"Hope" for People with Intractable Neurological Diseases in Japan

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This work was supported by JSPS KAKENHI Grant Number JP26463322.

Introduction

The study is part of research project, “the concept of ‘hope’ in end-of-life care for patients with intractable neurological diseases.” The ultimate aim of the project is to investigate specialist care for patients with intractable neurological diseases, and how care quality is currently evaluated. Therefore, it is focused on function and expertise in relation to nursing that supports the hope of patients with intractable neurological diseases and their families.

Patients with intractable neurological diseases experience various forms of emotional distress when they are diagnosed, as their illness progresses, and when choosing treatment options. Of all intractable neurological diseases, motor neurone disease progresses particularly quickly, forcing patients to make choices intimately connected to the end of their lives.

These patients take a positive view of reality and find hope as they live their lives.

In response to patients’ distress, nurses provide care that helps patients to find hope, and also act to support that hope. They do so by, for example, enabling patients to live in the way they want and respecting their reasons and potential for living.

Objective

This study aims to elucidate the types of hope MND patients find when they are confronted with the end of their lives and are in the process of making end-of-life-related decisions.

Method

1. Research design

Secondary analysis using patients’ personal memoirs and research papers

2. Procedure

(1) I researched the conceptual definitions of hope in philosophy, psychology, and sociology.

(2) From the personal memoirs of MND patients I identified what forms of hope patients found amidst the distress of decision making relating to the end of life.

(3) From research papers focusing on hope among MND patients, I clarified what hope was from the researchers’ perspectives.

3. Selection of sources

(1) MND patients’ personal memoirs → 5 books; 1 magazine article

Month accessed: May 2016

(2) Research papers relating to hope among MND patients → 10 papers

Date accessed: December 3, 2016

(3) Working definition of the concept of hope

Life-sustaining feelings and thoughts found amidst desperate circumstances when confronted by MND.

Results

1. Conceptual Definitions of Hope

Since the 1950s, “hope” has mainly been defined in the context of social science, and there have been various attempts at measuring it. However, exploring a unified view of the concept of “hope” is a difficult task.

The discussion of dimensionality explores whether “hope” is perceived as a one-dimensional or multi-dimensional concept. If the conceptual framework is reliable (certainty), measurement, i.e., observation, should be possible. Snyder and Herth each developed hope indices, but from completely different standpoints. Snyder expands on the one-dimensional theory of Stotland who emphasized goal achievement, and defines “hope” as being composed of cognitive components that recognize pathways and agency. Herth, on the other hand, conceptualizes “hope” in a multi-dimensional framework composed of temporality and future, positive readiness and expectancy, and interconnectedness. However, the experience of “hope” is composed of both visible and invisible elements, which means that while both measuring tools are capable of measuring reliable elements, they do not succeed in understanding the internal, uncertain experience of “hope.”

Studies of “hope” have been conducted in various subjects including elderly people, terminal patients, suicidal patients, caregivers and patients with chronic diseases. These studies have revealed that relationships with significant others and a strong connection with transcendental beings such as God and Buddha influence “hope.” Existential problems also have a deep connection with “hope.” Affirming one’s value, feeling happy about one’s own existence, sensing the significance and development of life, and other ways of thinking all strengthen “hope.” Meanwhile, events that reduce “hope” include threatening perceptions, distress, conflict, sense of loss, and sense of despair.

2. Sources of Hope Found by MND Patients and Hope Highlighted by Researchers

MND patients

The existence of family and other people with whom the patient interacts regularly

Advances in technology and strategies for finding alternative ways of doing things that can compensate for functional decline

The existence of someone/something to live for; Realising the role the patient him/herself plays

Encountering a sustaining faith

Researchers

The existence of other people who provide psychological support

Alleviation of difficulties in daily life; Opportunity to accept or decline medical procedures: Being able to live as the patient wants

Existence of a goal to strive for

Alleviation of physical pain

Alleviation of psychological pain

Conclusions

Some argue that “hope” is defined in two ways: one that is synonymous with expectation and another that is separate from expectation. “Hope” does not merely signify optimism for the future, but is also based on concepts such as vitality and unconditional love. “Hope” is therefore not limited to clear achievement of goals for the future; it is based on the assumption of trust in an undetermined future.

Meanwhile, in exploring the concept of “hope” in end-of-life care based, the concept of “hope” in cancer and nursing literature is internal and therefore invisible in situations based on the premise of death, and is perceived as having a so-called metaphysical nature. This involves seeking healing and survival, or seeking something separate from healing, while expecting healing to be difficult and anticipating death.

So, what is “hope” to patients with intractable neurological diseases? What are the consequences of supporting patients in finding and maintaining “hope”? To answer these questions, we need to clarify the “hope” held by patients with different conditions including motor neuron disease, multiple sclerosis and Parkinson’s disease.