

UNIVERSITY OF COPENHAGEN
FACULTY OF SOCIAL SCIENCES



The Tinkering M-Patient

An (Auto-)Praxiographic Study of Attuning to a Life with
Type 1 Diabetes through Online and Offline Support



PhD Dissertation 2018 · Natasja Kingod

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PhD Dissertation by

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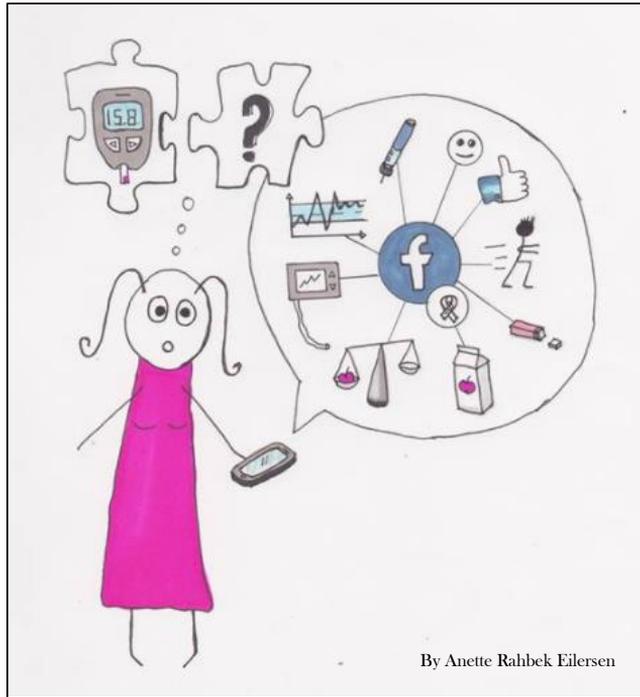


Figure 1: Doubt in self-care of type 1 diabetes and Facebook support

*For Olivia
and all individuals who fight with chronic illness*

Acknowledgement

Everything we know is co-constructed. This thesis is the result of a year-long (auto-)praxiographic endeavor of following adults with type 1 diabetes into online and offline social spaces where self-care is practiced and knowledge about illness is co-constructed. Innumerable interactions with adults with type 1 diabetes were involved, and I would like to dedicate this work to all those who took the time to share with me your innermost thoughts, stories, doubt, and hope about daily self-care practices and living with illness. You have allowed me to observe your practices of self-care, which include interactions and negotiations with digitalized self-care devices, and I have peeked over your shoulder when you navigated within communities on Facebook. At times, I have both cried and laughed with you during deep conversations throughout the period of fieldwork. I am truly blown away by the strength and patience it requires to live with this illness on a daily basis. I did not share the embodied feelings of a failing pancreas with the consequence of high and low blood glucose levels throughout the day; however, I share with you many similar experiences in relation to self-care for this illness on a daily basis on both a practical and an emotional level.

Exploring the lives and self-care of adults with type 1 diabetes, including their journeys into online and offline social spaces, has in many ways been a journey for me as well. My fieldwork of observing practices of self-care did not stop when I left the field. Ongoing (auto-)praxiography will continue at my home until my daughter is old enough to care for herself. This PhD is also dedicated to Olivia, who was just two years old when she was diagnosed with type 1 diabetes, two months into this research project. Together with your sister, you are my love and light and my biggest inspiration. Olivia, I am amazed by your strength at handling your life with this illness. I remember a conversation we had some months ago on a day where the illness was too present in your life. I said to you that I wished that I could take your illness. Just take it away from you. You replied that you would not want to inflict this illness on me or anyone else you know. “Just send it far, far away,” you said to me. I also want to thank my husband, who was diagnosed with type 1 diabetes a year before we met each other in 2007. My deepest gratitude for the way you have supported me, not only throughout the completion of this PhD project while I forced you to listen to an academic language distinct from yours and the details of another scientific discipline, but also my deepest indebtedness for the way we came through a major crisis in the wake of our daughter’s illness. Through my research, I believe that I now have another understanding of how it is to live with this illness. I have stopped being the diabetes police, peeking over your shoulder when you check your blood glucose and commenting on your food. Type 1 diabetes is an unwanted companion that will walk with you and with Olivia for the rest of your lives. I have rewritten this section many times because it has a therapeutic and emotional dimension. I do not feel emotional because I am sad but because the process of making this PhD has been such an important journey for me. I feel empathy for all individuals diagnosed with this illness who can never put self-care on hold or take a vacation from it. I am also grateful for the opportunity

to write about a topic I find fascinating and important on both an academic and a personal level. An (auto-)praxiography is also so much more than fieldwork. It has also been a highly reflexive endeavor, and I would argue that it has been a therapeutic journey as well.

I want to thank Steno Diabetes Center Copenhagen for inviting me to undertake this research. A special thanks to my manager, Ingrid Willaing, and colleagues within the Diabetes Management Research Unit for your support and understanding when I was forced to take sick leave with Olivia and for inspirational conversations and friendship over the years. It is truly an inspiring environment to be part of. I would also like to thank the Department of Anthropology in Copenhagen for lending me an office with a great view over the lakes. Similarly, it has been inspiring and insightful to participate in PhD lunches, research seminars, and courses. And a special expression of gratitude to my industrial supervisor, Bryan Cleal, and my university supervisor, Ayo Wahlberg. I have felt very privileged to have your academic guidance throughout my PhD work and your comments on articles, the op-ed and blog article, and the dissertation. I have learned a lot through brainstorming about ideas and analytical concepts with you. I also need to comment on your empathetic natures. I think the skill of empathetic listening and support is of equal importance to academic and analytic skills and knowledge. This is an emotional intelligence that the informants in this PhD dissertation often called for in the doctor-patient relationship.

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I would also like to dedicate this dissertation to my beloved sister Siff, who courageously struggles with another chronic illness on a daily basis. A warmhearted thanks to my good friends Annette and Heidi for your always-positive attitudes and for our great talks about the important things in life. Not

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