

EMPOWERING ELDERLY WITH CHRONIC DISEASES CAN OPTIMIZE THEIR TREATMENT

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Globally, healthcare spending is causing greater strains on public and private resources owing to the rising number of people with more than two chronic diseases, a phenomenon called “multimorbidity”. This phenomenon is owing to three related phenomenon: advances in science that have found more effective treatments of diseases that would lead to shorter life spans; rising demographics as “baby boomers” enter their golden years; and, among some, behaviors that negatively affect individual health including smoking, limited physical activity, and diet.

These effects are particularly challenging Denmark, where a publicly funded universal health care system is coming to terms with recent findings that over half of increasing post-65 population has two or more accelerating multimorbidity diseases (known as ELAMs). In addition, research in Denmark has found that Socio-economic status and education positively tend to correlate with less healthy behavior.

For these reasons, my research helps contribute to, and sheds light on, the ways in which patients might be better involved in, and part of, developing treatment planning. Such an orientation I argue, could also be expected to reduce health care costs, improve the lives of patient, and optimize overall allocation of resources.

This is an important focus: as an individual’s number of chronic conditions rises, the burden of symptoms, treatments, self-care and even risk of premature death, increases. People with multi-morbidity are more frequently hospitalized but, somewhat ironically, are also found to receive *conflicting* advice from health care providers. From the perspective of society, patients with multimorbidity are associated with substantial health care costs and labor market exclusion.

What do we need to know in order to provide appropriate care for people with multimorbidity and minimize the costs of treatments? Despite extensive public health services that cover all citizens in Denmark, there remain severe inequality challenges. Drawing on my ethnographic research among people with chronic diseases in rural Denmark, I offer potential ways towards more sufficient care and treatments that can be applied regardless the specific organization of health care. Ethnographic research has been developed as a way to gain knowledge not only *about* but also *from* the participants, which, scholars argue, is complementary to, but often generates additional insights, than quantitative statistical approaches.

ELDERLY LIVING WITH ACCELERATING MULTIMORBIDITY (ELAM)

The majority of those living with ELAM are associated with a range of demographic factors including low education, and socio-economic status. These, in turn, are found to correlate with a greater likelihood that individuals will engage in activities exacerbate, and contribute to, chronic conditions such as smoking and diet. These factors, in turn, are also found to create additional challenges for navigating and following treatments and self-care. While these factors help explain why many policy scholars target their research to addressing prescriptions to overcome “low health literacy”, my ethnographic research suggests that there are other important challenges that also need to be overcome:

1. Healthcare needs to be customized to everyday life:

Living with multimorbidity requires ongoing medical attention and self-care. Treatment consists of simultaneous, parallel treatment for each individual disease that is planned by highly specialized doctors with no knowledge of the patient's other treatments. I have found, that if treatment plans does not fit patient's everyday life, many will drop out of treatments, which can result in further diseases.

Consider the statements from two of my subjects:

“I can only do one thing or the other. So I choose to be the good wife and cook and bake even though my arthritis really gets worse from it but that's how I can remain a wife and not just a patient” (Bodil, 71, suffering from Sclerosis, Depression, Morbus Chron, Diabetes)

“Well, I know I'm not supposed to eat cake and all but it's a social thing, you know. That's part of being in the band” (Mogens, 77, playing trumpet in the local brass band and suffering from diabetes, hypertension, heart failure)

2. differences are embodied in the cultural landscape:

Men with multimorbidity die earlier and have more complications than women with multimorbidity. Accepting cultural perceptions of gender as showed can result in different expectations to women and men, respectively. Hence men will continue to do worse than women in relation to following treatments and self-care.

Two of my subject's statements illustrate these dynamics:

"As a woman, it is just always you who looks after the whole family. It's true I did take care of Eigil even though I was ill myself, but he couldn't do it himself. I had to help him" (Lily, 87, suffers from an autoimmune blood diseases, arthritis, cancer and had both legs amputated due to diabetes complications)

"He doesn't eat any veggies I think (laughter) but he has learned to cook beef, potatoes and gravy. I think that's pretty good for a man in his age" (Laura, 48, talking about her father Bent's self-care that should include a healthy diet)

3. ELAMs have a holistic approach to self-care.

Whereas many ELAMs were, researchers found, in noncompliance with the prescribed medicine, exercise and diet guidelines set by their doctors, I observed a more nuanced pattern. Carol who would often forget to take her medicine on time, a neglect which caused her great pain, refused to set an alarm to remind of the taking her pills. However the reason for this is that for her, the "active" effort of "forgetting" her medicine was part of a broader strategic plan to suppress the memory of her illness. Similarly, Johnny explained that his doctor prescribed walk would take all of his energy for the day. Instead, he very much preferred to ride the scooter to the clubhouse so that he could spend the energy on having a beer with his pals.

Policy implications: self-care approaches must be developed with patients, rather than handed to them.

If self-care plans are to improve the life of multi-morbid patients, policy makers and health professionals will need to incorporate patients' "lived" experiences. This requires incorporating individual values and beliefs. When Kirsten's doctor advised her to join a twice-weekly physiotherapist group for the elderly, she later declined as it coincided with her longstanding visits from her neighbor. While this decision might appear to be contrary to managing her arthritis, it was a positive sign of social self-care – which researchers tell us is fundamental to psychological and physical health. Therefore, by giving voice to ELAMs in planning treatments, society and policy makers might actually **optimize** the allocation of scarce resources. Such an approach would carry implications for how doctors currently plan self-care. For example, if involved

in treatment planning Lissie might not, owing to dizziness, throw out very costly medication payed for by governmental grants. Instead, she might find a way to find a mutually respectful and collaborative approach for managing side effects.

Though Denmark is taken as a point of departure here, empowering ELAMs to participate in a coordinated, timely and efficient planning of self-care through patient involvement is a cheap, effective way to ensure the quality of care all over the world. This will mean a lesser burden on the health services, and a better quality of life for each individual. In addition, health professionals will be able to spend more time on their core skills instead of wasting time eliminating damage from patient's nonadherence. Everybody wins.

1. Region Midtjylland (2013)