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FRIENDSHIP AND EMPOWERMENT: SUPPORT NETWORKS FOR PEOPLE WITH IMPERFECT OSTEOGENESIS

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ABSTRACT. The Imperfecta Osteogenesis (IO), best-know as bittle bone disease, is a cronic, rare and congenital illness. Its main characteristic is a bone fragility, that impacts on the self-image, social and psychological development of affected subjects. The study's objetive is to investigate friend's participation on Imperfecta Osteogenesiscarrier's life and its role dealing with the disease. A qualitative study, was realized, through the episodic interviews and thematic analysis for the data analysis. Participated in the study seven adults with IO diagnosis and in treatment. Main findings pointed out participants' high adaptation and coping by means of learning and acceptance about their health conditions, empowerment and autonomy, in addition to friendship's importance on the IO wide care and in the social support of the patient, contributing also for a better socialization, support the development of a leading atitude in social context. Therefore, friendship's crucial role in coping with the disease and in individual's personal development and its social position on society.

Keywords: Imperfecta osteogenesis; friendship; empowerment.

AMIZADE E EMPODERAMENTO: REDES DE APOIO DE PESSOAS COM OSTEOGÊNESE IMPERFEITA

RESUMO. A Osteogênese Imperfeita (OI), mais conhecida como doença dos ossos de vidro, é uma enfermidade crônica, rara e congênita, caracterizada pela fragilidade dos ossos, que afeta significativamente a autoimagem, o desenvolvimento social e psicológico dos sujeitos acometidos. O objetivo da presente pesquisa é investigar a participação dos amigos na vida dos portadores de Osteogênese Imperfeita e o seu papel no enfrentamento da doença. Para isso, realizou-se um estudo qualitativo, através de entrevistas episódicas e utilizou-se da análise temática para interpretação dos dados. Participaram do estudo sete adultos em acompanhamento da doença. Os resultados apontaram grandes índices de adaptação por parte dos portadores, por meio do conhecimento e aceitação de sua condição, empoderamento e autonomia, além da importante participação dos amigos no cuidado amplo da OI, ao contribuir para maior inclusão social e no desenvolvimento de uma postura mais ativa e protagonista em suas vidas. Logo, percebeu-se o papel crucial das amizades no enfrentamento da doença, no desenvolvimento pessoal e na posição social do indivíduo na sociedade.

Palavras-chave: Osteogênese imperfeita; amizade; empoderamento.

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AMISTAD Y EMPODERAMIENTO: REDES DE APOYO PARA PERSONAS COM OSTEOGENÉSIS IMPERFECTA

RESUMEN. La Osteogénesis Imperfecta (OI), mejor conocida como enfermedad de los huesos frágiles, es una enfermidad crónica, rar y congénita, su princial característica es la fragilidad ósea, que afecta significativamente la autoimagen, el desarrollo social y psicológico de los sujetos afectados. El objetivo general del presente estudio es investigar la participación de amigos en la vida de el portador y su papel frente a estas enfermedades. Para ello, se realizó un estudio cualitativo, através de entrevistas episódicas y análisis temático de los datos. Participaron del estudio siete adultos con diagnóstico de OI y en tratamiento. Los hallazgos señalaron la alta adaptación y aceptación de sus condiciones, por meio de lo conecimiento, empoderamiento y autonomía, además de la importancia de la participación de los amigos en el cuidado general de OI, apoyando una mayor inclusión social y contribuyendo para el desarrollo de una actitud líder en el contexto social. Por lo tanto, destaca el papel crucial de la amistad en lo enfrentamiento de la enfermedad y en el desarrollo personal del individuo y su posición social en la sociedad.

Palabras clave: Osteogénesis imperfecta; amistad; empoderamiento.

Introduction

Osteogenesis Imperfecta (OI) is considered a congenital, chronic, and rare disease. According to the Brazilian Association of Rare Diseases (ABDR, 2023), its incidence is one in every 20 thousand people in the country.

The main characteristics of this disease are fragility and deformities in the bones, brittle teeth that are more prone to cavities, changes in skin elasticity, bluish sclera, and abnormalities in the cells responsible for collagen, both in number and quality (Stephen, Roberts, Hayden & Chetty, 2016). Identifying OI is not always a quick process, due to the lack of knowledge and less attention paid by clinicians and researchers to rare diseases. Therefore, its diagnosis can be a difficult and often distressing process for the subject and their family members (Hill, Lewis, Riddington, Crowe, DeVile, Götherström & Chitty, 2019).

OI requires continuous care and precautions to avoid fractures, so people with the disease need to avoid risky activities and take time off from school and work for medication treatment that requires hospitalization (Lafage-Proust & Courtois, 2019). In addition to medication, treatment involves physical therapy exercises and orthopedic monitoring.

In view of this, OI influences the social and psychological development of the individual and may contribute to social isolation, increased dependence, and an impoverished construction of self-image (Fegran, Hall, Uhrenfeldt, Aagaard & Ludvigsen, 2014). Therefore, an interdisciplinary approach is essential, as it extends care beyond the physical aspects, including monitoring by parents/caregivers, becoming an important component of psychosocial support, from the moment it prepares them for physical and psychosocial challenges, also helping them in the process of transitioning from childhood to adulthood (Stephen et al., 2016).

A life marked by limitations, protection from third parties, and fears of the next fracture (Hill et al., 2019), as well as the routine of treatment, surgeries, and hospitalizations hinder the social integration of these individuals (Mello & Moreira, 2010). Furthermore, patients from the interior face other challenges when they move away from their social environment (Girardon-Perlini & Ângelo, 2017) to attend reference centers.

Due to the need for constant care in OI, feelings of overprotection, anxiety, and fear on the part of family members or primary caregivers are quite common and can hinder the process of independence and social integration of these individuals (Hill et al., 2019; Paiva, Oliveira & Almohalha, 2018). This differentiated treatment can also reinforce the stereotypical view of OI (Stephen et al., 2016).

Despite the difficulties faced by individuals with OI, these do not prevent them from seeking new ways of living. An important aspect of coping with the disease is the interest and deepening of knowledge about the disease, by providing explanations about procedures and recognizing limitations and potential (Mello & Moreira, 2010). Because it is a rare disease, there is little knowledge about the disease, and society in general is often unaware of its implications. Therefore, patients need to specialize to adapt to normal life, being cautious, and proactive, and acquiring a more positive perspective of themselves, not limiting themselves to the image of being sick and incapable (Balkfors, 2015).

Engaging in multiple activities, such as self-care, work, leisure, and household activities, as well as practices with important social components, such as religious groups, study groups, and groups of friends, are characteristic of the daily lives of people with OI (Paiva et al., 2018). Adapted and inclusive activities provide the development of a more positive view of different physical conditions and develop empathy (Sparkes, Martos, & Maher, 2017). In addition, interpersonal relationships are extremely important for providing social support and coping with OI; children who have greater support from parents and friends are more likely to adapt and cope with the adversities imposed by the disease (Mascarin, & Ferrari, 2019).

Regarding friendship, its complexity and difficulty of definition are undeniable, as it is subject to constant changes in the particular aspects of the subjects involved, their interaction, and the different contextual configurations that permeate friendship (Mascarin & Ferrari, 2019). Several authors discuss its concept, bringing its relationship to the similarity in activities with friends, self-disclosure, trust, commitment (Hinde, 2014), companionship, mutual help, intimacy, and affection (Mascarin & Ferrari, 2019).

Given this, friendship plays a crucial role in coping with the disease, providing greater social inclusion by integrating and supporting the individual with OI, playing an equally fundamental role in the person’s life when compared to other strategies such as spirituality and family support (Sanches & Gil, 2017). At school, friends also appear as facilitators, despite being an environment with physical obstacles that hinder accessibility, the school context also proves to be a place to make friends, especially with those who help to reestablish the social life of the affected individuals (Stephen et al., 2016).

Friendships provide greater space for attention to the individual's own needs, self-care, and self-image. In this way, the free and affectionate movement of friendship contrasts with the rigor and seriousness present in family relationships and the distance and formality found in healthcare institutions (Lopes, 2017). In this case, friends are generally immersed in a reciprocal and comfortable environment, exploring, through it, new ways of relating (Lopes, 2017).

Social forms of friendship show essential aspects for the constitution of an autonomous and empowered patient (Lopes, 2017). It is highly important to place friendships as the central point of the support network, giving space to the individual and relational aspects involved in the care process, and consequently, their direct relationship with the feeling of empowerment. Friendship does not propose rigid forms of care, but rather greater flexibility in the search for the path to self-care (Lopes, 2017).

Therefore, this study was a qualitative approach, focusing on the description of episodic reports about interpersonal friendship relationships, by delving into the role of friendship in coping with Osteogenesis Imperfecta, to investigate the participation of friends in the lives of OI patients and their role in coping with the disease.

Method

Semi-structured episodic interviews were conducted with seven adults, aged between 18 and 30, with osteogenesis imperfecta, of both sexes, who were being monitored by the referral hospital in Grande Vitória (state of Espírito Santo), which was the site of the research. This hospital offers a program focused on the long-term monitoring of patients with OI.

The interviews were conducted on the hospital premises, while patients were waiting for appointments and other procedures. However, this environment is recognized to be full of meanings and feelings, so priority was given to more private spaces that were far from the hospital routine experienced by the participants, to facilitate the evocation of affective memories related to friendship.

Before starting the collection, the institution signed the Consent Form, and in each interview, there was a moment for explanation and signing of the Informed Consent (IC). Respecting the ethical procedures outlined in Resolution 510/16 of the National Health Council (CNS), which aims to determine the Methodological Procedures Characteristic of the Areas of Human and Social Sciences. This research was approved and registered with the Brazil Platform under CAAE number 07740618.6.0000.5542.

The transcripts were analyzed based on thematic analysis (Clarke, 2017). From the identification, description, and organization of the data, insights/reflections on patterns of meaning, which would be the themes, are systematically offered.

Results and discussion

The results were organized into three axes for better understanding and discussion of the theme: Osteogenesis in participants' lives; friendship relationships; and the involvement of friends in coping with Osteogenesis.

1. Osteogenesis in participants' lives

This category was organized to compile sociodemographic data and aspects of the history of diagnosis and treatment of OI. Sociodemographic characteristics were irrelevant to the discussion about friendship relationships in coping with OI. Regarding the presence of the disease in other family members, no other differences were pointed out during the interview regarding either the care or friendship relationships of the subject. This result can be explained by the small number of participants, which did not allow a clear relationship between the data.

Regarding the moment of diagnosis, this did not prove significant in the lives of the subjects studied, as this was often made shortly after birth or in the first years of life. However, in some cases, the moment of explanation by caregivers and understanding of the disease had great relevance to the lives of the subjects.

On the other hand, one interviewee talked about the process of diagnosing her daughter, who also has OI, a long and distressing process, since her daughter had already fractured the same leg twice at the age of 8, had undergone several surgeries and the physicians had not identified anything different. The search for specialists was relentless until a diagnosis of OI was obtained, including that of the interviewee herself, who discovered the disease in adulthood due to her daughter's diagnosis.

At the start of treatment, often this started immediately after diagnosis, however, three reports differ from this reality. In the first case, the diagnosis occurred in adulthood, and treatment began years later after the participant reported pain and discomfort. In this case, OI did not cause fractures or more severe orthopedic deformities. The other two reports presented early diagnosis, in the first years of life, but treatment only began in adolescence, at age 14. Both reported that, upon diagnosis, there was no treatment in the public health system of the state of Espírito Santo. With this, it is possible to perceive the recent nature of clinical discoveries about the disease and, consequently, the provision of treatment.

Through early diagnosis and treatment, conditions during adulthood can be considered more stable. Monitoring consists of periodic consultations with an orthopedist, dentist, and other professionals specialized in rare diseases, scheduled in advance, allowing the patient to better plan and organize their life. However, there have been reports of implications in the daily lives of patients.

The interviewees who reported the greatest impact of the treatment routine on their personal lives were those from inland cities, who dedicated longer time to hospital visits. Their families usually make the whole day available to attend appointments, or when there is a need for a surgical procedure due to fractures. In addition to facing the challenges imposed by the disease and their treatment routine, patients from the interior face other challenges resulting from their social isolation (Girardon-Perlini & Ângelo, 2017).

The main themes that emerged regarding the participants' personal routines were: work outside the home; household chores; study; vocational courses and job search; individual activities; and online gaming. It is worth highlighting the significant presence of relatives in the individuals' routine activities. Activities with important social components, such as the presidency or other active participation in OI or rare disease groups, with great involvement in political discussions and specific knowledge of their condition, were also noted in some interviews.

Many people join organizations that support people with rare diseases, such as the Support Group for People with Physical Disabilities and the Reference Center for Osteogenesis Imperfecta (CROI) (Paiva et al., 2018). Knowledge about their condition drives development beyond self-knowledge, but also empowerment and reduced discrimination (Balkfors, 2015; Mello & Moreira, 2010).

Most interviewees perceived the implications of OI in their personal lives, but they also brought strategies to face them daily, showing resilience. The reports corresponded to events from childhood and adolescence from the participants' current perspective, which was very important to obtain the subjects' reflections on past moments. The impacts of OI were analyzed through three paths: specific aspects of OI; external causes; and causes originating from the individual.

The implication arising from the characteristics of the disease is mainly due to the unpredictability and the high chances of fracture and distancing from the social environment. Reports of learning delays resulting from school absences were frequent in the interviews, hindering both the individual's socialization and their learning process (Balkfors, 2015; Mello

& Moreira, 2010). Physical aspects such as pain, fatigue, and tiredness also contributed to the decrease in social function and participation in daily activities (Basel & Steiner, 2009; Fegran et al., 2014).

The analysis of external aspects was carried out in two directions: the first related to discrimination and the second to the lack of accessibility in public places. Concerning discrimination, the main subthemes that emerged were: bullying; shame; exclusion; sadness; incapacity; depression, and social isolation. The main forms of prejudice were directed at the lack of knowledge about the rare disease and its physical aspect. In today's society, despite noticing advances in this area, people with physical disabilities still face stigmas and prejudices, generally such discrimination is manifested through distancing, as well as reactions of indulgence, and feelings of "pity", and incapacity (Paiva et al., 2018).

The second thematic path in this analysis concerns accessibility, which is often precarious, in public places and roads. In this case, the impact of OI comes from physical barriers, difficulty in moving around due to the disease, and the limited and fragile infrastructure of public spaces, a consequence of low investment in universal access structures and adaptability of roads in society, in its general scope. Accessibility provides greater safety, independence, and autonomy for people with disabilities (Cruz, Silva, Pinto, Figueiredo, Sé, Fernandes & Machado, 2020). Without proper adaptation, people with disabilities, especially OI patients, need help from third parties for routine activities, contributing to the subject's dependence and hindering their process of autonomy.

The implications of the disease on the routine of people with OI are also perceived based on the self-perception of their condition. Reports of caution and fear by the participants themselves as reasons for stopping playing or practicing some sport or risky activity. The chronic and unpredictable nature also influences a more attentive and cautious attitude of the subject, avoiding some activities to minimize fractures and hospitalizations (Martins, Campos, Llerena & Soares, 2014).

Because of the difficulties mentioned by the interviewees, they also benefit from a support network that helps them in the process of adapting to and coping with OI. The main components of this network perceived by the participants are family members and the hospital's multidisciplinary team. As for the multidisciplinary team, the main themes that emerged were: treatment, physical appearance, medication, and benefits received from the government.

About relatives, the themes that appeared most were: company, social support, and their presence in most of their activities. These were composed of both the nuclear family and the extended family, including grandparents, godparents, and cousins, such coexistence contributes to the feeling of safety at different times and places (Balkfors, 2015).

2. Friendship relationships

In this section, we sought to describe the participants' friendship relationships. Regarding these, we noticed a limited number of friends. Despite having busy routines and reports of social interactions, when it comes to more intimate relationships, such as friendship, this network was restricted and mainly composed of family members.

Episodes of isolation or social restriction and dependence were identified in some statements, which resulted in an infantilized attitude from the subject. In one specific case, in addition to the shallow reports of her friends, throughout the conversation, the participant directed questions to her aunt, who accompanied her, which showed the participant's lack of autonomy and her great dependence. Overprotective behaviors on the part of family members or those who accompany individuals affected with OI, often unintentional, can influence the levels of dependence and social isolation (Stephen et al., 2016).

In the composition of the friendship network, most friends are family members, which also corroborates the perception of the limited social circle of OI patients. In these cases, the origin of the friendship was also restricted to family life. For those originating outside the family environment, their bonds were mostly built in childhood and maintained until adulthood, accompanying them through the difficult moments of the disease and being recognized as lifelong friends (Mascarin, & Ferrari, 2019).

The term “friend’s help” appeared at the beginning of friendships and important moments. Many became best friends due to their friend’s collaboration in school activities, when participants had to be absent, and in support and assistance during transportation and routine activities.

Although school is an environment with physical obstacles that hinder accessibility, the school context has also proven to be a place to make friends, especially in moments of help to strengthen social life, offering support in the adaptation and movement of individuals (Stephen et al., 2016). The context in which they met and the reasons for forming the bond of friendship permeates situations of help, support, and acceptance of the limitations of the OI. Traits of companionship, mutual help, intimacy, and affection (Mascarin & Ferrari, 2019) were present in the interviewees’ statements.

Differences were detected between friends made up of relatives and those made up of people from other circles in the analysis regarding the activities shared with friends. Friendship is directly related to the similarity of activities with friends (Hinde, 2014), which is not the case when considering the moments shared with family members. In these cases, the constitution of friendship was not due to common practices and similarities, but rather to the relationship of care. Regarding friends outside the family environment, made up of girlfriends, schoolmates, and neighbors, the activities focused on external programs, such as movies, beaches, shopping, parks, clubs, and parties, among other places. This dialogues with the equity and symmetry present in friendship relationships, providing a feeling of equality (Lopes, 2017).

In the selection and description of the remarkable episodes of each friendship, the presence of OI is perceived in the moments reported. OI is part of the subjects’ lives, the way they relate and position themselves permeates the conditions of the disease, therefore the great presence of the disease in social relationships was found. Given this, the episodes showed in some way moments of help and support from friends in the face of some difficulty arising from the disease, or their presence in some remarkable moment of coping with the disease.

However, some described moments outside the context of OI, without addressing their limitations or coping strategies. It is worth highlighting a specific episode reported about an outing the participant had taken with her mother, where she said that, at various times during the trip, she took the lead in resolving problems during the trip. The choice of this story shows the construction of the participant’s autonomous stance when making decisions and choices, which reveals the process of independence on the part of the interviewee.

A life marked by physical limitations, protection from third parties, and fears of the next fracture can often hinder the individual’s personal development and self-confidence (Stephen et al., 2016). Therefore, their active participation in choices and decision-making is extremely important for the development of their self-confidence, independence, and autonomy, aspects that favor the construction of their self-image and, consequently, their social posture (Mello & Moreira, 2010).

When analyzing the meaning of friendship for each research subject, the main themes that emerged were: acceptance, intimacy, learning, companionship, and similarity. Help was one of the reasons for building the bond of friendship most present in the reports, as it involved feelings of gratitude and recognition for the people who were there in difficult times, mainly due to OI, corroborating the characteristic traits of this relationship. Friendships are built through bonds of reciprocal help, where one can count on the other, and the context is an important factor that influences these relationships; it is from this that friendships are formed and changed, respecting the current conditions of each member (Mascarin & Ferrari, 2019).

Companionship and intimacy are other aspects that are worth highlighting. Present in most reports, the importance of the presence and support of friends during the phases of personal development and in the experience with OI is recognized by the participants and is the main characteristic of the friendship relationships set.

When talking about the practice of common activities as one of the main characteristics of friendship, sharing similar situations can also be considered a contributing factor to strengthening bonds. The interviewees reported getting closer due to the activities carried out, such as games, and similar situations experienced, such as the presence of a chronic disease. Lopes (2017) discusses the possibility of sharing similar experiences to promote friendly relationships in the group.

3. Involvement of friends in coping with Osteogenesis

The aspect that marked this section was not the presence or absence of the influences of the disease, but the way each participant found to deal with difficult situations and adversities. Much more than perceiving obstacles and adversities, identifying and exploring the coping strategies used is of great relevance to studying their impacts on the lives of the subjects, thus being able to relate them to concepts of resilience, well-being, and quality of life (Manning, Elliott, Brotkin, Maslow, & Pollock, 2021). The participants' reports, which focused on events from childhood and adolescence, made it possible to absorb information about the perceptions of the research subjects themselves about their past experiences and the paths taken to adapt to the reality of OI.

Regarding coping strategies, the three themes that emerged to compose this category were: good humor, knowledge, and maturity. Good humor was a strategy used to get closer to people, according to the report of a participant, many people avoided getting closer because of the stigma of illness and disability, along with the look of incapacity and childishness of the subject.

Knowledge also proved to be a coping strategy; discrimination and social isolation were often perceived by participants as a result of a lack of knowledge about the rare disease. This aspect reflects the interest in deepening and continuous learning about issues related to the disease, explaining to others about their conditions, and sharing knowledge about OI (Balkfors, 2015). Thus, knowledge is an important tool for the process of self-care and self-knowledge, as well as for confronting segregation and prejudice (Mello & Moreira, 2010).

The third theme is maturation, which involves personal development and self-knowledge. One interviewee mentioned acceptance as the main resource for living with a rare disease and added that this process occurs, in most cases, through the personal maturation of the individual. Studies that bring a developmental perspective to coping strategies consider changes in coping at different stages of life according to the subject's abilities and repertoire (Manning et al., 2021). Because it is a congenital and chronic disease, OI accompanies all stages of individuals' growth and in each phase, adaptation is different.

OI does not impede or affect the formation of new friendships in a more noticeable way, and its influence on activities with friends is also seen as moderate when it is perceived and does not harm the maintenance of friendship ties. On the one hand, there are references to the adaptation of their own activities by friends, and on the other, the perception of some structural limitations, often from the external environment.

In addition to the individual processes of the subjects with OI, some attitudes on the part of friends facilitated the lack or low involvement of OI in the activities between them. The terms used to address this positioning were: acceptance, solidarity, and understanding.

In the analysis of the interviews, a difference was noted in the role played by friends compared to relatives considered as friends and friends outside the family nucleus. The family members who make up the friendship network assumed a role closer to the treatment of OI in its hospital and medication nature, by accompanying the participants in consultations and hospitalizations, extending care to the domestic sphere, and providing safer environments with less possibility of fracture. In the literature review, this data is confirmed, by bringing family members as the main caregivers in general (Balkfors, 2015; Paiva et al., 2018).

In contrast, friends outside the family allowed greater freedom, by moving away from the rigor and seriousness present in family relationships (Lopes, 2017), thus distancing themselves from care and getting closer to the social context of the person with OI. In the interviews, the terms most used to refer to friends and their role in the care and the treatment routine were: solidarity, understanding, company, encouragement, support in school activities, relationships of equality, independence, and social integration.

The theme that stands out in this discussion is the relationship of equality present in friendships. The equal treatment present in relationships with friends helps in the process of independence and autonomy of the individual, while also strengthening their confidence for the development of skills, since in this relationship the individual with OI places themselves in an active position in their life, as addressed by Lopes (2017) when studying the relationships between the group of diabetics and health services.

This relationship can be observed in most cases, in reports about fun, when they were not treated differently for having a rare disease, but rather like any other child/adolescent. The presence of complicity and solidarity also make up this relationship when it comes to non-recommended activities, such as skipping school and other risky activities, pointing to friends as important partners in the lives of the interviewees, at different moments in their lives. Such memories also appeared as the most striking during the history of friendship with friends, illustrating the importance of friendship in enabling typical experiences of age that go beyond the limits and attention of the disease.

Friends also proved to be a source of support, especially at school with evaluative activities and subjects. Reports show the importance of this partnership for continuing studies. Furthermore, considering school as the main social environment for children and adolescents, in the case of people with OI, who often move away from this environment in favor of treatment for the disease, this individual's socialization may be impaired (Mello &

Moreira, 2010). In this context, friends can also help maintain this social bond with the school context.

Friendship plays a very important role in coping with the disease, providing greater social inclusion, integrating and supporting the person affected, and playing an equally fundamental role in the life of the subject when compared to other strategies (Sanches & Gil, 2017). In addition, they appear as important elements of friends' participation in direct care, by avoiding and advising about certain risky activities.

The themes addressed within friendship relationships characterize the relationship with a friend, but they are also essential for the different interpersonal relationships established throughout social life, by helping to empower the subject. (Van Staa, Hilberink, & Sattoe, 2021) defined empowerment as a process of awareness and knowledge that individuals have to influence both their behavior and that of others in favor of a better quality of life and well-being. The egalitarian relationship characteristic of relationships between friends encourages the development of a more active and empowered posture of the subject, which is reflected in the behaviors of caring for the disease and in the other contexts in which this subject will be inserted (Van Staa et al., 2021).

Therefore, it is possible to reflect on the important relationship between friendship and empowerment, based on the flexibility of their relationships, enabling the autonomy of the subject and encouraging protagonism in their other relationships. Therefore, the main driver for moving the changes necessary for greater social inclusion of people with physical disabilities needs to be within each individual.

Final considerations

From the discussions held, a certain dependence of the participants can be noted, mainly towards those who are closest to their caregivers, often family members. The fragility and scarcity of the social network beyond the family circle suggest the social distancing of the participants. In addition to the physical and mobility limitations imposed by the disease, overprotection contributes to the withdrawal from risky activities and consequently from greater social interaction. The fear and anxiety of the next fracture is recognized, on the other hand, the importance of allowing the subject to express themselves and their social posture is perceived.

Regarding friendship, the presence and influence of OI in their relationships were observed in the physical condition of the subjects. The main obstacle faced by the interviewees was the discrimination and difficulty of accessibility experienced by most of them. However, in most of the reports, positive statements and learning through coping with OI prevailed, mainly in partnership with friends and their equal relationships that helped in this process.

There is a difference between the support offered by relatives and friends outside the family environment, who help with broader care of the disease and collaborate towards greater social inclusion. Relationships of equality, help, and companionship provide a welcoming environment, more conducive to the acceptance and independence of the subject, which facilitates and stimulates the empowerment of people with OI. Those with a broader circle of friends showed movements to seek jobs and rights, establish intimate relationships, and show greater independence and autonomy in their daily lives.

This shows the importance of egalitarian and horizontal relationships, such as friendships, in expanding people's lives. Through these social interactions, individuals can re-signify and construct themselves as subjects, placing themselves as active protagonists of their lives. This also enables reflection on the contributions of friendships to other social interactions in the subject's life.

It is important to highlight some difficulties faced during the research. Finding participants and having them available for the interview was quite a challenge, since most of the subjects live in cities in the interior, and the routine of appointments and consultations also made it impossible to interview a larger number of people. The theme of interpersonal relationships is quite complex, and this study does not aim to end the discussion about friendship as a support network for coping with OI.

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