

Research on the transformation of public perception of rare disease patients from the perspective of life stories and public advocacy: a case study of the "Porcelain Doll" fashion show

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Abstract. Osteogenesis Imperfecta (OI) is a rare bone disorder that causes the bones to become fragile. This often leads to the labeling of society as "cute dolls", highlighting their fragility and the need for protection. This study explores how personal stories and public events, such as fashion shows, influence each other. It is possible to shift the public's perception of young people with OI from merely focusing on their illness to comprehensively understanding them as complete individuals. This study employed a case study method to explore the experiences of an individual with OI, the creative elements of the fashion show, as well as the insights gained from interviews with patients with other rare diseases. The research results indicate that by combining personal narratives with artistic expressions, including fashion design, music and stage sets, it goes beyond mere conscious cognition, effectively challenging stereotypes and promoting true understanding and empowerment. The research concludes that such advocacy platforms play a crucial role in redefining identities. Make patients no longer be regarded as passive recipients of medical treatment, but be treated as autonomous individuals with creativity and personal value. An important step towards social transformation is to shift from "disease labels" to "life stories". This helps to provide a richer and more equitable understanding of beauty and identity.

Keywords: osteogenesis imperfecta, rare diseases, public perception, life stories, fashion advocacy, empowerment

1. Introduction

Osteogenesis Imperfecta is a very rare illness that is hard to cure but still a big part of nowadays society. People with this illness always have weak bones that can be broken very easily and unintentionally. Because of the feature that we mentioned, people often describe them as "fragile" or "weak." These words always let more

people be aware of their situations. But they can also make others miss the real person. A person with OI is not just a sick person. They also have feelings, hobbies, dreams, and friends. They like some things and don't like others. They are normal people that have the same wants and needs [1].

So we not only need to see the serious illness, but also the whole picture of the special crowd. However, it's inevitable for people to see the illness only and ignore the rest. Young people with OI have stories to tell. They have things they want to do. They have ideas about beauty and style. So we should ask not just "What is wrong with them?" but also "Who are they?"

There is another thing. Many people know about it, but few people understand it. People may know the name and the problems, but they don't know what their real daily lives is like. Public talks often focus on medical facts and help. They don't focus on how young people with OI see themselves. So even with good intentions, we can still give a one-sided picture [2].

Also, giving help is not the same as giving power. Help is good. But giving power means letting people speak for themselves. It means letting them show their own value. The course materials we read also say that advocacy should not just give help, but also let the group express themselves.

So this study looks at how personal stories and public events can change the old image of young people with OI. We use the "Porcelain Doll" fashion show as an example. We look at how one person's story can start a public talk. We pay attention to clothes, music, lights, and words. All these things can build a new picture of young people with OI.

Our main question is: How can life stories and public events help young people with OI move past a simple label and be seen as full people? To answer this, we look at the person's life story, their wish to express themselves, interviews, and the fashion show's methods. We want to see how fashion and art can let people see not just the weak bones, but also the personality, creativity, and dreams of young people with OI.

2. Research design

This study focuses on the rare disease fashion show practice centered around Wang Man'ni. A comprehensive exploration of life narratives among individuals with osteogenesis imperfecta (also known as "brittle bone disease") and innovative public expressions within rare disease communities. Firstly, the study examined the medical characteristics of osteogenesis imperfecta and the current social perception of this condition. Patients with this rare disease have weak bones and limited mobility, but they are often misunderstood and stereotyped by the public [3]. The mainstream clothing market has further exacerbated their predicament: most adult clothing does not fit their body types. However, children's clothing is too childish in terms of color and design, and fails to meet the aesthetic needs and self-expression desires of patients with rare diseases in their adult years. Secondly, this study focuses on Wang Manni's personal life experiences and spiritual pursuits. Since childhood, she has frequently suffered from fractures and limited physical functions, but she has never bowed to fate. Although she was forced to suspend her regular studies due to her physical condition, she still persisted in self-study and obtained an associate degree and a bachelor's degree through self-assessment. Her indomitable spirit of struggle in adversity and her desire for self-transcendence constitute the core essence of this fashion show. Furthermore, this study incorporated the first-hand interview materials of patients with rare diseases, ensuring that the creative practice has genuine and emotionally resonant content support. The stage show used a full story-telling structure. The team picked G.E.M.'s "New Heartbeat" for background music. The song's lyrics talk about getting out of hard, messy trouble and welcoming a whole new start. This matches really well with Manny's real-life story. They used carefully-made lighting, and they got rid of the cloud and fog props in the show. Also there were theme designs, like Manny's favourite purple butterfly wings and magic

wand. The whole show showed really well how you fight through hard times and get a bright future, and the pictures were really moving. The main slogan "Unrestricted Light Belongs to Manny" makes this message even stronger. This paper looks at how art and fashion can change how people see rare-disease groups. When we look at these works, we can spread ideas about equality and being different. Lots of different parts are used: scene settings, clothes design, music, lighting and the theme slogan. Narrative medicine is about listening and respecting people's own life stories. It is not only about medical labels and illness results. It cares about how patients feel inside, what they want, and what they say about themselves [4]. The stage has lots of symbols: butterfly wings mean being reborn. Falling clouds stand for beating hard times. And the slogan "Marni, the free soul" shows Marni's own voice, and what she wants to say in public. G.E.M.'s song "New Heartbeat" make this message stronger. The lyrics fit Manny's life, and they can make listeners feel deep emotions. This performance let audiences know about osteoporosis, and also let them step into her world. It shows the difference between "getting help" and "getting power". Good rare-disease advocacy should help these groups show their own value, not only give them things they need [5]. The psychosocial burdens experienced by adult osteogenesis imperfecta patients also highlight the necessity of such patient-centered public expression [6].

3. Label empowerment

Manny has Osteogenesis Imperfecta (OI). In Chinese, people sometimes call it "brittle bone disease" or "porcelain doll disease". Our study asks two main questions. First, how do labels like "porcelain doll" or "weak patient" change how people think about rare-disease patients? These labels make people only see their sickness and body limits, and forget their personality, hobbies, dreams and skills. When people hear "porcelain doll", they will think of someone weak, fragile and need to be protected. Even if people mean to be kind, these words create fixed ideas for OI patients. It makes the illness become the most important part of who they are. So people care more about what patients can't do, instead of what they can do. This changes not only how society see them, but also how they see themselves [2].

The second question is: how can rare-disease patients use art like personal stories and fashion shows to speak for themselves and change how people see them? Grass-roots patient-led organizations and public activities provide feasible paths for rare-disease groups to achieve self-advocacy [7]. Art gives people a new way to share their own life. Patients don't have to let doctors, news or other people talk about them. They can tell their own stories. Fashion shows are especially important. Clothes and stages can show who you are, without only talking about your illness. Patients can show different sides of themselves through their clothes, look, movements, stories and choices. We pick this fashion show as our example because it shows that rare-disease patients are not just "patients". They are real people with their own identity and right to speak. So our research is not only to make people know more about osteogenesis imperfecta. More importantly, we want to see if public opinions can change: from only seeing the sickness, to seeing the real person behind the disease.

From the perspective of medical sociology, a person's patient identity is not equivalent to their complete personal identity. Medical sociology not only studies the disease itself, but also how society views the disease, and how the disease affects people's social identity and interpersonal relationships. In society, patients with osteogenesis imperfecta are sometimes described mainly by their physical condition. Therefore, others may only regard them as "patients" or feel that they need to be protected. For example, when people see people with obvious differences in their bodies, their first reaction may be to think of their health or physical limitations, not their personality or interests. In this way, the disease has become the main way for society to recognize this person.

This view mainly focuses on illness and physical limitations, but may ignore other aspects of their lives, such as their personality, interests, creativity, interpersonal relationships and life goals. Patients with osteogenesis imperfecta can have many identities at the same time. They can be students, friends, family members, artists, fashion lovers, or people with personal dreams and goals. Suffering from a rare disease is just a part of their lives. However, when society repeatedly uses the label "porcelain doll", the influence of this label may exceed personal identity. Although this word may sound gentle and considerate, it still makes people regard patients as fragile objects rather than independent individuals [1]. This situation may give people a single and stereotyped impression of patients with rare diseases, and it will also affect the way people communicate with them. Some people may become too careful or uncomfortable because they feel that patients can't do something. In this way, the social significance of the disease sometimes becomes as important as the physical condition itself. The fashion show in Guangzhou can be regarded as a challenge to this way of thinking. The event not only paid attention to Manny's condition, but also made the audience pay attention to her personal story, dressing style, creativity, and self-expression. It encourages the audience not only to ask "what disease does she have", but to ask "who she is" and "what she wants to express". This shift in perspective is an important part of understanding the social dimension of disease.

Disability studies can also help us understand this activity. Disability studies focus on the experience of the disabled and also question society's practice of setting up barriers and stereotypes for disability issues. An important difference is between "knowing" and "understanding". Knowing that there are rare diseases does not mean that people really understand the daily life and real experience of patients with rare diseases. For example, people may know that osteopaths affect bones and physical activity, but this basic knowledge does not let them know what it is like to grow up with this disease, communicate with others, make personal choices, or deal with social stereotypes. Therefore, Awareness is just the first step. True understanding requires listening to patients and treating them as individuals with their own unique experiences.

Another important difference is "get help" and "empowerment". Some public welfare activities mainly emphasize helping or sympathizing with the disabled. Although this kind of support is very important, sometimes it may make the disabled look like people who passively accept help. When the public only sees the disabled as people in need of charity assistance, the focus is still on what society can give them, not on what contributions they can make or express their own ideas. This may inadvertently create a power gap between the "helper" and the "recipient".

In contrast, "empowerment" means giving people the opportunity to express themselves and show their own value. This means that people with disabilities can actively participate in it and make choices about how to display their image. Rare-disease community empowerment emphasizes patients' own voice and subject status [8]. In this fashion show, Manny is not a person who only needs sympathy or help. She became an active participant in the activity, expressing her identity, experience and ideas through costumes and stage. The audience also can see her as a person who can make creative choices and tell her own stories. From this perspective, this activity reflects "empowerment", not just sympathy [5].

The difference between sympathy and empowerment is very important, because the purpose of public welfare activities should not only be to make people feel sorry for patients. We should also create opportunities for patients to express their voices. This fashion show provides such an opportunity. Manny is not only the object of attention of the audience, but also a part of the process of conveying information. This changes the relationship between patients and the audience. The audience no longer just looks at a rare patient and feel sympathy, but can listen to her story, understand her choices, and recognize her as an independent individual. In this sense, the fashion show creates a more equal way of communication between patients with rare diseases and the public.

4 Conclusion

A disease should never be used to define an entire person. The core of narrative medicine lies in listening to and acknowledging the life stories of individuals. It goes beyond the labels of pathology and the diagnosis itself, emphasizing the patients' personal feelings, inner desires and self-reports [4]. Take Manni as an example. The osteogenesis imperfecta she suffers from — also known as "doll-like" disease — is merely a medical label, not her entire identity. Apart from this diagnosis, she also has the ambition to continue her studies, loves G.E.M.'s music, and has a rich inner imagination. The stage performance refuses to reduce Manni to a vulnerable patient. Instead, it leaves room for her own story: her struggle in adversity and her longing to escape the predicament are all visually presented on the stage. The purple butterfly wings, magic wand and floating cloud-shaped props were used to externalize and present her inner experience. This practice is no longer limited to physical symptoms, but follows the principles of narrative medicine: respecting the subjective life experiences of individuals and revealing the true individuals behind the diseases. It indicates that the identity of a disease is not equivalent to the complete identity of an individual. The public advocacy and dissemination targeted at the rare disease community is different from the mere enhancement of public awareness. It places greater emphasis on the public's genuine understanding of rare diseases. Making the public aware of the existence of rare diseases is quite different from helping them truly understand how patients feel in their daily lives. This fashion show project avoids the common pitfalls of charity events — presenting patients merely as "objects in need of assistance". The performance did not simply portray Manie as a passive recipient of sympathy and assistance; instead, it empowered her [5].

This study looked at how life stories and public advocacy can change how people see young people with OI. From the "Porcelain Doll" fashion show, we found that we don't have to show OI only as weakness or need for care. Personal stories and creative expression can show a fuller picture.

First, we learned that a disease label is not the whole person. The old "porcelain doll" image mostly shows fragility. That can help explain the physical side, but it can also make people forget other sides. Clearly, the fashion show demonstrates another special parts, which are personality, fashion taste and personal goals. In this way, the story is not just about telling and explaining the illness, but also providing a perfect stage to show and help people to see more parts of the special people.

Second, when people know about the existence of the illness, they can really hard to feel and live with it. The fashion show used a different way to communicate. It mixed personal stories with fashion and stage performance. Through visuals and feelings, the audience could meet the person, not just the patient. So to change public views, we need more than just making rare diseases visible. We also need to change how they are shown and understood [2].

Third, we noticed the gap between getting help and being empowered. Help is useful, but empowerment also means letting people take part in defining themselves. In this case, the young person was not just someone receiving attention. Their stories were a essential part of the whole thing. Therefore, fashion is more than looking. In fact, it's a visual way to express who you are.

But this study has some limits. First, it is based on only one fashion show, so it cannot represent everyone with OI. Each person is different. Second, one event cannot change long-term stereotypes all at once. Public views are shaped by many things over time. So one project is not a complete solution. The course materials also said that lasting change needs ongoing and diverse efforts.

In the end, the value of the "Porcelain Doll" project is not just making young people with OI more visible. It is changing what people see when they look at them. The goal is to move from seeing a "weak patient" to seeing a whole person with a story, choices, style, and the ability to speak up. Stories and fashion expression cannot show everything and fix everything. However, they can be a great start. In one word, if we really want

to change the public's views, we need more than awarenesses. We need to understand, help and long-term actions.

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