

# The Development of the Evidence-Informed “OI Splint Kit” for Children with Osteogenesis Imperfecta and Their Families

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## ABSTRACT

**Background:** Children with osteogenesis imperfecta (OI) live in fear of fracturing their bones. As fractures are unpredictable, there is a need for tools and knowledge to immobilize a fracture during emergencies. Inspired by a patient with OI recognized for fracture management, the aim of this patient-initiated project was to establish best practices for the safe splinting of fractures during emergencies, including the creation of an evidence-informed OI Splint Kit.

**Methods:** A clinical practice guideline study was conducted to create an evidence-informed splint kit for patients. A systematic review of the literature was conducted to identify kits and materials used to immobilize fractures with splints during emergencies. An expert Task Force was convened to review the results and a timeline was established to create a splint kit. The prototype underwent iterative cycles of modifications based on feedback from the Task Force.

**Results:** Four electronic databases were searched (Medline, CINAHAL, PsychInfo, and Scopus), revealing zero publications pertaining to fracture immobilization kits. The Task Force used their clinical expertise and experiences to develop the OI Splint Kit. The following items were included: splinting tools, bilingual educational material, instructional cards, video tutorials, and memory card game.

**Conclusion:** A gap remains in terms of validated kits to assist in fracture immobilization during emergencies. A portable and practical OI Splint Kit was developed to assist in fracture immobilization emergencies, based on interprofessional clinical expertise and patient experiential knowledge. The kit is subject to ongoing testing and quality evaluations to ensure its suitability for use in various contexts.



## KEYWORDS

Osteogenesis imperfecta, Best practice guidelines, Splints, Fractures, Inter-professional care team

## 1 | INTRODUCTION

Affecting one in every 10,000 individuals, osteogenesis imperfecta (OI), also known as “brittle bone disease”, is a rare hereditary condition associated with bone fragility and fractures. (1) Consequently, children with OI live in fear of fracturing a bone which may curtail participation in activities and limit individuals who can handle them. (2-3) This extensive fear of fractures and situations that may cause fractures, ultimately affects children’s quality of life. (2, 4) In addition, the constant threat of any wrong movement or being mishandled also invokes fear of fractures in parents of children with OI. (2) As fractures may be inevitable and unplanned during the inherent ‘ups and downs’ associated with the daily lives of children with OI and their families, provisions are needed to optimally support them. (5-7) During these emergency situations, some children and their families have learned to temporarily immobilize their fractures to minimize the pain whilst being transported to medical facilities and/or awaiting treatment. Unfortunately, not all families are equipped with the knowledge, skills, and supplies to splint a fracture. (2) In the event of a fracture, readily accessible supplies and instructions may help immobilize the fracture, reduce the pain, help foster resilience, and offer some stress relief. (2) Establishing best practices with delineated safe handling procedures including the creation of an evidence-informed, portable splint kits offer a way forward to close a practice gap and help the OI community and those seeking to support them.

Throughout history, kits have proved to be useful and serve many purposes. The Indigenous people in the Plains region of Canada carried kits known as medicine bundles, which included a collection of spiritually significant items used for spiritual healing. (8) The widely known First Aid Kit, developed by the Johnson Johnson Family of Companies, was initially created to fulfill the need for readily available and accessible medical supplies to treat industrial injuries that occurred on railroad construction sites. (9) From there, the notion of a First Aid Kit, as a set of items needed to fulfill a specific purpose, has been shown to be clinically beneficial in many

areas of healthcare and in the community. In the pediatric clinical setting, Ballard and colleagues (10) developed two distraction kits containing items to help children manage procedural pain, and demonstrated that these kits were feasible and acceptable for use in pediatric emergency care. Kits created to treat medical emergencies, such as an opioid overdose, have been shown to be cost-effective and reduce opioid-overdose deaths. (11) Self-testing kits have also been developed, such as the Human Papillomavirus (HPV) kit used for cervical cancer screening. (12) These kits were convenient, easy to use, and cost-effective. Meanwhile, kits have also been created to facilitate knowledge translation. For instance, Freeman and colleagues (13) developed and evaluated the Youth KIT, a kit aimed at helping youth with disabilities during their transition into adulthood. The Youth KIT includes a set of modules and worksheets that focus on different aspects of adolescence, such as education and social activities, allowing youth with disabilities and others to better understand disability.

Hence, based on the collective benefits of other tested kits and inspired by the story of a patient and his family, clinical practice guidelines were developed to inform the creation of a portable splint kit for fracture management in OI. “...not if we break, but when we break.” (14) Carter Brown and his family know all too well the hardships following fractures. While learning to manage the multiple fractures to date, Carter and his mother, Jennifer Brown, have become resourceful in managing and immobilizing fractures during emergency situations. Their skillset was recognized in their local OI community. One afternoon, the Brown family was called upon by another family whose son with OI was discharged from the emergency room with an undiagnosed femur fracture. The fracture was undetected on x-ray; hence, the fracture and the accompanying severe pain went untreated. Still suffering, the other family did not know what to do and reached out to the Brown family for their expertise. The Brown family arrived with their ‘home grown’ splint kit to offer support. After the mother splinted the femur, instant pain relief was felt allowing the other family to re-group and seek medical care elsewhere. With this inherent reality associ-

ated with OI, Carter and his mother devised the idea of providing an “OI Splint Kit” to other OI families. They reached out to their hospital specialized in the treatment of OI for assistance. The Brown family sought to transform how children and their families manage fractures before arriving for emergency medical treatment, helping the global OI community. The family’s story of their commitment to help others made national headlines. Here lies how the Splint Kit was created in partnership with the family.

## 2 | METHODS

### 2.1 | Study Design, Goal, and Objectives

This clinical practice guideline study consisted of systematically reviewing the literature on existing kits or tools used to immobilize fractures during emergencies, as well as consulting key stakeholders, including patients, clinicians, and decision makers to create an evidence-informed portable “OI Splint Kit” for children with OI and their families. The methodology was guided by other evidence-based practice guidelines led by the research team and is described below. (6, 15)

### 2.2 | Expert Task Force Composition

An inter-professional Task Force was convened at the Shriners Hospitals for Children®-Canada (SHC-Canada), a university-affiliated, pediatric, orthopaedic hospital located in Montreal, Canada, and a member of the Brittle Bone Disorders Consortium. The 15-member Task Force was composed of healthcare professionals with expertise in OI, and included five registered nurses, 1 occupational therapist, 1 executive decision maker, 1 parent, 1 patient, 1 child life specialist, 1 pediatrician, 1 orthopaedic surgeon, and 1 scientist. Two undergraduate trainees from nursing and human anatomy were also part of the Task Force.

### 2.3 | Context and Setting

The development of the “OI Splint Kit” was conducted at the SHC-Canada where the OI program was founded in the 1990s and became internationally acclaimed as the standard of OI care. (16) The hospital provides care to a global cohort of children with OI. In 2014, it created and implemented the *Family and Patient Focused Care, Open Communication, Collaborative, Understanding and Compassionate, Safe and Seamless, Expertise and Education, and Driven by Research and Best Practices* (FOCUSSED™) philosophy of care, which guides the practice of all hospital staff. (17) The creation of the OI Splint Kit aligned with this philosophy of care.

### 2.4 | Literature Review, Extraction, Appraisal, and Synthesis

The search strategies were developed in collaboration with a librarian scientist, which consisted of subject headings and/or keywords relevant to “splint kits”, “fracture immobilization”, “osteogenesis imperfecta”, and “emergencies”. The following four electronic databases were searched for articles that suited the inclusion criteria (**Table 1**): Medline via Ovid (1980 to 2020), CINAHL via EBSCO-host (1980-2020), PsychInfo (2000-2020), and Scopus (1980-2020). Any discrepancies that arose in the process of the literature search were resolved by discussion with members of the Task Force until consensus was achieved. These discussions continued throughout the study duration.

### 2.5 | Consensus Development Based on Evidence

The Task Force reviewed the search strategy and results, prioritized relevant key items required for fracture immobilization, and established a timeline. The impetus for Splint Kit began in 2017 and was finalized in 2019. Iterative circulation of suggested items permitted the Task Force to determine if proposed content: (a) was suited for children with OI during fracture emergencies; and (b) could be understood by children and their fam-

ily caregivers during emergencies. Items included materials and instructional methods (cue cards and videos) needed to immobilize a fracture and led to the creation of a game to help children learn about their anatomy and provide distraction. Drafts of the OI Splint Kit prototype were circulated in person and by email to elicit feedback, obtain constructive comments, and establish consensus. The Task Force subsequently contributed to presenting the OI Splint Kit at an international OI meeting and drafted the manuscript.

## 2.6 | Guidelines and Conflict of Interest

The Task Force members requested that other clinicians and the OI community (e.g. individuals with OI and their families) provide critical, written and/or verbal feedback on the content, clarity, and utility of the Splint Kit. The kit was confirmed to be comprehensive and easy to use, with contents appropriate for splinting a child with OI following a fracture. The Task Force members did not have any conflicts of interest that may have altered the professional feedback and consensus generation. Furthermore, the study was not related to any financial or commercial activity.

## 2.7 | Revisions Dates and Plans for Updates

The development of the OI Splint Kit was in accordance with the current, clinically adopted ways of immobilizing children with OI at SHC-Canada. The OI Splint Kit responded to the idea of a child and his family desiring that all children have the knowledge and skills to be immediately immobilized following a fracture. (14) Since the creation of the Splint Kit, over 300 kits were distributed to children with OI and their families by their nurse coordinator inviting opportunities for teaching by members of the inter-professional team. Subsequently, a process was set-up at the hospital for families to purchase additional kits and replenish their supplies using the hospital's website. Ongoing fundraising campaigns by Carter and his family ensued to provide additional kits for school. Like any tool, guideline, or resource, the creation of the OI Splint Kit was a dynamic process requiring feedback from the inter-professional team including children with OI and their families. Therefore, the OI Splint Kit is subject to continuous review to remain clinically relevant, meaningful, and integrated into practice. Quality improvement evaluations are conducted to: (a) assess the usefulness of the kit during emergency fractures; (b) gauge convenience (e.g. daily portability); and

Search Strategy for Medline via Ovid (1980-2020), PsychInfo (2000-2020), and SCOPUS (1980-2020)		
Search	Keywords	Results
1	Osteogenesis Imperfecta OR OI OR Brittle Bone Disease	27,336
2	Splints/External Fixators/Medical Therapeutic Devices OR Splinting Tools OR Splint Kit	38,404
3	Emergency Management/Preparedness OR ER	832,840
4	S1 AND S2 AND S3	0
Selection Criteria		
	Inclusion Criteria	Exclusion Criteria
Population: Age and Diagnosis	All ages with diagnosis of any type of Osteogenesis Imperfecta	No diagnosis of any type of Osteogenesis Imperfecta
Study Design	Qualitative, quantitative, and mixed methods, abstracts, review articles, commentaries	None
Language	English or French	Any other language

**TABLE 1** Search Strategy and Selection Criteria

(c) determine if items require adaptation, addition, or removal. The Task Force will reconvene yearly to discuss revisions and modifications. We invite the OI community to adapt and implement these guidelines in their varying settings and contexts to help improve the safe handling of children with OI following a fracture.

### 3 | RESULTS

#### 3.1 | Search Results

Four literature database searches revealed zero publications pertaining to the subject headings and/or keywords (Table 1). As the electronic searches revealed zero results, no titles, abstracts, or full-text articles were screened or reviewed. The last search attempt occurred on February 28, 2020 following the creation of the Splint Kit to re-confirm the zero search result.

#### 3.2 | Compilation of Clinical Evidence

Due to the paucity of literature available for the creation of the Splint Kit, the Task Force used their clinical expertise and patient experiences to prioritize a list of items for inclusion (Table 2). Some of these items may be purchased at a local pharmacy (items 4 to 15 in Table 2); however, other items were synthesized by members of the Task Force, including the bilingual educational material, available in print, video and digital formats, to support the individual immobilizing the child following a fracture (items 1 to 3 and 16 to 23 in Table 2). The main immobilization procedures were illustrated on individual cards and served as a reminder of the main steps used for immobilization (Figure 1). Fourteen videos were created in French and English (83 minute and 43 seconds [English: 42 minutes and 35 seconds; French: 41 minutes and 8 seconds]) offering detailed instructions on how to immobilize a child (Figure 1) and ideally watched before a fracture occurs. These videos are available for viewing on the Vimeo website and children and parents were encouraged to share them with the child's network (e.g. grandparents, daycares, and schools) (Table 2).

Finally, a trilingual game (in French, Spanish and En-

glish) was created for the children called "Bones and Fractures Memory Game" (Figure 2), and is available as Supplemental Material. A preliminary list of terms and one-sentence descriptors were composed and validated by the Task Force. The nurses, pediatrician and cast technicians were instrumental in validating the common fractures and treatments associated with OI. They also selected terms that are used in everyday practice. The child life specialists aided in the one-sentence descriptors ensuring that the vocabulary was age-appropriate and clinically relevant. Changes were made to reflect their feedback. This iterative process occurred over three different cycles with the Task Force. The final prototype comprised 26 cards distributed over types of bones, fractures, and treatment options. The card images were subsequently illustrated by the study site graphic designer and validated by the clinicians to ensure the images accurately depicted the terms. A questionnaire (Appendix I) was created to evaluate various aspects of the game from the child's perspective, which was filled out by the children after one round of play with a member of the Task Force. Based on their comments, modifications were made to the game and the prototype was finalized.

### 4 | DISCUSSION

Our literature search revealed that no splint kits were published in the OI literature despite fractures serving as a primary feature of OI and source of fear for children and their families. (2, 7) In an effort to quickly address this gap in the quality of care and health services, our inter-professional team opted to translate their knowledge into a tangible, practical solution in partnership with Carter Brown and his family. The iterative process of creating the OI Splint Kit relied on the collective experience of Task Force team members who practice in an internationally-renowned hospital for the provision of OI care. Ongoing quality improvement evaluations will permit the OI team to revise and modify the OI Splint Kit as needed and continue to solicit input and offer their expertise to the global OI community.



**FIGURE 1** Instructional Methods Used to Teach Children and Family Caregivers How to Splint a Child with OI following a Fracture.

Carter Brown showcasing the contents of the splint kit. Instructional videos created by the cast room nurses, publicly available on Vimeo for viewing on Vimeo at <https://vimeo.com/showcase/5149282>.

When a fracture is suspected, children with OI and families are advised to immediately splint the fracture to minimize the acute pain and post-structural deformities, which may lessen the risk of developing chronic pain. (18-20) However, a fracture may occur *anywhere* or *anytime* and not necessarily with adequate skills, supplies, and personnel to treat it. During this emergency, children, their families, and other responders (e.g. teachers or lay person), often need to creatively problem-solve to successfully immobilize the fracture, decide *if*, *how*, and *where* to seek emergency help for their rare condition. Further, individuals with OI must remain vigilant of further injury from clinicians who “Don’t know how to treat [them]!” (21) The OI Splint Kit serves as a tool to bridge the gap between unprecedented fracture incidents and treatment accessibility including the provision

of instructions which may be shared with clinicians unfamiliar with OI.

We further encourage the use of the OI Splint Kit with the completion of the OI Good to Go Passport and other passports created by the OI Foundation (OIF) and OI Foundation of Europe (OIFE) to further communicate this rare condition to responders. (6) The OI Good to Go Passport is a wallet-sized card containing information to accommodate the transitioning needs of the OI population, including their medical condition and diagnosis, surgical history, medications, and contact information of their specific OI healthcare team. (6) Moreover, we encourage the adoption of the OI Splint Kit to foster children’s participation in their care (22) and reinforce collective efforts to prepare the transition of the OI population into adult-oriented health care systems. (6, 15,

Item	Description and Rationale	Unit #
1. Instructional Card #1	Illustration card: brief rationale of the project and links to the videos.	1
2. Instructional Card #2	Illustration of the main immobilization for upper extremities fracture (retro-verso: arm and forearm).	1
3. Instructional Card #3	Illustration of the main immobilization for lower extremities fracture (retro-verso: upper and lower leg).	1
4. ACE Bandage with Self Closure (3in)	An elastic bandage that may be wrapped around an injured area to control swelling or around a cast to secure it in place.	1
5. ACE Bandage with Self Closure (4in)	An elastic bandage that may be wrapped around an injured area to control swelling or around a cast to secure it in place.	1
6. 3M Coban Cohesive Bandage (3in)	A self-adherent elastic tape that may be wrapped around an injured area to control swelling or around a cast to secure it in place.	1
7. 3M Coban Cohesive Bandage (4in)	A self-adherent elastic tape that may be wrapped around an injured area to control swelling or around a cast to secure it in place.	1
8. Padding Cast (7.5cm)	Cotton bandage that may be wrapped around an injured area to provide padding and prevent friction.	1
9. Padding Cast (10cm)	Cotton bandage that may be wrapped around an injured area to provide padding and prevent friction.	1
10. One-Step Splint (3x35in)	A splint made of two layers of padding covering a fiberglass slab for an easy one step immobilization.	1
11. Scissors (5.5in)	To help cut the cast.	1
12. Stockinette	A thin layer of fabric that is applied directly on the skin when casting, preventing movement of the cotton padding and friction from the cast edge.	1
13. Human Bone Stress Ball	To help relieve stress and muscle tension. May be used as a distraction tool.	1
14. Drawstring bag	A bag to carry all the tools needed to immobilize a fracture.	1
15. Sam Splint (5.5x36in)	Splint made of soft aluminum with a foam coating that is applied to an injured area to stabilize a fracture.	1
16. Video #9	<i>Trousse de premiers soins OI - Immobilisation de la cheville ou du pied.</i>	1
17. Video #10	<i>Trousse de premiers soins OI - Immobilisation du bras.</i>	1
18. Video #11	<i>Trousse de premiers soins OI - Immobilisation de l'avant bras.</i>	1
19. Video #12	<i>OI Support Kit - Immobilization of the Forearm.</i>	1
20. Video #13	<i>OI Support Kit - Immobilization of the Femur</i>	1
21. Video #14	<i>OI Support Kit - Immobilization of the Arm.</i>	1
22. USB Key	Contains the content of the instructional cards and videos.	1
23. Bones and Fractures Memory Game	Helps children learn about their bones, fractures, and different therapies used in OI. Offers a potential distraction tool.	1

**TABLE 2** Description of Contents Contained in the Splint Kit Created for Children with Osteogenesis Imperfecta Following a Fracture and Requiring Immobilization

21) However, if and how to integrate the OI Splint Kit into the OI programs of various hospitals warrants discussion, decisions, and action at a local level, and may be supported by local OI foundations and other key stakeholders as well.

At every point of care, patients have unique experiences that make them knowledgeable about their illness and the care they receive. Thus, healthcare professionals need to create collaborative partnerships with patients and their families to optimize the provision of care.



**FIGURE 2** Examples of the Cards included the Bones and Fractures Memory Game

There are 26 cards (A to Z) included the Bones and Fractures Memory Game from. A = Human Skeleton (206 bones); I = Displaced Fractures; P = Backslab; Z = Bisphosphonate. The game is available in English, French, and Spanish.

“Patients as Partner” is a local program that encourages patients to express their opinions regarding their health and illness as a full member of the clinical team. This innovative and viable approach recognizes the experiential knowledge of patients allowing for the creative adaptation of practices to improve quality of life and establish more meaningful interactions with professionals. (23-24) Our approach, guided by our FOCUSED™ philosophy of care (16), recognized the lived experiences of Carter Brown’s and family and their expertise in adapting to unexpected situations. Similarly, Pomey and colleagues (23-24) concurred that chronically ill patients and their caregivers develop extensive knowledge concerning their symptoms and the effects of different interventions on their state of health and on their lives. Thus, creating partnerships with patients and their families to help inter-professional health care teams and researchers create innovations to help with their health care is critical.

## 4.1 | Strengths and Limitations

Without any published empirical knowledge, the development of the OI Splint Kit drew on the experiential knowledge of OI experts in partnership with a family with OI. Efforts to remove potential biases associated with the development of the OI Splint Kit included the formation of an inter-professional task force, acknowledgment of no conflicts of interests, and the adoption of a rigorous methodology to critically appraise and synthesize all available evidence. (6, 15) The OI Splint Kit was created in collaboration with a leading institution in the provision of OI and generated significant praises by the cohort of children and their families followed at the study site and at an international OI meeting. Yet, the OI Splint Kit may not be generalizable or transferable to all contexts, and there is no research to confirm its effectiveness. As the OI Splint Kit is meant for emergencies, the kit focuses on splinting methods and tools in such cases. Splinting is a safe and easy-to-replicate method for non-healthcare professionals in a home setting and reduces the risk of leverage fractures in the OI population. Thus, other methods, such as the use of plaster to immobilize fractures were not considered appropriate by our Task Force for use in the splint kit, or in our literature review. Similar to other guideline creations, clinical reasoning is essential for the clinicians to ensure best clinical care, especially since the OI Splint Kit has not been evaluated in practice. Furthermore, these kits need to be adapted to local contexts, expertise and resources.

## 4.2 | Future Directions

While other kits used in the pediatric healthcare setting have shown clinical efficacy (10-13), the OI Splint Kit requires a rigorous evaluation to determine its benefits in fracture management. To date, the OI Splint Kit has received informal feedback from patients and health care professionals, supporting its benefits. Albeit, evidence for the usefulness and effectiveness of the kit remains anecdotal. We will start a quality improvement initiative, guided by a leading implementation science framework



(25), to evaluate the OI Splint Kit. Namely, our future testing will give critical insight on the following points: (i) did the kit aid in fracture immobilization during emergencies; (ii) frequency of usage of the kit; (iii) did the kit help decrease pain; (iv) did the kit help ease anxiety during fractures; and (v) is the OI community satisfied with the kit. The evaluation will also collect requests for modifications to the OI Splint Kit. The comments will be shared with our inter-professional Task Force, and together with the research team, the kit will be iterated to satisfy the needs of the OI community. Implementation efforts will ensue to make the OI Splint Kit available in the long-term to the global OI population.

## 5 | CONCLUSION

Children with OI and their families live with the constant risk of unexpected fractures associated with their genetic condition creating distress and potentially diminishing one's quality of life. (2) The creation of the OI Splint Kit was in response to one family who desired to share their practical solution to cope with fears of fractures with other families. (2) Driven by a FOCUSED™ philosophy of care (17), and the multitude of benefits of partnering with children, families and the inter-professional team, an evidence-informed kit was created to help children and their families be better prepared during an emergency. While we encourage the adoption of the OI Splint Kit into practice, we remain mindful the kit has not been subjected to rigorous testing and rely on the clinical reasoning of the clinicians to determine if this kit is suitable for use in their local context and properly adapted to local expertise and resources.

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erosity of many donors permitted the provision of a free splint kit to each of the 360 families living with OI at Shriners Hospitals for Children-Canada.

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