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Research Article

Haemophilia and physical activity: the impact of the pandemic and the consequences for patients in prevention

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Haemophilia is a hereditary, recessive Congenital Haemorrhagic Disease (CJD) that almost exclusively affects males. The management of the disease has undergone profound transformations with the development of replacement therapy, but until a few decades ago, it was unthinkable for people with haemophilia to carry out even common daily activities such as sporting activities, because of the risk of possible bleeding. Physical exercise is on the contrary nowadays strongly encouraged for this type of patient as it provides a number of benefits both on a strictly physical level and also non-physically as a means of socialization, independence and self-esteem. The survey described here is a cross-sectional sociological observational study involving 258 individuals with haemophilia, divided into regionally representative quotas of four age groups. The aim of the study was to find out the prevalence, type and frequency of physical activity practiced by people with haemophilia A and B and to assess the impact of the pandemic on the practice of physical activity and sport. In fact, the pandemic situation has had a strong impact on care pathways especially of chronic patients, and regular performance of sport and physical activities shows to be severely curtailed, with this representing an element of impairment to the quality of life of hemophiliacs. The survey focused on Patient-Reported Outcomes (PRO). The research showed the prevalence of physical and sporting activity among people with haemophilia, noting that more than half of the sample is engaged in moderate or intense activity, and 40% in actual sport. On the other hand, an experience reported in paediatric age groups is markedly reduced in comparison to other age groups. Relevant changes in these activities have been detected during the pandemic period, following which around 27% of those surveyed stopped practicing sport or intense physical activity. This research outlined a very concerning picture, as the situation described severely compromises the achievement of an optimal quality of life for these patients and needs to be monitored during the following years.

Key words: Hemophilia, physical activity, high-impact sport, quality of life, coronavirus disease-19

INTRODUCTION

Congenital Hemorrhagic Disease (CJD) with a hereditary component known as haemophilia affects virtually exclusively men. The disease is caused by the absence or deficiency of one of the proteins involved in blood clotting due to a mutation in the gene for factor VIII, in the case of Haemophilia A, or factor IX, in Haemophilia B. In individuals suffering from haemophilia, the ability to stop bleeding is impaired, resulting in haemarthrosis, chronic pain and reduced joint function, and increased haemorrhagic risk (Franchini et al., 2013; Mannucci et al., 2004). There are approximately 5,000 haemophilic patients in Italy, with a clear prevalence of haemophilia A cases (4109) compared to B cases (882) and among them 43.8% and 33.9% respectively live with a severe form of the disease (Abbonizio et al., 2020).

The management of the disease has undergone profound transformations since the second half of the last century thanks to the identification of the antihaemophilic factor, a discovery that led to the development of replacement therapy within a few years (Franchini et al., 2013; Schramm, 2014). Today, thanks to the periodic administration of the missing factor, the life of haemophilic patients has changed radically, and with it the needs and requirements associated with carrying out daily activities for haemophilic patients. Looking back, it

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will be surprising to note that until a few decades ago, it was unthinkable for haemophiliacs to carry out even common daily activities such as sporting activities, which will be discussed in more detail. Thanks to technological advances, haemophilia is now a condition that people can live with and whose life expectancy is now equivalent to that of healthy individuals. However, as a chronic condition, it requires constant monitoring and daily management to avoid exacerbation and the onset of spontaneous bleeding, joint problems and haemorrhage. As is well known, the pandemic situation has had a strong impact on various aspects concerning the care pathway of patients, especially chronic patients, who have specific needs in terms of continuity of care. Moreover, already in the pre-Covid period, it had emerged that for haemophiliacs, one of the major fears compromising their quality of life was that of contracting infectious diseases (Trindade et al., 2019). Subsequent studies (Moynihan et al., 2021; NSO, 2020) showed that during the pandemic, this fear was compounded by additional problems, such as difficulties in accessing medication and routine visits, as well as access to psychological support. At a national level, there has therefore been a general reduction in prevention, with potentially important consequences in terms of worsening the health status of patients. Among the activities whose regular performance has been compromised by the pandemic situation, exercise also figures as a practice that has been severely curtailed.

The aim of the investigation presented here was to assess the impact of the pandemic on the practice of physical activity and sport in people with haemophilia A and B. It should be noted that until a few years ago, people with haemophilia were strongly advised against practicing sport and intense physical activity, particularly with high contact-impact, because of the risk of possible bleeding. With the therapeutic advancement, physical exercise is on the contrary nowadays strongly encouraged for this type of patient as it provides a number of benefits both on a strictly physical level, in terms of e.g. improved muscular function and endurance (Zettenberg et al., 2018), but also non-physically as a means of socialization, independence and self-esteem (Von Mackensen, 2007; Timmer et al., 2018). The severe backlash inflicted during the Covid-19 emergency on this now widespread and encouraged practice represents an element of impairment to the quality of life of haemophiliacs, as well as a further preventive practice to be discontinued, and needs to be further investigated with further analysis and monitoring.

MATERIALS AND METHODS

Premises for the methodological criteria of the survey

Within the social studies on health in recent decades, illness has gradually become a complex and multidimensional concept, not reducible solely to the physical-clinical plane, but requiring a holistic approach that is capable of encompassing the planes and sub-plans of illness, disease and sickness (Twaddle, 1968; Twaddle, 1979; Hoffman, 2002) and of healing the illusory separation that often leads to analyzing them as separate realities (Zempléni, 1985) these three orders, in fact, interact with each other and in order to be understood they require an all-encompassing study of the experience of illness. It has been noted, however, that such a breakdown of the concept of illness within the 'Twaddle triad' is sometimes insufficient to encompass experiences such as those of haemophilic patients, particularly because of the lack of attention paid to the relationship between diagnosis and the social construction of illness. A further specification of these dimensions has therefore been reported in the literature on 'theories of health and illness', proposing the splitting of the concept of Illness and Sickness in the so-called P-Model (Maturo, 2007). In it, Imaginary Sickness (or Sickscape); Institutional Sickness; Semantics of Illness and Experienced Illness are added (Rocino et al., 2020). Many contemporary researches have inherited and implemented this new model in their analyses of health and society, developing a person-centered approach, now seen as a subject who cannot be identified solely by the clinically defined pathology he or she has.

From this point of view, physical activity in people with haemophilia is one of those heuristic bridges that help to understand intuitively the need for the recomposition of these dimensions in a unitary view that goes beyond the distinction between the different levels of the disease, recovering the unitary experience lived by the patient. On the clinical level of disease, it is, in fact, a practice with real evidence-based benefits recognized by the scientific community (Eime et al., 2013), but it is also an activity that calls into question various components carrying enormous significance in people's lives that refer back to the social representations of illness (imaginary sickness), such as the possibility of feeling part of a group and the sense of social acceptance and inclusion that derives from not feeling discriminated against because of one's state of health (Farrugia et al., 2018).

Specifically, physical activity can lead to a wide range of benefits for the chronically ill patient, as a proven strategy for primary and secondary prevention (Warburton et al., 2017). It may also succeed in triggering transformations on the level of experienced illness, which refer to the deeper relationship with the body as experienced by the chronic patient. The latter sometimes finds himself living, as expressed in some accounts of illness, a dual and divided condition capable of questioning one of the six characteristics of the 'common sense reality' elaborated by Shutz (Good, 1999), namely the capacity to live a 'totally undivided self', developing a sense of antagonism towards his own body. Further analysis should be conducted to ascertain to what extent physical and sporting activity, by encouraging the development of so-called body control (Farrugia et al., 2018), is able to reduce the conflict and duality experienced by chronic subjects, in this case haemophiliacs.

The consequences of these reflections lead to the need to reflect on a broader health-disease context that requires instruments to detect and evaluate outcomes that are not only strictly clinical in nature. In order to be able to intercept and evaluate the experience of haemophilic subjects, the survey therefore focused on Patient-Reported Outcomes (PRO), i.e. on the detection of what was reported by the patients themselves, and thus subjectively perceived, regarding their health condition and their way of being and acting in relation to it (Patrick et al., 2011).

These dimensions can be considered as surrogate outcomes and outcomes based on the subjectivity of the patient, understanding them as a continuum between "simple pathophysiological values to true quality-of-life estimates" (Niero, 2008).

It should be noted that perceived measurements (PRO) do not always correlate with physiological measures. For example, the assumption that the achievement of clinical results and physiological healing is consequently an indication of the patient's perceived health may be incorrect (Kunz et al., 2008). Biomedical language tends, in fact, to identify the concept of cure with that of treatment, judging its efficacy in terms of the mere achievement of a state of health understood as the restoration of normal biological values (Pizza, 2019), operating in clinical practice a distinction between well-being and health that ignores the unification recognized on a theoretical level. On the contrary, healing must be seen as a state of global restoration of the fractures made in the individual along the different levels on which the disease manifests itself.

The 2020 nationwide survey conducted by Bhave is a cross-sectional sociological observational study involving 258 individuals with haemophilia, divided into regionally representative quotas of four age groups: 0-18 years, 19-40 years, 41-60 years and over 60 years. Among them, 80% of the subjects suffered from haemophilia A, and 48% of the sample had a severe form of the disease. The survey of PROs was conducted by means of a standardized questionnaire with measures quantifying the patient's view of their own health and life as main or complementary end-points. This survey has the merit of reducing the distance between the medical and humanistic disciplines and of further centering the assessment and evaluation process of outcomes on the patient. The interviews were conducted by means of a questionnaire filled in using CAWI (Computer Assisted Web Interviewing) and CATI (Computer Assisted Telephone Interviewing) methods. The aim of the study was to find out the prevalence, type and frequency of physical activity practiced by people with haemophilia A and B. Once the picture was outlined, we then wanted to understand whether and how this practice underwent changes during the lockdown caused by the Covid-19 emergency.

RESULTS

Some results obtained in the screening phase are fundamental for a better understanding of the context and the type of patients with whom the topic under study was addressed. In particular, a large majority of the sample manifested a high degree of awareness of their condition as they considered themselves very or extremely well informed on the subject of haemophilia (75.3%) and found this type of information in direct interaction with other haemophiliacs (28%) or healthcare professionals (21%). In addition, an interesting finding concerns the high percentage of subjects who state that they have a sedentary job or activity (58%), particularly among young patients (62%).

Turning instead to the data on sport and physical activity, the WHO (World Health Organization) defines the latter as "any movement determined by the musculoskeletal system that involves a greater expenditure of energy than in resting conditions" (WHO, 2010). Exercise, on the other hand, is defined as structured, planned and regularly performed activity that is subject to precise rules. National data on physical activity are monitored by the Ministry of Health through the PASSI (Progressi delle Aziende Sanitarie per la Salute in Italia) surveillance system.

Looking at the results on physical activity, more than half of the sample stated that they practiced moderate physical activity (51%), by which they meant walking about three times a week for 45 minutes. A smaller number of subjects, on the other hand, practice intense physical activity (5%), i.e. running for an average of one hour once a day, while 4% stated that they practice both types of exercise. These data show that around 40% of people with haemophilia do not engage in any physical activity, but the highest percentage is among those with mild haemophilia and those with no family history of haemophilia (in both cases, 52% of the sample).

Analysing the prevalence of sporting practices in the narrower sense among people with haemophilia, it was found that 40% of the sample is involved in a sport, a practice that is particularly widespread among those suffering from Haemophilia B (50%). The most commonly practiced sports are jogging (53.5%), followed by gymnastics, apparatus and dance (21.1%). Furthermore, if we relate these findings to the various age groups, we can see that there is a greater practice among young adults (52%) and that, on the contrary, this percentage drops dramatically in the paediatric age group, to 28% (Figure 1). Again, the highest percentage of people who do not practice sporting activity is found among those living with a mild form of the disease (76%).

From this initial overview it is possible to highlight some significant data. Firstly, despite the fact that the majority of individuals carry out sedentary activities or jobs, a considerable number of individuals do not compensate for this sedentariness with physical activity, neither moderate nor intense, with possible consequences in terms of muscular atrophy, instability and reduced motor capacity (de la Corte-Rodriguez et al., 2013).

Moreover, those who do not exercise or participate in actual sport are mainly those who present with the disease in a mild form, a fact that must be put down to the greater likelihood of bleeding due to the absence of prophylaxis (McGee et al., 2015). The same high percentage is also to be found among those for whom familiarity is ruled out, leading one to speculate on the influence that family experiences of haemophilia may have on the subjects' awareness of exercise. Adopting a holistic approach that looks at the disease and treatment as complex and multidimensional practices, physical and sporting activity figures as one of the factors enabling a general improvement in quality of life for haemophiliacs (Bertamino et al., 2017; Moretti et al., 2021). Indeed, it belongs to both common sense and systematic studies (Eime et al., 2013) that physical activity can, in both children and adults, increase feelings of general (physical and psychosocial) well- being and reduce anxiety and stress, benefits that seem to increase in team or group activities due to the social context of participation (Eime et al., 2010). In addition to these general benefits, some of the specific benefits for haemophiliacs include increased bone mineral density and muscle mass and tone, which can reduce the frequency of bleeding and joint problems, as well as increase joint range of motion (Souza et al., 2012).

In the light of these considerations, a worrying fact concerns the prevalence of sporting activity in the first age group: a large majority of the children and adolescents interviewed are in fact not involved in any sport, despite the fact that the risks associated with practicing it has clearly decreased thanks to current therapies. It has also been shown how this may adversely affect the level of physical activity that these subjects will practice in adulthood, having not been active during childhood (Tammelin et al., 2003), with all the repercussions in terms of psychophysical wellbeing that we have previously identified, also linked to the prevention of the exacerbation of their pathology.

The reasons for this consistent decline in the prevalence of sporting activity among children could be linked to an over-protective attitude on the part of parents, who are concerned that their children may incur bleeding and joint pain and who lead them to favor, as was also found during the survey for the other age groups, individual, low-impact activities such as running, gymnastics or cycling (Figure 2).

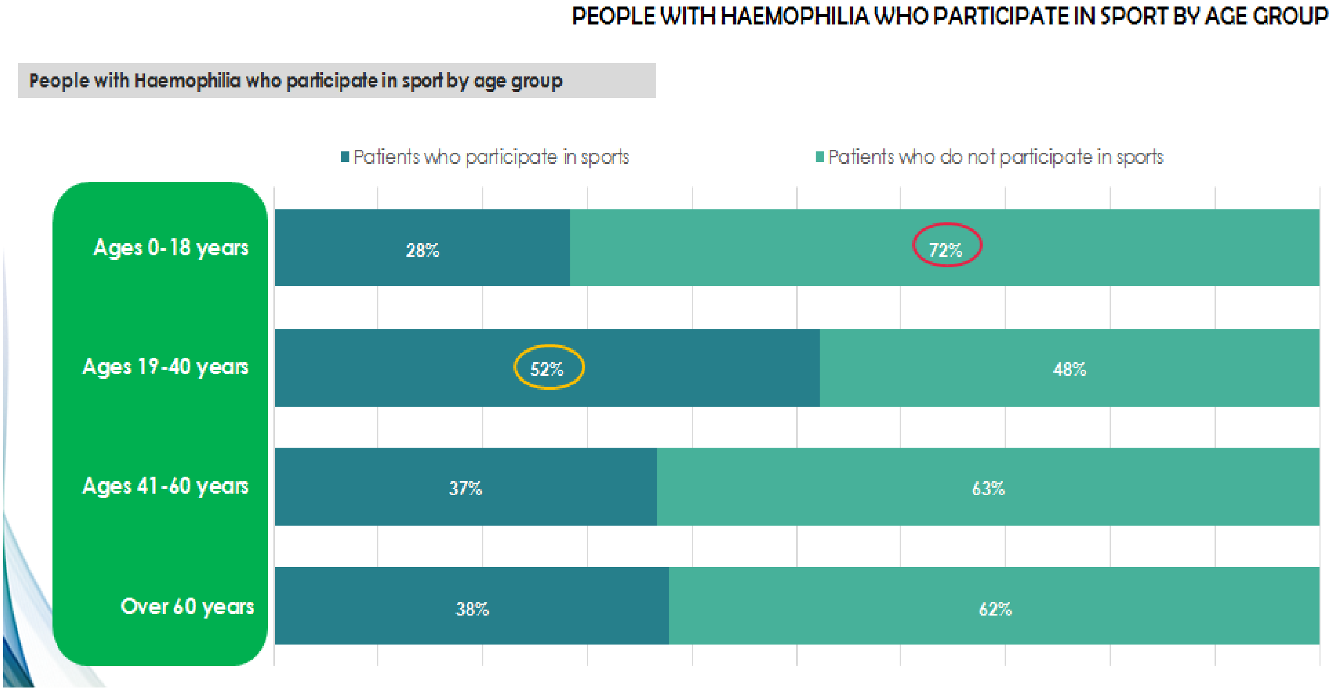

Figure 1. People with haemophilia who participate in sport by age group. [Note: (■) Patients who participate in sports, (■) Patients who do not participate in sports].

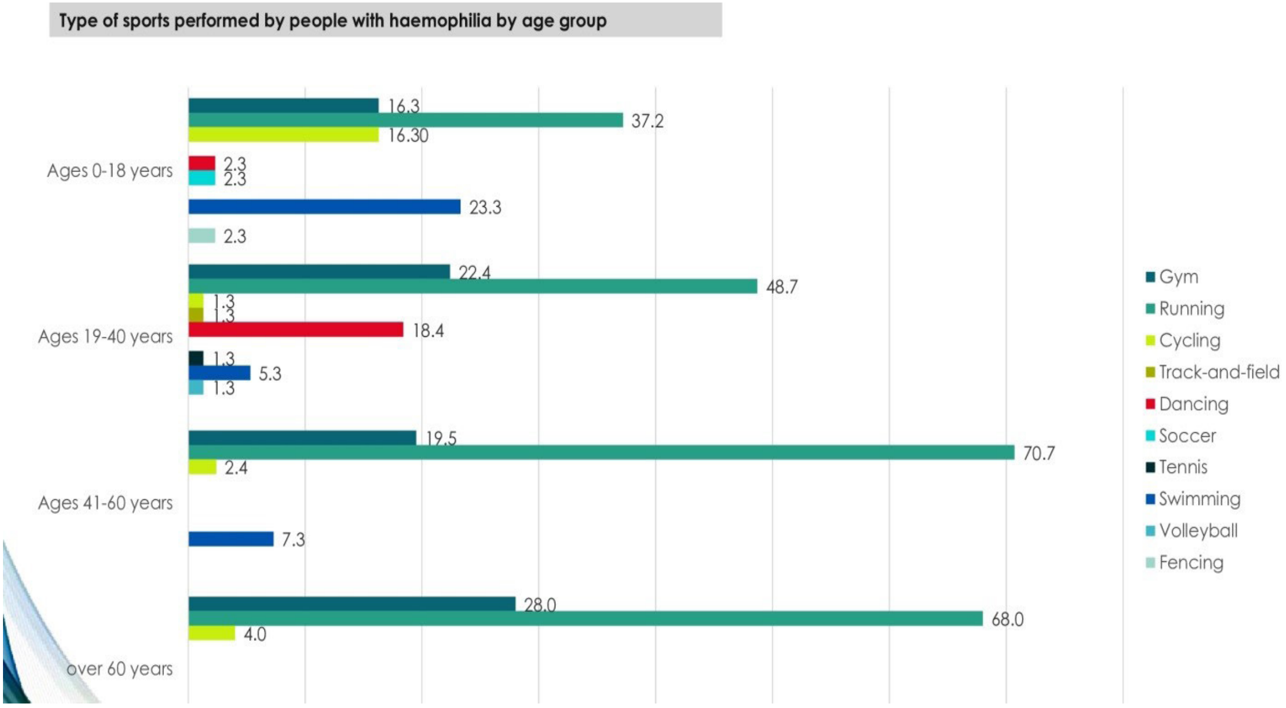

Figure 2. Type of sports activity performed by people with haemophilia, by age group. [Note: (■) Gym, (■) Running, (■) Cycling, (■) Track-and-field, (■) Dancing, (■) Soccer, (■) Tennis, (■) Swimming, (■) Volley ball, (■) Fencing)]

THE IMPACT OF THE COVID-19 EMERGENCY

The above analysis shows that physical and sporting activity is an important element in preventing and improving the quality of life for haemophilia patients. In this scenario, what impact did the Covid-19 emergency and the first lockdown have? The difficulties associated with the management of haemophilia during the health emergency affected various aspects of the patient's life, such as major impediments in access to drugs and hospital facilities. In fact, it has been estimated that during the first wave, access to treatment was reduced by approximately one third (Moynihan et al., 2021), a collapse mainly due to the blockage of outpatient activities on the territory and in hospital by doctors, and the high perception of infectious risk by users (NSO, 2020). This has resulted in the near-zeroing of new diagnoses, the cancellation of prescriptive switches and the reduction in several cases of patient adherence to treatment. Other difficulties concerned access to psychological support or home assistance and delays, cancellations and rescheduling of routine visits. Analyzing the data in relation to the different age groups, it emerged that the situation was not homogeneous, but that it was the over-60's who encountered the main problems, especially in relation to access to medicines, while in the paediatric age group, a substantial part of the sample (37%) stated that they had not encountered any difficulties in particular.

Looking specifically at physical and sports activity, according to the outcomes reported by the subjects interviewed during the quarantine, there was a general decrease in the frequency of both intense and moderate physical activity, which was totally interrupted in 32% and 18% of cases respectively. The same scenario emerged for those who practiced a sport, where more than 34% of subjects stopped exercising, and 11.8% decreased their frequency. If these data were alarming, but predictable, an element of greater concern and in need of further monitoring over time concerns what patients said about the persistence of these changes following lockdown, especially in patients with severe pathology (Figure 3).

At a general level, there was therefore a cessation of sport and intense physical activity in 27% of cases compared to before the lockdown, corresponding to a worsened or significantly worsened perception of health in 10% of cases. A survey carried out in 2021 in Italy by the Department of Sport to assess any changes in pre and post-pandemic sporting practice showed that a decrease in physical activity was a generalized phenomenon, especially among children and young people, with repercussions in terms of increased anxiety, sadness and apathy moods that many studies have shown to be reducible through exercise (Stubbs et al., 2017; Eime et al., 2010). These changes have even more dramatic outcomes for those who deal daily with a chronic, as well as rare, condition such as haemophilia, which requires ongoing treatment to achieve optimal prevention of its acute phenomena.

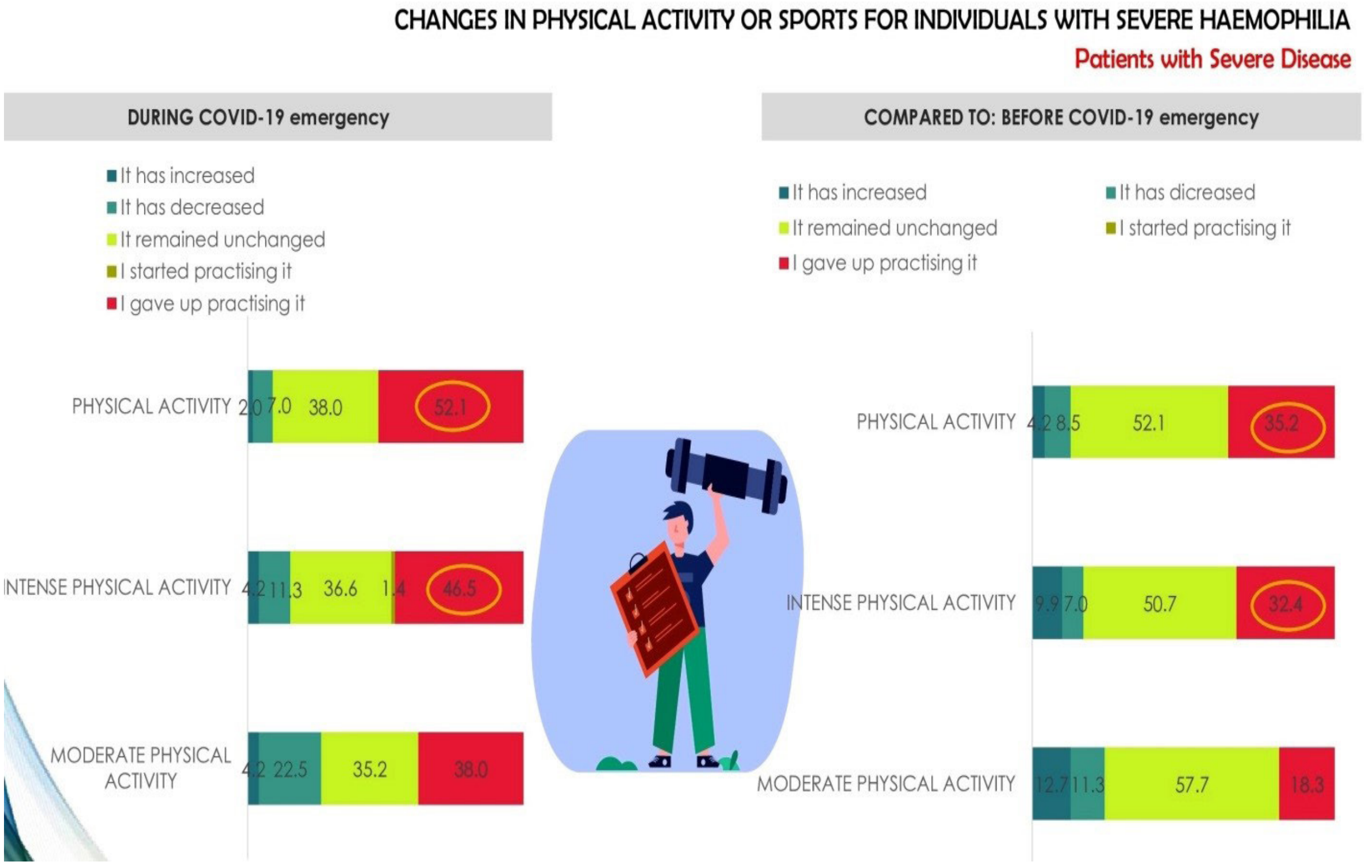

Figure 3. Changes in physical activity or sport for individuals with severe haemophilia. [Note: During COVID-19 Emergency: (▮) It has increased, (▬) It has decreased, (🟩) It remained unchanged, (▬) I started practising it, (🟥) I gave up practising it; Compared to: Before COVID-19 emergency: (▮) It has increased, (▬) It has decreased, (🟩) It remained unchanged, (▬) I started practising it, (🟥) I gave up practising it)

DISCUSSION

The research showed the prevalence of physical and sporting activity among people with haemophilia, noting that more than half of the sample is engaged in moderate or intense activity, and 40% in actual sport. Although these data represent a huge step forward, achieved thanks to the therapeutic developments of the last few decades, the experiences reported in paediatric age groups, for whom the practice of physical and sporting activity is markedly reduced in comparison to other age groups, are of concern.

A further element that needs to be monitored concerns what has emerged about the changes in these activities during the pandemic period, following which around 27% of those surveyed stopped practicing sport or intense physical activity. In light of the numerous benefits highlighted, particularly for chronic and, specifically, haemophilic individuals, it is evident that the situation observed after the lockdown requires careful monitoring and intervention by institutions in respect of changes that compromise the achievement of an optimal quality of life for individuals with haemophilia.

Surveys on quality of life, even prior to the pandemic period, show how its level for persons with haemophilia remains significantly lower than that of the general population (Klamroth et al., 2011). The concept, however, is controversial and lacks uniformity in meaning (Hunt, 1997; Barofsky, 2012), but at the same time extremely relevant today. Quality of life has become, in fact, one of the main paradigms of health assessment and analysis in contemporary medical research, as well as the horizon towards which current health practices and policies are oriented. A key instrument for its complete detection are no longer only biomedical outcomes, but reported by the patients themselves, to whom the present research has addressed, highlighting some critical elements in the current life of subjects with haemophilia.

CONCLUSION

From this point of view, Patient-Reported Outcomes increasingly need to be structured in such a way as to be able to explore every dimension of the patient's experience, in the different planes of the disease identified by the Twaddle triad and the P-Model. Promoting quality of life, therefore, means going beyond strictly sectorial analyses, but recomposing the research through a transversal and all-inclusive concept that looks at the unity of the subject's experience. Only in this way will it be possible to approach an understanding of the specific experiences of health and illness and to structure policies that respond to the real needs of these people, especially for those who experience rare and chronic pathologies such as haemophilia on a daily basis.

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CONFLICT OF INTEREST

All authors report no conflict of interests.

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