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Participants and Observations

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Participants and Observations

Dementia and the Challenge for Anthropology

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Roughly forty professional and student anthropologists from around the world gathered together on September 19th and 20th, 2019 to share their research on dementia and dementia care. Hosted by the University of Copenhagen (Denmark), and the second conference-style workshop of a much larger European Research Council funded project entitled 'VITAL: The Vitality of Disease – Quality of Life in the Making,' *The Arts of Caring, Arts of Knowing: Dementia and Knowledge Practices* workshop gave anthropologists (and other social scientists) an opportunity to develop and discuss new ways of thinking about alternative imaginaries, discourses, and practices with respect to dementia. On Thursday September 19th, 2019, the workshop began with two back to back morning keynote addresses. For the first address, Janelle Taylor (University of Toronto) spoke passionately about the role of the arts in dementia care. She touched upon the concept of the caregiver as a craftsperson and tinkerer, and spoke about the importance of attending to issues of dwelling and attunement in improving the quality of life for those with dementia. Following on from this, Annette Leibing (Université de Montréal) delivered the second keynote address, which delved into the intellectual history of the pharmacological treatment of dementia. Leibing drew case material from her own fieldwork in Brazil, and floated the idea of what it might mean if dementia could be taken up epistemologically as a kind of psychotherapy via particular life histories. The rest of the workshop fell into five working groups that provided a chance for more intimate and focused paper presentations and conversations. These working groups were broken down according to the following thematic titles: 1) Living with dementia in time: Still there or not? 2) Crafting, Improvising, and Playing: Creative Engagements with Dementia 3) Care in Places, Negotiating Good Life 4) Ethics in Question: How We Respond to (Intimate) Others and 5) How Do We Know (about) Others with Dementia?

The discussion emanating from the first working group focused on the experiences of those with dementia, providing a platform for thinking more about the relationship between time and space. Participants posited the 'out of synch' phenomenon as a heuristic for better understanding the shortcomings of conventional care in various dementia wards. Pivoting to the second workshop, a lively discussion ensued about the role of the caregiver in dementia, and how the usage of mobile media technologies and even music therapy open up new opportunities and meanings in the crafting of particular care relationships. The papers from the third working group, which kicked off on the second day of the conference, focused on what is actually done in the name of care, and how 'care' empowers particular institutional practices and decision-making at the expense of wellbeing and quality of care for those with dementia. Two papers from the fourth working group dealt specifically with the issue of lying in clinical practice. They offered ethnographic instances into how and why particular kinds of lies were being used by caregivers in the context of dementia. By focusing on the linguistics and ethics of lying, these papers showed that even in the adoption of 'person-centered care,' clinical untruths were not entirely without function or sympathy. Last but not least, the papers in the final working group tackled the deficiencies associated with our dependence on verbal language in conveying how dementia is experienced and interacted in places like residential care homes. By using new forms of data collection such as charting, visual methodology, and even arts-based participatory approaches to 'dementia expression', the

participants in this workshop invoked cutting edge anthropological theories and research design, offering new perspectives and scopes for future investigations.

By taking seriously the multi-perspectives attendant to dementia sufferers and their (in)formal caregivers, this two-day workshop called for creative and innovative solutions for improving our understanding of dementia as well as identified how to generate better quality of life decisions, deliberations, and engagements. Rather than take 'quality of life' as just another sound-bite or unit of bureaucratic measurement, workshop participants deliberated on issues relating to the historical dimension of dementia and its various cross-cultural treatment. Additionally, participants shared findings and observations relating to the changing nature of knowledge, especially with respect to levels of authority (for example, biomedical knowledge versus caregiver knowledge, and even self-knowledge). Attention was also paid to how dementia maps onto the human/social body, and the consequences of particular etiologies. Discussions stemming from some of the presented papers also illuminated the evolving interpersonal relationships in the context of dementia and dementia care. There were instances during the workshop where people talked about the ethical and political consequences arising from various conceptualizations of dementia. In the end, all of these themes only go to stress that larger structural forces often shape how those affected by the disease (either directly or indirectly) come to live with and through dementia in particular ways. What has to be dealt is the issue of how we can work to improve these 'dementia lives.' Fortunately, that is a challenge that anthropologists who conduct research into this area can and should take up critically.

Anthropologists are trained to conduct research in contexts where ongoing translation is not only necessary but oftentimes approaches a kind of methodological second nature. They are constantly making sense of new terms and categories, cross-checking their understandings with local informants, whilst re-evaluating their own taken-for-granted notions of how things in the world are constituted and made relational. They come to 'hang out' and even live long-term in places radically different from where they were raised. Through the process of ongoing translation, anthropologists not only identify deeper structures of meaning from linguistic and symbolic perspectives, but also in their translational work they compare how different models of culture, personhood, sociality, and illness are dealt with and rendered meaningful in the world. For many anthropologists, especially of the medical sort, dementia, and the cultural context of how that disease is constructed and played out interpersonally in various (micro)systems of care, presents an altogether new sort of challenge. As Alzheimer's and other similar dementia diseases come to grip aging communities around the world, anthropologists do not have to travel far to encounter this most challenging terrain. In many cases, the challenge of the 'other' is in their own backyard. Culturally-inflected notions of personhood will of course determine how dementia is conceptualized and attended to in various social and institutional settings. Research into this area will provide ways for improving how we manage care and stigma. In the context of the West for example, Mahnaz Hashmi (2011) writes, "Alzheimer's disease resonates in Western societies by the simultaneous embodiment of the fear of aging, fear of becoming dependent and fear of losing ourselves" (208). Dementia defies our everyday and normative understandings of autonomy, the self, 'others,' and the double-sided nature of our reliance on biomedicalization. Dementia's Latin roots, *dement*—or rather without/out of one's mind—still underpins our discourse about diseases and conditions that deal with declines in memory, language, and cognitive abilities. So much for the advances in our biomedicalized technology; we have not even made progress jettisoning ourselves out of our crude etymologies!

Nevertheless, anthropologists have been writing about dementia in useful and in some cases quite personal ways (e.g., Leibing and Cohen 2006; Lock 2013; McLean 2007). Most recently, Arthur Kleinman recounts his own caregiving journey with his late wife Joan, who suffered from an early-onset of Alzheimer's. In the *Soul of Care*, Kleinman (2019) reveals that what is at stake in our medical anthropology

is not just accommodation to the cultural construction of disease or even what students learn as ‘cultural competency,’ but a greater attunement to theorizing about the social and moral nature of caregiving itself. In a very personal and early passage in his latest book, Kleinman (2019) shares with us the following regarding his late wife’s misperceiving of her surroundings and other symptomologies: “As in Joan’s case, it most often is episodic, short-lived, and readily forgotten, but for those close to the sufferer, it can be world-shattering—as if a bond that has taken decades to forge can be broken in an instant” (2). Another way in which recent approaches to caregiving for those with dementia has taken off positively on the ground in community-based and residential care settings has been linked to Anne Basting’s TimeSlips work (see Basting 2013). By drawing from creative storytelling, Anne Basting gets participants to take cues from pictures and other resources in producing and sharing narratives without having those with dementia worrying about remembering the correct ‘facts.’ Imagination is leveraged in these instances of person-centered care, so that those with dementia are able to connect with others including family members in meaningful, therapeutic, and fun ways. Similarly, the notion of narrative care as promoted by William Randall (2009) provides a further refinement. Rather than let others voice and characterize the lives of those with dementia, narrative care gets people, regardless of their state of decline, to construct their own lives as lived out and sought out stories. For Randall, narrative care is core care because of the medicinal qualities inherent in giving people dignity and agency, continuing the crucial work of narrative development into late life.

At the conclusion of *The Arts of Caring, Arts of Knowing: Dementia and Knowledge Practices* workshop, and on the very next day in fact, the World Alzheimer Report 2019: Attitudes to Dementia released its latest findings to the public.¹ According to the report, which also happens to be the largest worldwide ‘attitudes to dementia’ survey ever conducted, a rising number of people in the world are concerned about getting dementia. Unsurprisingly, stigma is still a growing concern. Thirty-five percent (35%) of carers across the world said that they have hidden the diagnosis of dementia of a family member from at least one person. Clearly, there is still much more work to be done, and anthropologists can play a crucial role not only in reversing negative misperceptions and translating the experience of those with dementia and their caregivers, but more importantly they can engage the larger biomedical community on issues of how to appropriately pathologize aspects of dementia whilst simultaneously integrating approaches to treatment that emphasize mutuality and an emics of care. Because dementia adds another layer of complexity to our communicative practices especially in instances of severe memory loss and cognitive impairment, there is work to be done in those situations where ‘normalcy’ seems to be hi-jacked and the ontological tables turned upside down. In times where claims to the truth and experience are at odds, remembering that our work should be towards evaluating persons as human beings will be important. Just as those who love and provide the necessary care for those with dementia, anthropologists too must look to situate their work in and across various levels of scale. The challenge for this kind of anthropology is to achieve a critical closeness to theorizing without losing the ideals that resonate so much with our informants, which include sincerity, authenticity and professionalism.

Notes

¹ Alzheimer’s Disease International. “World Alzheimer Report 2019: Attitudes to dementia.” Accessed February 6, 2020, <https://www.alz.co.uk/research/world-report-2019>

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