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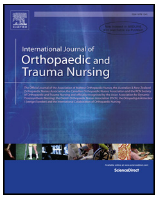

Development of the Good2Go MyHealth Passport for individuals with Osteogenesis Imperfecta: A knowledge-synthesis study

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Introduction

Osteogenesis Imperfecta (OI) is a rare hereditary genetic disorder, commonly known as “brittle bonedisease”, affecting 1 in 10 000 lives (Rauch and Glorieux, 2004). It is described as low bone mass and bone fragility; leading to susceptibilty to frequent fractures. OI is influenced by the type and location of the genetic mutation and the quality and quantity of the type I collagen, affecting bone density by changing the microstructure of the bony skeleton, and causing bone structure to deteriorate (Gil et al., 2017). Individuals with OI may develop skeletal deformities, exhibit grey sclera, have skin hyperlaxity, show signs of Wormian bones in the sutures of the skull, and are often affected by dentinogenesis imperfecta (Gil et al., 2017; Rauch and Glorieux, 2004). Currently, there are various clinical classifications that distinguish between individuals with different types OI ranging from OI Type I upwards (Trejo and Rauch, 2016). The types are categorized based on the changes in gene expression, severity, and skeletal manifestations, which ultimately affect ’individuals' pain, physical capabilities, and quality of life (Dahan-Oliel et al., 2016; Nghiem et al., 2017, 2018; Trejo and Rauch, 2016; Tsimicalis et al., 2016, 2018). Although there is no known cure for OI, bisphosphonates have been used to increase bone mineral density and reduce the number of fractures (Trejo and Rauch, 2016).

Even with pharmacological, orthopedic, and rehabilitation interventions that address the underlying impairments of bone fragility, deformity, and fractures (Dahan-Oliel et al., 2016), children and adults with OI face many barriers that can hinder their quality of life (Tsimicalis et al., 2016). Many children and adults have a fear of fractures due to their delicate bones (Tsimicalis et al., 2016), and are concerned about their physical safety (Dogba et al., 2013). Children with OI and their families may have periods of sudden crises as well as periods of stability, which are often referred to as the ‘ups and downs’ of OI (Dogba et al., 2013). These periods with and without injuries or fractures may result in several “care transitions” (RNAO, 2014) occurring during emergency (e.g. a sudden car crash) and non-emergency (e.g. seeing a new specialist) situations. Individuals with OI may receieve care from health care providers, emergency responders, good Samaritans, and laymen who are unaware that they may sustain a fracture due to the slightest movement. In such situations, those with OI could benefit from a portable tool to help them communicate their rare condition to others. One promising tool is the ‘Good2Go MyHealth Passport’ (i.e. MyHealth Passport), which is available for 67 childhood onset conditions (of which 6 are “under construction”, one is a generic passport, one is a general medication passport, and one is a passport for the general geriatric population), but currently the passport is not available for individuals with OI. Thus, the ultimate goal of this study was to develop an evidence-based passport for the OI population.

Good2Go MyHealth Passport Program

The MyHealth Passport is an extension of a transitional care program called Good2Go, launched in 2009, by Dr. Miriam Kaufman from The Hospital for Sick Children in Toronto, Canada. The initial vision of the Good2Go Program was to prepare adolescents with chronic health conditions to leave the pediatric health care system with the skills and knowledge to advocate for themselves, maintain health promoting behaviours, and utilize adult health services (Grant and Pan, 2011). This vision led to the creation of the MyHealth Passport which is a free, easy-to-use, online tool allowing individuals with chronic health conditions to be proactive with their health care, across all ages, on a global scale. The portable medical record can be created via the MyHealth Passport portal (www.sickkids.ca/myhealthpassport). Depending on the individual, they can complete its complimentary ‘cheat sheet’ with their clinician before entering the same data into the online portal. Upon completion, individuals can print and place their personalized card into their wallet, which can then be used during various care transitions (RNAO, 2014). The MyHealth Passport can be easily updated at the

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individual's discretion as needed.

Methodology

Study design, goal, and aims

This study involved systematically reviewing the literature and consulting key stakeholders, including patients and clinicians, to develop an evidence-based MyHealth Passport for OI. The study aims were to systematically review and synthesize studies about: a) the Good2Go MyHealth Passport Program; b) use of any portable, health-related tools for care transitions and; c) the care transitions for individuals with OI. These review findings then provided insight for the creation of the MyHealth Passport for OI. The methodology used to develop the OI MyHealth Passport was guided by the creation of evidence-based practice guidelines (Tsimicalis et al., 2011).

Expert task force composition

An inter-professional Task Force was convened at the Shriners Hospitals for Children®, located in Montreal, Canada, which is a member of the Brittle Bone Disorders Consortium. The Task Force was composed of eleven members with expertise in OI and included: one senior physician/scientist, two nurse coordinators, a physiotherapist, an occupational therapist, a nurse scientist, a social worker, one research trainee, a former patient (who is also a research assistant), and a representative from The Hospital for Sick Children Good2Go liaison who provided guideance for creating the OI MyHealth Passport. The liaison also had expertise in OI as an occupational therapist.

Literature review, extraction, appraisal and synthesis

A 3-fold literature search was conducted to address the three study aims. The search strategies were developed in collaboration with a librarian scientist, which consisted of MeSH headings, subject headings, and/or keywords relevant to “MyHealth Passport” (Aim 1); “medical reference cards”, “tool” (Aim 2), and “Osteogenesis Imperfecta”, “transfers”, “transitions”, and “emergencies” (Aim 3). Five electronic databases were searched for eligible articles and included: Medline via Ovid (1980–2017), CINHAL via EBSCO-host (1980–2017), Pubmed (1970–2017), PsychInfo (2000–2017), and Scopus (1980–2017). After removing duplicate titles/abstracts, all published studies, along with commentaries and protocols in English, were reviewed for inclusion (Table 1). After independently screening titles and abstracts of potentially relevant articles, full-text articles of the selected titles and abstracts were obtained. These obtainable full-texts were then assessed for inclusion. References from all included articles were further examined to identify further relevant studies. Full-texts that could not be obtained were excluded after using the university-affiliated interlibrary loan services or contacting the author. Any issues that arose were resolved by discussion among the Task Force until consensus was achieved.

Table 1
Inclusion & exclusion criteria of literature search.

Inclusion Criteria	Exclusion Criteria
English Meta-analyses, Systemic Reviews, Clinical Studies Commentaries, Protocols, Guidelines	Duplicate titles and abstract French Unattainable articles from interlibrary loan services and/or author
Of stated types of articles, if they discussed: 1) Good2Go MyHealth Passport Program 2) OI and care-transition tools 3) Other similar passport-like tools	

All data were extracted, appraised, and synthesized to understand the benefits of using the MyHealth Passport and other portable, health-related tools for care transitions. Due to the lack of published literature available within Canada, the U.S., and globally, the websites of The Hospital for Sick Children Good2Go Program, the OI Foundation (OIF), and Canadian Association of Pediatric Health Centres (CAPHC) were also consulted. These searches were also conducted alongside other in-progress studies led by the study site relevant to the topic (Carrier et al., 2018; Michalovic et al., 2015, 2016). These actions collectively helped create the content of the OI MyHealth Passport and its corresponding 'cheat' sheet.

Consensus development based on evidence

Members of the Task Force reviewed the literature, analyzed the evidence, discussed the relevant key primary health care needs, and established a timeline to create the OI MyHealth Passport. The completion of the OI MyHealth Passport was finalized over a four-month period (May-August 2017). Several suggestions were proposed in collaboration with the Task Force based on the analyzed data, evidence appraised, and guidelines for passport creation which included two templates derived from the Spina Bifida and Muscular Dystrophy MyHealth Passports. Drafts were reviewed in person and via video meetings, telephone calls, and emails; offering feedback to generate the key content of the OI MyHealth Passport. Iterative questioning permitted the Task Force to determine if the proposed content: a) was suited for the OI population; b) was relevant to primary health care needs of individuals with OI; c) could be used in emergency situations; d) could be understood by paramedics or good Samaritans in emergency situations and; e) provided a comprehensive patient overview. It was a priority for the Task Force to consider the comprehensiveness and relevance of the MyHealth Passport for the global OI community. Thus, generic names of conditions, medications, and other key information were used. To fit into a wallet-sized portable card, the Task Force members were assiduous in revising the content of the card to be concise, coherent and relevant. The detailed process of creating the OI Passport is outlined in Fig. 1.

Guidelines and conflict of interest

The Task Force members requested other colleagues (e.g. physicians, nurses, physiotherapists, occupational therapists, pharmacists, social workers, and the OI community) (e.g. individuals with OI and their families) to provide critical, written and/or verbal feedback about the portability, content, clarity, and utility of the OI MyHealth Passport. The feedback received indicated that the OI MyHealth Passport was comprehensive and easy to use, and that the questions were relevant and useful for care transitions. The Task Force members did not have any conflicts of interest (e.g. financial intent or other interests) that may have altered the feedback or generate consensus.

Revisions dates and plans for updates

The development of the OI MyHealth Passport was in accordance with the current clinically appropriate transition needs of individuals with OI. As needs may change overtime, the OI MyHealth Passport must undergo continuous reviews and revisions to ensure clinical relevance. Quality improvement evaluations will be conducted to: a) assess the usefulness of the OI MyHealth Passport in care transitions; b) completeness on part of the individual and health care professional(s); c) convenience of its portability; and d) determine if other tools require development. As there were no other revisions suggested, the Task Force team will reconvene every year to discuss possible revisions, and discuss potential modifications to the design, portal, and accessibility with the Good2Go program. Clinicians are advised to check the Good2Go MyHealth Passport website (https://www.sickkids.ca/

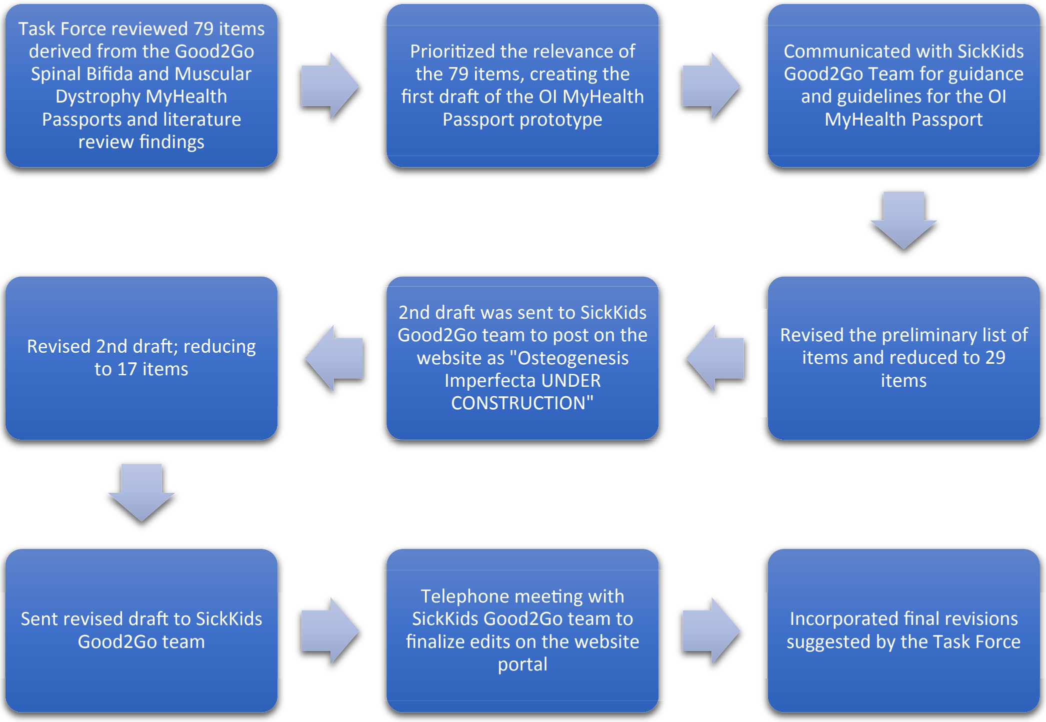


Fig. 1. Process of creating the OI passport.

myhealthpassport/) for the latest updates and revisions. Individuals are strongly encouraged to update their OI MyHealth Passport if there are any changes or if issues arise from their condition. Notice of the passport was posted on the Facebook page of the OIF during the development and will be continued to be communicated through the OI community (e.g. the OIF and OI Foundation of Europe) through newsletter publications and use of social and academic networks.

Definition of terms

A few key terms relevant to the OI MyHealth Passport are defined in the Supplementary Section (Supplementary table 1).

Results

A total of 644 titles and abstracts were assessed for inclusion. Of the 24 full-text articles reviewed, 12 studies were included in this review. The results section is presented according to the empirical evidence on the Good2Go MyHealth Passport Program and other “passport-like” tools used in health care transitions and settings, and the paucity of research on care transitions for individuals with OI. Findings from these studies lend insight into the creation of the OI MyHealth Passport.

Good2Go MyHealth Passport research

Five studies have been conducted about the Good2Go MyHealth Passport (Supplementary table 2).

Evidence summary and recommendation

The impetus for the creation of the Good2Go MyHealth Passport was to provide adolescents with chronic health conditions with an easy tool that is portable, helps educate, and encourages cohesive communications with health care professionals and improves self-efficiency (Wolfstadt et al., 2011). The MyHealth Passport supports adolescents, transitioning from the pediatric health-care system to the adult health-care system, to feel more empowered, to take ownership of their health, to become more self-sustaining problem solvers, and to gain vital self-management skills to support responsible decision-making and independence (Amaria et al., 2011). The MyHealth Passport was desinged to encourage individuals, of any age, to be proactive in their health management (Spencer et al., 2011) and foster collaborative partnerships (Wolfstadt et al., 2011).

The MyHealth Passport Program was initially evaluated using a phenomenological design with 34 young adults who created a passport (the generic version or a version of one of 40 conditions) (Wolfstadt et al., 2011). The process of creating a passport, tailored to their chronic condition, helped the young adults become more knowledgeable about their condition and feel more in control and confident with their health history (Wolfstadt et al., 2011). The young adults also perceived that health care professionals paid more attention to them when using the card. They appreciated the convenience of its portability and simplicity. The benefits of carrying the passport in their wallets included offering them reassurance; knowing that in a potential emergency situation, paramedics or other responders would have access to their passport, providing immediate access to their health history. Subsequent research revealed how the MyHealth Passport was crucial for showcasing what resources are available and assessing readiness for transfers into different health care settings (Benchimol et al., 2011). By using the MyHealth Passport, clinicians learned about their patients' condition-related knowledge, which helped them to know whether or not to educate further or reiterate important information to their patients. Finally, by expanding its availability to diverse populations and age ranges globally, including parents of toddlers and the elderly with chronic conditions, the tool has demonstrated many benefits to easing care transitions (Spencer et al., 2011).

Status of evidence

Research on the benefits of the Good2Go MyHealth Passport was derived from five studies including three case-study evaluations (Benchimol et al., 2011; Spencer et al., 2011; Wolfstadt et al., 2011), a position statement (Amaria et al., 2011), and a presentation of five transition programs available in Canada (Grant and Pan, 2011).

Other "passports" used in the health care setting

Evidence summary and recommendation

A second literature search revealed the availability of other "passports". These studies were reviewed to infer potential benefits of using passports in care transitions (Supplemental Table 3). Balkin et al. (2017) reported an improvement in communication, pain and symptom management, and documentation of the child's death when giving medical residents convenient, portable, educational reference cards for use with their patients. Similarly, Podolsky et al. (2015) and Sparks et al. (2015) reported improved communication and documentation skills of physicians with the use of pocket cards.

Status of evidence

The evidence compiled is from case and descriptive studies describing the benefits of eight tools containing consolidated health-related information for use in clinical practice (Ash et al., 1982; Balkin et al., 2017; Bass et al., 2015; Blais, 2008; Kardas and Tunali, 2006; Lambrinoudakis and Gritzalis, 2000; Podolsky et al., 2015; Sparks et al., 2015; Volertas and Rossi-Foulkes, 2017).

Care transitions in individuals with Osteogenesis Imperfecta

Evidence summary and recommendation

As the present study was conducted alongside another review led by our study site, our collective efforts revealed the paucity of research on care transitions for individuals with OI (Carrier et al., 2018). Carrier et al. (2018), identified the best practices needed to accommodate the transition needs of the OI population. Care transitions for individuals with OI must be done in a timely fashion, with the full cooperation of health care providers in order to ensure the continuity of care. The review also led to the creation of a transfer tool called "OI Transfer Summary". The tool includes 11 sections providing the recently transitioned patient, and their new healthcare professional, in the adult primary healthcare system with a comprehensive summary of the care they received in the child healthcare system.

Status of evidence

The evidence compiled from clinical anecdotal experiences, the expertise of the OIF, and a review that led to the creation of a transfer summary for OI (Shapiro and Germain-Lee, 2012; Dogba et al., 2014; OIF, 2016; Carrier et al., 2018).

Use of existing evidence to create the OI MyHealth passport

Evidence summary and recommendation

Our literature search revealed no published studies considering a portable tool for OI. Thus, an iterative process was used to create the OI MyHealth Passport, which included a comprehensive literature search, reliance on varying in-progress studies led by the study site (Carrier et al., 2018; Michalovic et al., 2015, 2016), creation of multiple drafts for review, and generation of consensus through discussion and feedback. The initial draft contained over 79 items for consideration in the passport; however, over a series of five meetings and eight drafts, the Task Force prioritized 15 core items for inclusion in the passport. The final version of the OI MyHealth Passport contains criteria that capture key information within the templates created by the Good2Go Program. A 'cheat sheet' (Fig. 2) was also created to help individuals collect the information needed to complete their passport with health care professionals. The OI MyHealth Passport categories are displayed in Fig. 3, and an example of a completed sample of the OI MyHealth Passport can be seen in Fig. 4.

Status of the evidence

The OI MyHealth Passport and its complimentary 'cheat sheet' were created with the expertise of the Good2Go Program, the clinical expertise of the Task Force in OI, and the results generated from this review.

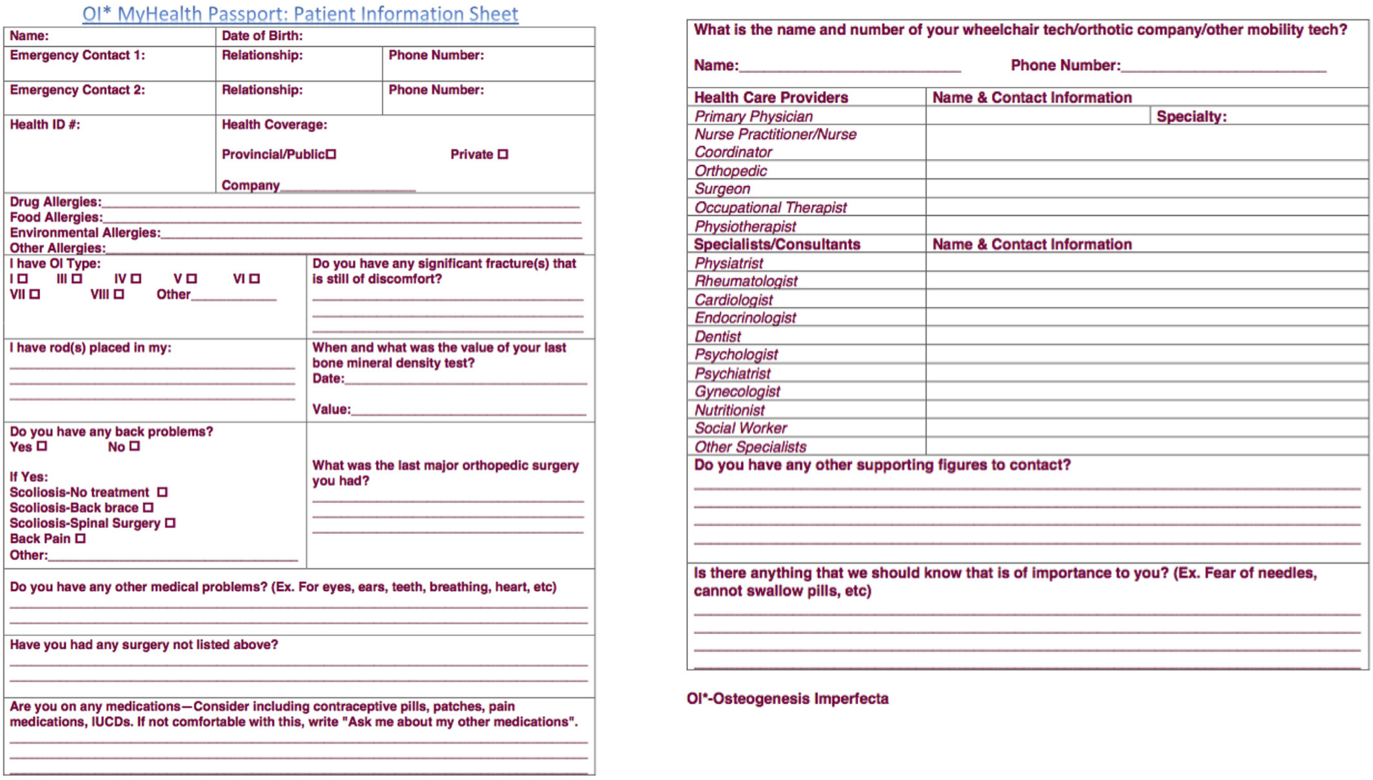
Discussion

The creation of the OI MyHealth Passport and its 'cheat sheet' was conducted by an inter-professional team internationally recognized for the provision of OI care in partnership with an internationally renowned hospital that is recognized for their Good2Go Transition Program. The iterative process of creating the OI MyHealth Passport relied on the collective expertise of Task Force team to delineate what questions were most pertinent for inclusion, and drew from empirical and experiential knowledge to finalize this evidence-based, portable tool. This section will describe the potential benefits for use of the OI MyHealth Passport, generate implications for practice and research, and acknowledge the study strengths and limitations.

Similar to other transition programs and interventions such as the GOT Transition, National Health Services' Four Problem-Oriented Models of Transition, and Kerr & O'Halloran's eight interventions of transition (Carrier et al., 2018; Grant and Pan, 2011; Kerr & O'Halloran, 2017; Field and Jette, 2007), the Good2Go Program has an important role in the facilitating the transition of young adults into the adult health care systems (Grant and Pan, 2011; Amaria et al., 2011; Spencer et al., 2011; and Benchimol et al., 2011). Presently, individuals with chronic health conditions who use MyHealth Passports available from the Good2Go Program gain a plethora of benefits (Spencer et al., 2011). Individuals demonstrate greater knowledge of their condition and competency in accessing their health care information, experience feelings of empowerment and confidence, and feel reassured that there is continuity in their health care provided by health care professionals once transitioned in the adult health care system (Benchimol et al., 2011). There are also benefits for clinicians who may use the passport to assess their patients' knowledge and readiness for transitions, as well as for education purposes (Benchimol et al., 2011). With free, universal, global access to the OI MyHealth Passport, clinicians may begin incorporating this tool into their transition programs and practices. The tool fulfils a gap in the availability of transition-related tools and may offer reassurance to individuals with OI (Dogba et al., 2014; Shapiro and Germain-Lee, 2012).

Although the official transfer from pediatric to adult healthcare settings happens commonly at the age of 18 or 21 years, the transition process can start at as young as 14 years old (Shapiro and Germain-Lee, 2012; Dogba et al., 2014; OIF, 2006; Schlucter et al., 2015; van Staa et al., 2011; and AAP, AAFP, & ACP., 2002). Opportunities to engage children and, subsequently, young adults in discussions, decisions, and actions relating to their care may begin at as early as 3 years old, with tools available to facilitate their participation (Wang et al., 2018). Thus, the use of the OI MyHealth Passport should not be guided solely by the patient's age but rather by the assessment of the patient's readiness for transition (Carrier et al., 2018; van Staa et al., 2011; and AAP, AAFP, & ACP., 2002). Several tools are available for the assessment of transition readiness (Ruck and Dahan-Oliel, 2010; van Staa et al., 2011) and the administration of these tools, as well as the planning and coordination of the transition, often falls under nursing (Carrier et al., 2018). Finally, the evidence suggests older people also use such passports (Spencer et al., 2011). There are several long-term health outcomes associated with OI, such as hearing loss, cardiovascular conditions, and others (Nghiem et al., 2018; Radunovic and Steine, 2015; Swinnen et al., 2012); requiring medical management in adulthood, so the tool may also be beneficial for adults.

Empirical evidence derived from other "Passports" used in the health care setting suggest that there are also other benefits. These benefits may also be transferable when using the OI MyHealth Passport, and may include engaging individuals with OI and their families in their health care, and fostering a therapeutic and collaborative relationship with members of the health care team. The passport may



OI* MyHealth Passport: Patient Information Sheet

Name:	**Date of Birth:**	
Emergency Contact 1:	**Relationship:**	**Phone Number:**
Emergency Contact 2:	**Relationship:**	**Phone Number:**
Health ID #:	**Health Coverage:** **Provincial/Public** ☐ **Private** ☐ **Company**_______________	

Drug Allergies:___
Food Allergies:___
Environmental Allergies:___
Other Allergies:___

I have OI Type: I ☐ III ☐ IV ☐ V ☐ VI ☐ VII ☐ VIII ☐ Other___	**Do you have any significant fracture(s) that is still of discomfort?** ___ ___ ___
I have rod(s) placed in my: ___ ___ ___	**When and what was the value of your last bone mineral density test?** **Date:**___ **Value:**___
Do you have any back problems? **Yes** ☐ **No** ☐ **If Yes:** **Scoliosis-No treatment** ☐ **Scoliosis-Back brace** ☐ **Scoliosis-Spinal Surgery** ☐ **Back Pain** ☐ **Other:**___	**What was the last major orthopedic surgery you had?** ___ ___ ___

Do you have any other medical problems? (Ex. For eyes, ears, teeth, breathing, heart, etc)
___
___

Have you had any surgery not listed above?
___
___

Are you on any medications—Consider including contraceptive pills, patches, pain medications, IUCDs. If not comfortable with this, write "Ask me about my other medications".
___
___
___

What is the name and number of your wheelchair tech/orthotic company/other mobility tech?

Name:___ **Phone Number:**___

Health Care Providers	**Name & Contact Information**	
Primary Physician		**Specialty:**
Nurse Practitioner/Nurse Coordinator		
Orthopedic		
Surgeon		
Occupational Therapist		
Physiotherapist		
Specialists/Consultants	**Name & Contact Information**	
Physiatrist		
Rheumatologist		
Cardiologist		
Endocrinologist		
Dentist		
Psychologist		
Psychiatrist		
Gynecologist		
Nutritionist		
Social Worker		
Other Specialists		

Do you have any other supporting figures to contact?
___
___
___
___

Is there anything that we should know that is of importance to you? (Ex. Fear of needles, cannot swallow pills, etc)
___
___
___
___

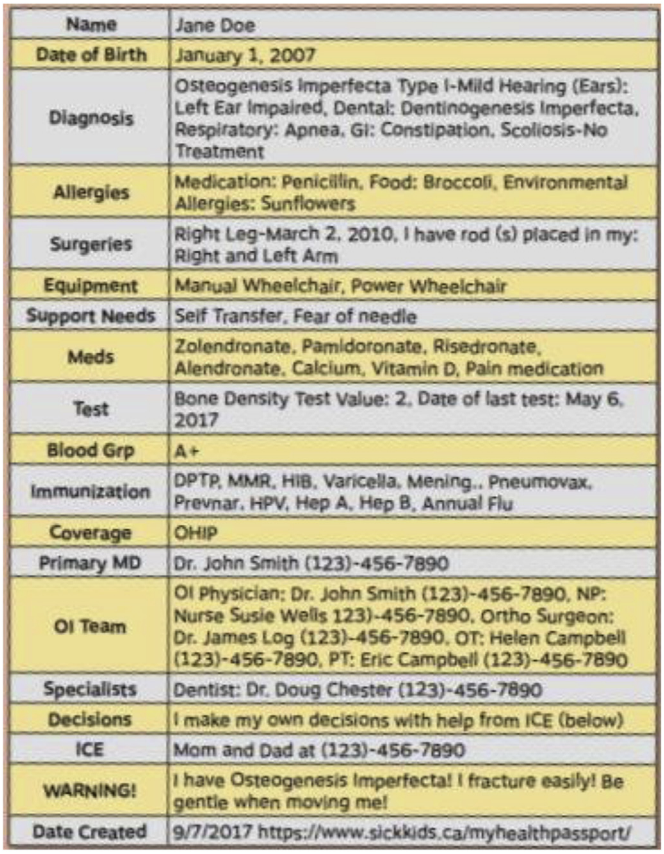
OI*-Osteogenesis Imperfecta

Fig. 2. Image of the cheat sheet.

prompt patient-physician communication, encourage dialogue and discussion (e.g. how to handle an individual with OI), and educate clinicians who may be unfamiliar with OI (Balkin et al., 2017; Podolsky et al., 2015; Sparks et al., 2015). A similarity between these tools is the provision of portable and condensed summaries in formats appealing to the patient. The use of electronic platforms is easily used by end-users including residents and other members of the health care team along with patients and families (Volertas and Rossi-Foulkes, 2017). Collectively, the use of passports may engage individuals in being more accountable and actively participate and contribute to managing their health condition (Blais, 2008). Thus, due to the potential benefits associated with the use of MyHealth Passport for OI, evaluation of optimal usage and potential benefits is warranted.

With the potential benefits associated with the OI MyHealth Passport, it needs to be integrated into transitional care programs for young people with OI. In somke countries, the transitional care programs are being created and led by best practice initiatives (Carrier et al., 2018; Kerr & O'Halloran, 2017; Field and Jette, 2007). How the OI MyHealth Passport may be integrated into these programs warrants discussion, decisions and action at a local level which may be guided by

Fig. 3. Categories of the OI MyHealth passport.



Name	Jane Doe
Date of Birth	January 1, 2007
Diagnosis	Osteogenesis Imperfecta Type I-Mild Hearing (Ears): Left Ear Impaired, Dental: Dentinogenesis Imperfecta, Respiratory: Apnea, GI: Constipation, Scoliosis-No Treatment
Allergies	Medication: Penicillin, Food: Broccoli, Environmental Allergies: Sunflowers
Surgeries	Right Leg-March 2, 2010, I have rod (s) placed in my: Right and Left Arm
Equipment	Manual Wheelchair, Power Wheelchair
Support Needs	Self Transfer, Fear of needle
Meds	Zolendronate, Pamidoronate, Risedronate, Alendronate, Calcium, Vitamin D, Pain medication
Test	Bone Density Test Value: 2, Date of last test: May 6, 2017
Blood Grp	A+
Immunization	DPTP, MMR, HIB, Varicella, Mening., Pneumovax, Prevnar, HPV, Hep A, Hep B, Annual Flu
Coverage	OHIP
Primary MD	Dr. John Smith (123)-456-7890
OI Team	OI Physician: Dr. John Smith (123)-456-7890, NP: Nurse Susie Wells 123)-456-7890, Ortho Surgeon: Dr. James Log (123)-456-7890, OT: Helen Campbell (123)-456-7890, PT: Eric Campbell (123)-456-7890
Specialists	Dentist: Dr. Doug Chester (123)-456-7890
Decisions	I make my own decisions with help from ICE (below)
ICE	Mom and Dad at (123)-456-7890
WARNING!	I have Osteogenesis Imperfecta! I fracture easily! Be gentle when moving me!
Date Created	9/7/2017 https://www.sickkids.ca/myhealthpassport/

Fig. 4. Completed sample of OI MyHealth passport.

the eight interventions that contribute to effective transitions (Kerr & O'Halloran, 2017). At our local hospital, efforts are currently underway to create a comprehensive, interactive, transitional care and self-management program to fill a gap in the delivery of health care services for the OI community (Dogba et al., 2014). The program, to be delivered over the Internet, will be comprised of OI education, offer opportunities to foster self-management and transition skills, establish meaningful peer support, and connect young people, families and clinicians with resources. Integral to the program will be discussions about transitioning into the adult health care systems (Amaria et al., 2011). Preliminary work, derived from our setting, has revealed that young adults with OI felt they were "dropped in the jungle, with no one to call", and were confronted with clinicians in the adult health care system who did not know how to treat them (Michalovic et al., 2015, 2016). This is a reality for many young adults with chronic conditions who transition into the adult health care systems and are confronted with clinicians less knowledgeable of their condition (Callahan et al., 2001). Therefore, to promote optimal usage of the OI MyHealth Passport, it should be integrated within a transitional care practice setting. Since the transitional care program is not ready for implementation, the Task Force has incorporated the OI My Health Passport into their longstanding practice of using the "OI card". Since 2008, the OI team has been providing every child with OI and their family a card (the size of a business card), which indicates the child is an OI patient of the hospital, and if there are any questions, to please contact the hospital. The card offers the children and their families' reassurance that the hospital will provide access to their specialty knowledge; especially for clinicians unfamiliar with this rare condition and for families who remain at risk of being acused of physical abuse (Youngblom et al., 2016). Now, the card will accompany the OI MyHealth Passport, with the aim of enhancing the transitional care services.

The creation of the OI MyHealth Passport offers the OI community a new, easy-to-use resource to fill a gap in the provision of transitional care globally (Dogba et al., 2013). Nurses are uniquely positioned to use this free tool to help understand the patients' experiences (Manderson et al., 2011), and to actively involve patients in the management of their own care as well as fostering their autonomy (Kerr & O'Halloran, 2017). Often, individuals living with OI face healthcare professionals unfamiliar with their rare condition, resulting in loss of confidence and trust in their knowledge and skills (Carrier et al., 2018). Nurses need to reinforce the importance of patient self-advocacy, which includes patients communicating their expert knowledge to healthcare professionals and teaching them about their rare condition. The use of this tool, in partnership with the patient, serves as an excellent platform, for education and advocacy, and may help reduce the fragmentation associated with care transitions. With this passport containing conveniently summarized healthcare information tailored to the patient, feelings of anxiety and distress (Chesshir et al., 2013) and other potential complications associated with care transition may lessen (Manderson et al., 2011). Nurses will be key in implementing this passport and ensuring proper education and planning are conducted in their respective settings (Kerr et al., 2018).

Strengths and limitations

The development of the OI MyHealth Passport and corresponding 'cheat sheet' was derived from: (a) evidence supportive of use of the Good2Go Program and My Health Passport; (b) reliance on research derived from other 'passports' used in health care settings and; (c) the transition literature in OI and the ongoing research led by the study site (Carrier et al., 2018; Michalovic et al., 2015, 2016; Wang et al., 2018; Dogba et al., 2013) Efforts to remove potential biases associated with the development of the OI MyHealth Passport included the formation of an interprofessional task force, acknowledgment of no conflicts of interests, and the adoption of a rigorous methodology to critically appraise and synthesize all available evidence (Lenzer et al., 2013; Tsimicalis et al., 2011). The passport was created in collaboration with leading institutions in the provision of OI and transition-related care, and has already generated a few 'likes' by patients and families of the OIF Facebook community during its creation, suggesting potential uptake. Yet, the tool may not be generalizable or transferable to all contexts, and there is no research to confirm the effectiveness of such programs. Similar to other guideline creations, clinical reasoning is essential for the clinicians to ensure best clinical care, especially since the OI MyHealth Passport has not been evaluated in practice (Sniderman et al., 2013). Presently, there is no research that confirms the effectiveness of these programs, and the OI MyHealth Passport has not been evaluated in practice. Nevertheless, a rigorous methodology was adopted to critically appraise and synthesize all available evidence to create the evidence-based passport. While none of the information entered in the MyHealth Passport is kept by the Good2Go program, there is an inherent risk with the potential loss of personal information (*e.g.* date of birth, contact information). This loss of information may result from individuals keeping a hard copy in their wallet or sending a digital copy to their email address. This limitation may warrant discussion with individuals about privacy and confidentiality.

Future directions

Future quality improvement initiatives will commence to implement and evaluate the OI MyHealth Passport into routine practice in clinics. Initiatives will determine if the passport: a) facilitates continuity of care between the pediatric and the adult health care systems; b) guides individuals unfamiliar with the patient's medical condition how to handle an emergency situation accordingly; c) optimizes patient assessment and follow-up outcomes and; d) satisfies the needs of the OI community. Therefore, based on the needs of the OI community, the Task Force will update OI MyHealth Passport template in collaboration with members of the Good2Go Program. Members of the Good2Go Program are currently devising a mobile application for the MyHealth Passport; thus, the OI passport will also be available on mobile devices within the near future. We welcome users for their feedback, questions, and suggestions via the website's link, which appears when creating a passport.

Conclusion

The creation of the OI MyHealth Passport augments the resources available for the OI community who need resources to facilitate care transitions. Future quality improvement initiatives include implementing and evaluating the OI Passport into routine practice.

Conflicts of interest

The authors declare that they have no conflicts of interests.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijotn.2018.11.005.

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