

Medical Librarians in The Role of Research Facilitators: A Case Report (Immune Deficiency Clinic of Mashhad Akbar Children's Hospital)

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Abstract

Introduction: Clinical librarians or information specialists working in hospitals and medical schools are typically graduates of medical or general librarianship programs. Through the knowledge and expertise they acquire during their academic training and internships, they serve as valuable resources in meeting the information and research needs of physicians and clinical staff across healthcare systems. In this report, we examined the impact of the clinical librarian's presence in the hospital's immunodeficiency clinic registry project and addressed the challenges involved in registering immunocompromised patients and establishing the registry system.

Objective: The impact of the clinical librarian's presence as a research facilitator in the immunodeficiency patient registry project.

Case Presentation: The immunodeficiency clinic at Akbar Children's Hospital, serving 250 patients, is among the most active of its kind in the country. While some patients attend regularly and receive their medications, others—previously hospitalized and diagnosed with immunodeficiency—discontinue follow-up due to factors such as long travel distances, high costs of medication and treatment, and other barriers. This report outlines, step by step, the process of activating the patient registry within Rabbit (the health research information management infrastructure), highlighting the clinical librarian's facilitating role in implementing this system.

Conclusion: The presence of clinical librarians or general librarians (on the condition of passing familiarization units with medical terms, etc.) in research projects as research facilitators, research assistants, or research experts, due to familiarity with the specializations and skills required for research, can have a significant contribution to the progress of the project.

Key Words: Immunodeficiency clinic, Immunodeficiency patients, Librarians, Research facilitator.

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1- INTRODUCTION

In medical research, data collection methods play a pivotal role in generating reliable evidence and advancing clinical knowledge. Among these methods, patient registries have emerged as essential tools for systematically gathering, organizing, and analyzing health data—particularly in rare or complex conditions such as primary immunodeficiency disorders. Registries not only support clinical decision-making and epidemiological studies but also facilitate the identification of missing patients and the design of targeted interventions.

One often overlooked yet increasingly valuable contributor to the success of such data-driven initiatives is the clinical librarian. A clinical librarian is a health information specialist who collaborates directly with healthcare teams and researchers to enhance evidence-based practice. Librarians are naturally inclined helpers due to the nature of their profession. "Enthusiastic and confident librarians are a key element in reinventing the clinical librarian role in today's highly information-based practice of medicine" (1), which remains true especially as librarians discover novel ways to offer services and collaborate with their users (2). In other words, "A clinical librarian is someone who provides library services within a hospital setting and plays a significant role—both directly and indirectly—in patient care (3). Accordingly, clinical librarianship serves as a strategy for evidence-based medicine, offering services that accelerate healthcare professionals' access to reliable and up-to-date medical resources (4)."

Their expertise includes advanced literature searching, critical appraisal of sources, management of bibliographic data, and training in the use of medical databases and citation tools. By integrating into clinical and research environments, clinical librarians help ensure that data

collection and documentation processes are both rigorous and efficient.

Although case reports are traditionally focused on clinical observations or treatment outcomes, this report highlights a different dimension: the impact of a clinical librarian on the development and activation of a patient registry. Specifically, it examines the role of the librarian in initiating and supporting the registry for immunodeficiency patients at Akbar Children's Hospital. Through active participation in the research team, the librarian contributed to identifying missing patients, organizing data workflows, and facilitating the registration process.

Previous studies have shown that the involvement of clinical librarians in research and therapeutic projects enhances the quality of literature searches, improves methodological documentation, and facilitates the dissemination of scientific findings (1, 2, 5-9). In Iran, although a limited number of articles and case reports have addressed the role of clinical librarians in medical and health-related fields (3, 10, 11), case reports specifically focusing on their contribution to patient registry systems remain extremely scarce and are largely confined to isolated experiences of collaboration with clinical teams.

Given the theoretical nature of medical librarianship and the limited number of case reports in this subfield, this study offers a novel perspective. However, unlike previous reports where the librarian acted as an external advisor, this case presents the librarian as a core team member, akin to a captain on the field, actively shaping the research process from within. This case report aims to explore the broader impact of integrating a clinical librarian as a research facilitator within medical research projects, and more specifically, their role in initiating and managing the patient registry system at the Immunodeficiency Clinic of Akbar

Children's Hospital. The goal was to activate and operationalize a registry for patients with immunodeficiency disorders, improving follow-up and data accuracy.

2- CASE PRESENTATION

The Immunodeficiency Clinic at Akbar Children's Hospital, which serves over 250 patients, is recognized as one of the most active centers of its kind in the country. While many patients attend regularly to receive their medications, a significant number—previously hospitalized and diagnosed with immunodeficiency—become lost to follow-up due to various challenges such as geographic distance, high treatment costs, and limited access to care.

To address this issue, the clinic's director had long envisioned establishing a patient registry system to track and manage these cases. Initial groundwork was laid with support from university research experts using the Rabbit system, a health research information management infrastructure. However, due to a lack of specialized personnel—those familiar with medical terminology, search strategies, and knowledge management—the system's shortcomings were neither fully assessed nor adapted to the clinic's specific needs.

At the suggestion of the clinic manager, a clinical librarian was invited to join the project as a collaborator. The process unfolded in the following steps:

1. Introducing the librarian to the patient population and reviewing their medical records.
2. Integrating the librarian into the clinic's educational programs to facilitate the transfer of both explicit and tacit knowledge related to immunodeficiency terminology, enhancing communication with patients.
3. Collaborating with the clinic secretary to gather informal insights about patient histories and logistical details, helping streamline communication and avoid redundant efforts.

4. Engaging with clinic residents to revise registry entries based on observations and feedback from clinical visits.

5. Compiling a list of necessary corrections and submitting it to the Rabbit system administrator for implementation.

6. Initiating the registration of patients and resuming follow-up for those who had not visited the clinic in over a year.

3- DISCUSSION

The lack of specialized experts in medical research projects has long been one of the most significant challenges in the field of health sciences. Graduates from various medical disciplines are typically trained in clinical practice but often lack the necessary skills in research methodology, information management, and technological tools. Only a small number possess both clinical knowledge and proficiency in computer systems, software applications, and interdisciplinary research.

Clinical librarians, or information specialists working in hospitals and medical schools, are usually trained in medical librarianship or general library science. Through their academic education and practical internships, they acquire expertise in information retrieval, knowledge organization, and evidence-based research. As such, they serve as invaluable resources for physicians and clinical teams, helping to meet their information and research needs effectively. Given the limited number of case reports in the subfield of medical librarianship—largely due to its theoretical and foundational nature within medical sciences—this report represents a potential turning point. It emphasizes a strategy-driven and process-oriented approach to documenting the librarian's contribution. It aligns with international examples—such as those by Price et al (2), Rigby et al (9), and Haley et al (12)—which demonstrate

the strategic value of librarian integration in healthcare settings.

Consistent with previous studies, the findings of this case report highlight the effective involvement of the clinical librarian in the immunodeficiency patient registry project, demonstrating their critical role in enhancing research infrastructure and interdisciplinary collaboration.

4- CONCLUSION

Although librarians have long contributed to clinical research projects, their involvement is often informal and undocumented. This involvement is typically recounted anecdotally by physicians and researchers rather than systematically recorded. As a result, the value of their participation remains largely implicit in the minds of many professionals, with few instances where librarians are formally recognized as collaborators in documented research efforts.

This case report presents a clear and well-documented example of a clinical librarian's active role in a research project, highlighting their impact on accelerating workflow and improving project efficiency. It is hoped that this example will encourage other researchers, particularly in clinical disciplines and more broadly across scientific fields, to engage specialized librarians as integral members of their research teams. This could involve their participation as subject matter experts, research assistants, or information strategists.

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