

Exploring Osteogenesis Imperfecta: A Clinical Condition Through an Autobiographical Narrative Perspective in Trying To Grow

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Abstract

This article aims to explore and gain a deep understanding of Osteogenesis Imperfecta (OI) through personal narratives that focus on lived experiences. The primary objective of this article is to examine the clinical and social definition of OI as a medical condition by analysing its clinical characteristics. Then, to analyse the lived experience of the author, focusing on how the condition personally impacts their daily life and shapes their individual perspective. To further explore how OI restricts individuals in achieving their goals in life. Firdaus Kanga, a notable Indian writer, describes his struggles of being born with OI in his semi-autobiographical novel *Trying to Grow* (1990) in the Indian context. This article delves into exploring OI as a medical condition through an objective clinical lens. This article fills the critical gap by analysing the lived subjective experience as portrayed through *Trying to Grow*. Through analysing the lived narrative, this article reveals that OI is more than a clinical diagnosis and it is a complex personal experience shaped by various factors. Ultimately, this study demonstrates that the medical condition OI, through *Trying to Grow*, provides a profound understanding of the challenges faced by people living with OI.

Keywords: Osteogenesis Imperfecta, medical condition, narrative, literature, biography.

Introduction:

Disability studies is defined as the “discipline which reformulates the study of disability by perceiving the problem of disability as a social phenomenon, social construct, metaphor and culture” (Karna, 2001, p. 250). Disability Studies emerged as an interdisciplinary field in the late twentieth century, and still, there occurs new emergence that relate various fields to disability studies. Disability literary perspectives help understand the structure, genre and narrative form that shifts the theoretical paradigm in a new perspective (Hall, 2015). Historically, disability studies have shifted in understanding throughout the years from different models to clear perspectives and understandings.

Disability studies initially evolved from the idea of the medical model, which views disability as a problem in the body and mind that is to be treated (Zaks, 2023). Then there arises a shift in understanding that disability is not merely always a medical condition to be treated, but a focus moved from a medical view to a social view emerged then focused on viewing disability through a social model lens perspective. By the 1980's and the 1990's, the social model was the prominent model that introduced the concept to include societal and environmental barriers that made a person's disability even more difficult to survive with the existing disability in their body (Marks, 2014).

Then arose the biopsychosocial model in the mid-20th century, which stemmed from the 1960s- 1990's it, rooted as a response to the bodily limitations form medical model and invoked an idea to view disability as biological, psychological and social factors involved in it (Lumen Learning, n.d.). Some medical conditions are viewed through the lens of connecting two models for a better understanding. Disability is not seen through the ideas of the medical model, that the problem is within the body, or through the social model's idea that society fails to accommodate them, but it is tangled with both together. Osteogenesis Imperfecta is a medical condition that connects the ideas of the medical and social models in reality (Goodley et al., 2014; Naraian, 2021).

With this understanding this present study aims to examine the clinical and social definition of Osteogenesis Imperfecta by analysing its clinical characteristics, to understand the condition through the lived life narrative of Firdaus Kanga's *Trying to Grow*. Additionally, to analyse the lived experience of the author to explore how the medical condition personally shaped their daily life and individual perspectives.

Literature Review:

The article titled “A systematic literature review of the impact and measurement of mobility impairment in rare bone diseases” (2025) by Ines Alves et.al., discusses that mobility impairment in rare bone disease is not just a physical problem; it affects the person's daily activities, including pain in walking, difficulties in personal care and also affects the quality of life. This study also contributes to the current measurement tools, which are limited

because many do not fully capture real-life disability or the burdens experienced by patients. In simple terms, this study aligns with the idea that the problems in movement create long-term practical and emotional strain, and not only medical difficulties. This previous study helps in explaining why disability is related to Osteogenesis Imperfecta, and congenital conditions often become a financial burden since the reduced mobility makes the affected more dependent on care, assistive devices, proper treatments and physical support.

Labanca et al. in the article titled “Clinical-functional features of individuals with Osteogenesis Imperfecta and Ehlers-Danlos syndromes: A scoping review of assessment tools and ICF model” (2023) found that individuals with Osteogenesis Imperfecta and Ehlers-Danlos syndrome experience multiple functional limitations that include pain, fatigue, impaired balance and reduced mobility, which affects both the bodily function and daily participation of persons affected. This review also states that the existing assessment tools are varied and do not fully capture the lived impact of these conditions. Thus, this review contributes to the reduced mobility and chronic functional limitations that often increase dependence on care, transport, treatment, and assistive devices, which can add to the financial burden of disability.

Engelbert et al., in the article “Osteogenesis imperfecta in childhood: impairment and disability--a follow-up study” (1999) exhibits how children with Osteogenesis Imperfecta impairment parameters, such as joint motion and muscle strength, did not change significantly over follow-up, while some disabilities related outcomes were improved. This article suggests that treatments should focus not only on physical impairments but it should be also on improving functional ability in everyday life.

The qualitative study “Living with osteogenesis imperfecta: A qualitative study exploring experiences and psychosocial impact from the perspective of patients, parents and professionals” (2021) by Hill et al. demonstrates that Osteogenesis Imperfecta includes the consequences that are beyond bodily fragility, by affecting emotional health, family relationships and the management of everyday life. These authors emphasise that the recurrent fractures, pain, fatigue and mobility limitations can restrict daily activities and increase the intensity of the support needs that affect them and their families.

Research Gap

Previous studies on Osteogenesis Imperfecta include exploration of the condition as a clinical diagnosis, clinical features of its genetic traits, complications associated with it, and pathological and epistemological understanding. Yet, a notable gap remains in the exploration of Osteogenesis Imperfecta in a qualitative study and more through the reconstruction from lived narrative than the pattern of recessive cause. This study addresses the gap by centring the lived, first-person experience of living with Osteogenesis Imperfecta in an Indian narrative.

Objectives

1. To examine the clinical and social definition of Osteogenesis Imperfecta as a medical condition by analysing its clinical characteristics.
2. To understand Osteogenesis Imperfecta as a medical condition through the life narrative *Trying to Grow*.
3. To analyse the lived experience of the author, focusing on how the condition personally impacts their daily life and shapes their individual perspective.

Methodology

The methodology adopted for this study is qualitative textual analysis based on critical disability studies. The primary text *Trying to Grow* is examined and explored through a close reading method to identify how disability, identity, embodiment, familial relations and social exclusion are represented in the narrative. This method is interpretative rather than empirical data that focuses on the language, characterisation, plot structure and symbolic patterns throughout the novel that constructs subjectivity of people with disabilities. Thus, this approach attempts to examine how the text challenges the ableist norms and reimagines disability as a medical condition through the primary text.

Discussion

Osteogenesis Imperfecta – an overview:

Osteogenesis Imperfecta, also known as brittle bone disease, was first named in 1849 by Dutch anatomist Willem Vrolik, a pioneer in the field of vertebrate teratology, which is the study of abnormalities that involve the physiological development in organisms during their life span (Baljet, 2002, p.1). Historically, a few pieces of

literature related to medicine state that the coinage of this term is also attributed to the French physician Jean-Francois Lobstein, who contributed to the understanding of this medical condition in 1835. Osteogenesis Imperfecta is a rare genetic disorder that affects the connective tissue, characterised by bones that fracture easily, and often it's from little or no apparent trauma (Osteogenesis Imperfecta Foundation, 2003; Rauch & Glorieux, 2004).

It's found that the prevalence of Osteogenesis Imperfecta is about 1/15,000-20,000, including the diagnosis after birth, it's observed to be much less compared to other impairments related to bones, which are mainly characterised by the symptom of fragile bones, skeletal deformities, and abnormal, frequent fractures. (Chaugule et al., 2025; Hartman & Judy, 2003; Kruse, 2020). It is observed to affect males and females in the same proportion, and it's not gender specific like other diseases (Hartman & Judy, 2003, p. 1). This can sometimes cause severe physical complications that lead to intrauterine fractures, in the bone that can happen before birth, while the baby is still in the womb, or Perinatal lethality, causing the death of the infant during birth or soon after, and the prevalence is very low due to the perinatal mortality (Byers & Rustad, 2020; Kruse, 2020; Rauch & Glorieux, 2004).

Structurally, for a person with Osteogenesis Imperfecta, the bones may appear harder at the material level, as they contain more minerals or might feel denser; however, even then, they can break when deformed or pressured, or stress is applied and even when daily simple tasks are done (Rauch and Glorieux 1379&80). Osteogenesis Imperfecta is also a genetic disorder that mainly affects the pathogenic variations COL1A1 and COL1A2 that interfere with type I collagen production, and this results in bone fragility and multi- system issues in the bone and body (Wallace et al., 2026, p.1).

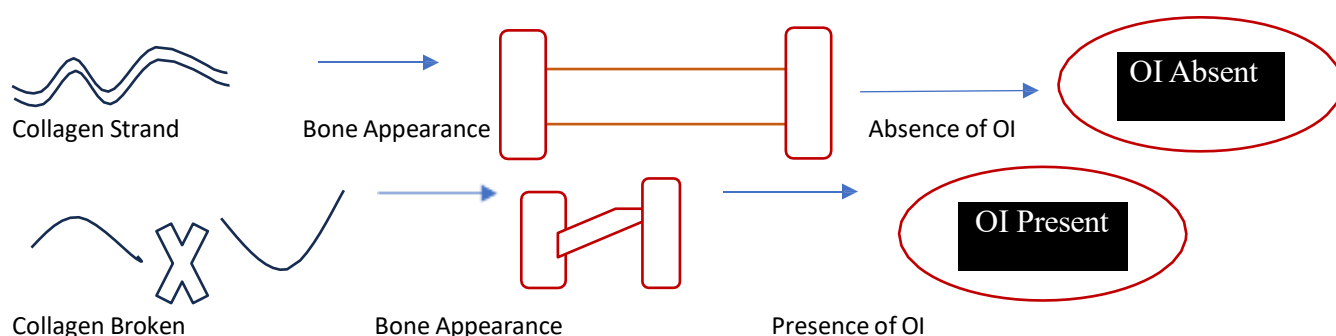


Fig. 1 shows the appearance of the broken collagen and the presence of OI.

The following Fig.1 shows the appearance of the collagen present in the bones and the appearance of the bone if Osteogenesis Imperfecta is present and absent (Chaugule et al., 2025, p. 598). If the collagen strand appears to be normal, then the bone also appears normal, and the person is free from Osteogenesis Imperfecta, but if the collagen strand appears to be broken in shape, then the bone is fragile and prone to break, and this is diagnosed as the presence of Osteogenesis Imperfecta (Wallace et al., 2026, p.1).

Osteogenesis Imperfecta and its types:

Osteogenesis Imperfecta is classified into several types based on its impact on one's body. Type 1 is the mildest form; it has characteristics such as blue sclera, hearing deficits and multiple fractures in the bone. This genetic basis is caused by COL1A1 or COL1A2 mutation that reduces type 1 collagen production; its inheritance pattern is autosomal dominant (Deguchi et al., 2021; Sam & Dharmalingam, 2017). Type II is the most severe, that are often fatal before or soon after birth, involving extreme bone fragility and respiratory issues. The genetic basics of this type include severe collagen gene mutation, and its inheritance pattern is autosomal and dominant (Etich et al. 2020; Fratzl-Zelman et al. 2015).

Type III has the characteristics of severe bone abnormalities accompanied by multiple fractures, short stature and spinal curvature. The genetic basis of this type includes COL1A1 or COL1A2 mutation, causing structural defects, which follows the inheritance pattern of autosomal dominance (Balusani et al., 2025; Etich et al., 2020). Type IV consists of characteristics such as moderate severity, mild to moderate short stature, involving bone abnormalities and also normal or blue sclera. The genetic basis of this type is collagen gene mutations; its inheritance pattern is autosomal dominant (Semler et al., 2012).

Osteogenesis Imperfecta includes many other types, too, but these four are the dominant types. Kanga was diagnosed with Type III, due to the reasons that he is only four feet tall, his bones break easily, and his teeth break easily. These are evident through his semi-autobiographical narrative *Trying to Grow*.

Table 1. Evidence of the characteristics through the narrative, *Trying to Grow*.

Type III – Characteristics	Evidence through narratives
Frequently breaking bones	“Your boy is born with bones as brittle as glass” (Kanga, 1999, p. 30) “His bones are brittle like biscuits; you hold him too hard, they’ll crumble” (Kanga, 1999, p. 31)
Short stature	“I’m four feet” (Kanga, 1999, p. 152) “He’ll grow till he’s four feet tall.” (Kanga, 1999, p. 35)
Breaking of teeth	“His teeth will break as soon as he bites into anything hard” (Kanga, 1999, p. 30). “My teeth would battle with the chocolate” (Kanga, 1999, p. 33).
Triangular face structure	“His face is a perfect triangle!” (Kanga, 1999, p.31)

Osteogenesis Imperfecta affects:

Osteogenesis Imperfecta results in fracture susceptibility, where Osteogenesis Imperfecta lead to bones that are fragile and brittle, which can break easily, and it affects the long bones such as the femur, tibia and humerus (Bishop, 2016; Rauch & Glorieux, 2004). This includes the skeletal abnormalities such as spinal deformities, limb deformities and chest wall abnormalities that lead to respiratory issues (Bishop, 2016; Castelein et al., 2019). This also affects the growth impairments resulting in abnormal bone growth as short stature, and worsened by the repeated fractures (Botor et al., 2021; Deguchi et al., 2021; Marini et al., 2017; Rauch & Glorieux, 2004). Osteogenesis Imperfecta comprises the ocular manifestations, where the blue sclera is due to thin collagen- rich connective tissue, revealing the blood vessels (Reurniet et al., 2022; Thomas & DiMeglio, 2016). The auditory issues comprise hearing loss, typically starting in early adulthood due to middle ear bone anomalies (Balusani et al., 2025; Carré et al., 2019). Dental issues are also accompanied by discolouration in teeth with weak dentin structure (Balusani et al., 2025; Ventura et al., 2024). Their skin also appears to be delicate, with frequent bruising resulting from weakness in the connective tissue (Sam & Dharmalingam, 2017; Yu et al., 2023). The systemic impacts on skeletal structures and connective tissues (Deguchi et al., 2021; Marom et al., 2020). Thus, these are the ways that Osteogenesis Imperfecta affects one's body internally and externally.

Treatments for Osteogenesis Imperfecta:

The treatments for persons with Osteogenesis Imperfecta include Bisphosphonates that help improve bone density, reduce fractures and relieve bone pain. Typically, this is used with Vitamin D and Calcium (Gnoli et al., 2023; Liu et al., 2023; Palomo et al., 2017). Denosumab is an alternative used for patients as an unresponsive to bisphosphonates. Antisclerostin antibodies that encourage bone formation are considered a potential new treatment (Balusani et al., 2025; Liu et al., 2023). Surgical interventions, such as metal rods in long bones, provide stability in preventing deformities (Balusani et al., 2025; Thomas & DiMeglio, 2016). Physical therapy helps in enhancing mobility by strengthening the muscles and coordination through non-jarring exercises (Botor et al., 2021; Deguchi et al., 2021; Etich et al., 2020; Palomo et al., 2017; Thomas & DiMeglio, 2016). Assistive technology usage, such as wheelchairs, walkers and braces, to maintain independence (Cho et al., 2020; Hoyer-Kuhn et al., 2015). Gene therapy and stem cell therapy aim to correct genetic defects that cause Osteogenesis Imperfecta and improve bone formation by repairing (Balusani et al., 2025; Schindeler et al., 2022).

Kanga as a Lived Experience:

Firdaus Kanga is an Indian writer in the field of Literary disabilities. He was born in 1961 in Bombay to a Parsi family with Osteogenesis Imperfecta. Due to this, he has spent most of his childhood bedridden, not attending school, and only leaves his home occasionally to engage with family and watch cinema. In his nineteen years, he got his own wheelchair. His family wanted him to become a solicitor, but his experience in law school was not satisfying him, and he started studying journalism. In 1987, he was awarded the prize in the British Council short-story competition. He then moved to England in 1989 and began his career in publishing after completing his

degree from the University of Bombay. He published *Trying to Grow* in 1999, a semi-autobiography as his own life narrative that covers being in a wheelchair and in India. *Heaven on Wheels*, in 1991 a travelogue that shares his travel experience from India to England, and now it is said that he is working on another novel that is set in India (Hawley, 2003).

This article focuses on the semi-autobiographical novel *Trying to Grow*, as it shares the medical experiences not in a clinical way but through his narratives. His narratives share deeper insights about the medical conditions that are explained in many of the clinical books and articles. Kanga describes Osteogenesis Imperfecta as a medical condition through the character Brit Kotwal, as he was named Birt by his sister because his bones were fragile and brittle that can break easily.

Osteogenesis Imperfecta and Trying to Grow

Diagnosis and physical suffering:

Osteogenesis Imperfecta, as a medical condition, mainly affects the bones. The doctor diagnosed that Brit is affected by Osteogenesis Imperfecta, he says, “Your boy is born with bones brittle as glass” (Kanga, 1999, p 30). He then describes the depth of understanding this medical condition, as the bones will be fragile and it should be cautiously cared for like a glass, he says, “his legs are delicate as test tubes; I doubt he’ll ever walk” (Kanga, 1999, p 30). The Doctor again stresses about this condition that Brit should be careful, even while eating, he utters, “his teeth will break as soon as he bites into anything hard” (Kanga, 1999, p.30), which is another symptom of Osteogenesis Imperfecta type III. Brit himself says that these conditions mentioned by the Doctor were very true. He says, “The doctor was proved right. I broke my legs eleven times before I was five years old” (Kanga, 1999, p.33). He then expresses his extreme suffering by stating that “I didn’t just live with this bunch of weirdos, I also lived with osteo. Or, to give the devil his full name, osteogenesis imperfecta” (Kanga, 1999, pp.30). These quotes, directly from the semi-autobiographical narrative, share the reasons and how he was diagnosed with Osteogenesis Imperfecta and the physical sufferings involved in it.

Pain, Fear and Daily Struggle:

Kanga doesn’t think that he is different from others around him; he always embraces who he is. It is evident through the quote from the novel that Brit says, “I liked being different from most people” (Kanga, 1999, pp.30). Not just Brit tries to normalise him, but his parents are also trying to make him comfortable and normalise him by framing disability as a difference in identity by saying “he’s a boy like any other; only his body has problems” (Kanga, 1999, pp.31). The character Brit himself says that “It tickled me. Though it didn’t tickle me when I came into life howling with pain” (Kanga, 1999, pp.30) and expresses his struggles of surviving with Osteogenesis Imperfecta in real life. Even though he acts casual, he still has the fear that his bones might break even while doing the regular activities that he does. His fear is seen when he utters “Bone-deep fear stays” (Kanga, 1999, pp.44). Brit also shares his experience of being with Osteogenesis Imperfecta and carrying the struggles of feeling awkward about being fragile; he states, “It tickled me. Though it didn’t tickle me when I came into life howling with pain” (Kanga, 1999, pp.30).

Kanga, through Brit, expresses his pain that he underwent because of being affected with Osteogenesis Imperfecta; he says that “Four times worse than anyone else’s” (Kanga, 1999, pp.44). This line from Brit clearly states the worst pain, which made him utter this. His pain from the broken bones gave him the fear of living that expresses the trench of pain, saying, “Maybe this time it will kill me. Maybe” The nights were the worst.). He then emphasises sleeping with pain and states that during nighttime, the pain will be more severe compared to daytime. He states, “The nights were the worst” (Kanga, 1999, pp.44) and also “Sleeplessness drove my thoughts recklessly round the craziest bends” (Kanga, 1999, pp.44) through which empathy for him can be felt. He then remembers the silence that always surrounds him as “No one to divert me with whispers” (Kanga, 1999, pp.44). He expresses a silence that had offered no distraction from the pain that he suffered alone.

Social Life, Stigma and Identity:

He challenges the norms about bravery, which means not suppressing pain but insisting that honesty about suffering is more courageous. He articulates this through the quote “I don’t think so. I’d be brave if I didn’t cry when I broke my leg” (Kanga, 1999, pp.56). The limitations of being with Osteogenesis Imperfecta are also captured in the book as Brit says, “But you know how it is, when you can’t do some things people feel you can’t do anything” (Kanga, 1999, pp.50), through which he expresses that one’s limitation can be misread as total incapacity in the eyes of others.

Osteogenesis as a medical condition sometimes made him erase his gender, and people saw him as a person with disability first and then brought in his gender “I wasn’t male” (Kanga, 1999, pp.40). The society around him has derived an equation involving the medical condition that excludes him from his desire: “The magic mirrors of their minds had invented a formula: osteo = sexlessness” (Kanga, 1999, pp.40). He then expresses that the small acts can become as claiming dignity and autonomy for him. This is explained in the quote “I felt I was kind of enforcing my rights. That’s all” (Kanga, 1999, pp.60).

Agency, Resistance and Self-awareness:

He reflects on the invisible cost of cruelty by suggesting that harm rebounds on its doer. He states, “That when you do something awful to someone, you end up doing something worse to yourself” (Kanga, 1999, pp.60). He then includes a metaphor that insists on the fluid perspective: “You can look at a scene from a thousand different windows, and you’ll see something new every time” (Kanga, 1999, pp.55), through which he gains positivity about creating his identity. He observes the value of the vulnerability, and the value lies in making the cherished easily broken. It is mentioned that “Precious things are brittle, aren’t they?” (Kanga, 1999, pp.55). He also mentions being honest about his limitations as a form of courage, even when it contradicts the heroic myths; he states, “That’s brave! Being able to say you’re not” (Kanga, 1999, pp.56).

Perception, Family and Emotional complexity:

When the surroundings restrict him from believing that someone with a body with disability, he was very brave to say and differentiate things that he was able to do and not able to “People are going to find it very difficult to trust you to solve their problems” (Kanga, 1999, pp.63). He set an example of being the source of wisdom or help. He names the absurd logic that equates the physical difference with intellectual deficiency, he states, “To a lot of people you seem stupid because you are so short and, I know it’s absurd, because you can’t walk” (Kanga, 1999, pp.63). He addresses the weary tolerance in acknowledging that people’s limited vision is shaped by their own fears; he states it as “I can’t blame them” (Kanga, 1999, pp.63). His surroundings emphasise that intelligence is viewed with suspicion when it appears in a body with disability, one of the character states “He’s a s-m-a-r-t one” (Kanga, 1999, pp.52). Brit values independence and resisting the expectation that he must always be accompanied or managed by someone. He states, “I didn’t want someone always to be there” (Kanga, 1999, pp.59).

Findings:

Thus, the analysis reveals that an understanding of Osteogenesis Imperfecta can also be gained through clinical articles and books. The central finding of the study focuses completely on Osteogenesis Imperfecta, a chronic illness, by analysing it as a medical condition through a lived life narrative, *Trying to Grow*, which provides various insights about being born and surviving with Osteogenesis Imperfecta. The life narrative *Trying to Grow* also focuses on living with Osteogenesis Imperfecta, accompanied by the psychological aspects, such as living with pain, fear that leads life, struggles that are involved, the social stigma that surrounds, the identity involved in agency through resistance and self-awareness, the perception involved in family and being with emotional complexity.

Scope for Further Study:

Further, there can be studies conducted on focusing on explaining the medical conditions through narratives that are not explored and need awareness to the readers. Medical conditions and their expenditure involved in Osteogenesis Imperfecta can also be discussed in future studies.

Conclusion:

This study on exploring Osteogenesis Imperfecta as a medical condition through the life narrative helps in understanding a clinical condition that was underexplored. *Trying to Grow* provides immense ideas about how a person with Osteogenesis Imperfecta is diagnosed, lives, and struggles to live with pain and sufferings that surround him as a social stigma. Being with disability itself creates social stigma, but living with a chronic illness that is still under recognition makes his life difficult in the Indian context.

Through this analysis, this study has demonstrated that Osteogenesis Imperfecta is both a clinical condition and a deeply lived experience. *Trying to Grow* communicates this condition beyond medical description, and also reveals how it shapes the author’s daily life and identity involved in the medical condition.

Conflicts of Interest:

The author declares no conflict of interest with respect to the study.

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