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### Experiencing Lupus: An Illness Narrative

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TOWARD A BETTER UNDERSTANDING OF...

## EXPERIENCING LUPUS: AN ILLNESS NARRATIVE

*Jerik Leung*

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The aim of this research is to foreground individuals' experiences with Lupus including encounters with diagnosis, treatment, and disease course in order to highlight how social misunderstandings and stigma about this condition affect the delivery of care. An overarching theme of ambiguity plays a prominent role in numerous facets of the individual illness experience. From a biomedical perspective, Lupus is a notoriously ambiguous disease without a concrete method of diagnosis or stable course of disease. While there is a wealth of literature that aims to explore Lupus in the context of its ambiguity, it primarily represents the positions of health care providers who typically lack experiential evidence of living with Lupus. Through in-depth interviews and ethnographic fieldwork, I sought to understand how people with Lupus themselves understand and find meaning in the ambiguity of their illness. In viewing Lupus from these differing perspectives of health care providers and individual sufferers, tension between these two parties caused by Lupus' inherent ambiguity becomes clear. Health care providers experience pressure to deliver clinically certain models to an illness in which uncertainty is one of the primary facets of the illness experience. In exploring this tension, I primarily draw on anthropological work surrounding models of chronic illness and social dimensions of immunology in order to contextualize how individuals with Lupus situate themselves in these frameworks. I present potential practical implications of integrating ethnographic findings as a means of improving existing treatment for individuals with Lupus.