Cogitare Enfermagem

ORIGINAL ARTICLE

# Perceptions and self-care practices of children and adolescents with osteogenesis imperfecta: a qualitative study

## HIGHLIGHTS

1. Children with OI engage in meaningful self-care in daily life.
2. Self-care is multidimensional: clinical, emotional, and social.
3. Persistent fractures demand adaptations and ongoing support.
4. Listening to children supports shared decision-making and individualized plans.

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## ABSTRACT

**Objective:** To understand the perception and self-care practices among children and adolescents with osteogenesis imperfecta. **Method:** A qualitative, descriptive study carried out with 14 children and adolescents at a public referral hospital in Brasília, between August 2024 and June 2025, using the Creativity and Sensitivity Dynamics–Body-Knowledge and thematic analysis. **Results:** The thematic analysis revealed three categories: (1) activities that promote self-care and participation; (2) recurrent fractures and functional limitations; and (3) activities that sustain self-care. **Final considerations:** Even in the face of the restrictions imposed by the disease, the children report strategies of protection, pain management, adaptations to the environment, and organization of activities to reduce risks and preserve autonomy and well-being.

**DESCRIPTORS:** Pediatric Nursing; Child; Adolescent; Osteogenesis Imperfecta; Self Care.

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## INTRODUCTION

Osteogenesis imperfecta (OI) is a rare genetic connective tissue disorder resulting from alterations in the synthesis of type I collagen, which lead to bone fragility and systemic complications, with a broad phenotypic spectrum and an impact on quality of life[1].

Clinically, the *Sillence* I-V classification is commonly used for practical purposes (from mild to severe, compatible with life, with specific features in type V), while also recognizing the recent expansion of molecular knowledge[2]. Therapeutic advances, such as the use of bisphosphonates, have shown improvements in bone mineral density and a reduction in fractures[3], but challenges persist regarding early diagnosis, access to treatment, and the day-to-day management of the condition by families[3-4].

Despite the literature's emphasis on medical interventions, everyday perceptions and practices of self-care, especially from the perspective of children and adolescents, remain underexplored[5]. In light of the theory of self-care (Orem) and of self-management approaches in chronic conditions, self-care is understood as the capacity to monitor signs, assess their intensity, and adopt strategies of protection and well-being, fostering functionality and autonomy appropriate to age[4].

Incorporating active participation, proportional to maturity, assent, and shared decision-making with the family and the team is central to more humanized and safe care practices[5-6]. In view of these gaps, this study asks: what is the knowledge about self-care among children and adolescents with OI?

Thus, the present study sought to understand the perception and self-care practices among children and adolescents with osteogenesis imperfecta.

## METHOD

This is a qualitative, descriptive-exploratory study, conducted through the Creativity and Sensitivity Dynamics (DCS), Body-Knowledge method, carried out between August 2024 and June 2025 at the Children and Adolescents Care Unit (UCA) of the Public Hospital in Brasília. In order to ensure scientific robustness, the writing of this study followed the precepts proposed by the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) guidelines for qualitative studies[7].

Fourteen children and adolescents participated in the study, aged between six and fifteen years, with a diagnosis of osteogenesis imperfecta and undergoing follow-up in the pediatric inpatient unit. As inclusion criteria, the clinical and cognitive capacity to understand and participate in the proposed activities was considered, in addition to the assent of the participants and the authorization of the parents and/or legal guardians. Those who presented acute clinical conditions, severe pain, and cognitive and/or communicative limitations that would preclude participation in the study activities were excluded.

The number of participants was defined by theoretical saturation, understood as the point at which new data collection no longer added relevant information about the phenomenon[8]. Data collection took place at the bedside, individually, during scheduled hospital infusions, in the presence of the guardians. Two instruments were used: (a) a form completed by the guardians, with sociodemographic, educational, and health information; and (b) the DCS/Body-Knowledge[9-10], used here as a mediating device for expression.

In the DCS, each child was presented with a human silhouette on A4 paper and was asked to draw and answer prompting questions: What is self-care to you? What do you

do to take care of your health because of osteogenesis imperfecta? How long have you had this disease? What things do you do to keep yourself safe and healthy? Is there any care that you fail to do? What is the hardest part of taking care of yourself? Considering the variation in age and schooling, the script was adapted to favor comprehension. No aesthetic analysis of the graphic production was carried out; the drawing served to elicit narratives. The statements were audio-recorded, fully transcribed, and subsequently analyzed through thematic analysis[11]: pre-analysis; exploration of the material; treatment and interpretation.

Regarding ethical aspects, the project was approved by a Research Ethics Committee (Opinion No. 7.118.001). To preserve the anonymity of the participants, alphanumeric codenames were used (P1, P2, P3...), corresponding to the identification of the statements.

## RESULTS

The results regarding the profile of the children and adolescents with osteogenesis imperfecta totaled 14 participants (n = 14). Regarding the descriptive variables, the participants' age range varied from six to 15 years, with a mean of 10 years. The number of people in the household ranged from three to six residents, with a mean of four individuals per household. As for family income, variation was observed between one minimum wage and R$ 10,000.00, with a mean of R$ 4,890.00.

It was observed that 13 participants were enrolled in and attending school; the only absence was explained by difficulty of access associated with the location of the residence. The participants are distributed from the 1st to the 8th grade of elementary school. As for the effect of osteogenesis imperfecta on school performance, eight (57.1%) reported a negative impact on achievement. Among the type IV children, generally of intermediate severity, four are in the group that reported no impact.

Regarding the diagnosis of OI, 10 (71.4%) children were identified while still in the neonatal period or before completing one year of life, whereas three (21.4%) received the diagnosis during the gestational period through prenatal examinations. In one case (7.1%), the diagnosis was established after the first year of life. The presence of special health needs was observed in the school context, with repercussions on the learning process and academic performance. It was also identified that, in the more severe forms of osteogenesis imperfecta, the diagnosis can be established while still in the intrauterine period or at birth, whereas, in the postnatal period.

In the postnatal context, the diagnosis is based on family history, clinical-radiological findings, and bone densitometry. Regarding the history of previous hospitalizations, 13 (92.9%) children reported at least one prior hospitalization. The only participant without a previous hospitalization had type IV osteogenesis imperfecta, a classification generally associated with intermediate severity. The number of hospitalizations ranged from one to >30 over the years. The duration of the hospitalizations ranged from one day to three months, with a typical stay of between one week and 15 days per episode.

Regarding the regular use of home medications, five (35.7%) children reported calcium, vitamin D, and bronchodilators. As for fractures, wide variation was observed, from six to 200 events per child over their lifetime, with an approximate mean of 40; the highest frequency was concentrated in Type III cases. Regarding orthopedic interventions, eight (57.1%) had already undergone intramedullary rod surgery.

The thematic analysis revealed three categories: (1) activities that promote self-care and participation; (2) recurrent fractures and functional limitations; and (3) activities that sustain self-care.

## Category 1 - Activities that promote self-care and participation

The narratives indicate that self-care is conceived as a central practice for protecting life and health, articulating objective and subjective dimensions of living with OI. Statements emerged that directly associate self-care and personal responsibility:

*I think self-care is when we really value our health.* (P1)

*Taking care of yourself is like taking care of our only life. We only have one life, so we need to take very good care of it.* (P2).

Beyond the prescriptive dimension, the meaning also rests on affects and well-being:

*Self-care is happiness. To me it is happiness.* (P3)

*It is having responsibility for yourself; taking care of yourself and preventing everything that can hurt you.* (P4)

The DCS/Body-Knowledge also favored the expression of these meanings through graphic productions, as illustrated in Figure 1.

**Figure 1.** P3. Brasília, DF, 2025
Source: The authors (2025).

Such statements reveal that the children construct a situated "know-how," in which vigilance over risks coexists with the pursuit of joy, belonging, and continuity of daily life.

In parallel, situational risk adjustments are consolidated, an organizing axis of daily life:

*I do my best not to get hurt; I don't get into fights.* (P2)

*Avoiding getting hurt.* (P5)

Although protective, such strategies imply a restriction of experiences typical of childhood; nevertheless, when mediated by family, school, and team, they enable gains in autonomy and perceived normalcy:

*I live like a normal person; I don't keep thinking that I'm going to get hurt.* (P1)

*I like to play […] and go to school too.* (P3)

## Category 2 - Recurrent fractures and functional limitations

The narratives indicate that, even when they incorporate protective routines and management strategies learned while living with OI, the children remain exposed to recurrent episodes of fractures and to relevant functional limitations. Such recurrence marks a structural limit of self-care in the face of the bone fragility intrinsic to the condition. The statements make explicit the magnitudes and topographies of fracture:

*I've already broken my spine twice, then my leg again, and then my wrist.* (P2)

*I've fractured more than 200 times.* (P6)

The statements refer, simultaneously, to the physical and emotional impact of these events. The experience of recovery is also incorporated into the repertoire of self-care, as suggested by the representation of the plaster cast immobilization in Figure 2.

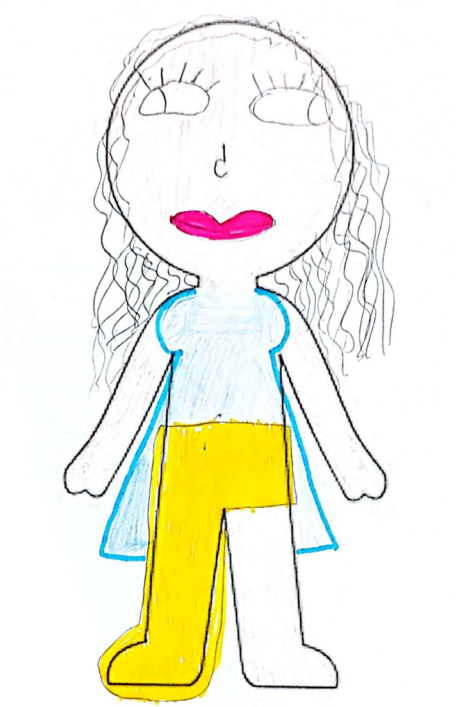

**Figure 2. P7. Brasília, DF, 2025**

Source: The authors (2025).

Faced with this scenario, the children develop situational micro-adaptations aimed at calibrating risk and presence in the world. They describe everyday calculations that operate as protective heuristics:

*I have to calculate how much I have to run so as not to get hurt.* (P8)

*I do what everyone does, only with some adaptations. Staying as still as possible.* (P9)

Such adjustments, although they signal agency and practical competence, impose a regime of constant vigilance over the body, with evident subjective costs: a reduction in playful spontaneity, a retraction of initiatives, and the need to anticipate danger scenarios in ordinary contexts (play, movements, interactions with peers).

### Category 3 - Activities that sustain self-care

The narratives indicate that self-care is sustained, to a large extent, by engagement in physical, therapeutic, and artistic activities that preserve freedom, pleasure, and identity, even under the restrictions imposed by osteogenesis imperfecta. The children describe participation in varied modalities, often adapted to their functional conditions, demonstrating movement as a form of self-care:

*I can do ballet, soccer, volleyball, swimming... a lot of things.* (P2)

*I used to do physical therapy and I also used to swim.* (P7)

*I do art therapy, music therapy.* (P10)

In the school context, the experience is described as diverse and possible with supports and adjustments:

*In physical education, I can do a lot of things... soccer or dodgeball... there are more games too, it's varied.* (P9)

## DISCUSSION

The findings reveal that self-care, for children and adolescents with OI, is less a set of prescribed tasks and more a performative arrangement that combines meanings (protecting life, feeling well), bodily/therapeutic routines, and situational micro-adjustments to risk. This configuration shifts the notion of "adherence" as binary and reconstructs it as a practical competence distributed among the child, family, school, and health services. Such a reading converges with approaches to self-care in chronic conditions that describe it as a process of resignification and a project of autonomy, not mere compliance with instructions[4-6].

At the center of the analysis is the safety-participation paradox. The children construct protective heuristics (calculating how much to run, doing things with adaptations), but the persistence of recurrent fractures indicates a structural limit of self-care in the face of the bone fragility inherent to OI. This limit does not stem from a "lack of care," but from the relationship established between the elevated baseline risk (especially in more severe phenotypes) and the living environments (school, leisure) that presuppose mobility and unpredictability. The literature describes a gradient of fracture severity by type (greater in type III, intermediate in type IV), which helps to understand why prudential strategies can reduce, but not eliminate, events[12-13].

The analysis also highlights the ecological character of self-care. In addition, the data suggest that the experience with the condition is marked by different strategies of care and coping, which demand continuous follow-up and interventions adjusted to the individual needs of each child[14-15]. Likewise, dietary choices that prioritize calcium with good bioavailability and vitamin D have biological plausibility[16]; however, their real effect depends on the therapeutic set and the phenotype. Therefore, what appears to be "individual self-care" is, in practice, co-produced by family, school, and clinical arrangements.

Self-care in children and adolescents with chronic conditions should be understood as a relational, progressive process that is strongly mediated by the family, school, and care context, and not only as individual adherence to therapeutic recommendations. Studies have shown that, in these conditions, everyday care frequently has repercussions on the organization of the family routine, continuous vigilance in the face of risks, and the need for negotiation between protection and autonomy, with a direct impact on both the child and their caregivers[17-19]. In this scenario, self-care is constituted in a shared manner, sustained by situated learning, emotional support, and the agreement of strategies compatible with the clinical and social needs of childhood[18-19].

Among the findings of the present study, play emerged as a central element, although historically undervalued in contexts of chronicity. The literature points out that play is a structuring activity of child development, with repercussions on cognition, socialization, emotional expression, and quality of life, including among children and adolescents with physical limitations or chronic diseases[19-21]. In the case of osteogenesis imperfecta, play acquires even greater relevance because it represents not only a playful experience but also a form of belonging, bodily experimentation, and preservation of childhood, provided that it is mediated by adaptations and minimal safety conditions[22-23]. Thus, more than restricting the activity, care needs to favor possible, safe, and meaningful modalities of play, preventing protection from turning into a deprivation of experiences characteristic of childhood.

The school, in turn, was constituted as a decisive space of coexistence and participation, although this aspect requires greater analytical depth. Evidence from the literature shows that the school experience of children and adolescents with chronic conditions is crossed by challenges related to accessibility, stigma, pedagogical adaptations, and the management of physical activities, but it can also be a powerful setting for inclusion, the strengthening of bonds, and the development of autonomy[24-25]. In the case of osteogenesis imperfecta, the presence of institutional supports, reasonable adaptations, and qualified interaction with teachers and classmates contributes to expanding participation and reducing the impact of functional limitations on the daily school routine[20-22]. In this way, the school should not be understood only as a space of attendance, but as a territory for the production of belonging and social recognition[21].

The data also indicate that the children seek to maintain practices compatible with everyday life, such as attending school, playing, and participating in activities adjusted to their possibilities, which expresses a permanent tension between risk and participation. This negotiation is recurrent in other pediatric chronic conditions and reveals that the quality of care depends on the capacity to sustain sufficient safety without producing isolation or excessive restriction[17,23]. In osteogenesis imperfecta, this balance is particularly relevant, since bone fragility imposes real limits but does not eliminate the need for experiences of autonomy, sociability, and movement[2,12,24].

From a care perspective, the findings reinforce the role of Nursing and multiprofessional teams in formulating care strategies centered on the child, the family, and social participation. This includes individualized guidance, support for shared self-care, planning of safe activities, coordination with the school, and valuing play as a legitimate component of health care[23,25]. Thus, the results indicate that caring in osteogenesis imperfecta requires recognizing that protection, when excessive, can reduce opportunities for development, whereas qualified care should foster autonomy, inclusion, and quality of life[14,25].

The regime of vigilance necessary for the prevention of traumas imposes subjective costs, expressed by the reduction of playful spontaneity, the self-restriction of initiatives, and the permanent need to anticipate risk scenarios, effects already described in the literature on pediatric chronicity[16-18]. Simultaneously, markers of biographical continuity emerge (going to school, practicing sports, doing what everyone does, with adaptations)

and goals of competence (eating on one's own, opening doors, riding a bicycle) that function as indicators of self-efficacy and belonging.

The literature on participation and physical activity in childhood with chronic conditions supports this dual movement: functional and social benefits when there is adaptation and supervision, but also structural barriers and a risk of sedentary behavior if the system does not offer the means[21,25]. Therefore, the children construct, in practice, a balance between protection and participation, accepting residual risks when these are perceived as smaller than the gains in autonomy, inclusion, and quality of life[14,24].

Some mechanisms help to explain this picture: situated learning, through which clinical information is converted into everyday practices adjusted to pace, intensity, and context; the support of the family and the school, which enables progressively safer experiences; and the active role of the team, through guidance, warning signs, and contingency plans[17-24]. When these elements are articulated, self-care ceases to be essentially defensive and comes to assume a proactive character[14-19].

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Regarding transferability, the results dialogue with other pediatric chronic conditions that demand continuous negotiation of risk, but OI imposes specificities, bone fragility, and phenotypic heterogeneity, which limit generalizations and reinforce the requirement for individualized plans[1-3]. A notable contribution of the study is the centrality given to the child's voice, generally mediated by adults in OI; this centrality exposes gaps in approaches that focus only on preventing fractures and disregard participation in the composition of quality of life.

Among the limitations, the intentional sample from a single referral service and the wide age range, which brings together different stages of development, stand out. The absence of longitudinal follow-up restricts inferences about the relationship between self-care strategies and the occurrence of fractures over time.

In terms of implications for Nursing and multiprofessional teams, the data support: (a) active listening and shared decision-making proportional to maturity, with the child as a subject of care; (b) prevention protocols oriented toward participation rather than interdiction, with playful materials, checklists, and contingency plans for falls and post-fracture management; (c) prescription of movement with graduated goals and load/recovery indicators; (d) school arrangements for reasonable adaptations in physical education and recess; and (e) clinical monitoring that includes, in addition to biomedical outcomes, person-centered indicators such as participation and self-esteem. In view of this, the analysis indicates that caring in OI is to articulate sufficient safety with meaningful participation; when the care system is capable of producing this balance, children's self-care ceases to be a strategy of containment and becomes a device for life.

## FINAL CONSIDERATIONS

The participating children and adolescents understand self-care and incorporate it into daily life through strategies adjusted to their reality, such as the correct use of medication, guided nutrition, prevention of traumas, and engagement in adapted physical and therapeutic activities. The statements indicate that self-care exceeds the

biological dimension, encompassing emotional and social components that foster the construction of autonomy and the continuity of daily activities.

The implications for practice include the need to organize child-centered care, with shared decision-making, educational materials appropriate to the age range, individualized plans for the prevention of traumas, and intersectoral coordination with the school to enable safe participation. For future investigations, the conduct of longitudinal studies and the evaluation of co-produced interventions that integrate health education, safe-handling training, and prescription of adapted activity are recommended.

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**Role of Authors:**
Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Resende TJ, de Morais RCM.** Drafting the work or revising it critically for important intellectual content - **Resende TJ, Boeckmann LMM, Amaral FMGS, Barbosa LR, de Morais RCM.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Resende TJ, de Morais RCM.** All authors approved the final version of the text.

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The authors have no conflicts of interest to declare.

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