Using Ethnography to Understand Patients’ Perspectives on Medication Use
Lau, Sofie Rosenlund

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Using Ethnography to Understand Patients’ Perspectives on Medication Use: The Case of Hypercholesterolemia and Statins

M.Sc. Pharm, PhD Fellow Sofie Rosenlund Lau

Study title: In Between Sickness and Health: Lay perspectives on life with elevated cholesterol

Department of Anthropology, University of Copenhagen
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Background
In 2013 more than 600,000 Danes received a prescription for a statin (equaling +11% of all Danes) 1. In individuals with a 5-year risk of major cardiovascular events between 10%-20% (high risk), the Numbers Needed to Treat (NNT) to prevent one major cardiovascular event with statins as primary prevention is 333 (Absolute risk reduction = 0.3%) 2. The 5-year risk of major cardiovascular events between 10%-20% (high risk), the Numbers Needed to Treat (NNT) to prevent one major cardiovascular event with statins as primary prevention is 333 (Absolute risk reduction = 0.3%). In 2013 more than 600,000 Danes received a prescription for a statin (equaling +11% of all Danes) 1.

Research questions
• What mechanisms underlie the constitution of high cholesterol as a risk factor and what impact does it have on the treatment of hypercholesterolemia?
• How do we interpret the risk associated with elevated cholesterol and from what is this knowledge of risk constructed?
• How does knowledge of risk manifest itself in everyday lives and practices?
• Including, is the interpretation of risk affecting people’s choices of primary prevention and statin use?

Methodology
What is ethnography?
• Ethnographic methods aim to capture the social meanings of people in their natural settings.
• The goal is to provide rich, holistic insights into people’s views and actions.
• The focus is on the meaning of a few individuals’ actions and explanations, rather than their quantification.
• It emphasizes the importance of context, including the effects of the research and research strategy.
• It implies a mixed method approach, including: Interviews, focus groups, observations and test analysis.
• Both formal (e.g. audio-taped interviews) and informal (conversational) data counts. Informal accounts of everyday life are rich in details and make it possible to elicit highly candid accounts from the informants 3,4.

Data collection
• Meeting informants initially through general practice, then using snowball sampling to recruit further informants through social networks.
• Repeated ethnographic interviews with informants in their homes and/or workplace.
• Participant observation at consultations in general practice and hospitals.
• Interviewing health professionals in the field.
• Participating in workplace health assessments.
• Participating in public meetings in regard to preventive health and national health strategies.
• Tracking related social media e.g. the Facebook group “Cholesterol – myths and realities”.
• Continuous follow-up on scientific and public literature related to statins and cholesterol.

Following the technology
The figure illustrates how I investigate cholesterol, approached as a social phenomenon, as it unfolds in different places and situations. In everyday life when questions on how to live a healthy life cause confusion and uncertainty. Where muscle pain may be a side effect or may be a sign of age. Where or statins present the number one out of many regular medications thus become embedded in everyday practices and routines. But such practices cannot be interpreted as single, isolated moments of actions. They are situated around a myriad of other cultural, political and economic events and structures, which can be hard to embrace using a single methodology. Thus, ethnography provides a way to shed light on this complex network of elements related to cholesterol and statin use, as the methodology allows me to find and compare data from multiple sources and layers within the society. My aim is to describe how interpretations of cholesterol among laymen are linked to scientific notions of cholesterol from a time when statins where still in the making. I follow how such notions have been transformed into contemporary healthcare along with new discoveries from especially epidemiological research. This includes analysing the effects of a wide range of actors in the field including mass media and the Internet, social networks such as the family and the workplace, healthcare professionals including the general practitioner and the pharmacy. But also tracking information back to the making of scientific evidence from guidelines produced by experts and derived from R&D in close connection with the pharmaceutical industry.

References

Preliminary findings
Contemporary healthcare is increasingly focused on risk factors and diagnosing on the basis of numerical deviations rather than symptoms thus impacting our thinking about health and illness 5. Most people with elevated cholesterol do not experience any overt signs of illness yet are somehow diseased because of a blood analysis. Annamaria Mol describes how monitoring blood sugar in people with diabetes may shift one’s attention away from the physical sensations of low blood sugar towards the numbers measured 6. However, when it comes to elevated cholesterol the lack of any physical signs makes the cholesterol number the only way to deal with the condition in practice. Very few informants are actually able to explain the meaning of cholesterol – what it is, and why they are getting treatment. Some know it is some kind of lipid, but are not exactly sure. Others do even have a clue as to how to explain it. Still, most informants know their number and often refer to “my cholesterol number” as a colloquial expression for their health status. Thus, the numbers are embedded in everyday speech as the main way to talk about cholesterol, both from a professional and lay-perspective. Hence, with the following examples from my material it is evident that the numbers have become a tangible way to talk about an otherwise symptomless condition that might be difficult to explain in medical terminology.

Brighty (67 years old) initiated statin therapy half a year ago. She is very aware of her health, takes conscientiously her statin every night and is able to list her cholesterol numbers from every measurement the past two years, including LDL and HDL. She is keeping track of these numbers in a small book, because, as she explains, “Then I know where to find it”. However, despite her knowledge of her cholesterol number she is still in doubt when it comes to explaining what cholesterol is. “It is some kind of lipid, right? Which can make your body ill. With about what and kind of thing, if you get too much of it, right?” (30.09.13 p 36).

John (59 years old) has taken statins for 10 years. I ask him, how to explain elevated cholesterol? “I don’t even know what to say if someone asked me (what high cholesterol is)... Maybe, if I have had some Kind of symptom before I started on the pills, then maybe I could say something. But I haven’t experienced anything!” (14.05.14 t10:37). According to John he is actually suffering from cholesterol deficiency and therefore implicitly enough taken cholesterol pills. “Many don’t know that they have too little cholesterol. I get 40 mg cholesterol!” (14.05.14 t09:05).

Do to the lack of symptoms the reassurance that the number is down on an acceptable level seems to be what matters most. Like John, Brighty never had any symptoms. However, when I ask her how she feels about taking preventive medication, she explains: “Well, now that my number is, well last time it was 3.6, and I don’t have any trouble with the medicines, so then I don’t feel about it” (30.09.13 p 10). General practice plays an important role in making invisible disease visible by translating blood samples into numbers and linking these numbers to a so-called risk. But such practices can be interpreted as single, isolated moments of actions. They are situated around a myriad of other cultural, political and economic events and structures, which can be hard to embrace using a single methodology. Thus, ethnography provides a way to shed light on this complex network of elements related to cholesterol and statin use, as the methodology allows me to find and compare data from multiple sources and layers within the society. My aim is to describe how interpretations of cholesterol among laymen are linked to scientific notions of cholesterol from a time when statins where still in the making. I follow how such notions have been transformed into contemporary healthcare along with new discoveries from especially epidemiological research. This includes analysing the effects of a wide range of actors in the field including mass media and the Internet, social networks such as the family and the workplace, healthcare professionals including the general practitioner and the pharmacy. But also tracking information back to the making of scientific evidence from guidelines produced by experts and derived from R&D in close connection with the pharmaceutical industry.

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- Insights from users of medicines not normally revealed through regular qualitative research.
- New ways of theorizing concepts of health and disease.
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Numeros used are pseudonyms.

Designed by Filip Raminski, Copenhagen