

# 9 Discovering the Hidden Depths of Health Care: Lay Beliefs, Social Support, and Informal Care

## Learning Objectives

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- Describe the role of lay beliefs in defining the meaning of good health
- Classify the five thematic components that frame lay beliefs in what it means to be in good health
- Analyze how four illness belief dimensions shape people's meanings of illness and explain illness behaviour
- Examine how lay beliefs and biomedicine interact in people's understandings of health and illness
- Present a typology of self-care behaviour
- Establish the role social networks play in achieving health outcomes.
- Demonstrate how illness narratives can help us gain insight into the hidden depths of health care

## Summary

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The chapter introduces the student to the “iceberg metaphor” as there are a number of different ways the iceberg metaphor has been used in the field.

Healthcare can be divided into that which is visible or measured (above the water), and that which is invisible or unmeasured (below the water). Symptoms comprise only a small proportion of an individual's health-care experiences. The iceberg represents numerous layers of formal and informal health care; although distinct, each layer is permeable.

There is considerable focus on the important role of lay perceptions and conceptions in defining the meaning of health. Five thematic components that can be found in people's lay definitions of health are presented: the absence of illness, physical and psychological fitness, sense of well-being, ability to carry out daily tasks, and health as a resource for living.

People's lay beliefs also influence how they attempt to make sense of illness. Although science and medicine can provide treatment for illness, they cannot answer the question “why me?” Four illness belief dimensions are presented to make sense of the meaning of illness. These categories are not necessarily mutually exclusive but rather can be interconnected. The first dimension, causality, examines whether an individual believes the cause of illness is due to either internal or external factor. Although the trend is to explain illness through external or environmental causes, there are some notable differences by age: older people are more likely to explain cause internally compared to younger people who look outward.

Second is controllability, which looks at whether the outcome of the illness or disease can be controlled to change the course of the illness, for example through compliance with physician's care.

Individuals differ in terms of their “perceived vulnerability,” which is the third illness belief. An individual who had pneumonia as a child may always worry that they are susceptible to illnesses that affect the lungs.

The fourth illness belief dimension is seriousness, and has three parts: how long does the illness last; how responsive it is to treatment; and is medical attention necessary.

Overall the lay sector is more open to new health treatment and ideas than is the biomedical sector. For the biomedical sector, rigid testing and validation of the treatment is needed before supporting any new treatment, in theory.

Self-health management spans a range of activities in the hidden health care system that individuals draw on when deciding what is good for their health (exercise, alcohol consumption, eating habits). This also includes self-care practices when ill (going to bed early, taking acetaminophen, etc.). Most health issues are handled informally and not through healthcare consultations. For this reason, it is faulty to assume that health care and medical care are one and the same.

The textbook authors present an alternative model of health care that includes informal medical care. In so doing, the iceberg disappears and is replaced by a model in which there are no hidden depths of health care. The role of government also changes in relation to self-care. The expectation would be for the government to encourage and support self-health management. Thus self-care and professional care need to be integrated and work together.

Self-care is multi-dimensional and has been categorized into four types. Regulatory self-care (health maintenance activities) and preventative self-care (actions taken to avoid illness) are categorized as health behaviour. Reactive self-care, in contrast, is viewed as illness behaviour. The fourth type of self-care is restorative self-care. Here, the goal of a sick individual is to either get better or to achieve optimum functioning level in chronic cases.

There are numerous studies that report the positive effect of social support in health and well-being. Social networks are particularly helpful in buffering stressful events and their potential effect on psychological health and possibly physical illness. Social networks do not only operate on individual levels but also at societal levels. Building strong communities that are based on models of social cohesion can have a positive effect on the lives of the residents.

Finally, the authors review the role illness narratives play in helping us understand how people make sense of the symptoms they are experiencing. A significant amount of attention is paid to the issue of chronic pain, the most prevalent symptom experienced by the population. This is in part because self-health management becomes particularly important in cases where there are symptoms in the absence of diagnosis and chronic pain.

## Key Concepts/Terms

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**Biographical disruption:** The understanding of chronic illness as interference in an individual’s life story, since it creates considerable uncertainty about the ill person’s health and social life (p. 308).

**Causality:** The illness belief dimension that assumes that every identified disease has a specific underlying cause or combination of causal factors (p. 276).

**Controllability:** The illness belief dimension that refers to the extent to which individuals believe that illness is controllable and can be managed by either the sick person or another person such as a health care provider (p. 278).

**Emotional support:** Supportive social relationships that contribute to feelings of being contribute to feelings of being cared for and valued, which help us to feel part of a meaningful network or group of people (p. 295).

**Health as absence of illness or disease:** A negative conception of health-in-a-vacuum that understands health in terms of what is absent from the individual's life: illness and/or disease (p. 272).

**Health as fitness:** A conception of health that understands health to mean being physically active and having a healthy body with psychological energy and vitality (p. 273).

**Health as functionality:** A conception of health that emphasizes the individual's ability to carry out daily tasks and cope with the demands of everyday life and social roles (p. 274).

**Health as resource for living:** A conception of health that combines the social, psychological, and physical dimensions and understands health as an asset to be managed (p. 274).

**Health as a sense of well-being:** A conception of health that emphasizes positive psychological aspects of health, such as feelings of healthiness and happiness along with rewarding relationships (p. 274).

**Health behaviour:** Routine health-protective activities, including personal self-care regulatory and preventive practices (e.g. exercise, nutrition), risk reduction, and disease prevention (e.g., smoking cessation) (p. 291).

**Health belief system:** A systematic set of ideas with regard to health, healing and self-care that are shaped by aspects of culture and social location (p. 282).

**Health reserve:** The concept of health as an asset to be managed (p. 274).

**Illness behaviour:** Perception and evaluation of the meaning of daily symptoms (e.g., perceived seriousness, causal attributions) and reactive self-care practices, including self-medication and illness-related activity restrictions (e.g., sick days) (p. 293).

**Informational support:** Supportive social relationships that are an important source of information about health-related matters (p. 295).

**Instrumental support:** Supportive social relationships that provide individuals with practical assistance with the activities of daily living (p. 295).

**Lay beliefs:** Ideas and perspectives employed by ordinary people to make sense of and find meaning in their everyday life experiences, such as health and illness (p. 270).

**Mutual aid:** Ways people informally come together to offer each other mutually beneficial forms of support or reciprocal assistance (p. 288).

**Perceived susceptibility:** The illness belief dimension that reflects the degree to which a person believes that she is vulnerable to or might experience health problems (p. 279).

**Preventive self-care:** Deliberate health actions undertaken to reduce the risk of illness (p.291).

**Reactive self-care:** Self-initiated responses to symptoms that have not been diagnosed by a physician (p. 293).

**Regulatory self-care:** Daily habits of living that affect health but may not be viewed as actions that are explicitly intended to improve health and well-being (p. 291).

**Restorative self-care:** Actions intended to overcome health problems in the case of acute disease or to adjust one's daily life to achieve an optimum level of functioning in the case of chronic disease (p. 293).

**Seriousness:** The illness belief dimension that reflects whether a person believes the condition is long-lasting, difficult to cure and requires medical attention (p. 280).

**Self-health groups:** Organizations that help people deal with specific common health-related problems by bringing them together to fill a gap that may exist between informal caregiving networks and formal professional health care (p. 288).

**Self-health management:** A term that reflects the fact that members of the public routinely engage in personal health practices, including health protective and illness treatment activities, that are an expression of personal autonomy and active involvement in a complex decision making process (p. 286).

**Sick role behaviour:** Informal and formal help-seeking behavior such as lay conceptions and the use of formal health-care services (p. 293).

**Social support:** The sense of self-worth and resources available for dealing with life's challenges that are part of belonging to a social network and result in health benefits (p. 296).

## Study Questions

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1. What does the “iceberg of health care” refer to?
2. What are three general orientations in lay descriptions of health?
3. Describe five lay descriptions of health.
4. What are the assumptions behind common lay beliefs about illness?
5. How does age influence causal attributions for illness?
6. What are the four dimensions most frequently examined in research associated with illness beliefs?
7. What methodological issues could be addressed in research on lay beliefs about health and illness?
8. What are different dimensions of self-care?
9. What is the effect of social networks on health?
10. What does biographical disruption refer to?

## Explore and Discuss Questions

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1. Use the lay concept of “health reserve” to explain the health effect of drinking heavily throughout an individual’s four years in university.
2. Ask five friends and family members who are not in your class to describe how they would define health. Which lay conceptions of health match their descriptions? Self-health management is believed to be part of the “reserve of health.” Explain how this is the case. Apply the concept of health reserve to an actual illness example.
3. Given the major findings related to social support and health, how should universities create supportive health environments for their students?
4. Discuss the issues “non-diseases” raise for health practitioners.

## Further Exploration

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- Frick, U., H. Irving, and J. Rehm. 2012. Social relationships as a major determinant in the valuation of health states. *Quality of Life Research*, 21 (2), 209-213.
- Gonzalez-Polledo, E., J. Tarr. 2016. The thing about pain: The remaking of illness narratives in chronic pain expressions on social media. *New Media and Society*, 18(8), 1455-1472.
- Jutel, A. Truth and lies: disclosure and the power of diagnosis. *Social Science and Medicine*, 165, 92-98.
- Lee, J.E.C., C. Dallaire, M.P. L. Markon, et.al. 2014. ‘I can choose’: the reflected prominence of personal control in representations of health risk in Canada. *Health, Risk & Society*, 16:2, 117-135.
- Locock, L. , S. Nettleton, S. Kirkpatrick et.al. 2016. ‘I knew before I was told’: Breaches, cues and clues in the diagnostic assemblage. *Social Science and Medicine*, 154, 85-92.
- Lupton, D. 2016. Digitised health, medicine and risk. *Health Risk and Society*, 17 (7-8), 473-478.
- Lupton, D. 2015. ‘It’s like having a physician in your pocket!’ A critical analysis of self-diagnosis smartphone apps. *Social Science and Medicine*, 133, 128-135.
- Michaelson, V., W. Pickett, E. Vandermeer, et.al. 2016. A mixed methods study of Canadian adolescents’ perceptions of health. *International Journal of Qualitative Studies on Health and Well-being*, 11, 32891.

Witavaara, B. C. Bengs and C. Brulin. 2016. Well I'm health but...lay perspectives on health among people with musculoskeletal disorders. *Disability and Rehabilitation*, 38(1), 71-80.

## Recommended Films

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1. **Lorenzo's Oil (1992)**

Feature film. A boy develops a disease so rare that nobody is working on a cure, so his father decides to learn all about it and tackle the problem himself.

<http://www.imdb.com/title/tt0104756/>

2. **Is it hot in here? : a film about menopause (1986)**

This documentary explores the major aspects of menopause through interviews with women and health professionals and examines historical and contemporary social attitudes towards menopause and medical treatments for certain conditions related to menopause

3. **My Left Foot (1989)**

Feature film. Christy Brown, born with cerebral palsy, learns to paint and write with his only controllable limb—his left foot.

<http://www.imdb.com/title/tt0097937/>

## Recommended Websites

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1. **Alcoholics Anonymous**

Alcoholics Anonymous is an international fellowship of men and women who have had a drinking problem. It is nonprofessional, self-supporting, multiracial, apolitical, and available almost everywhere.

<http://www.aa.org/>

2. **AIDS Committee of Toronto**

ACT provides support services that empower men, women and young people living with HIV to achieve self-determination, informed decision-making, independence, and overall well-being.

<http://www.actoronto.org/>

3. **Living With a Chronic Illness**

“This blog is written in relation to my life experiences with chronic illness. Although my illnesses span a period of over thirty years, the information is not meant to replace the advice of your doctor.”

<http://livingwithachronicillness.blogspot.ca/>