

Promoting Evidence-Based Health and Welfare Policies for People with Disabilities: Proposing a "Definition of Health" for a Care-Focused Mature Society

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Introduction

The Global Burden of Diseases, Injuries, and Risk Factors Study 2010 showed that the main contributor to the global disease burden was deaths of children under five years of age. However, presently, the majority of the factors include musculoskeletal disorders, mental illnesses, and trauma, and such burdens increase as people live longer [1].

Japanese society is aging faster than that of the rest of the world, and we must respond to a decreasing birthrate and an aging population. In 2025, the "baby boomer" generation will be over 75 years old (i.e., the "late elderly") and account for 18% of the whole population in Japan [2]. In 2035, the "baby boomer juniors" will be over 65 years old. Both the population and the workforce will continue to decrease; at present, Japan is the only country where the declining birthrate and the aging population are progressing simultaneously among developed countries [3]. In addition, in March 2015, the total number of people with disabilities was 7.879 million, which is approximately 6.2% of the total population of Japan. This number has been increasing steadily, with the aging of the society [4].

Drastic reforms in healthcare are required in Japan [5]. Japan's current vision is to further develop healthcare and lead the world as a maturing nation. "Japan Vision: Healthcare 2035" [6] aims to achieve a paradigm shift toward "care-centered healthcare," "quality improvement," "patient-centered values," "discipline by concerned parties," and "integration" by 2035.

We compared evidence-based health policies (EBHPs) across lifestyle diseases, especially cancer, and trauma (injuries, damage, and sequelae) in Japan, to identify measures for information infrastructure development as well as clarify the definition of "health" in a carefocused mature society.

Commentary

In Japan, EBHPs have been promoted for lifestyle diseases, and the information necessary for EBHPs for cancer countermeasures is accumulated in the "Cancer Registry" and utilized by medical institutions and public health centers according to law. Evidence such as survival rates of cancer is useful not only for healthcare providers and policymakers, but also for cancer patients in executing the right to self-determination in promoting health [7].

Meanwhile, epidemiological statistics on trauma are limited to "patient registration at the onset of injuries and illnesses" presently; hence, evidence regarding the long-term outcomes of trauma in Japan is overwhelmingly lacking. In Japan, since the 1960s, the number of injuries and deaths from traffic-related trauma has increased rapidly along with the rate of emergency care [8]. With such changes, the estimated number of "those with sequelae and disabilities acquired from trauma" has increased. The incidence of trauma is estimated to be comparable to that of neoplasms in the 2014 national patient survey. We viewed trauma prognoses in terms of "acquired disability outcomes," and proposed reviewing the healthcare and welfare measures for people with disabilities in a longitudinal epidemiological study to "understand the disease from the viewpoint of the concerned party as a living person" [9-12].

To realize this review in a care-focused society, we focused on the Clinical Efficacy Databases, which contain information related to diagnoses, treatment process, treatment efficacy, etc. of patients examined and/or treated at all medical institutions in Japan. These databases are usually developed by academic clinical associations categorically based on disease/injuries [13,14]. However, the bulk of each comprises registry information of patients classified by disease/injury. To evaluate the clinical efficacy of such databases, it is necessary to assess the outcomes through a follow-up study. However, it is currently difficult to perform a satisfactory assessment of outcome information.

Furthermore, in Japan, all citizens have guaranteed access to the necessary medical treatment by the National Health Insurance System [15]. However, due to societal aging, difficulties related to the state of public finance continue, and it is necessary to invest the scarce resources efficiently. To help achieve this, we focused on accumulating information for evaluating clinical effects as part of the movement for a sustainable health policy for people with disabilities. As one achievable outcome information area, we proposed the establishment of a disability registry database ("Disability Registry"). [16] Currently, it is compulsory for local governments to control information related to the health and welfare of people with disabilities, such as information in the "Certification for Persons with Physical Disabilities" using a logbook. It is the responsibility of prefectural governors and mayors of cities, but these parties have not yet made full use of such information for purposes such as analysis and evaluation of health policies for people with disabilities. Therefore, we are currently conducting a study based on the proposal that each prefecture collects and stores this information within the jurisdiction of its respective city. These data are anonymized in each prefecture and stored in the "Injuries/Diseases Health and Welfare Database," which we are proposing as "Disability Registry." In the context of this proposal, we are proceeding with studies on the regional model development of the "Injuries/Diseases Medical Treatment, Nursing, Health, and Welfare Database."

In 1948, the WHO charter defined "health" as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" [17]. Since 1948, this definition has continued to be used in Japan. However, the global trends in health have changed greatly since 1948. Particularly, the concepts excluded from this definition of health, such as disabilities, are not reflected in the health policy of Japan [16]. We intend to develop a disability registry considering the additional definition of "health" in a matured society, by including the concept of "health of the people with disabilities."

Conclusion

Necessity to construct an injury/disease-related, medical, health, and welfare database including a disability registry was identified from the perspective of viewing the healthcare and welfare measures for people with disabilities in a longitudinal epidemiological study and to evaluate health policies. We are proceeding with studies on the regional model development of the "Injuries/Diseases Medical Treatment, Nursing, Health, and Welfare Databases," which we are proposing as"Disability Registry."

In a care-focused mature society, considering the disease burden and various other social, physical, and psychological problems, maintaining patients' quality of life, enabling them to exercise control over their own lives, offering them opportunity for independent functioning, and fostering their self-actualization should be included in the definition of health.

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