2008; Pols 2006) are constantly betrayed in practice, which is captured in the photos that she shows and the suicidal thoughts that she confesses. While calling for more social support for people with dementia and their caregivers for their humane lives, however, this kind of narrative ironically reiterates how frightening and dehumanizing dementia is for both parties—a carer-victim and burden-(non)person. It speaks to the fear of potential and complete abjection, much more frightening than death, with the body's enduring, burdensome presence—dirty and insane, demanding yet oblivious.

How can one accept this figure of abjection as one's own future, especially when the duration of this burdensome presence is unknown? A public awareness campaign emphasizing the possibility of living well with dementia, if diagnosed early and “managed” well, is under way, and the first TV project aimed at portraying people with early-stage dementia as active and lively citizens came out in 2018. However, this does not cancel out the gloomy final years to come. Rather, it shows only another stage of dementia, as one of the project's participants put it, that can be prolonged with “effort” to avoid the gruesome future that is deeply engrained in the popular imaginary of dementia in Korea (Latimer 2018; Lamb 2014; Kaufman 2006). As such, “you have dementia!” can still be a curse that might be heard as: you are an idiot, even though you don't feel like that now; even worse, you are on the road toward insanity; your face may lose out to

your feces; or, you may be too burdensome to your family and “abandoned” by them to nursing homes or worse.<sup>1</sup>

When I asked family caregivers and doctors why they would not disclose the diagnosis to patients, they often said that they did not want to harm the person’s *jajonshim*. Roughly translated as self-esteem or self-respect, *jajonshim* is hard to comprehend outside of social encounters and relations. It can be “hurt” or “harmed” by feeling dismissed, mistreated, or humiliated in social encounters (Han et al. 2012); it can be kept up when being praised or respected by others as one feels that one deserves. If diagnostic disclosure is avoided in order not to harm one’s *jajonshim*, it is because this involves not only shock and despair about the irreversible loss of self, but also the fundamental transformation of the person into a burden<sup>2</sup>—s/he could become the demanding undead, much worse than the “living dead”, who could provoke murderous thoughts.

### **To Initiate a Life with/out Dementia**

I didn’t tell him because I was worried that I would be in trouble, perhaps more so than he was troubled by the diagnosis, because he has such a strong sense of *jajonshim*. So, even when we went to the clinic for a test, I told him I felt there was something wrong with me, and asked him to get the test together. So, he agreed. We arranged to see the doctor one by one; he went in first and I did it

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<sup>1</sup> “Abandonment” has long been a central image through which the fear of old age is imagined in Japan and other East Asian countries, where a folk tale about abandoning an old mother in the mountains is found (Danely 2014). *Koryeojang*, a term that refers to the practice of abandoning the old parent in the folk tale, still appears in discussions about the issues of caring for the elderly.

<sup>2</sup> Anxiety about becoming a burden has been reported in different Asian countries, such as India (Vatuk 1990) and Japan (Traphagan 2000), where the problem of dependency is not so much about the loss of independence as one’s own place within intimate social relations.

later. [...] If I had told him that he should get the test because he had an issue, he would probably have responded: “no, nothing’s wrong with me. I won’t have it.”

It was only possible because we did it together.

Three years ago, Sunwoo, a retired schoolteacher in her eighties, noticed her husband’s subtle memory problems. She tricked him into getting diagnosed with dementia by pretending that she was concerned about her own memory. She has been withholding the diagnosis from her husband ever since. Everything that he does to slow down the progress of dementia, from taking medication to various activities, has been glossed over as “preventive” measures rather than treatments. Multiple tricks, or what one might call “deceptions”, have become an indispensable part of the couple’s everyday life. Those small tricks may be seen as a means for her to manage his actions, but if we attend to the relational and processual aspect of care, these seemingly deceptive practices can be seen rather as an ethical commitment to care.

In its very early stage, there is a phase during which individuals affected with dementia become aware that something is going awry. S/he may attempt to hide it from others—until close family and friends begin to notice problems (Steeman et al. 2006). The person with dementia might refuse to get tested, not wanting to know or have it confirmed that s/he has dementia, because this could indicate s/he will eventually turn into a burdensome presence without being aware of it, regardless of what his/her present condition is. Sunwoo was going against her husband’s will, or at least she thought she was doing so, as she anticipated refusal from the outset. Yet, she had to initiate the diagnostic process, not simply to discover the truth about his current state, but also to gain access to medication and welfare services to carry on living with him. What matters

here is *what can be done* to better care for the person who might have dementia. It concerns how to start care and keep it ongoing. Of course, the individual's will should not simply be ignored for therapeutic rationales. But, what if the life of the person with dementia is inextricably entangled with the life of someone else who cares about them, cares for them, and feels obligated to do so?

Using “tricks” to get the person diagnosed and then withholding the diagnosis are not unusual practices in Korea. Even medical professionals, including doctors who specialize in dementia and DSC staff members, acknowledge that they are quite common, and they too are involved in these processes. The fear of dementia and the reluctance or even resistance to take diagnostic tests among the elderly makes it a difficult task to simply take the person (suspected of having dementia) to clinics or DSCs for diagnosis. Family members actively seek and share among themselves the small tricks that have worked, and sometimes reach out to medical professionals at the clinics and DSCs for advice. They are not necessarily comfortable with tricking those who might have dementia, but they do so because they cannot neglect those persons while knowing/believing that something can/should be done, both for the persons with dementia and the caregivers themselves.

*Jajonshim*, a sense of self-worth to be maintained/harmed in relationships, is particularly important here. Sunwoo was concerned about her husband's potential reaction to the diagnostic disclosure, in terms not only of his own emotional upheaval, but also of her everyday interactions with him, which might become difficult if his *jajonshim* was harmed. While Sunwoo did not articulate what kind of trouble the disclosure might have caused, I was told that many family caregivers who tried to deliver

the diagnosis to patients faced a serious challenge: for instance, the person with dementia would blame them for falsely “accusing” him/her of having dementia, and become hostile to the family member who delivers the bad news, as someone attempting to discredit a perfectly normal person for some reason.

Physicians and DSC staff are also concerned about this. One psychiatrist says that she would tell a person directly only if it is obvious that the patient seems able to accept the diagnosis, and is interested in learning the truth. But, “when the person’s *jajonshim* seems to be at stake”, she would rather say: “I just want you to maintain the present condition, and there are ways to help you do so, so let’s try them,” instead of “you have dementia so you should get treatment”. She says, “when they come to the hospital, most people are aware that they have some problems. They know, but there are many people who don’t want to hear about it directly.” Another physician said: “One might be left with the feeling that s/he was forcefully exposed to an unpleasant situation, which makes it difficult to get him/her back to the clinic.” For these medical practitioners, it is first a matter of building and maintaining a good therapeutic relationship with the person with dementia. At the same time, it is an acknowledgement of the wish of the diagnosed, brought to the clinic by others, who did not want to be officially named as a “patient with dementia”. It is not always clear what the person’s preference may have been, but they are concerned that the consequences of disclosure might be detrimental to the care relationship.

The whole series of actions during the diagnostic phase can be seen as a *process to make care possible and sustainable*. The diagnosis is sought to find ways to intervene in its progress, to get prescription drugs and receive doctors’ notes that help caregivers

gain access to the services provided by long-term care insurance. It is not so much truth as hope that governs this process (Moreira 2010). It concerns the present and near future, which one hopes to make better through coordinated efforts to manage dementia's progression, rather than the anticipated end-of-life, for which advanced care plans and other forms of decisions need to be made. While the diagnosis itself might be made against the will of the person with dementia, it is withheld in order to keep his/her sense of self-worth intact, and to prevent further conflicts between the person with dementia and the people who care for them. In any case, his/her life cannot be thought of as dissociated from others, or from the anticipated increasing demands for care, most likely from his/her family, given the less-than-ideal welfare provisions in Korea. While one might want to deny this bleak future, caregivers think that something should/could be done, both for the person with dementia and for themselves. The concern is how not to harm both the person's sense of self and the relation of care (or the possibility for it) with the diagnosis. The diagnosis is made, but not directly communicated to the patient, in order to create and maintain the relationship and enable care. The patient's desire not to be found out might have been compromised through the diagnosis, but the diagnosis also becomes a basis by which the person's autonomy, agency, and subjectivity come to matter in a different way.

### **“Somewhere In-between”**

In the narratives of family caregivers about their trajectories of illness and caregiving, the timeline of “living with dementia” tends to be quite ambiguous, without a definite point of onset. Memory problems and personality changes that they noticed but did not



consider symptoms of dementia are often part of the caregivers' narratives. If the diagnosis can be seen as a decisive moment in the caregiving trajectory, it is partly because it crystallizes the vague sense of changes and peculiarity in the person's actions into symptoms of dementia to be perceived and responded to differently than before. When certain actions are taken as "behavioral symptoms" of dementia, there is always a risk of ignoring the will of the person with dementia, his/her subjectivity, and agency as they manifest in those actions (Herskovits 1995). Yet, the diagnosis and its withholding may also initiate a process through which the person's subjectivity and agency finally come to matter and are given attention by the caregivers, as they try to recalibrate how to relate to the person with dementia.

Back to Jimin's story with which I opened this paper. She recollects that her grandmother started showing certain "symptoms" in 2010, which mostly concerned personality changes—being more suspicious, angry, irritable, and depressed than she used to be. Since her grandmother still passed the "screening" tests for two more years, however, they were seen as aspects of her difficult personality exacerbated by aging. As they worsened and some family members started suspecting that she might have dementia, they sought a diagnosis. It was a turning point for Jimin's family. It rendered visible the fact that something was happening and actions needed to be taken—including getting the grandmother to take her medication on a daily basis and assisting her with everyday life.

The diagnosis demanded that the family, and particularly Jimin, who was spending most time with her grandmother, find ways to live with dementia, and with a woman who not only needed attention and assistance but whose acts and words needed to

be carefully calibrated. It also turned the “nuisance” related to the grandmother’s statements and actions into symptoms of dementia. While it was never clear whether these could be explained away as symptoms of dementia, they were now accepted as such, something that the family members should consider differently and tolerate rather than confront as usual. Perusing information about dementia and “how-to” guides from available sources, and trying out various ways to make it possible for them to sustain care, are part of “experiments for co-existence” as Jimin put it. From establishing a routine for both her and her grandmother so that Jimin could secure time for her own studies, to seeking a way to communicate with her better, these experiments were aimed at finding ways to live with her grandmother, now with dementia, who cannot be lived with in the same way as before. Since then, Jimin and her family have been living with someone with dementia, who does not know that she has dementia, and difficult ethical questions have become part of everyday life.

In the midst of these [ethical] questions, like whether we’re deceiving her or not, I thought there’s something wrong about flattering her 24/7. But, I thought, it’s also not right to react to *those unpleasant scenes caused by all the symptoms of dementia* in the exact same way I would do in other contexts—like I did before, confronting her as a [usual] person. If neither this nor that is the right answer, what can it be...? *I think it’s somewhere in-between.* I feel we have acquired some know-how, some kinds of know-how about how to respond to her. [...] Her condition has worsened, but I feel the atmosphere in our home is actually better. Caregivers often tell themselves that “it’s not the person, but dementia” that speaks and acts in troublesome ways. Jimin does this to some extent, but also wonders how she can

draw the boundary between the two. The refrain “it’s not the person, but dementia” has been criticized by many commentators as an example of the “medicalization of deviance” which contributes to the “erasure of the individual’s subjectivity and agency” (Herskovits 1995:152), taking away the person’s will from their actions (Brittain et al. 2017), while leaving room for only “passive, beneficent” personhood (Seaman and Stone 2017:70). Yet, rather than completely canceling out the subjectivity or agency that are manifested through her words and speeches, it can also give room for family caregivers to recalibrate how to understand, feel about, and respond to the person with dementia. Also, it cannot be ignored that family caregivers, in their everyday interactions with the person with dementia, cannot simply erase the person’s agency and subjectivity. As they are hurt by the offensive, accusatory, and provocative words and actions of people with dementia and frustrated by their changed behaviors and personalities, family caregivers struggle to take them as being actions due to dementia, not the person. Here, where the subjectivity and agency of the person with dementia starts and ends becomes a question to sustain the difficult task of care. Jimin’s answer to this question is “somewhere in-between”, between the total dominance of dementia over her grandmother’s acts and full awareness and intentionality behind them. Finding a place in-between requires constant recalibrations in different situations.

Knowing the diagnosis is not the only way to make things better, and it does not always do so, either. If one relies solely on the biomedical model of brain impairment, the diagnosis can easily lead caregivers to find “impairment everywhere” (Gubrium and Lynott 1987:271). Yet, it can at least help caregivers not to be too offended or frustrated by what is said and done by the person with dementia, which is essential in sustaining

care relations. Furthermore, knowing it can, although not always, give some room for caregivers to recalibrate their interactions with, interpretations of, and responses to the person with dementia. Indeed, everyday interactions and communication cannot always be considerate or well thought through, but are often habitual and unguarded. Deviance from the usual in everyday familial life is not always appreciated, and inappropriate behaviors are still frustrating even though they are considered a “normal” part of aging. In a sense, the medicalized notion of dementia, rather than eroding personhood, opens an avenue for the caregiver to strive to understand what is happening to the person with dementia, reserving her own immediate emotional and habitual reaction to what has happened. It gives the caregiver a distance and time from the person with dementia, which may further allow the caregiver to learn how to appreciate the values and meanings of gestures from the person with dementia (Taylor 2008) and find ways to engage with him/her differently from the habitual mode of interaction (Hendriks 2012), rather than being affected and swayed by difficult situations.

In this way, the subjectivity and agency of the person with dementia come to matter differently, if not more significantly, than before—one has to ask, because one cannot take it for granted. There is no solution, but constant recalibrations and experiments around somewhere in-between. Additionally, the simple daily practice of giving the medication, glossed over as a “dementia prevention pill”, is both part and reminder of the ethical experiments which are full of tensions and negotiations over the subjectivity and agency of the person with dementia, and through which living with/out dementia is made possible.

## **Caring for a Life with/out Dementia**

One might still ask whether the person with dementia is completely unaware of the fact that s/he has been diagnosed with dementia and is being treated as someone with dementia. Wouldn't s/he notice something odd about her/his everyday interactions with the caregiver? Is it even possible for the caregiver to completely hide the diagnosis from the person with dementia? And, if the person with dementia notices that the diagnosis has been withheld, wouldn't s/he be upset about that, too? Especially because *jajonshim* looms large in the decision not to disclose the diagnosis, this can be an issue. Yet, the efforts to respect and protect his/her *jajonshim*, as well as to care for him/her by nondisclosure, or how it is "handled with care" (Van Hollen 2018) might equally matter. At least, that is how Sunwoo sees her everyday interactions with and care for her husband.

After the diagnosis, Sunwoo changed her style of communication and the tone of everyday interactions with him. Since she learned that it would not work to confront and argue with him as they used to do before, she started trying to persuade him by patiently explaining how she feels and what she thinks. She also sets the tone of everyday interaction to be as cheerful as possible with more laughter, physical contact and even children's songs. Whatever she does, however, she would not tell him that he has dementia.

I don't say something like "you have dementia". Rather, I tell him "if you keep doing this, you might get dementia. If I do so, I might, too." By saying "you might get dementia", I am also suggesting that he does *not* have dementia. [When

I tell him not to do something] I say, “if we act like this and others see it, they will think that you and I are the elderly with dementia.” He nods, “okay, I get it”.

As Jimin does with her grandmother, Sunwoo not only hides the diagnosis from her husband, but also actively tells him, or at least suggests to him, that he does not have dementia yet. Furthermore, she grants him the position of a person without dementia. Being asked to do this and that *in order not to get* dementia, or not to be seen as a person with dementia, he is living *as if* he were yet to get dementia. Dementia has not yet come, but is worried about and feared, which makes it possible for a caregiver like Sunwoo to persuade the person with dementia to take medication and engage in certain activities for prevention. She also brings herself into the picture—as an aging/aged companion who is also at risk of getting dementia sooner or later, or of being (mis)recognized as a person with dementia. These statements pull the couple back to a time before the diagnosis, before he finally got dementia, even though his memory is now significantly compromised, and he is attended by her most of the time. When she tries to get him to “understand that [what he is doing right now] is for prevention”, dementia is not necessarily what is being lived with right now, but is displaced in time as the potential future.

While it is mostly Sunwoo who directs her husband to conduct himself in this or that way, she constantly tries to create for him a position to agree with what she suggests. When things are difficult, she talks with him, “as though I’m consulting him about my difficult situation” so that “he can understand” and help her out. To consult with, be understood, and agreed with—being responded to with care by the person with dementia. These gestures enact communication between two equal parties and give the husband a

position from which to speak as someone without dementia. This is not how they as a couple have been living so far, and not the way she used to live. “I used to be very impatient, but I learned that I should be more patient and wait for him. And, I also realized that I should not make him feel, ‘oh, my condition is that bad’.” Not making him feel, or not giving him a sense of, his deterioration requires her to make efforts to actively hide it, and give him a position from which he can act and respond as someone without dementia.

It is possible that he is aware of his own memory problems, and wonders whether he has dementia or not. His wife’s changes are also noticeable—as she wakes him up in the morning with a cheerful children’s song at which he laughs or smiles, the secret can exude. Keeping it a secret may require hard work by both parties, but this potentially mutual performance of secrecy, in this couple’s case, entails gestures of care by both. The couple is living with dementia—not simply as an impairment in the brain, but also as a generative force that changes how they live everyday life—even though it is constantly portrayed as absent or only existing as a future possibility. He is taking part in a new way of living that is mostly initiated and sustained by his wife’s efforts to keep dementia at bay, even in its presence and with its anticipated progress. He is living simultaneously with and without dementia, which is in large part due to Sunwoo’s efforts to let him take part in her project of living with/out dementia.

While offering him opportunities to be persuaded by her and to agree with her, Sunwoo also came to appreciate how her husband also helps her in going about everyday life: “he knows how hard I try”. As she grants a place for him to decide on everyday matters, albeit within certain limits, she is also convinced that he can still make sound

judgements, to an extent that sometimes makes her wonder whether he really does have dementia—not because she believes dementia would destroy his ability to do so, but rather because she can now appreciate his ability to respond. This cannot, of course, be done without giving him opportunities to do so.

Dementia is simultaneously enacted and made absent. In her interactions with him, which aim to make the couple's life with dementia easier, dementia is enacted as a relational matter. At the same time, it is enacted as something that they are as yet living without. Even though he is taking medication to ameliorate the symptoms of dementia, this does not enact dementia as his present condition but as something preventable. While dementia is made absent by these efforts, it works as a force that drives her efforts to make the condition absent in their everyday interactions. While it is motivated by practical concerns about sustaining care without harming the person's sense of self-worth, maintaining the state of living with/out dementia itself adds another layer to care relations that require the caregiver to constantly recalibrate the relations with, and subjectivity and agency of, the person with dementia. Whereas the debate on the ethics of "disclosure" tends to foreground the individual who is diagnosed and his/her rights and well-being, the living with/out dementia that comes after the seemingly problematic nondisclosure calls for attention to ethical questions and practices that emerge in the relational un/doing of the dementia diagnosis, through which people who care for the person with dementia transform themselves.

## **Conclusion**



Diagnosis is a significantly important event in the trajectory of living with dementia, not only for the person with dementia but also for their family members. The disclosure debate around highly stigmatized or terminal conditions tends to take for granted the importance of knowing the truth for an individual's autonomy. The bioethical prescription that is now commonly accepted, although not necessarily the most common practice in actual clinical settings, at least in Korea, is to disclose the diagnosis with great care and provide post-diagnostic psychological support, so that autonomy and well-being can both be ensured—making the transition for the patient to a life *with* dementia as smooth as possible. However, the stakes could be much higher than they appear to be, especially because what is at stake is not only the person's own sense of self but his/her relations with the people who surround him/her; hence, “denial” might mean not only denying the diagnosis but also denying the trustworthiness or good intentions of caregivers. Yet, diagnostic nondisclosure does not mean that the person with dementia is not affected by the diagnosis itself. Everyone else around that person starts living with the diagnosis, learning to live with the dementia that has intruded upon the family's ordinary life, and dealing with the diagnosed family member as a person/patient “with” dementia, often trying not to make her/him feel that s/he has dementia.

Living with/out dementia is a paradoxical form of living that has emerged through its increasing biomedicalization, the (imperfect, never satisfactory) socialization of elder care, and the enduring fear of dementia in particular and old-age dependency in general. It is also a form of living that makes us ask what “ethical” means in our “ethical” discussions. Of particular interest are the notions of “self”, autonomy, agency, and subjectivity, both in medical ethics and sometimes also in studies that are critical of

biomedicine. Neither prescriptive discussions in medical ethics, nor critiques of the medicalization of dementia may get us much further. Ethical discussions cannot stop at the prescriptive “should”; rather, they need to attend to the doings that generate further questions about goods. And, I would add to or include in “doing” several other terms: recalibrating, facing questions that lead them to question, and becoming different. With these terms, I want to emphasize the relational aspect of care and, more specifically, its ethical significance as a process and practice through which the self and other need to be not only connected, but also refigured—not according to an abstract ethical principle or a commonsense notion of self/personhood, but in practical ways that make it possible to maintain care.

Another question that living with/out dementia raises is how we should think of the many lives that are being lived with certain diseases without the patients being aware of them, or without identifying them as such. Are they living with it or not? To what extent? And, in what ways? Can we study these experiences of “living with”, or should we find other terms to make sense of them? So, we end with more questions than answers: like the caregivers, for whom everyday life becomes a series of unsolvable ethical questions that can only be experimented with.

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