Survey on the usefulness and effectiveness of the DX¶-introduced chronic disability registry

Abstract

This survey presents methods for enhancing and promoting health information for each life course, especially resilient way of life course, to introduce an example of surveys for realization of the field of disability health. In this survey, we will verify the usefulness of data utilization related to health from the viewpoint of self-management performed by "individuals" such as persons with disabilities/families. To this end, we will first develop and evaluate onset/exacerbation algorithms in normal times using biometric information sensors and environmental sensors. Next, assuming an emergency with health risks, we will verify them by measuring their changes. In addition to a qualitative survey, we will propose "matters necessary for preparation for normal times" from the perspective of the parties concerned. Through these, we will explore the usefulness of data utilization for "individuals" and "groups" while adding the perspectives of patients/parties.

Keywords: disability registry, DX (digital transformation), PHR (personal health record), individual life course, wearable device, outcome information, resilience (resilient way of life course), perspectives of patients/parties

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Introduction

Japan is called the model of UHC (Universal Health Coverage), and access to medical care is guaranteed.[1] In 2013, the Cabinet Office enacted the "Japan Revitalization Strategy" as a way to extend the healthy life expectancy of the people,[2] requiring all medical insurers to create a data health plan. The aim of the data health plan is to increase the effectiveness of the medical insurance business by utilizing data and taking a scientific approach. Since then, the data health plan has been continued, and the "health/medical/long-term care" database has been linked and prepared for utilization. However, it seems that the database has an issue of enriching outcome information centering on the chronic phase after the end of injury and illness treatment, and in this survey, as one of the feasible improvement measures, disability (impairment/disability/handicaĪpped) health and welfare information will be focused on. In recent years, it has become increasingly important to take measures against chronic diseases that continue after treatment of trauma and acute diseases.[3,4] Japan's medical and social security system, which is the top runner in the world to have an aging population, is required to shift from "Cure" to "Care and support" (Health Care in 2035[5]). There is an increasing need to build and utilize a "disability registry"[6] by collecting data such as QOL from the perspective of the parties concerned/patients as well as data from the perspective of the care and welfare service providers.

Purpose

At present, for example, the head of a local government is legally obliged to manage the notebook certification information for persons with disabilities (health care and welfare information for persons with disabilities). However, it is hard to say that such information is used to evaluate the effectiveness of health measures for people with disabilities. In order to invest limited resources more efficiently, it is important to enhance information that contributes to the evaluation of intervention effects and the evaluation of measures and policies in order to build evidence in this field. On the other hand, with the spread of mobile devices, the movement to receive services tailored to each individual by managing and utilizing data related to individual health has been spreading in recent years. So what should we do to realize such a disability database? In order to present an example of such a survey that can be the "next step", in this survey, we will build a medical/health/welfare/long-term care database for disabilities and propose a regional model that also includes data verification.

Features

Most of the initial information storing in the database to be constructed is not new survey data, but information already held by local governments such as municipalities. Therefore, the researcher does not have to devote a lot to the work of "collecting data and building a database." Rather, in the first year, much can be devoted to creating a mechanism for collecting, accumulating, and utilizing information in collaboration with local governments, local health research institutes, universities, medical associations, and so on. Therefore, it is possible for local governments to independently operate the database at a relatively low cost and sustainably, rather than simply constructing a database.

Local use of anonymously processed medical information collected on a large scale is not easy. In addition, since the search for wearable health monitoring device data continues, research using them for families of disabled patients has not yet been conducted. In this survey, algorithm analysis of wearable health monitoring device data will be performed for the first time in collaboration with disabled patients/families. The "disability registry,"[6] in this way, aims to accumulate and utilizes, including not only the perspectives of service providers such as care and welfare providers, but also the perspectives of the patients/parties concerned of monitoring data such

as QOL. This is one of the most important respects of this survey which uniqueness and creativity exist.

Overseas examples include research in the field of psychiatry that analyzes daily heartbeats with a wearable electrocardiogram measuring device to identify depression with 90% accuracy.[7] Usually clinically, a 10-15% increase in resting heart rate is a burden for patients with heart failure. Therefore, for example, it is considered useful to grasp how these values change in an emergency such as a disaster response and utilize them in preparation.

If a regional model expected by algorithm analysis of the data extracted in this survey can be created, it will lead to alleviation of differences in approach methods depending on "various fields" related to health. In this way, it is possible to promote efforts in a community-based society according to more specific circumstances. In addition, this survey is extremely practical because it not only collects, accumulates, and utilizes database information that is academically significant, but also "model development." Therefore, for medical personnel involved in the analysis of medical information, it is possible to immediately make progress in improving the medical information infrastructure by PHR (personal health record),[8] including the construction and utilization of the disability registry. This would be able to be expected to contribute to a large reduction in the medical burden. The METI (Ministry of Economy, Trade and Industry) is promoting the speedy promotion of digital transformation (DX: Digital Transformation), which develops unprecedented business models using new digital technologies in all industries.[9] One of the most important features is to provide a solution to the "medical tightness" that became apparent in the COVID-19 pandemic and to contribute to reducing the medical burden.

What, how, and how much will this survey reveal?

In this survey, we will extract items necessary for the survey, such as signs centered on chronic pain and living functions, based on the continuously measured biological data of individuals. Algorithm analysis will be performed to verify the usefulness of data utilization for individuals and create regional models. In addition, through participation and discussion in the evacuation center management game (HUG),[10] we will conduct a qualitative survey on the ideal way of depositing and utilizing information for the families of the target patients with disabilities. At the same time, we propose to prepare for disaster response by utilizing data through analysis of algorithms using biological sensors and environmental sensors.

The specific objectives to be achieved are the following three items.

I. The related wearable health monitoring device data is extracted from the information related to the physical condition change of the family of the disabled patient.

II. Environmental data such as weather is added to the extracted biometric data, algorithm analysis is performed, and a regional model of data utilization is created.

III. Encourage families of patients with disabilities to participate in the HUG,[10] and provide them with an opportunity to experience the difference in consciousness between residents and the management side. After that, through discussions, etc., we will propose preparations for normal times regarding the ideal way of depositing and utilizing own information.

Conclusion

In Japan, where the disease structure is changing and the birthrate is declining and the population is aging, the importance of measures against chronic injuries/diseases is increasing. Japan in Society 5.0[11] is required to have increasingly efficient and effective health policies with the aim of achieving the SDGs (Sustainable Development Goals)[12] by 2030. In order to resolve this, as pointed out toward Healthcare 2035,[5,6,13] it is necessary to supplement the lack of data in the current medical information infrastructure and strive to promote EBM (evidence based medicine).[14] The "disability registry" could be a measure to enhance and strengthen the information infrastructure for managing an individual's health life course.

Acknowledgements

Conflicts of interest

References

1. The World Bank. Universal Health Coverage for Inclusive and Sustainable Development. 2020.

2. Prime Minister of Japan and His Cabinet. Japan Revitalization Strategy. JAPAN is BACK. June 14, 2013.

3. Haidong Wang, Laura Dwyer-Lindgren, Katherine T Lofgren, et al. Age-specific and sex-specific mortality in 187 countries, 1970-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2071–2094.

4. Christopher J L Murray, Theo Vos, Rafael Lozano, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: A systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2197–223.

5. Miyata H, Satoshi Ezoe, Manami Hori, et al. Japan's vision for health care in 2035. Lancet. 2015;385(9987):2549–2550.

6. Tachibana T. Who and what should manage each person's lifelong outcome information. Int J Fam Commun Med. 2020;4(6):162–164.

7. Medical X press. 2020.

8. Alex Roehrs, Cristiano André da Costa, Rodrigo da Rosa Righi, et al. Personal Health Records: A Systematic Literature Review. J Med Internet Res. 2017;19(1):e13.

9. METI: Ministry of Economy, Trade and Industry. METI Releases a Report on Digital Transformation: Overcoming of '2025 Digital Cliff' Involving IT Systems and Full-fledged Development of Efforts for Digital Transformation. 2018.

10. Certified NPO corporation Kanagawa 311 network. HUG (Hinanzyo Unei Game ⇒Shelter Management Game).

11. Cabinet Office. Society 5.0. 2020.

12. United Nations. The 17 Goals. 2020.

13. Ministry of Health, Labour and Welfare. Japan Vision: Health Care. 2015.

14. Djulbegovic B, Gordon H Guyatt. Progress in evidence-based medicine: a quarter century on. Lancet. 2017;390(10092):415–423.