

Narrative empowerment: life stories of young people with osteogenesis imperfecta and the reconstruction of public perceptions

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Abstract. People with rare diseases are often represented through medical labels and vulnerability narratives. Osteogenesis Imperfecta (OI), called "porcelain doll disease," is easily reduced to fragility, dependence, and incapacity. Charity-centered communication may attract attention but obscure aspirations, preferences, creativity. This case study explores how life narrative and artistic self-expression can reconstruct public perceptions of young people with OI. It focuses on "Mannie Group," a five-member female research and creative group formed on July 30, 2026, around Wang Mannie, a young woman with OI. Data include a semi-structured interview, field observation, informal conversations, and a participatory fashion show held on August 4, 2026, in Guangzhou, with about 100 audience members. Analysis covers Mannie's life narrative, experiences, self-expression, clothing preferences, mobility, and symbolic elements including clothing style, purple color, wing imagery, music, and the slogan "肆意的曼妮是曼妮." ("Mannie in her fullest expression is simply Mannie") Findings show a gap between attention and understanding. Mannie's story challenges reductionist representation. The fashion show turned the body from a medical object into a medium of self-expression, with aesthetic choices based on Mannie's own ideas. Narrative empowerment can replace pity- and charity-centered images with recognition, equality, and appreciation, but artistic expression alone cannot remove structural barriers. It must be part of broader social and institutional empowerment.

Keywords: osteogenesis imperfecta, rare disease, narrative empowerment, life narrative, public perception, disability studies, artistic expression, social inclusion

1. Introduction

Rare diseases create medical challenges. They also create social and cultural challenges. People with rare diseases often have limited medical resources. They face low public knowledge. They face poor accessibility. They also face problems in education, work, cultural life, and relationships. Other people often define them by their disease. This happens more when the disease is visible.

Osteogenesis Imperfecta (OI) is a genetic disorder. It causes bone fragility. It also makes bones break more easily. In China, people often call people with OI "porcelain dolls." This name highlights physical fragility.

The name sounds caring at first. But it also carries a strong cultural message. It tells others that the person is fragile and needs protection.

The problem is not that physical vulnerability is fake. People with OI do have real physical limits. They may need different types of help. The problem comes when fragility becomes the main way to understand the whole person. When a person is reduced to a disease label, other parts of their identity disappear. Their education goals, work skills, romantic wishes, taste, friendships, hobbies, humor, independence, and creativity become less important than the diagnosis.

This problem is very clear in public interest communication. Charity campaigns and awareness activities often use sad images of suffering. These stories can get attention and donations. But they can also create a split between the giver and the receiver. They can also split the normal from the abnormal. The person with a rare disease becomes someone to rescue. They are not seen as someone who can help define social relationships equally [1-3].

This study asks a different question. What happens when people with rare diseases tell their own stories? What happens when they control how their bodies and identities are shown?

This study does not look at OI only as a medical condition. It uses ideas from medical sociology, narrative approaches, disability studies, and symbolic interactionism [4-10]. It studies the link between self-narration and public perception. It asks how an individual can move from being a "patient" to being seen as a full social subject.

The case of Wang Mannie gives a useful example. Mannie received an OI diagnosis when she was about three months old. She uses a wheelchair. She has had many physical effects from bone fragility all her life. But her life also includes many experiences that do not fit the label of fragility. She finished junior middle school. She could not continue normal high school because of her physical condition. But starting in 2017, she studied Chinese Language and Literature by herself. She earned an undergraduate degree from Hubei University in May 2023. She worked as a customer-service representative for several online stores. She got good performance reviews. She also traveled alone by wheelchair to Beijing and Guangzhou. She likes museums a lot.

These experiences show a different story structure. Mannie's story is not only a story of illness. It is a story of education, work, travel, beauty, family, friendship, independence, and personal dreams.

This study looks at "Mannie Group." Mannie Group is a five-member all-female research and creative group. It formed on July 30, 2026. The members came from different parts of China. They came from Taiwan, Beijing, Hangzhou, and Wuhan. Wang Mannie was not one of the five researchers. She was the central participant and narrative collaborator. Her life experiences formed the core of the study.

The group later helped plan and carry out a fashion-show project. The event happened on August 4, 2026 at the Shiguangli Social Innovation Center in Guangzhou. Fewer than 20 people worked on the wider planning process. About 100 people came to watch.

2. Conceptual framework

2.1. From disease identity to social identity

Medical diagnoses are useful. They give information about health. They help people get the right medical services. But a diagnosis does not cover a person's whole social identity.

This study separates "having a disease" from "being defined by a disease." The first is a medical fact. The second is a social process.

When people see a wheelchair user with OI, they may quickly assume dependence, suffering, inability to work, or lack of independence. These assumptions can happen before any real talk. The disease label becomes a shortcut. It replaces real human understanding.

Narrative empowerment challenges this shortcut. It does not only ask, "What is wrong with this person?" It also asks, "How does this person understand her own life? What life does she want to create?"

2.2. Narrative and identity

Narrative approaches say that people make sense of life through stories [5-7]. A life is not just a list of events in time. People interpret experiences. They link the past and the present. They imagine possible futures.

Narrative is very important for people with chronic illness or disability [11]. Medical language often puts outside labels on them. The patient becomes a set of symptoms, diagnoses, treatments, and limits.

Narrative practice creates a different space. It lets people describe what happened to their bodies. It also lets them say what those experiences mean to them.

In this study, Mannie's narrative includes limits and agency. Her physical condition is real and important. But it does not stop her from having interests, making decisions, studying on her own, working, traveling, joining fashion activities, and imagining future options.

2.3. Narrative empowerment

Empowerment here does not mean only making someone feel better. It means changing who has the power to define meaning.

If other people hold all power to define a person as fragile, dependent, or inspirational, that person stays an object of representation.

Narrative empowerment happens when the person becomes an active maker of meaning.

This idea matters for the fashion-show project. The clothing style, color palette, wing images, music, and slogan came from Mannie's own ideas [12]. The research group did not build an image of her. The group gave her a place to join in defining how she wanted to be seen.

3. Research design and methods

3.1. Research design and methods

This study uses a qualitative case-study design.

"Mannie Group" is a five-member all-female research and creative group. It formed on July 30, 2026. The members came from different parts of China. They came from Taiwan, Beijing, Hangzhou, and Wuhan. Their different locations gave different views on disability, urban life, accessibility, gender, and public perception.

Wang Mannie was not one of the five researchers. She was the central participant and narrative collaborator.

This detail matters. The study does not say the five researchers are people with OI. The group is a team around one central life-story participant.

3.2. Data collection

The researchers used several qualitative methods.

First, the researchers did a face-to-face semi-structured interview with Mannie. The interview covered daily life, physical experiences, education, travel, transportation, fashion, beauty, hobbies, family, and personal

likes.

Second, the researchers had informal talks during the fashion-show preparation. These talks gave context that formal questions could not easily get.

Third, the researchers observed the fashion-related activities and the final show.

Fourth, the researchers studied the symbols in the fashion show. They looked at clothing, colors, visual motifs, music, stage presentation, and slogan.

Using different types of qualitative material helped the study go beyond one interview. It showed how narrative was built in words and in images.

3.3. The fashion-show project

The fashion show took place at 3:30 p.m. on August 4, 2026. It was held at the Shiguangli Social Innovation Center in Guangzhou.

Fewer than 20 people worked on the wider planning and carrying out of the event. About 100 people came as audience members.

The key method point was this. Mannie's own ideas shaped the central aesthetic choices. The research group did not pick the clothing style, music, slogan, or main visual symbols for her.

The clothing style had a youthful and doll-like look. Purple was the main color. Wings were a central visual element. The slogan was "肆意的曼妮是曼妮." ("Mannie in her fullest expression is simply Mannie") In English, this means "Mannie in her fullest expression is simply Mannie."

The music selected for the presentation was "A New Beginning" by the well-known Chinese singer G.E.M. Tang.

These choices are analyzed not as isolated aesthetic objects but as components of a symbolic narrative.

3.4. Data analysis

The interview material was examined through thematic qualitative analysis [7]. The analysis focused on recurring themes including:

1. disease identity;
2. public misunderstanding;
3. autonomy;
4. education;
5. employment;
6. independent mobility;
7. aesthetics and fashion;
8. interpersonal relationships;
9. self-expression;
10. social inclusion.

The fashion presentation was subsequently analyzed through symbolic interpretation. Particular attention was given to the relationship between physical vulnerability and visual representation.

Rather than claiming that the fashion show "proved" a measurable change in public attitudes, this study interprets the event as a qualitative site of interaction in which alternative representations of OI became possible.

4. Findings

4.1. The gap between "attention" and "understanding"

One of the strongest themes emerging from the interview material was the distinction between being noticed and being understood.

Mannie described situations in which others focused heavily on her medical condition and offered material assistance, while rarely asking about her ordinary aspirations. The problem was therefore not necessarily an absence of kindness. Instead, kindness itself could become limited when it was based on assumptions about what a disabled person should need.

A person may need medication, accessible transportation, physical assistance, or medical care. At the same time, she may also want fashionable clothing, meaningful employment, romantic relationships, travel, friendship, entertainment, and opportunities for self-expression.

These desires do not conflict.

People often view those with OI mainly through medical needs. This creates a recognition gap. The public may see the wheelchair. They may know the disease. They may feel sympathy. But they may fail to see the person in the wheelchair.

Visibility and recognition are different. This difference matters.

Visibility asks, "Can we see this person?"

Recognition asks, "Can we understand this person as someone like us?"

The second question is harder. It needs interaction, not just observation.

4.2. Mannie's life beyond the disease label

Mannie's life challenges a purely medical view.

She got an OI diagnosis as a baby. She grew up with big physical limits. After junior middle school, she could not go to normal high school. Her health condition prevented this. But this stop did not end her education dreams.

In 2017, she started studying Chinese Language and Literature by herself. In May 2023, she got an undergraduate diploma from Hubei University.

Her education path shows agency. One institutional path was closed. So she found another path.

Her work experience also challenges the idea of dependence. She worked as a customer-service representative for several online stores at the same time. She often got strong performance reviews. She also used her savings to help her family pay for a new home.

Her travel experience is also important. She has traveled alone by wheelchair to many cities, like Beijing and Guangzhou. She likes museums a lot.

These details matter. They change the story structure.

A usual disease-centered story starts with: "She has very fragile bones. She needs a wheelchair."

A life-centered story starts differently: "She is a young woman who studies, works, travels, likes museums, cares about clothes and looks, and makes her own choices while living with OI."

The second story does not ignore disability. But it does not let disability be the only story.

4.3. Everyday aesthetics as an expression of personhood

The interview showed a lot of attention to clothes, makeup, hair, accessories, and appearance.

These topics may seem unrelated to rare-disease research at first. But they matter in social terms. Aesthetic preference is a normal part of identity.

Mannie liked youthful and feminine styles, comfort, and attractive clothes. Her comments on makeup, hairstyles, clothing quality, and accessories showed she did not care only about medical function.

This corrects a common idea. Many think disabled people care most about safety and comfort.

Comfort matters. Accessibility matters. Safety matters.

But these needs do not remove the desire for beauty.

These needs exist together. This shows the complexity of identity. A wheelchair user is still a young woman. A person with a rare disease still has aesthetic likes.

This is one reason the fashion-show project was a good medium for narrative expression.

4.4. From the medical body to the expressive body

In conventional medical discourse, the body of a person with OI is primarily a body that requires protection.

In the fashion-show project, the body became an expressive medium.

This transformation does not mean that physical vulnerability disappeared. Instead, its meaning was temporarily reorganized.

The clothing style looked youthful and doll-like. It showed femininity and youth. It did not show illness. Purple became a main color. Wings added another meaning. They did not suggest fragility. They suggested imagination, movement, aspiration, and freedom.

The slogan was "肆意的曼妮是曼妮." This was important. It put the person's name at the center. It did not put the disease at the center.

The statement does not say, "Look at this patient."

It says, "This is Mannie."

This difference is small but strong.

4.5. Music and a new beginning story

The song choice was G.E.M. Tang's "A New Beginning." This song also helped the show's story.

Music does not share medical facts. It shares mood, memory, rhythm, and feelings.

The song is about starting again. This fits Mannie's life path. Her educational journey, work experience, travel, and continued engagement with social activities all contain elements of reconstruction and continuation.

The fashion show therefore did not present a narrative of "overcoming" disability in the simplistic sense of defeating a disease. Instead, it presented a narrative of continuing to construct a meaningful life under conditions of disability.

This distinction is theoretically important.

The purpose of narrative empowerment is not to prove that disabled people are "strong despite everything." Such narratives can create another form of pressure, in which disabled people are expected to become extraordinary inspirational figures.

The more important principle is that they should have the right to be ordinary human beings.

They can be ambitious, tired, fashionable, frustrated, humorous, emotional, independent, dependent, successful, uncertain, or simply ordinary.

4.6. From "being helped" to "participating"

Traditional charitable relationships often follow a one-directional structure:

donor → recipient

Within this structure, the recipient is expected to receive assistance and express gratitude.

Narrative empowerment introduces another structure:

participant ↔ participant

In the latter model, the person with a rare disease contributes ideas, preferences, creativity, and interpretation [3].

The fashion project illustrates this transformation. Mannie was not merely the person being photographed or displayed. Her own preferences determined key elements of the presentation.

The researchers therefore functioned less as people "speaking for" her and more as collaborators creating conditions in which she could speak through her own aesthetic language.

5. Discussion

5.1. Reconstructing the power of representation

Representation is never neutral [8, 9].

When a social group is repeatedly represented through a single image, that image can become a social expectation. If people with OI are repeatedly represented as fragile children or passive recipients of charity, the public may gradually assume that fragility and dependency constitute their essential identities.

Narrative empowerment interrupts this process by introducing alternative representations.

The importance of the Mannie Group case is therefore not that a fashion show can magically change public opinion. Its importance lies in demonstrating that the meaning of a disabled body is not fixed.

The same wheelchair can be interpreted through multiple frameworks.

It can signify:

- dependence;
- medical vulnerability;
- restricted mobility;
- accessibility rights;
- independence;
- fashion;
- identity;
- social participation.

The meaning depends partly on the narrative context in which the body is presented.

5.2. The difference between pity and recognition

Pity is emotionally powerful but socially limited.

When the public feels pity, the person with a disability may become an object of compassion. Recognition is different because recognition requires equality.

To recognize Mannie is not merely to say:

"She has suffered a lot."

It is to say:

"She has suffered, but she also has preferences, abilities, ambitions, relationships, and the right to define herself."

This shift from pity to recognition is one of the central mechanisms of narrative empowerment.

5.3. The importance of self-determined representation

An especially important finding is that the major aesthetic choices of the fashion show were Mannie's ideas.

This point should not be treated as a minor methodological detail.

If researchers had independently chosen the clothing, color, music, and slogan and then claimed that these elements "empowered" Mannie, the project could reproduce the very power imbalance it sought to challenge.

Empowerment requires participation in decision-making.

Therefore, the value of the fashion show lies not simply in its visual effect but in the process through which its visual language was created.

The research group supported rather than replaced Mannie's agency.

5.4. Gender and disability

The case also highlights the intersection between gender and disability [8, 9].

Disabled women may face a double form of social invisibility. They may be perceived through disability while simultaneously being excluded from conventional representations of femininity.

Questions of clothing, beauty, romance, attractiveness, and sexuality can become uncomfortable or invisible when a woman is assumed to be primarily a "patient."

Mannie's interest in clothing, makeup, hair, and appearance challenges this assumption.

Her femininity does not contradict her disability.

Instead, recognizing both dimensions allows a more complete understanding of her identity.

5.5. Beyond the "supercrip" narrative

A potential danger in disability representation is replacing one stereotype with another.

If the old representation is:

"Disabled people are weak and helpless."

the new representation should not simply become:

"Disabled people are extraordinarily strong and inspirational."

The second representation may appear positive but can also be restrictive. It can place disabled people under pressure to constantly demonstrate courage and achievement.

Mannie's story should therefore not be interpreted merely as an inspirational story of "overcoming."

Her life is more valuable as an example of complexity.

She has encountered barriers, but she has also experienced ordinary happiness, interests, frustration, curiosity, humor, and aspiration.

Narrative empowerment should make space for this complexity.

5.6. Limitations of artistic expression

Despite its potential, artistic expression cannot substitute for structural change.

The field material indicates that people with mobility impairments may still encounter inaccessible transportation, difficulties using public facilities, discrimination in employment, and practical barriers to independent living.

A successful fashion presentation can change the atmosphere of a room for several hours. It cannot by itself redesign a subway station.

It can challenge an audience member's assumptions. It cannot by itself guarantee employment equality.

It can make a person visible. It cannot automatically guarantee institutional recognition.

This distinction is essential.

Narrative empowerment operates primarily at the level of meaning, identity, and interpersonal perception. Institutional empowerment operates at the level of law, policy, infrastructure, employment, education, and resource distribution.

The two should therefore be connected.

6. Implications for health communication and social work

The findings have several implications.

First, health communication should move beyond disease-centered storytelling [1-3].

Public campaigns should avoid presenting people with rare diseases exclusively through images of pain, hospitalization, poverty, or dependence. Such images may attract attention but can reinforce stereotypes.

Second, communication should include ordinary life.

People with rare diseases should be represented studying, working, travelling, shopping, making friends, participating in culture, choosing clothes, and pursuing relationships.

Third, people with rare diseases should participate in the production of public narratives about themselves.

We should not only ask: "What story will attract the audience?" We should also ask: "What story does the person want to tell?"

Fourth, social workers should use an empowerment approach. They should not speak for disabled people all the time. They can create chances for self-expression and group participation.

Fifth, art projects can be used as research and social action spaces [12]. Fashion, photography, theatre, music, film, and other cultural work can create new spaces. In these spaces, marginalized bodies become visible. Medical language does not fully control this visibility.

But these projects need structural advocacy too.

7. Ethical considerations

This research involves a person with a rare disease. It uses personal life experiences. So ethics matter a lot.

First, we must respect the participant's independence. We should include health, family, education, work, and personal life details only when they are relevant. We also need proper permission.

Second, the participant should control how her image and story are shown.

Third, researchers should not turn suffering into entertainment.

We do not show Mannie's story to create emotional shock. We do not want people to stare at disability. We want to see how self-made stories can challenge social labels.

Fourth, the research should not make big claims. One fashion show with about 100 audience members cannot prove a statistical change in public views.

So the right claim is qualitative: the event made a new space for representation. It gave some evidence that stories and art may help change interpretation.

When the public sees a person primarily as a "porcelain doll," physical fragility can become a totalizing identity. The person disappears behind the diagnosis.

Mannie's life story demonstrates the inadequacy of this representation. Her educational experience, employment history, independent travel, interest in museums, attention to fashion and beauty, and participation in creative activities reveal a multidimensional individual whose identity cannot be reduced to OI.

The fashion-show project created an alternative representational framework.

Its youthful and doll-like clothing style, purple color palette, wing imagery, selected music, and slogan "肆意的曼妮是曼妮" were based on Mannie's own ideas. These elements transformed the fashion presentation

from an exhibition of disability into an act of self-expression.

The significance of the project therefore lies not simply in whether audiences were "moved." Its deeper significance lies in who had the authority to define the meaning of the body.

Narrative empowerment redistributes this interpretive authority.

Instead of asking the public to feel sorry for a person with a rare disease, it invites the public to encounter her as a complete individual.

Instead of:

patient → recipient

it proposes:

person → participant → creator → co-constructor of social meaning.

Nevertheless, narrative empowerment has clear limitations. A change in representation does not automatically produce accessible transportation, equal employment opportunities, inclusive education, or legal protection. Public recognition must eventually be translated into institutional change.

So the final goal should not be just to make people with rare diseases visible. The goal should be to create a society where they do not have to show great courage just to be seen as fully human. Narrative empowerment can open the door. Institutional empowerment must keep that door open.

Future research should go beyond one case. It should examine many people with OI. These people should come from different regions, genders, age groups, and economic backgrounds. Mixed qualitative and quantitative methods may also be used [7]. Researchers can use these methods to see if long-term exposure to self-defined disability stories can change public attitudes in measurable ways.

The wider theoretical point is this. Rare-disease advocacy should move from showing suffering to showing personhood. It should also move from charity-centered communication to participatory communication. Only when people with rare diseases can define themselves can public recognition become real social equality. They should not be defined only by other people.

8. Conclusion

Mannie's life story suggests that a person with OI cannot be reduced to a medical label. Her education, work, independent travel, museum visits, and interest in fashion and beauty show a multifaceted identity.

The fashion show offered her a space for self-expression. The clothing style, purple color, wing imagery, music, and slogan came from her own ideas. These choices turned her body from an object of medical observation into a medium of expression.

Narrative empowerment may help shift public perception from pity toward recognition. However, it is unlikely to replace structural change. Accessible transportation, employment equality, inclusive education, and legal protection still require institutional effort.

Future research could examine more people with OI across different regions, genders, age groups, and socioeconomic backgrounds. Mixed methods might help assess whether long-term exposure to self-defined narratives changes public attitudes. When people with rare diseases can define themselves, public recognition may become a form of social equality.

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