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Learning from the experience of a long-standing interprofessional osteogenesis imperfecta clinic: A case study evaluation

Maman Joyce Dogba [a, b, *], Frank Rauch [a], François Fassier [a], Michaela Durigova [a], Stephanie Gould [a], Kathleen Montpetit [a], Judy Costello [a], Francis H. Glorieux [a], Christophe Bedos [c, d]

[a] Shriners Hospital for Children, 1529 Cedar Avenue, Montreal, QC, H3G 1A6, Canada
[b] Department of Family and Emergency Medicine, Faculty of Medicine, Université Laval, 1050 Medicine Avenue, QC, G1V0A6, Canada
[c] Faculty of Dentistry, McGill University, 3550 University Street, Montreal, QC, H3A 2A7, Canada
[d] Department of Social and Preventive Medicine, Faculty of Medicine, Université de Montréal, C.P. 6128, Succ. Centre-Ville, Montreal, QC, H3C 3J7, Canada

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ABSTRACT

Background: Osteogenesis imperfecta (OI) is a rare genetic disorder whose management requires an interprofessional approach. The Shriners Hospital for Children Canada in Montreal has one of the longest-running interprofessional osteogenesis imperfecta clinics (or OICs) for patients with severe cases of this complex disease.
Purpose: To gain insight into the barriers and facilitators of interprofessional collaboration based on the experience of the Shriners Hospital interprofessional OICs.
Method: We conducted a qualitative process evaluation using semi-structured interviews, and observations. Participants were 17 key informants representing front-line staff, hospital administrators, external observers, and 16 patients with severe OI.
Discussion: Facilitators of OIC included shared values and balancing individual professional goals with organizational goals; logistical challenges and a lack of systematic monitoring and evaluation were barriers to implementation.
Conclusions: Results of the study provide insight into factors that should be taken into consideration when replicating this interprofessional model in other clinical settings.

1. Introduction

Osteogenesis imperfecta (OI) is a rare genetic disorder that affects approximately 1 in 10,000 newborns.[1,2] The hallmark feature of the disease is increased bone fragility that ranges in severity from mild to high increases in fracture risk to perinatal death. Seven clinically defined types of OI are recognized (types I–VII), although some genetically defined types have also been described.[1–3] Apart from fractures, OI can be associated with short stature, limb and spine deformities, restricted mobility as well as extra-skeletal symptoms, such as blue sclera, teeth abnormalities and hearing impairment. The occurrence of fractures may lead to suspicion of abuse and neglect, especially in young children with milder forms of OI and atypical symptoms of the disease.[4]

As with many other genetic disorders, the management of OI requires an interprofessional approach to treatment and management.[5,6] Medical interventions like the intravenous infusion of bisphosphonates are used for disease management, to reduce fracture rates and alleviate pain in more severe forms of OI.[7] Orthopedic treatment with intramedullary rods is routinely used to straighten tibias and femurs, and thus allow for ambulation.[8] Rehabilitation is used to promote gross motor development and functional independence, and is usually provided by physiotherapists and occupational therapists.[9] Furthermore, fractures may result in the need for emergency care, while professionals like dentists, cardiologists and ENT specialists may occasionally be consulted.

The Shriners Hospital for Children Canada (SHC) in Montreal specializes in interprofessional care for patients diagnosed with

* Corresponding author. Department of Family and Emergency Medicine, Faculty of Medicine, Université Laval, 1050 Avenue de la Médecine, Québec, QC, G1V 0A6, Canada.
E-mail address: joyce-maman.dogba@fmed.ulaval.ca (M.J. Dogba).

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OI.[10] In 1990, the hospital instituted formal OI interprofessional Clinics (OIC) with the goal of more effectively managing patient cases. These clinics involve varying degrees of collaboration among professionals. However, while research shows that effective interprofessional collaboration (IPC) can improve patient outcomes, it also presents many challenges in practice.[11,12] Previous studies have shown that implementing a new interprofessional approach within an institution can lead to uncertainty about professional roles, and blur professional boundaries and scopes of practice.[11] Moreover, because each team member tells their patients' stories using the language and perspective of their profession, and only has insight into a segment of the patient experience, all team members must be aware of these shortcoming and work together.[13] Issues internal and external to the team may arise that impede collaboration such as communication barriers between professions because each has its own unique culture and value system.[14,15] Furthermore, interprofessional teamwork is based on collaborative practice meaning that roles, values, and cultures, which were traditionally based on a hierarchical power structure with the physician at the top are now renegotiated.[16] This shift in power structure requires that all team members understand each others' roles and practice good communication and problem-solving skills in order to achieve a common goal.[14] Given the shift towards IPC and the many challenges it presents, there has been an increase in the number of formal interprofessional education (IPE) training programs offered in both academic and clinical settings.[17,18] However there continues to be a need to systematically learn from these experiences.[19]

Long-standing interprofessional practices, especially those embedded in complex settings such as healthcare organizations and that serve as a model for care and research, can provide invaluable insight to the fields of IPE and IPC. In order to better understand the facilitators and barriers to the implementation and maintenance of the OIC in view of its replication elsewhere, we conducted a qualitative process evaluation of the OIC[20] gathering information both from staff (organizational perspective) and users (specifically caregivers of persons with OI). Our objectives were to: 1) describe the OIC model; 2) provide qualitative data on stakeholder perceptions of barriers and facilitators in the implementation and maintenance of the OIC over its 23-year history; and 3) examine the generalizability and transferability of the OIC model to other clinical settings. These stakeholders, namely hospital administrators, families and health care professionals all indicated their interest in using the conclusions of this evaluation to improve the OIC.

1.1. Description of the OIC

1.1.1. Origins

The first OIC at the SHC was organized in 1990 by an orthopedic surgeon with a particular focus on OI who realized that an IPC was needed to improve services for patients and facilitate therapeutic decision-making in the treatment of such a complex condition. A geneticist confirmed this need as patients often reported receiving conflicting advice about available treatment options for OI. This led to the first interprofessional clinic, later called OIC. The SHC administration became aware of the potential benefits of the OIC for patients and institutionalized the clinic on a monthly or bimonthly basis.

1.1.2. Structure

The core OIC team consists of eight to ten people (specifically, one medical fellow, one nurse, one orthopedic surgeon, one pediatric bone specialist, one occupational therapist, one physiotherapist, one social worker and one research coordinator) who work in close collaboration. External observers and students are occasionally invited to the clinics.

Neurosurgeons, dentists, dieticians and psychologists involved in the management of patients with severe OI may be consulted but do not attend the clinics, as they are not part of the core OIC team. Finally, support staff, including a nurse coordinator, a medical secretary, and a coordinator of transportation and housing services assist in the preparation of each OIC.

1.1.3. Target population

The OIC is designed for patients aged 0–18 years, with severe OI (the majority are patients diagnosed with types III, IV, V and VI), and whose clinical condition needs review by the health care team to determine further treatment options.

1.1.4. Organization

Based on the recommendations of the pediatric bone specialist and the medical record summaries, the nurse coordinator identifies patients who are due to attend the OIC. In accordance with the Shriners mandate, patients may be helped with transportation and housing based on a prior recommendation from social services.[10] The medical secretary, in collaboration with transportation, housing, and social services, schedules an appointment with each family. A typical OIC day consists of “preparation” in the morning, followed by a “team activity” in the afternoon. “Preparation” starts with the arrival of the patient and their family at the hospital. The patient first undergoes physical examinations (blood tests, bone density measurements, X-rays) and possibly, bisphosphonate treatment and then sees the occupational therapist, the physiotherapist and the clinician. During the afternoon “team activity”, each patient and their family members, meet with the entire care team. Prior to meeting the patient and his or her family, the clinician presents the case and the care team briefly discusses the patient's condition. The meeting begins with an examination of the patient, primarily by the orthopedic surgeon, followed by a period of in-depth discussion with the patient and their family. Referrals to other clinicians (e.g., spine surgeon, dentist, orthodontist, and nutritionist) are provided as needed. Families generally choose to follow-up with clinicians who are closer to their homes, but some prefer to consult with SHC clinicians. During the meeting the social worker also draws attention to any significant family issues that need to be addressed (e.g. difficulty coping with the disease). During the course of the afternoon up to seven patients and their families are seen in 30–45 min sessions. While waiting for their meeting, the patients and their families have access to the SHC library and playroom, or are entertained by performers like clowns and/or musicians. This period of waiting also provides families with the opportunity to interact with each other and share experiences about parenting a child with OI.

2. Material and methods

We used a qualitative descriptive research design[21] to develop a comprehensive description of the OIC and identify facilitators and barriers to its implementation over a 23-year period. Qualitative descriptive research is a non-categorical design that allows the researcher to obtain simple and direct answers to questions of particular relevance to practitioners.[22] Ethical approval for this study was obtained from the McGill University Institutional Review Board.

Between January 2013 and February 2014, we collected data using three main methods: interviews, observation, and the review of documents. We opted for face-to-face semi-structured interviews for two reasons. First because the varied professional, educational and personal histories of the sample precluded the use of a standardized interview guide.[23] Second, because semi-