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ARTICLE

Physiotherapy for New Actors: Disputes and Innovations in Care for Chronically Ill Children

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Abstract *Based on interviews with physiotherapists, we explored the arguments produced by them about their actions and the relationships of a change that has been taking place in the profile of illness in children, where an increased prevalence of complex chronic conditions has been observed. Structured in a qualitative approach, data were generated based on two provocative affirmations that generated arguments by the professionals. Data analysis revealed statements that can be referred to as results of power struggles over the performance in this new field of knowledge. Physiotherapists seek to affirm themselves through their knowledge and by approaching other professional categories, especially Medicine, in order to feel recognized and valued. However, we see that these professionals use a simpler discourse with family and caregivers, creating a bond of trust and identification with them, which facilitates their care and access to children. We point out the need for the hospital environment to be recognized as a place for the action of other categories, besides Medicine and Nursing, and the valuation in pediatric physiotherapy.*

Key words *Physiotherapy, Chronic illness, Child, Stigma, Professional perspective*

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Introduction

Child health care faces new challenges today. In this respect, Moreira and Goldani[1] highlight the emergence of a new pattern of health and disease, characterized by a decreased number of acute diseases and an increased incidence of chronic diseases. Access to sophisticated technologies, the creation of new vaccines, more effective drugs and the development of pediatric surgery contributed to the survival of these children, resulting in a higher care demand to health services[1], highlighting the more specific healthcare levels, with prolonged hospitalizations and high use of rehabilitation services. In this scenario, it is urgent to reflect on "new pediatrics" focused on the demands and knowledge required to care for this group of children[1].

Corroborating this idea, Gomes[2] states that this new profile of illness, with a more significant proportion of chronic cases, results in a greater need for multidisciplinary care and more complex hospital services, with increased demand for technological resources for both diagnosis and treatment.

According to Moreira et al.[3], chronic childhood diseases are characterized by the presence in the child for more than three months, or with three or more recurrent clinical manifestations in the past year; presence of functional limitations and the need for adaptations; impairment of the specific sociability realms of childhood, such as missing school days and limited daily activities; need for support to interact, communicate and express themselves, as well as life technological support; vulnerability associated with physical, emotional, developmental and behavioral conditions, requiring primary home care and differentiated health services; possible relationships of association between genetic/family factors and pre and post-neonatal factors[3].

Cohen et al.[4] specifies within this group those recognized as "children with medical complexity" that is characterized: (a) by increased health services needs in the household, such as doctors, specialized therapies, and differentiated educational demands, including financial impact on the household core; (b) by the presence of one or more chronic conditions associated with high morbidity or mortality rates; (c) by functional, usually severe limitations requiring the use of technologies such as tracheostomy, gastrostomy or wheelchair; (d) by the elevated use of health services, with frequent hospitalizations, multiple surgeries and multidisciplinary care.

According to Moreira et al.[3], these children must incorporate the complexity of the disease experience into their social, political, economic, and emotional realms. Duarte et al.[5] report that this population has a high frequency of hospital readmissions, which implies the problematic access to hospital services adequate to their health demands in their municipality. Sá and Gomes[6] point out that physiotherapists struggle in dealing with these children, noting that these difficulties may be associated with a change in the profile of the population served characterized by chronic diseases.

In light of the above, we propose to explore – based on previous research – the arguments produced by physiotherapists about the relationship between this change in the profile of illness in children and their actions.

A theoretical preamble: The stigma of chronicity in children and the action of physiotherapists

The association between the complex chronic condition in children and the various symbolic marks that vary with the different affected systems deserves to be correlated here with the discussion of stigma. According to Goffman[7], the social interactions in the meeting environment qualify preconceptions from marks, linking to normative expectations about behaviors and capacities. In this interactional environment, face-to-face meetings, those that are closest to the experience of the subjects who have the marks of illnesses and deficiencies, recognized as informed – family, friends and professionals, for example – and those who share the stigmas, the equals – other sick and disabled – are organized.

Physiotherapists as "informed" in the care relationships they establish with children with chronic health conditions are knowledgeable about the characteristics of the diseases and techniques required for care. In the case of physiotherapists with children with complex chronic health conditions, we stress that they face two challenges, considering the limitations of their training: (a) the hegemony of a graduate training that favors generic apprehension of rehabilitation models, not valuing the subjects and health promotion, with little emphasis on child care; (b) and when it comes to pediatrics, the model is still that of the child that is hardly close to the children with elaborate care. Thus, hypothetically, the training continues without questioning or providing contents to this context where the

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child's marks dialogue with the challenges of the complex chronic health condition.

Sá and Gomes[6] recognize that the physiotherapeutic practice, firmly based on the biomedical model, centered on the disease and not the subject, does not favor comprehensive healthcare to the chronically ill children. Physiotherapeutic actions are focused on the aggravation of base diseases, in the clinic and the measurements, with no margin for health promotion and extended health care. When showing many associated comorbidities, these children challenge professionals to develop prevention and comprehensive care work, since they are focused on the resolution of emergencies and exacerbations of chronic diseases.

Advancing the dialogue between the recognition of the stigmas of the complex chronic condition in children and the professional baggage that hardly values this new body and its challenges, Moreira et al.[8] trigger recognition that professional interaction with the complex chronic child can instigate new health care practices, and can generate learning that will favor the care of all the children who need differentiated strategies and reception.

Moreover, as another point of dialogue between the stigma of chronicity in children and vocational training, we emphasize that pediatric specialization is seen with less value within professional training. Sá and Gomes[6] point out that the pediatric specialty is deemed a "minor" area in Physiotherapy, poorly valued by physiotherapists themselves. Moreira and Souza[9] point out that pediatrics and psychiatry are perceived as minor specialties by their practitioners because they develop with subjects who are given the status of minors, more complicated because they carry the mark of dependence, incapacity, unexpectedness, violence, transgression, and spontaneity, namely, children and the demented. Moreover, the prestige or devaluation of work is linked to the object and place in which it is exercised, and there is an internal ethos to the health professions that assigns to Pediatrics a lower valuation. Santos and Moreira[10] says that nursing care relationships in an environment where the experience of the chronic illness of children and adolescents predominates promote shared meanings and representations, which extrapolate to the professional realm. They feel helpless in the face of limited personal and professional resources, as well as difficulties in identifying and dealing with their feelings.

We assume that professionals can be identified with the symbols and meanings that characterize their object of work or the people to whom they provide their work. Thus, it can be argued that these stigmas that mark these children can promote not only feelings of inferiority in the professionals, but can also sustain historically and socially constructed rationale that hinders prioritization of children and adolescent health care programs.

Concerning pediatric physiotherapy in the United States, Spake[11] points out that although most undergraduate programs have locations available for pediatric clinical practice, few considered it mandatory. Schreiber et al.[12] found that although 70% of the institutions studied indicated that the number of existing sites for pediatric clinical practice met the curricular needs, only 7% of the programs made experience mandatory. Guedes et al.[13] point out that the teaching of pediatric physiotherapy follows disease-oriented practices, and recommend the introduction of new contents and increase the workload of disciplines focused on pediatrics, as well as improving the theoretical-practical articulation and creating physical spaces for this practice.

In 2002, the National Education Council (CNE)[14] established new skills and competencies for the teaching of physiotherapy in Brazil. Thus, the curricular matrices of the courses were reformulated to meet the new profile of the graduate, and different contents were included. Even so, pediatric physiotherapy is still a discipline offered, in general, in the last year of graduation, with a small workload that should consider the entire content of the physiotherapeutic approach for this population. From the documents cited here, we can observe the reduced space reserved for Pediatrics in the training of physiotherapists, whether in the hours or spaces for practice, can result in possible absence on the work specifics of these professionals, particularly concerning children with complex chronic conditions.

Material and methods

This paper explored the argumentative analysis. We used Fairclough[15] to interpret data, which facilitated the meeting with studies on argumentative analysis located within the critical analysis of discourse. Language is considered a type of social practice, where individuals act on the world and others and are contingent by the social structure: by classes, specific relationships of particular institutions, classification systems, norms, and conventions. Analyzing a specific discourse, we rec-

ognize that it is produced, distributed and consumed in the context of, for example, particular institutional environments with power relations and ideologies, and where subjects will express their positions from that context. This critical perspective of the author can be dialogued with Foucauldian analyses of power struggles and knowledge that permeate social practices. The respondents' arguments are in the context of a "new physiotherapy" for "new subjects", in the case of children with complex chronic health conditions, that (a) carry the marks and stigmas of their chronicity imprinted on their infant bodies[7], and experience the interactions of the "informed" with them, in this case physiotherapists as reference professionals; (b) the field of dispute relationships among other professions, besides the internal ones of physiotherapy itself. To this end, we approached Bourdieu[16] in his understanding of professions as social constructions. Every statement updates other statements that are part of a set and play a role, based on and distinguishing itself from other texts. There is no text without context, and every discursive practice is linked to so many texts and references. As we study a group of physiotherapy professionals in a specialized pediatric health service, we understand their arguments as being based on mediations related to the professional rationale that govern them.

We used the technique of qualitative interview[17], promoting the understanding of the relationships between the social actors and their situation. We provide respondents two provocative statements, and ask them to either defend them or refuse them: (a) A chronic child and an adolescent are seen as less essential subjects; (b) A physiotherapist who acts with them may also be considered less critical. These statements were provided from other studies[10,18] where the controversies and seemingly contradictory discourses emerged, conflicting in the relationship to a practice of full and dedicated care with chronic children. That is, we saw a productive dialogue in the same discourse between the stance of the refusal of the provided sentences, at first, and the emergence of support that justifies those visions that may seem skewed later in the course of the interview. A table was created where each of the statements was associated with the selected excerpts to analyze the material, viewing the excerpts from the interviews and the interpretations related to the main arguments developed by the subjects.

As an end step, an interpretation was constructed in terms of the general context and argument of the subjects. The interviews took place from June to September 2015.

The field of study was a reference hospital located in the city of Rio de Janeiro. The research subjects were physiotherapists who work in the child and adolescent care in this place, which gathers reference care for children with complex chronic health conditions. The project was approved.

Results

Twenty-one subjects participated: seven professionals with up to ten years of training and fourteen with more than ten years of professional practice. Of these seven respondents, four were residents. Thirteen respondents started their careers attending pediatric patients. Of the twenty-one respondents, seventeen did specialty courses or courses in the pediatric area, and the same number had up to ten years' professional experience in the institution under study, while four had more than ten years. Only two professionals were male. Four professionals could not be interviewed as they were not available when fieldwork had taken place.

The transcriptions were read by the leading investigator and submitted to a reading session by the two counselors. The analysis of the interviews facilitated the identification of tension in the argumentative structure of the subjects, at the interface between building in contact with the children and concomitantly developing as a physiotherapist in the service studied. Thus, two argumentative axes were configured: (1) Physiotherapy for New Actors: Disputes and Innovations for Care for Chronically Ill Children; (2) Support / Mediation to Care for Chronically Ill Children: Associating Technologies, Knowledge, and Experience. For this paper, we will present the first axis.

Discussion

At the professional encounter with children, health professionals are provoked towards childhood memories and sensibilities, personal experiences to sustain their limits in practice[18]. At the same time, contents of knowledge, professional curricula and practical learning that do not seem to be considered in physiotherapy courses in the pediatric context[6,11] are triggered as necessary. The term "encounter" used here gains concept

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outlines when associated with Goffman's'[19] discussion of social interactions and the perspectives of encounters in face-to-face relationships.

Two effects were produced in the field when we used two controversial statements to provoke the interviews: first, we saw a self-reflective position of presenting and rejecting hypotheses, in the elaboration of a discussion with oneself, where options of stances and arguments were raised to defend such positions. Another effect refers to an evaluation for the audience, that is, what they could or could not present to the researcher, because these controversial statements generate a priori a movement of denial. However, in the course of the interviews, subjects continue to develop their arguments, with even ambiguous positions in their statements. This effect is in agreement with what we explained above in the method when we presented the two statements. The idea was to spark the discourse, the different arguments, and positions by the same subject, in the relationship with the external audience represented by the researcher, and the internal, self-reflexive that based experience and censorship.

The arguments presented are the result of a social interaction, where the subject seeks to adapt to the immediate context of the act of speech and the interlocutor[20]. The dialogical character of discourse is also highlighted in Barros' reading of Bakhtin[21], where dialogism is the language and the meaning of discourse, which is constructed between at least two interlocutors and relates with other discourses. Fairclough[15] says that through discourse, people act on the world and others, just as they use them as a mode of representation.

It is interesting to note that in this coming and going of agreements and disagreements with their statements, the respondents are evaluating and re-evaluating what can be said, without them being put in a situation of disadvantage vis-à-vis the interlocutor. According to Resende and Ramalho[22], there is an interactional perspective between the speaker and the listener; in this dialogical view, discourses respond to previous discourses and anticipate later discourses.

We resorted to Bourdieu[16] to find elements to find the subjects' look at their professional practice, clarifying our understanding of it. The author removes from the definition of profession an essentialist, functional perspective of neutrality in the social scene: the professions are social constructions, with the use of specific resources aiming at demarcating their field in the social space and having visibility, in the struggle for recognition and a monopoly of professional performance. In the case of the selection of this paper, this tension is marked by the power relations existing between the actors that underpin the health sector, and for specific ideas familiar to both professionals and laymen that in the hospital: *The essence of patient care is, necessarily, the doctor and nurse* [...] *if you do not have a physiotherapist on duty today, all patients will receive care by the doctor and the nurse ... and if you do not have a doctor? You cannot ... and if you do not have a nurse, technician ... the thing doesn't happen ...* [Participant 2]

Supported by Bourdieu[16], we can argue that the different professional categories coexist in a movement in which they seek to advocate the definition of the social world that best meets their interests. Professional hierarchization in health services appears as an effect of the struggle for hegemony and recognition, where some professional categories are often still recognized as occupying a level more necessary than others within this microcosm of health professionals.

By definition, a complex chronic child[4] is one with several devices and systems compromised. In this perspective, a multidisciplinary approach becomes urgent, emphasizing the synergistic action of physiotherapists. This consideration allows us to relativize the position raised by the respondent above, from the fact that a new actor – the chronically ill child – requires new practices, which include for their clinical needs physiotherapeutic care that articulates the respiratory and motor system: [...] *nowadays, as there are more chronic respiratory conditions, I have seen a little more than just a lung is required, I must improve this posture.* [Participant 3]

In the same way as a motor [physiotherapist] *has to know respiratory* [physiotherapy], *because otherwise we arrive with our chronic patient who is aggravated and we cannot do anything,* [...] [Participant 3]

Acting with children in complex chronic health conditions represents a challenge, and at the same time paves the way to affirm competence in a contentious field. The struggle appears in the conflict pointed out in the statements of some respondents when referring to respiratory physiotherapy as a competence of their category within an intensive care unit: *a place* [intensive care unit] *in which the physiotherapist manages to have a little more mastering than a few physicians, because they* [physiotherapists] *study this part of the mechanic ventilation of physiology a lot, and then doctors also no longer want to have this hassle*

very much, so physiotherapists believe it's good for them, they're going to be better because they will fiddle with mechanic ventilation [...] [Participant 12]

This struggle for an affirmation of own place among the other professional categories traverses a market dispute, where social actors use their cultural, social and symbolic capital[16] to define their privileged positions within institutions. In the above passage, the intonation of the participant, permeated by a critical intervention, expresses arguments that affirm a field of competence, where medicine may have left gaps.

This discussion becomes important when we think that the current health of children experiences the emergence of a "new pediatrics"[1] and, therefore, of children that are labeled as chronically ill and complex[3,4]. Costa et al.[23] point out that, since the 1980s, there has been an increasing number of children and adolescents with chronic dependence on pulmonary mechanical ventilation (CDPMV), most of whom are restricted to hospitals, particularly in pediatric intensive care units. This emergence will move the scene of the professions so that there are repositions, a field open to disputes and affirmation of power and competence.

When Bispo Júnior[24] explores the models of training of physiotherapists in Brazil, he will point to the dispute between physiatrists and physiotherapists, based on corporatism and market interests. Sá[25] points out the predominance of the American school to the detriment of the European in the model of training of the Brazilian physiotherapist, favoring the privatist logic of adult rehabilitation centers. Ribeiro and Medeiros Júnior[26] are moving towards dialogue with a field that promotes interdisciplinarity.

Thus, in the light of Bourdieu[16], we may discuss the struggles for hegemony in a professional field where work and training models refer to social interest and perspectives, with power struggles and dispute of fields of knowledge. Disputes do not occur only when physiotherapists refer doctors and nurses, but also when they point out that physiotherapy itself may experience tensions between the motor and respiratory areas, especially in the scenario studied.

In the case of these conflicts in the professional field, it is worth mentioning the so-called distinguishing marks that contribute to the construction of identity traits[27]. The relation of distinction incorporates approximations and deviations, in order to delimit the differences. Considering that Medicine is a highly recognized profession and status, with a more blatant hegemonic action along with Nursing, especially in the hospital space, it is relevant to question the relationship between objects of knowledge/competent intervention/social recognition. In the case of the relationship between Physiotherapy and Medicine, which has in common as a subject of professional intervention the child's health and guidance to his relative, a dispute arises between the fields of knowledge, with the professional seeking to assert himself through his knowledge, specifying responsibilities: [...] *the very issue of mechanic ventilation that was something that we drew to ourselves, then the whole discussion of the medical act came up* [...], *I think that physiotherapists who reaffirm themselves in the places to prove things is still required, but this may no longer be required in a while* [...] [Participant 8]

However, I spoke with the doctors in their same language, and some doctors there did not even know it, they had never seen it [referring to a specific pathology], so at times I knew much more than the doctor who was there ... and I could even help because I knew more than them. [Participant 12]

In the above excerpts, the importance attributed by professionals to two aspects is highlighted: (a) the selection of one aspect, which concerns child healthcare, handling it as an object of competence of the physiotherapist, in the case of respiratory ventilation and parametric data; (b) the dispute over the knowledge about the clinic and a particular disease, with the experience linked to the treatment articulated to a competent discourse.

Several official body documents related to physiotherapy respond in the professional and market regulation settings on the demarcation of the management of invasive or non-invasive ventilation support by the intensivist physiotherapist, as well as his measurement and evaluation instruments[28]; advocating physiotherapists as part of a multidisciplinary team and highlighting their non-subordination even in the face of other professional categories[29].

Given this scenario, where the dispute over fields of knowledge can define privileged positions of the professional categories, we see, on the part of the professional bodies and in the professional formation itself, an encouragement towards taking or holding own competence monopoly.

According to Foucault[30], power relations necessarily imply the establishment and appropriation of a field of knowledge, the reverse being true, where knowledge intertwines and defines

power relations. One has to be careful with a reactive discourse of opposition that reproduces a good-versus-bad dichotomy, where the physiotherapist would hold the positive position, and the other professions, the negative. The valid interpretation here, triggering the analysis of critical discourse, is that there is no way to locate someone who is not producing power relations and therefore assuming, in some moments, discourses difficult to be heard by some actors, such as the relatives. Thus, it is not the prerogative of any profession to be "welcoming, respectful to the bond".

We understand that physiotherapy, in the broader field of professions, intends to affirm and be recognized in a field where the practices and knowledge of Medicine are recognized as hegemonic. Therefore, the way professionals seek to conquer their space, ranges from assimilating knowledge of another category to clashing with it. [...] *the physiotherapist who assumed this role within the ICU also ventilates patients, not only the doctor.* [Participant 6]

[...] *however, I spoke with the doctors in their language, and some doctors there did not even know it, they had never seen it, so there were times when I knew a lot more than the doctor who was there.* [Participant 12]

In the case of physiotherapy, we can infer that the emergence of these children as new care subjects, characterized by the complexity of the clinical conditions, drive the development of techniques, knowledge and, therefore, professional assertion, and a new market of action. Using Goffman[7], it is necessary to reflect that these children and their body marks, stigmas of chronicity, challenge the models of development and corporeality, beauty standards of beauty expected for the infant body. The interaction with these children, as informed, but not equal, causes a revolution in the view and professional practices, which deserves to be reverted to the pediatrics training environment.

Professions are social constructions[16], the product of social work of building a group and of representing the groups, are immersed in relations of strength, power and dispute for a monopoly of competence. Thus, from a new object for public health, namely, the emergence of children with chronic health conditions, which can generate concerns that require the production of new knowledge to meet them, professionals seek to shape new practices to account for this open field of contention. This subject is a novelty in the institutional environment of health care, which defies the diagnostic/treatment/cure circuit, and whose chronic disease conflicts with what would be expected for development in childhood, emerges as a new object for professional intervention.

This scenario calls for a dialogue with Bourdieu[16] in the discussion between socially devalued objects and the professionals' effort to make them important scientific objects. This movement on the part of professionals is characterized as a way to be seen and show own value, but that by putting the professional on display, can make him feel insecure and at risk of showing his failures: [...] *clinical case discussion within a unit* [...] *I go there because I will also learn, if the doctors know more, I go there with the doctors because I will learn* [...], *but the person people are afraid, they do not want to expose themselves, they are afraid to do the wrong thing because they do not know*. [Participant 12]

In an environment where the medical profession is seen as imperial[31] and that historically, through monopolistic practices, it maintains its prestige by establishing barriers compared to other professions[32], to assert themselves in the field of health professions, the physiotherapists attempt to approach this category, staying close to discussions about patients and absorbing the scientific language used in the ethos of the medical profession: *Because we are with them* [to the hospital doctors], *now the physiotherapist who is there in the clinic, in his office ... is not so well known* [...] [Participant 4]

This is how it goes here. Respiratory physiotherapists take care of BIPAP; doctors take care of UPG. However, I do it, another [physiotherapist] *does it, we take it off, put it back, we always do that. Then, as the physiotherapist assumed part of this function, the hospitals acquired greater independence in this regard, 'that's fine, he is ventilated, but he can stay out there, Physiotherapy takes care of him'* [Participant 6]

The emphasis on the time-related perspective of the presence that extends in the care unit allows a bonding, adaptation of care that value play and corporal expressions, in the case of the children's audience, with the technique.

In a previous study, Silva and Moreira[33] pointed out that an essential criterion for the professional to consider himself belonging to space and the team is related to the presence in the unit. The authors emphasize that the proximity of the child's location also favors the recognition of the professional as being part of the group, which would promote positive reactions

and relationships for teamwork. Therefore, the position in time and space influences the way the team considers their co-workers as being part of the group or not.

Highlighting the multidisciplinary work, the above study states that: (a) although these teams are a reality in hospital care environments, this does not ensure interdisciplinary work; (b) segmentation by specialties and professional sectorization, with hospital architecture and the subordination of professionals to the hierarchy among specialties leads to a fragmented service and inefficient teamwork; (c) group work is achieved through the relational feelings of commitment, solidarity, responsibility and experience that permeate the group, not only through the imposition of norms and hierarchical impositions.

In a study with physiotherapists, Ghisleni[34] stresses that appreciation is linked to the recognition of the other, be it a co-worker, a patient or relative. The author also points out that when the physiotherapist has a more significant interaction with doctors and nurses, characterizing more time in the unit, there is a tendency of greater recognition of their work. On the other hand, when the professional has lower interaction with the other categories, a trust relationship is not developed and their work is not recognized.

Conclusion

The care for children with complex chronic health conditions demands new knowledge and new practices, which include, for their clinical needs, physiotherapeutic care. The professionals seek to specialize in meeting this demand and facing the power struggles that aim to have primacy over the performance with this new subject of care. In the hospital context, physiotherapists seek assertion through their knowledge and approach to other professional categories, especially Medicine. This approach comes to be recognized as an essential element to the team, where it can contribute and stand out in this environment that is still seen as a place belonging to Medicine and Nursing, and the other categories would be considered as something more, not primordial.

Although the hospital has traditionally been thought of as the exclusive space for biomedical action, represented by doctors and nurses, we understand that there is a scenario in which new technologies in health and knowledge of other categories, such as Physiotherapy, must be recognized as essential.

It is necessary to recognize the need to keep investing in the graduation in the knowledge and spaces of action with children, incorporating the demands for contents not only of physiotherapeutic techniques but of the humanities area, working the dilemmas on stigma and body marked by complex chronic conditions.

Collaborators

AF Madureira, MCN Moreira and MC Sá contributed equally in all stages of the papers.

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