

TOWARD SOCIAL EQUITY IN QUALITATIVE RESEARCH

Toward social equity research evidence: the social context of breathlessness among  
underserved patients

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### Abstract

As outlined in the scientific literature, poverty and access to care have important consequences for the health of individuals. Yet we still know little about social dimensions of self-care and health care experience for underprivileged people living with chronic illness. We discuss a qualitative study using semi-structured interviews and interpretative analysis of transcribed data with individuals who have asthma. In this study we explore complex interactions between experience of chronic disability, including self care practices, health care seeking behaviour and social experience of illness. Low income individuals afflicted by asthma face important clinical as well social consequences due to their condition. They experience precarious living conditions, social isolation, limited access to continuous health care and “non-compliant stigma” in their encounters with health care professionals. Our findings point to the importance of incorporating social and health policy implications in qualitative research in order to promote social equity.

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Introduction

In the United States, health disparities concerning chronic illness still remaining and constitute the principal reason for recourse to health care. (1) Despite many efforts to develop better access to care, health disparities in access to care for underprivileged still represent a challenge for researchers, practitioners and decision-makers in public health.(2)

Lifestyle and health behaviour has been traditionally considered in public health as the primary determinants of chronic conditions and as the target for preventive interventions. Regardless of a growing recognition on the role of social determinants in the experience of health and illnesses, preventive programs and health interventions have mostly focused on modification of individual risk factors. Yet, we have little information on how the social context shapes the chronic illness experience among underserved patients.

The following paper discusses two main points: 1) the need to understand how social dimensions affect the experience of chronic illness and the experience of health care among vulnerable populations; 2) the contribution of qualitative health research for tackling social inequities in health.

## Methodology

### *Research design*

Our qualitative research was based on a socio-subjective perspective. (3, 4) This perspective was relevant to our research questions and to the way we envisage health/illness and health care experience. Although chronic illness experience is an embodied experience, our main concern was to understand this experience as a socio subjective process.

Thus, we were more interested by how individuals perceive illness and conceive the self-treatment in relation to the social experience of illness. We conceived social experience of illness as a subjective experience for individuals that are intrinsically related to and influenced by multiple levels of social action and/or socialisation (work, family, health care system, etc.).

### *Data collection and analysis*

Semi-structured interviews with individuals afflicted by asthma were conducted by a researcher trained in qualitative health research. Interviews were recorded and lasted from 90 to 120 minutes. Interview guide content covers experience of asthma, general health, self-care practice and health care trajectories. Tape-recorded interviews were transcribed and indexed with pre selected themes by qualitative software. Interpretative

analysis, debriefing sessions with researchers and coding structured the inductive and iterative analytic process.

## Results

Our purposive sample included 24 adults, 18 of whom recently had an emergency hospital visit for asthma. All the participants have participated in an asthma education program at least once, and for some of them before their attendance at the emergency. Participants in our study are coming from diverse educational and socio-professional background.

Among our participants, 8 were unemployed or unskilled workers living with a low-income. Our study reveals that those participants who were living in precarious socio-economic conditions encountered important difficulties in getting expensive anti-asthma preventive medication and could not control housing triggers, accordingly to the medical recommendations. Meanwhile, we identified that low-income patients have experienced negative health care experience and have faced difficulties in getting timely access to health care. Social context shapes the subjective experience of illness of individuals who live with asthma. In order to illustrate this, we provide three key elements that emerge from our results.

### *Living conditions*

All of our participants have experienced at some time in their life important difficulties with self-management of asthma and did not follow prescribed medical recommendations.. Those difficulties were mostly related to their life conditions

circumstances. Life conditions were associated to work conditions (stress, exposure to toxic agents, etc.), health lifestyle (smoking, instability, social isolation, etc.) or quality of housing. Unfortunately, some of our participants were not aware of how those life conditions can worsen their asthma. For example, this was the case for young unskilled workers, for instance men, who did not have a responsible primary care physician.

Despite that some of them were aware of the consequences their work conditions have for their asthma, they didn't envisage leaving their job. For example, a participant who works under sub optimal conditions explained how he endured his symptoms:

*My work is a physical one. I work in pretty bad conditions for an asthmatic person like me. Presently, I install doors and windows. I'm always working in dust, old dust, always with dust. I'm just doing my job. I'm doing my job and sometime I stop and take my medication. Once, I took all the blue one (ventolin) in only three weeks.*

#### *Lack of social awareness of asthma severity*

According to the participants, a tendency to minimize asthma crisis and an important misunderstanding on the severity of this illness subsist in their entourage. Participants felt that persons in their entourage were not aware of the gravity of their illness. They experienced severe crisis and for some of them went to the hospital by car without any help and in a severe state of respiratory distress.

*I was in my car following another car and there was some smoke. Then I started to feel stifled. So I stopped the car beside the road. A policeman came to my window, he start yelling at me that I cannot stay there. But, I told him to leave me alone, I felt pretty bad and try to explain how I felt but I could not. And finally, he left me there.*

Many of our participants express a lack of comprehension from their entourage. Meanwhile, and paradoxically, they sometime hesitate to ask for help. They feel ashamed to experienced symptoms of asthma and isolated themselves and faced asthma crisis alone. Some participants felt that their relatives tend to minimize the seriousness of their condition by ignoring their symptoms or ignoring the importance of consequences allergies have on their respiratory condition.

*Non-compliant stigma and health care experience*

Some of our participants expressed concerns about their experience at the hospital emergency. This health care experience was for most of them a very stressful and emotional experience. Some of our participants, especially those who don't have a responsible primary physician, waited a long time before seeking for medical help. They were afraid of dying while they were sitting at the waiting room and complain about the waiting time and the health professional's attitude toward them. Many participants and especially smokers and low-income patients, express that they feel stigmatised at the hospital. They received bad commentaries or recriminations from medical staff about their non-compliance with asthma regimens.

*Yes, I felt judged. A lot, a lot recently, yes, a lot more, since the last two years. I wait before seeking for healthcare, I wait a long time before I decide to go. My brother, like me, he has asthma and he smokes. But he waits so long before he takes his medicine...maybe that's why he doesn't want to see a doctor.*

## Discussion

Research in public health has few considerate in a comprehensive way how underprivileged people are affected by their social conditions when they suffer from a chronic condition. Moreover, despite a wide range of qualitative studies on illness experience, few have considered the impact of social structure. (5) Chronic illness have a *social course* and as Kleinman and colleagues have suggested, the study of this process allows researchers to show how institutional, economic and social factors play a central role in the clinical and social consequences of chronic illness. (6)

Our study revealed important social aspects that undermined the chronic illness and health care experience. The results we obtained suggest that a better understanding of subjective and social experience of chronic illness can enhance preventive care and health promotion interventions, especially for underserved individuals.

Is it possible to be involved in a qualitative research project in public health without a profound and lively interest toward the understanding of causes of social inequities *à l'oeuvre* in our societies? My answer is obviously in favour of more research with a deliberated non-neutral perspective in public health. I will argue that as researchers involved in qualitative health research, we must assume a social responsibility and try to reveal and address social inequities in health.

Based on what is aforementioned, I will argue that qualitative research can help us to clarify complex macrosocial factors that shape the health/illness experience of vulnerable people with chronic condition. Furthermore, qualitative research could be envisaged as a vector of a movement toward social equity in the public health research.

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