Identifying and Validating Data Elements and Main Characteristics of a Teleconsultation and Televisit System for Patients with Multiple Sclerosis in Iran

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Abstract

Background: *Patients with multiple sclerosis (MS) face barriers and disparities in accessing care for evaluation and treatment. Given the unmet needs and barriers to access to care, teleservices (e.g., teleconsultation and televisit) could support these patients by providing reliable information, offering specialty care and managing symptoms. The objective of this work was to identify and validate the data elements and main characteristics required for the design and implementation of a teleconsultation and televisit system for patients with MS.*

Methods: *This descriptive, cross-sectional, multicenter study was completed through three main stages in 2023–2024. Various methods, including literature review, focus group discussion, and the Delphi technique, were employed to identify the data elements. A review of the literature was carried on electronic databases to detect the elements for the system. A focus group was established to review, add, or delete the data elements obtained from searching the literature. The Delphi technique was employed to achieve consensus and validate the preliminary system design.*

Results: *A total of 97 data elements were classified into seven distinct categories, including patients' demographic information, physicians' demographic information, clinical information, teleconsultation, televisit, statistics/reports generation, and other system capabilities. Overall, 104 data elements were approved by the specialists for inclusion in the system.*

Conclusions: *In this research, the necessary data elements for the design and implementation of a teleconsultation and televisit system for patients with MS were suggested. System developers and decision makers can utilize these data elements to recognize the specific information required in the system while initiating the design process for various systems for patients with MS.*

Keywords: *multiple sclerosis, teleconsultation, televisit, data element, requirements, telemedicine*

Introduction

Multiple sclerosis (MS) is an incurable, chronic inflammatory, and neurodegenerative condition of the central nervous system with an unknown primary etiology, in which autoimmunity has a major role in the susceptibility and progression of the disease. The course of the disease is highly variable and has different types. Over 2 million people are affected by MS worldwide, and it is more prevalent in women. The disease onset usually occurs between ages 20 and 40 years.[1,2] MS has a long-term, progressive, and debilitating nature that disrupts people's personal lives and social conditions.[3] A variety of neurological deficits (e.g., fatigue, cognitive problems, visual impairments, altered sensation, spasticity, pain, and bladder dysfunctions) occur during the disease, hindering patients' ability to seek specialized medical attention. The management of MS has become increasingly difficult due to the availability of more disease-modifying therapies

Overall, the article provides valuable insights into the requirements related to the design of teleconsultation and televisit systems for patients with MS, highlighting the crucial role of data elements in enhancing care delivery and addressing unmet needs and access barriers faced by this patient population. The findings of this study have implications for health care providers, policymakers, and researchers involved in enhancing health care delivery to patients with MS through telemedicine interventions.

This article makes an important cooperation to the area of telemedicine by identifying and validating data elements for teleconsultation and televisit systems for patients with MS. The study has the potential to inform the development of more effective and patient-centered telemedicine solutions for MS care.

Confirmation Statement

Each author confirms that their research is supported by Shiraz University of Medical Sciences, an institution primarily involved in education and research.

Acknowledgments

The authors sincerely acknowledge all the MS fellowships who collaborated in answering the questionnaire. The authors are grateful to Shiraz University of Medical Sciences, Shiraz, Iran, and also the Center for Development of Clinical Research of Nemazee Hospital and Dr. Nasrin Shokrpour for editorial assistance.

Authors' Contributions

R.S. was the research supervisor. F.S., R.S., and L.E. contributed to the study design. F.S. and M.P. contributed to the data collection. F.S., M.P., R.S., L.E., and R.K. prepared the article draft. All authors have read and approved the article.

Data Availability Statement

All data are presented in the article submission.

Ethics Approval and Consent to Participate

The study was approved by the Ethics Committee of Shiraz University of Medical Sciences (Ethical code: IR.SUMS.NUMIMG.REC.1402.133). All methods were carried out in accordance with the relevant guidelines and regulations. Informed consent was obtained from all the participants.

Disclosure Statement

The authors declare that there are no conflicts of interest.

Funding Information

This study was part of the first author's PhD dissertation and financially supported by Shiraz University of Medical Sciences.

Supplementary Material

Supplementary Table SA1
Supplementary Table SA2
Supplementary Table SA3

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