
Book review

Dissonant disabilities: women with chronic illnesses explore their lives

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As the title implies, this compelling collection of essays examines the discordant lives of women living with chronic illnesses. The content is meaningful, not only to those afflicted with similar conditions, but also to a wide audience—including physicians, researchers, policy-makers and the general public—who will benefit from both the scholarship of this presentation and the unique perspectives that detail each enlightening story.

This anthology by women with chronic illnesses provides a forum for the discussion of shared barriers and is the first anthology of its kind in Canada. The distinguishing feature of this book is the first-hand accounts of illnesses shared by those directly experiencing the disease versus accounts of the disease process or self-help treatments based on a medical model. While the authors had every intention to represent a variety of women, they acknowledge the level of privilege with respect to time and ability required to submit an essay and the resulting disproportionate representation of women from academia and women with post-secondary educations.

The authors' selection of articles poignantly identifies issues significant to the lives of women living with a range of chronic illnesses, including physical, cognitive, visible, invisible and contested illnesses. The authors chose to restrict this anthology to women to highlight the increased prevalence of chronic illnesses among women and to raise awareness of prevailing risk factors, including psychosocial and socioeconomic determinants. Each essay

shares the personal story of a woman with a particular illness, her challenges and accomplishments with the illness itself and her environment, including the institutional policies that affect her home and working life.

The definition of disability used throughout the book is based on the social model where disability is viewed as the inability of society to account for those with impairments, thereby excluding them from mainstream society. The social model sees the lack of a ramp as the problem and not the use of a wheelchair. This form of discrimination and social oppression is paralleled to racism or sexism. The authors further discuss historical perspectives of disability that saw a person with a disability as being in a constant state of sickness, lacking independence and wanting to get well. These attitudes linger today and come to surface as a common theme uniting the stories in the book shared by the women from various cultural and socioeconomic backgrounds. For the reader with a chronic illness, these common struggles are easily identified with and when their outcomes are positive, they serve as a source of inspiration; when negative, they arouse empathy. For the health policy-maker, these stories should inspire change.

The authors' portrayal of the lives of women with chronic illnesses was not meant as an in-depth description of the epidemiology of each condition, but a presentation of the facts of daily life for each woman, supported by current research and legislative evidence. To

balance the discussion of barriers faced by women with chronic illnesses, the authors saw fit to include essays demonstrating the strong will and resistance these women have to existing social ideas.

The book is divided into five parts. In each section, different women with chronic illnesses share key concepts that form the barriers they face and show their resistance to prevailing social norms. In Part One: "Clashing Expectations," the focus is on societal attitudes towards women with chronic illnesses and the isolating feelings of shame, doubt and powerlessness evoked when expectations of continual production are unmet. In this section, the authors raise awareness of the "changing landscape" of health experienced by women with chronic illnesses and society's lack of acceptance of this fluctuation in functioning and, to a greater extent, society's expectation of "soldiering on" despite illness.

In Part Two: "Unpredictable Bodies," the focus is on idealizations of the female body and the impact of chronic illness. To emphasize the far-reaching and global nature of women's struggles with chronic illnesses, including body dissatisfaction, the authors wisely included essays discussing the effects of Western society's preoccupation with weight on the cultural expectations of Asian nations. An essay focusing on women with chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivities recognizes the duality of experiencing a chronic illness: the knowledge that you are the same person while you become a different

person. When dealing with a contested illness the situation only intensifies as the medical community or employers fail to validate the limitations of these women. The authors recognize the importance of association with others who have the same illness in order to overcome such ambiguities and gain comfort in the shared experiences of others.

In Part Three: “Disturbing Work,” the authors explore how women with chronic illnesses both disturb work and find work disturbing. The authors chose an essay describing the life of a driven researcher whose ambitions eventually led to a chronic state of anxiety. For anyone associated with academia, this story draws many parallels and helps to identify the early warning signs of mental and physical exhaustion and the steps to take to prioritize one’s health and wellness. In contrast, the next essay in this section describes the challenges faced by a young woman with a chronic illness seeking a graduate degree. This story highlights the inflexibility of institutional policies to recognize the uncertainty germane to chronic illness.

In Part Four: “Shifting Relationships,” the many relationships women with chronic illnesses must develop and negotiate are examined. The authors highlight the impact of chronic illness not only on the person directly affected, but also on how those who provide financial, emotional or physical support are challenged and adapt. Finally, in Part Five: “Traversing Dissonance,” the authors inspire readers with uplifting stories of how women with chronic illnesses deal with the often contradictory barriers to societal participation and how some barriers are transformed into new opportunities for growth, such as gaining a sense of control, experiencing new challenges and setting new goals. The book concludes by leaving the reader with a philosophical dilemma: “Can a society that is ideologically (if not economically) committed to preventing, avoiding or ending most forms of involuntary suffering appreciate people who are suffering?” This highlights the common theme of the book, namely, the need to reform society’s

structural (environmental) and conceptual acceptance of women with chronic illnesses.

The authors’ purpose for compiling this series of stories told by women with chronic illnesses was to portray the many different ways a disability may infiltrate the lives of those affected. Each personal narrative gives a glimpse into the life of a different woman—young or old, early or late into her career. The reader grows to appreciate how chronic illness affects her daily routine, her life ambitions and all those around her. What sets this book apart is its ability to relay the limitations faced by women with chronic illnesses while simultaneously demonstrating their strength and resilience, combining strong feminist ideals with critical disability theories.

This unique perspective serves many who interact with women with chronic illnesses. For the physician, it emphasizes the needs of a potential patient – needs that may reach beyond medication, such as life- or stress-management, or exercise and nutritional counselling. For the policy-maker, it introduces the concept of uncertainty in one’s daily physical and mental functioning, for which there should be some flexibility in place. Researchers and epidemiologists will find the contents of this book useful when developing conceptual models, for example, examining the role of psychosocial barriers to recovery for those with chronic illnesses. Finally, for the general public, the stories shared in this book foster an understanding and respect for the challenges faced by women with chronic illnesses.

The authors were successful in their attempt to provoke thought among their readers. They acknowledge the gaps in the literature and share their hope that more work in the area of critical disability studies will follow.

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June 7-10, 2009
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June 9-11, 2009
Zilina, Slovakia
<http://www.foodandfunction.com/>

20th World Diabetes Congress

October 18-22, 2009
Montreal, Quebec
<http://www.worlddiabetescongress.org/>

Canadian Cardiovascular Congress

October 24-28, 2009
Edmonton, Alberta
http://www.cardiocongress.org/English/Home_EN.html

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