



University  
of Victoria

Graduate Studies

Notice of the Final Oral Examination  
for the Degree of Doctor of Philosophy

of

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MA (University of Victoria, 2008)

BA (Queen's University, 2006)

**“Making Appropriate Care Possible: An Institutional Ethnography of  
Rare Patient Healthwork in British Columbia”**

Department of Sociology

Monday, April 15, 2024

11:00 A.M.

Clearihue Building  
Room B019 and Virtual

Supervisory Committee:

Dr. William Carroll, Department of Sociology, University of Victoria (Supervisor)

Dr. Katelin Albert, Department of Sociology, UVic (Member)

Dr. Anne Bruce, School of Nursing, UVic (Outside Member)

External Examiner:

Dr. Naomi Nichols, Department of Sociology, Trent University

Chair of Oral Examination:

Dr. Justin Leifso, Department of Political Science, UVic

## Abstract

The Canadian Medical Association defined appropriateness in health care as “the right care, provided by the right providers, to the right patient, in the right place, at the right time, resulting in ultimate quality care” (2015:2). As a resident of British Columbia, institutional claims of appropriate care provision surround me; however, as a rare disease patient, I am often left alone to make appropriate care possible for my body imbued with an exceptional foundation (rare physiology, anatomy, and tissue composition). Using institutional ethnography as my method of inquiry, this autoethnographic research brings readers into three communal health-care settings beginning from my standpoint as a rare disease patient. The primary goal of this project is to explicate the rare patient healthwork I undertake to make appropriate care possible for myself within a health-care system organized to textually account for appropriate care provision at a population health level.

To begin, I walk readers through the work of communicating complexity on a standard medical history form at the doctor’s office. Next, I tackle the challenges of obtaining appropriate testing for a common medical condition at an outpatient laboratory using a standard laboratory requisition. Finally, I introduce my body book, which is an interventional text I have created to help health-care providers to support my rare skin needs in perioperative care spaces (“pre-op and the recovery room”). Throughout my dissertation, I focus on healthwork that strives to reach three overarching goals to make appropriate care possible for me:

1. To prioritize and communicate the relevant complexities of my body within the temporal, spatial, and conceptual constraints organized within a standardized form or setting

2. To offer support to health-care providers when requesting adaptations to their physical or textual work processes to account for my complexities within communal care settings and on standardized forms

3. When needed, to convince health-care providers to move beyond treatment plans based on probabilities and assumptions embedded in health-care practices and orient them to other possible approaches to my care.

While explicating my healthwork, I argue that when rare patient bodies are exposed to the standardized work practices utilized in communal care spaces, even those diagnosed with treatable rare conditions are at risk of harm. As a patient with reliable access to life-sustaining care, I continue to face alarming dangers in communal spaces. By making the actualities of my everyday life visible, I provide an opportunity for patients, HCPs, researchers, and public servants to re-examine how we think about the challenges rare patients face and offer knowledge to help reorganize the ruling relations of health care to make appropriate care possible for all British Columbians.