

ISA ONLINE GUEST LECTURE

# CAREFUL WAITING AT THE END OF LIFE

## NARRATIVE NAVIGATION OF DYING IN ACEH, INDONESIA

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Practices of caregiving when facing advanced illness entail the narrative navigation of anticipating death and recovery. Drawing on anthropological theory on narrative re-orientation in/through caregiving and the problematization of a notion of care as inherently 'good', I ask how people narratively navigate care at the end of life, when their future (in this world) is becoming increasingly limited. In the Islamic context of Aceh, Indonesia, it is the notion of death as a transition rather than an endpoint that helps caregivers of people living with end-stage AIDS to foster ethical orientations toward both recovery and death. In situations where biomedical, curative care might give hope but can also be violently limiting through endless waiting, silence about dying, and the near absence of palliation, my interlocutors navigated when and how waiting for death or biomedical/miraculous recovery could be forms of 'good care'. I zoom in on the stories of women who cared for a loved one dying of AIDS to explore how living with indeterminacy, waiting for recovery, and waiting for death may become virtuous forms of care, simultaneously or at different times. Here, it is the ambivalence about what is good (or the best possible) care and an orientation toward indeterminacy that take center stage, making room for thinking of care as narrative navigation within limits that are continuously in flux.



**Annemarie Samuels** is Assistant Professor of Cultural Anthropology and Development Sociology at Leiden University. She is Principal Investigator of the ERC Starting project "Globalizing Palliative Care? A Multi-sited Ethnographic Study of Practices, Policies and Discourses of Care at the End of Life." (2020-2025). From January 2017 to December 2018, she was a Marie-Sklodowska Curie Global Fellow at Harvard University and Leiden University with the project "The Power of Silence: A Medical Anthropological Approach to AIDS Care Narratives." She has extensive ethnographic research experience in Indonesia and has published widely on the topics of care, narrative, HIV/AIDS, and disaster. Her monograph *After the Tsunami: Disaster Narratives and the Remaking of Everyday Life in Aceh* was published by the University of Hawai'i Press in 2019.

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