

# Original Articles

## Study on heteronomy in the health care to children and adolescents with special needs

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### Abstract

This study aimed to understand, from a bioethical concept of heteronomy, the relationship between a health professional and children or teenagers with special needs concerning decision-making process faced by professionals when attending patients with different disability levels. Ten professionals that assist these patients in specialized public service participated of the semi-structured interview, allowing the analysis of six thematic axes: discussion about the treatment; communication between the health professional and the patient; participation of the person with special needs (PSN) in decisions; differences in health care; difficulties faced by health professionals; and participation of third parties. Most professionals agree that a PSN should take part on the discussions about the intervention; although the later does participate in the decision-making related to intervention. Conflict situations in view of third parties participation in the professional-PSN relationship were referred. Findings show that there is a need to protect the PSN and professional capacity building activities.

**Key words:** Bioethics. Disabled persons. Personal autonomy.

### CEP Approval no. 99/10



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A Person with Special Needs (PSN) is one that during part of his/her life or for an undetermined period requires special care, and, due to a limitation, health care depends on the disposal or management of difficulties either in the physical, emotional, intellectual, behavioral, or social aspects. This is a generic term that includes patients who need diverse and / or specific care, which may not form part of the everyday practice of a professional <sup>1</sup>.

The 1988 Federal Constitution brought progress in relation to social issues, guarantee of rights and citizenship in this field. By way of example, art. 23, subsection II of Chapter II determines that *it is common competence of the Union, the states, the District and the Municipalities to provide health care and public assistance, protection and security to*



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*people with disabilities*. In its turn, art. 24 sub-section XIV determines the protection and social integration of disabled persons <sup>2</sup>.

A legal instrument that deserves mentioning is Law 8069 of July 13, 1990, which sets forth the Statute of *the Child and Adolescent (ECA)* <sup>3</sup>. In Title I, Art. 5, it states that *no child or adolescent will be subjected to any form of neglect, discrimination, exploitation, violence, cruelty and oppression, punishable as provided by law for any violation, by action or omission, of their fundamental rights* <sup>3</sup>. And that, in Title II, Chapter I, Art 11, paragraph 1, it states that *children and adolescents with disabilities will receive special care* <sup>3</sup>.

For Peres, Peres and Silva <sup>4</sup>, *any person who has physical, organic, intellectual, social or emotional alterations, be they acute or chronic, simple or complex, requiring special education and supplemental instruction, temporary or definitely*, is considered a special patient. In this perspective, the concept is broad and may include persons subjected to various conditions or limitations. The PSN requires special attention targeted to their limitations. *Special* is understood as being one's own, unique or singular. The knowledge gained by families and health professionals provides parameters for the recognition or identification of the special character of the person from the comparison between individuals <sup>5</sup>.

The perception of diversity in society is permeated by stigmas, stereotypes, and inequalities, built in subjective, historical, social and cultural ways by the community and also by individual aspects of perception of the differences, related to personal experiences, ethical and moral values, which are after all, their history of life. Thus, health care for these clients become more complex due to the imaginary and the social representations on disability <sup>6</sup>. Although humans are different from each other, people with special needs possess differences that,

often, are not tolerated socially<sup>7</sup>.

The Convention on the Rights of Persons with Disabilities<sup>8</sup> requires from health professionals that the quality of services is the same for everyone, regardless of whether they have disabilities or not. To meet this goal, activities must be held aimed at training and defining ethical conducts for the sectors of public and private health, rendering awareness in professionals about human rights, dignity, autonomy and the needs of special people. It is understood that people should be recognized as whole beings, worthy, with a right to physical and moral integrity.

Values such as dignity, inclusion and accessibility, improving living conditions and access to environments and public services such as education, health, transportation and security are aspects of public policy in which the country has been acting and consolidating action<sup>9</sup>. According to Silva, Panhoca and Blachman<sup>5</sup>, it should be a concern and priority in health care college training to understand human beings and their socio-historical context. Education also must evaluate and prioritize work and study in teams comprised of professionals from different areas, to provide comprehensive training and multifaceted in order to understand the health-illness process.

Felicio and Pessini<sup>10</sup> also highlight the role of the multidisciplinary team, which should include diverse professionals – including psychiatrists, neurologists,

psychologists, nurses, occupational therapists, physiotherapists, nurses and social workers and educators - who work primarily in actions aimed at promotion of health and social inclusion of the PSN. For these authors, care has to be understood as an action aimed at the best possible social integration of the special patient or as a practice of ethical commitment to citizens and their rights, and of reflection about distress caused by the excluding social norms and values<sup>10</sup>. Furthermore, for a service that prioritizes the needs of the patient, the professional must be informed about the implications that the special condition causes to the individual and which is the priority care for their treatment.

Attention to the family of the disabled person is characterized as fundamental to a qualified service, extensive and efficient, with psychosocial support and guidance for carrying out daily life activities<sup>11</sup>.

Finally, regarding the patient who needs special care, establishing a link between professional and patient requires diverse skills from the first of the two, including taking into consideration the possible difficulties of communication and collaboration with treatment. Sensitivity, creativity, and the ability of the professional in searching ways to communicate with the particular patient should be constant objectives in this relationship. Thus, one must note that this is a different patient and not a difficult patient, a term often used to describe the PSN<sup>4</sup>.

## Heteronomy, autonomy, and beneficence in health practices

The word heteronomy is Greek in origin: *hetero* means different, and *norm* means law, rule. According to Kant, heteronomy is the individual's subjection to the will of others, or to the desire of a community, not belonging to reason and moral laws <sup>12</sup>. For Marchi and Sztajn <sup>13</sup>, heteronomy is *the given power, or that some professionals intend to have, to determine how their patients should behave, therefore imposing their will and ignoring the person and his/her dignity.*

The principle of autonomy incorporates the capacity that the individual has to deliberate and decide on what concerns him, about the advisability and timing of the acts that threaten his interests and assume the consequences of that decision. The word autonomy comes from the Greek (*auto* – me, my own; *nomos* – law, rule, dominion, government) and it signifies self-determination, self-management. It involves the connotation of individual choice, free from coercion

<sup>14,15</sup>. From this perspective, to be autonomous is to have the right to self-determination and to consider that the other does the same. Therefore, autonomy is not without a sense of reciprocity <sup>16</sup> and its application shows respect for the other person.

Moral awareness evolves from heteronomy to autonomy. That is, the individual, in its development process, begins to internalize the family and sociocultural

norms fearing punishment, as well as by observation of positive role models from significant persons - heteronomy - and this situation progresses to the highest level which consists of self-determination on the basis of moral principles and values that are justified by reason (autonomy). However, not all individuals can reach the level of autonomy <sup>17</sup>.

The principle of beneficence refers to the obligation to act morally in favor of or in the interest of the other, understanding the need to help others to ensure legitimate interests. In the context of health care, it aims health promotion and disease prevention, seeking to prioritize the good and to minimize the bad <sup>15,18</sup>. This principle, however, cannot be regarded as absolute. Beneficence also has its limits: the necessity of knowing what is good for the patient, the non-acceptance of a paternalistic behavior, respect for personal autonomy when deciding what they think best for themselves aside from health care and using the criteria of justice or equity in health <sup>19</sup>.

When the professional ignores the ability of the person to make his own decisions and assume the responsibilities implied, his actions exceed beneficence and goes into paternalism, i.e., authority establishes itself in the relationship between professional and patient <sup>20,21</sup>. Paternalism happens when the health professional, justifying actions in the interest of the person under his care, interferes with the will of the later <sup>18</sup>. This

attitude can be explained by the asymmetric nature of their relationship. The professional has a knowledge differential that provides authority and control over the patient, which, in turn, is in a position of submission and fragility, when he surrenders to the other for health care. Paternalism, therefore, can be understood as the passage of knowledge or technical expertise that the professional has into power or domination, ignoring the individual as a moral person, his life history and individuality <sup>20,21</sup>.

Kottow <sup>14</sup> states that, for some authors, none are more heteronomous or deprived of freedom than the subjects of bioethical action: patients, minorities, the discriminated, the disabled, in short, people in different contexts of vulnerability. By understanding and accepting autonomy as a bioethical value, the intention is to reduce non-autonomy, i.e. the lack of autonomy of these social groups attending to their interests and decision-making freedom and independence, in agreement or harmony with their individual aspirations in different situations.

Bernardes, Maior, Spezia and Araújo<sup>22</sup> consider that people with disabilities are potentially at risk of having their autonomy destroyed as it is common to confuse disability with inability of judgment and decision, prompting in non-disabled people the paternalistic premise of decision-making that the disabled person could accomplish by himself. Although the lesion may generate some kind of disability, it does not necessarily impair judgment or the ability of decision-making.

A warped sense of autonomy in terms of disability ultimately sponsors overprotective, authoritarian, and infantilizing treatment by health professionals, and family caregivers. These characteristics may accentuate when the PSN is a child or adolescent. Frequently, the professional adopts and justifies paternalistic attitude having the principle of beneficence as argument. However, research on communication in health point out constraints - and perhaps even losses - for the professional-patient relationship guided only in technical knowledge, without considering other information channels.

Professionals should be aware of the difficulties of PSN, physical and intellectual, emotional and affective, but cannot underestimate the capacity of these patients in regards to their options and choices. Furthermore, the patient's freedom to participate in treatment or not should be respected. A clear statement of aims, procedures, and care should be a point of transparency, and consent or not by the patient should always be an important target of the queries <sup>5</sup>.

Leone <sup>23</sup> states that, in human relations, respect for autonomy should only cease when there is a well established certainty that one element of this relation is completely incapable to decide, according to his free will: he is unable to receive the necessary information to exercise it, to understand correctly, to evaluate and/or, for some reason, unable to decide.

Children, adolescents, the mentally disabled, people on drugs and / or in a coma have their autonomy reduced on a temporary or permanent basis. Emotional or mental disorders can also reduce the patient's autonomy, which could compromise their ability to decide rationally <sup>24</sup>. According to Marchi and Sztajn <sup>13</sup>, *it is admitted that some people are incapable of validly and effectively express their will. This is the case of children, adolescents, the insane and those subject to the influence of superiors, for example. In such cases, ignorance, coercion, errors, by influencing on autonomy, may result in heteronomy in the guise of autonomy.*

The professional will review the capability to understand and to decide, regardless if the patient is able or not. Even in situations where it does not have full autonomy, for example, children and adolescents with special needs, professionals must not fail to listen to them, because they are those most interested in treatment and in their health <sup>25</sup>.

Marchi and Sztajn <sup>13</sup> advocate an ethics detached from heteronomous concepts, valuing trust, confidence, and sensitivity in the professional-patient relationship, and respect for personal autonomy. The patient should be able to reflect, identify and agree or not, freely, about any determinate action, besides being able to bear the consequences. Professional qualification is necessary for the exercise of the activity. Therefore, health professionals and patients are submitted

to heteronomous limitations, provided they are legitimate under the bioethical point of view and that they ensure respect for the rights of others.

The professional cannot ignore anymore the individual's right to be recognized as such in situations of physical, mental, and/or social distress. Although these conditions involve issues that are difficult, people do not lose their dignity - a characteristic inherent to humans. The patient with special needs cannot be isolated, ignored or disqualified in his expression of will as a citizen, by not being guided, informed, and mainly, being heard, whenever possible and in the best applicable way.

For this particular patient, notably children and adolescents, *it is a limitation on the competence to answer fully for the consequences of their choices, and requires support of the professional through a more beneficent work, so that the patient can really enjoy his rights and autonomy* <sup>10</sup>. Thus, it is considered that the patient with special needs is an individual who, at some point, has a limitation, a difficulty. The boundaries of respect must involve the relationship with this individual to ensure the preservation of their differences, therefore not permitting unequal treatment.

This study aimed to understand in light of the bioethical concept of heteronomy, the relationship between health professional and child or adolescent with special needs in the practice of personal



assistance with regard to decision-making processes faced by skilled professionals of different expertise, in the attention to patients with different levels of disability, requiring continuous special care. It also aimed to describe and discuss the limitations and difficulties perceived by professionals in caring for children and adolescents with special needs, who were attended in a specialized unit in the Federal District, and to identify those professionals' perception about the possibility of interaction/communication with child and adolescent patients with special needs.

## Method

This is a descriptive study, outlined for quality, which used individual semi structured interviews as a technique for data collection. Following approval by the Research Ethics Committee of the Federal District Health Secretariat (SES / DF), the study was conducted with the voluntary participation of health professionals who also care for people with special needs in the Federal District, at the Medical Psycho pedagogical Orientation Center's (Compp) mental health unit connected with the Health Secretariat.

This institution works with multidisciplinary and interdisciplinary care. It aims to diagnose, advise and attend children and adolescents in the bio-psychosocial aspect, with language disorders, emotional, behavioral disorders and disability, and mental psychiatric disorders.

Compp applies an overview set of actions to address the problems of childhood and youth from the health, education, and social service standpoint, and provides mental health service for the age range from zero to 18 years old. Various professional specialties work at Compp such as: psychology, pedagogy, physical education, psychomotricity, psychopedagogy and psychiatry <sup>26</sup>.

Compp was chosen for the study because of its multiprofessional features and having the clientele that is being focused on this work. Furthermore, the proposal was to investigate professionals from public institutions, related to health policies. The study was carried out exclusively in the said institution, because there was no other in the Federal District with these features.

Of the 13 invited professionals, three refused to participate in the survey and the final number counted ten people, all female aged between 29 and 57 years: two physicians, a nurse, a nurse technician, a speech pathologist, a psychologist, a physical educator, an educational therapist, one occupational therapy assistant, and a social worker. The time of formation of the professionals varied between 6 and 32 years, an average of 18 years, and the average service time with PSN of the professionals interviewed was 14 years. Only one professional reported specific training in the area. The data collection initiated on June 16 and ended on the August 4, 2010.

A semi-structured interview was prepared to address questions about the socio-demographic features of participants' professional training and questions that focused on the theme and objectives of the study. The interviews were undertaken in the institution after the presentation and signing of an informed consent (IC), in which the professional agreed to participate. The interviews - recorded on tape and that lasted between 30 and 40 minutes - were individual and took place in rooms in good conditions of comfort and privacy.

Initially, the interviews were transcribed, for analysis, and the resulting reports organized and analyzed according to the method of content analysis<sup>27</sup>. After initial reading of their transcripts, the verbal reports were analyzed and categorized, including identification, appointment, and frequency of the categories of each theme. We selected bits and pieces of the reports that were considered illustrative of the categories or subcategories.

The semi-structured interview script guided the subjects focused on the present study, allowing investigation of the six thematic lines described below.

## Results

### Discussion of the work to be done with the PSN

The first theme addressed the discussion of the work to be performed with the PSN, if it was discussed with parents, guardians, and patients with special

needs and/or others from the professional staff. The reports from this line were classified into three categories: discussion with officials and staff, discussions with whoever was held responsible, team and PSN; discussion with the team. All respondents said that the discussion of the intervention is to be held with the staff. Moreover, those responsible and professionals participated in the discussion of treatment, according to most participants. Of these, six professionals (P2, P3, P4, P5, P7 and P9) stated that the discussion also included patients. One participant (P8) said that the discussion was held only with the team of professionals.

The P6 report illustrates category discussion with managers and staff: *"We have case study each week with a group of professionals who are directly connected with the care of these patients, psychiatrists, neurologists, psychologists, social workers, nurses, speech therapists. The group takes a certain position on what will be done with the patient. Parallel to the group of children is the work done with parents. With the patient there is no discussion because they are all children under 8 years. So when we have to discuss something it is only with the parents"*.

The excerpts of P5 and P9 speeches exemplified the second category - discussion with the responsible, team and PSN:



"Here we discuss with the team the showed three categories: 1) difficulty therapeutic project for that patient. related to patient's impairment, 2) Parents also participate (...) I state very difficulty lies in the family, 3) adaptation clearly to the person in charge that what and experience reduce difficulties. For has been said about that teenager, I the first category, two professionals (P4 would like it to be said also in his and P8) stated that the difficulty of presence, because it is about him, and he interaction relates to patient's impair- has a right to know (...) The treatment ment, according to P4 report: "Yes, when itself is also discussed with him (patient). I the case is more serious, it is difficult to respect his autonomy "(P5); "Yes, we interact. I have a Down syndrome case have a weekly staff meeting; (...) with the and he arrived with a diagnosis of mild responsible I discuss about it the whole mental deficiency, and we think it is a bit time, because we attend children. With more serious and it is very difficult to patients, I always try, I think that there is a make him understand any command". person who is listening to everything about herself, even though the cognitive does not help, or something similar, it is the first person that I speak to"(P9).

The third category of this topic, team discussion, was expressed in the following excerpt brought forth by P8: "We have a team that meets every week when we discuss the cases, which direction will be possible for the patient, which is the best therapy for him (...) The team always decides what is best for the patient".

### **The difficulty of professional-patient interaction/communication**

A second theme explored was if the professional perceives the possibility of interaction and / or communication with the patient with special needs. All interviewees expressed that, somehow, there is possibility to interact/communicate with the PSN. The data analysis

A second category refers to the difficulty within the family, illustrated by P1: "I have trouble, especially with the responsible family member (...) the family member is difficult. The patient is the easiest (...) the patient is much better than the family member who is very committed, both in terms of psychological and intellectual as well as from a social viewpoint. I do not know if it's something chronic, suffering, special difficulties, (...) financial, social, or educational deprivation, there is a deprivation and hardship build-up (...) and thus it becomes difficult, but I think that this is all together, not just an isolated problem (...) Attendance is good, especially when the responsible family member encourages, because there are some of them that not to allow the patient to be (...) that want to be with him, speak for him, think for him and act for him, and this worsens the evolution of treatment. But when he (responsible) helps, the evolution is great".

Two professionals reported that this interaction requires adaptation and/or professional experience (P2 and P9), and two (P5 and P7) said that the difficulties of interaction occurred only at the beginning of their experience seeing special patients. In these cases, it was highlighted that there had been a reduction in difficulties. The speeches of P2, P9, and P7 respectively, exemplify this third category: *"The difficulties that happen are pertaining to his disability, but you can always adapt and get some interaction. Of course, when the patient has a capacity for greater understanding, cognitive, mainly, well developed, you have the possibility to argue, discuss with him. When there is no possibility in that direction, we can at least explain, within his possibilities and with a simpler vocabulary, always seeking collaboration (P2); "Depends on what you consider 'communication', because there are 'patients who do not express verbally, who manifest differently, physically, well, I think that communication is possible since it is felt. It is a tough and challenging relationship in the sense that it requires another attitude from the professional, it requires creativity, perception, and sensitivity on the professional's side" (P9); "Not today, but at the beginning yes, when I was invited to join the team. I was afraid, afraid of the unknown, of the most impaired child (...) but today I do not have any trouble. Communication is carried out normally" (P7).*

### **PSN's Participation in decision-making**

Three of the respondents (P1, P2 and P5) reported that PSN participates in decision making about the treatment being performed, and the others stated that PSN does not participate in decision making. P4 said that decision-making does not involve the PSN; the team makes the decision. Professionals P6, P7, P9, and P10 observed that the special patients did not participate in the decision because they are children or adolescents, and thus decision is made by the person in charge.

Thus, the reports allowed identification of two categories: PSN participates and PSN does not participate in the decision. Some aspects differed in reports for both categories, allowing identification of subcategories. For category, *PSN participates in the decision*, three subcategories were outlined, according to the designation below: *participation takes place within limits* refers to the first subcategory and it is exemplified in report by P5: *"Patient participates in decision-making almost always. There are exceptions (...) his participation is within limits, the understanding, his grasp on reality is limited. So it is done in the same way as with one that has no limitation".*

The second subcategory, *family's involvement*, was evidenced by the speech of P1, according to the excerpt: *"Yes. Sometimes, people are surprised by the reaction of a patient that we were not expecting much from and he responds very well. Much depends on the stimulation of the family.*

*The diagnosis sometimes interferes, because more serious disabilities can cause more damage. P2 described the professional's role sub-category, as per the following example: "It depends (...) I always believe, but (...) it's just a tripartite decision: his parents, me and him (Patient). I consider their opinion, but one important thing is we have to leave everyone well informed. (...) It is very common that the child says that the medicine is bad and then I have to negotiate with him saying that it is good for him, it will make him better, and what matters is the".*

In the second category identified in this theme - *PSN does not participate in the decision* – two subcategories were observed, derived from reports by professionals. The subcategory *decision is the professional's role* can be illustrated by what P4 says: *"The patient, no. It's much more the team. So, almost always we do the decision making as a team."* P8 also has this view: *"No, even because they have no conditions, they are autistic, have no notion of anything, there are no ways in which they can participate, in any case"*.

'*Patient is a child*' was the reply in P7, P8 and P9 interviews and it refers to the second subcategory. P9's report underlines this aspect: *"For children here in Compp I don't think so. It is not the child who comes for help, parents brought she/he, then (...) he will participate of what I'll work with him, we talk with him about it. But now, this decision-making is difficult, so parents will make the decision for them."*

### **Differences in care**

The fourth main theme dealt with the differences in care in two foci: differences between PSN and the person who does not need special care; and differences between the PSNs.

All professionals stated that the PSN care is differentiated. However, analysis of reports for this axis showed four categories in the first focus and two categories for the second. The category *different goals and same procedures* are illustrated by P2's report: *"I do the same things with both. The procedure is the same, but it will depend on the degree of communication, if there is an easier exchange or not, but the procedure is the same"*.

The second category, *PSN's response time* is evidenced by excerpt from P3's report: *"When I first started here I kept thinking poor thing (...) today, with the experience, I see that we have to fight so that these patients get treated in the normally (...) It is a procedure that needs a little more care, monitoring, attention (...) The other patient you give a direction and he will follow, the response is immediate"*.

The category *specific knowledge to deal with and intervene* was brought by P7: *"It's because you have to know how each patient is. You must know how to deal with him, because otherwise he will get frustrated in therapy."* The fourth category refers to the *lower participation of PSN* expressed in the speech of P6: *"They (non special patients) speak what they feel, say what they need, you can discuss and they and participate in decision making. Not here; here they do not have the autonomy to decide; who always decides is the person responsible"*.

For the differences among people with special needs, the first category shows PSN's demand, described by P1: "When a person takes more from you, you give more, according to his demand (...)the patient sometimes does not have any idea of what he needs because he is so unresponsive, so withdrawn that he does not even know what he can enjoy."

The following fragment by P9 expresses, in another category, that difference depends on individual needs,: "Their thought".

limitation requires a different way of working, because if someone needs to be worked in speech is one thing, if he needs to be worked in motor activities it is another, but they all come with this proposal of being included (...) the general goal is the same for everyone, but the specifics are different due to demand."

### Difficulties perceived by the professional

A fifth topic focused on whether there is difficulty on the part of professionals to assist PSN and the interviews revealed two categories: *absence* and *presence of difficulties* perceived by staff member. For the first category, four professionals (P2, P4, P8, and P10) stated that there is difficulty in taking care of the PSN, and P8 said experience is important so that it does not happen. For most of the interviewees (P1, P3, P5, P6, P7, and P9) there is some sort of difficulty or reluctance to assist PSN. This second category allowed the delineation of the following subcategories:

*personal difficulties, initial difficulties and adjustment of the professional, self-aggression and resistance to the staff.*

P1 report exemplified *personal difficulty* subcategory: "The difficulty is to have to explain, re-explain, and guide them (...) I get stressed. It is my problem (...) I'm a little stressed and have to work it out".

The second subcategory referred to the *initial difficulty* and *adjustment of the professional*, as expressed in P6 words: "I had a little trouble adjusting when I came here (...) but, as you get in contact, you see that is not as scary as you thought".

*Self-aggression* was identified as a subcategory exemplified by the following excerpt from P7: "I have difficulty when the child hurts itself, it touches me. When this happens we take out for a case study, orientation for the mother, suggest therapeutic riding, a swimming course to calm him, a return to medication".

Another subcategory referred to the *resistance to the professional staff*, as evidenced by P9's report: "I have difficulty team-work (professional teams) with patients with mental disabilities (...) because it is more socially labeled (...) when discussing these cases I don't feel acceptance, it is a patient who shows a strong resistance to the staff. I get analysis to help, I also study, I think that studying helps, because the practice is addictive, the discourse of the team is addictive. Theoretically it is very different from practice. I study to comfort this side".

**Attending people whose participation is delegated to third parties**

This topic was approached from two aspects: care of people whose participation is often the responsibility of third parties causes annoyance/discomfort; and the occurrence of conflict/disagreement situations faced by the professional due to the interference of another person in the work process.

For most professionals there is no disturbance or discomfort before the person whose decision-making power was delegated to others, and only one professional reported discomfort in this regard.

Situations of conflict or divergence of opinion when another person participated in the decision-making on PSN treatment were seen by most respondents. Only one of the professionals stated that he did not experience those when treating patients.

Thus, the reports on this theme were classified into three categories: *presence of annoyance/discomfort, absence of annoyance/discomfort and the presence of conflict situations/divergence of opinion*. The first category was expressed by P1's report: *"Because sometimes the person responsible does not understand what the needs of the child are and he decides something totally different from what he needs or what he wants. He (responsible) understands it in his way and there is not only one I have to work with, it is the responsible and the patient (...)* hence, it is harder work".

A second category outlined the *absence of disturbance or discomfort* and some aspects differentiated the descriptions identifying three sub-categories. The first, *the professional's role*, is exemplified by P2: *"I think parents have the power in the family and they decide. Now, from a technical standpoint, I have to say what I think, what is technically better, and who decides whether or not that will happen is the parents (...)* Now, *if parents are not sure they should wait and research (...)* I indicate scientific sources, which are in appropriate language for them to search, read, and I place myself at their disposal so we can talk about it."

P9 spoke on the *need of a third person* was subcategory, *"No, I think I'm helping. Not in childhood, which I think is so, parents decide for their children. "Also in this sense, the description of P5 exemplifies this need: "Because it must be so, I think there is a co-participation. I seek to make him (patient) feel as if taking the lead (...)* it is another way to cope, but in most cases it is possible."

The third subcategory indicated *absence of annoyance* as, regardless of the patient, a third person is always needed, according to the excerpt from the interview of P6: *"It does not bother because when the patient is not special family and always more than one person has to make the decision"*.

Still for the main theme, care of people whose decision is delegated to others, the third category identified in reports was

the presence of numerous situations of A fourth sub-category, *institutional rules, conflict or divergence of opinion* which is corroborated in P4 reports: "Because presented five subcategories. The of internal rules of service, for example, subcategory *secondary gain of the family every three consecutive absences the* was evidenced by the interviews of P1 *child loses the vacancy. We give* and P3: "Sometimes, it's the opposite, the discharge for evasion and then the father patient has the diagnosis and the father returns and says: no, I want, because wants him to have it. He wants, quote, the this happened, and that (...) Then there diagnosis for the enjoyment of some are conflicts in that sense. Regarding benefit "(P1); "there are those parents treatment, there is none". who want the child to have benefits.

These are the worst, because when they The fifth subcategory mentioned by P9 see that the boy is better, they make up refers to conflict as something positive: something, no longer gives the medicine, "Yes, but it's so nice to work with, I think does not bring in to Compp" (P3). that it's important to have, because we also work out the issue of not knowing

Treatment dropout is a subcategory everything about the patient (...) exemplified by P7: "It frustrates when you Sometimes the patient starts answering see a parent evade attention, because things about himself and we are taken by they decide about the care." The third surprise by the patient himself, the sub-theme that is not accept-family, mother also (...) but that's what makes it illustrated by the words of P3: "We have a cool to work".

case of a schizophrenic child whose father thinks he is normal. The mother Discussion does not stop coming here and wherever

we send her, she goes and does it. The The results of the study showed that father has been here several times (...) most professionals understand that PSN but he always said he did not believe his and those responsible must participate son is schizophrenic (...) Because they along with the team of professionals, in (parents) are divided: the ones who are the discussion about the intervention to aware, the ones who are semiconscious, be performed. Therefore, It is observed parents who accept and cope very well, that PSN, from participants' viewpoint, parents who cope up to a certain point: if although with reduced autonomy, there the boy is not in a crisis he's fine. If he's in is no restrain as to participation in the crisis is not my problem, we will take to discussions concerning them. Compp. There are those who are in total denial, and even those who want the child to make profits from welfare".



For Cohen and Salgado, in situations of absence or loss of the ability to self-govern, there is the need for professional intervention with competence, skill, updating, understanding, wisdom, and sensitivity for the other, so that the PSN have possibilities to acquire their autonomy <sup>28</sup>.

Nevertheless, it is still possible to observe attitudes that seem to value heteronomy in the practice of care, exemplified by team's position, which centralizes decision about what is best for the patient. This attitude refers to the paternalistic argument, when one considers the non-perception, by the professional, of the person as a subject. This concept may favor an asymmetrical relationship between the one who possesses differentiated technical knowledge that gives him authority and rule, and the patient in a vulnerable condition. Thus, paternalism tends to disregard the person as moral subject and all of his life history <sup>20, 21</sup>.

However, the exception is that paternalism can be legitimated when one observes a decrease or lack of autonomy under certain situations. It is acceptable as an exception when there is a clear reduction in the individual's capacity to exercise his autonomous will <sup>29</sup>. It is worth noting that children and adolescents treated by participating professionals possessed varied diagnoses, including developmental disorders (Autism) and severe mental disorder (psychoses), for example, involving different levels of cognitive impairment and other personal skill disabilities. This context would make understandable the occurrence of paternalistic practices on the part of the professional team.

Although the professionals often are guided by beneficent actions, the patient's decision cannot be ignored to the detriment of what the professional considers more appropriate. In the viewpoint of not harming but protecting him, the professional must be cautious when applying beneficial actions <sup>18</sup>. Even facing cases with a level of impairment that decreases autonomy, the professional should make efforts to explain and communicate the purpose of intervention and the procedures to be performed, that so that the PSN's will is respected <sup>5</sup>. The professional's thoughtful understanding of the other with their limitations can be the difference between ignoring the individual and respecting their ability to take decisions autonomously. Therefore, the perception of human dignity and subject of rights should guide this relationship.

All professionals have made it clear that, somehow, there is the possibility of interaction / communication with the PSN. The difficulties for this interaction to happen relate to the involvement of patients and their families; in addition, the adaptation and experience of the professional minimizes the difficulties.

It is observed that it is important to determine the possibility whether the patient, both child and adolescent is able to make decisions, i.e. to understand the information, reflect on the possibilities of choosing and communicating with the person in charge of care <sup>30</sup>. Verification of competency must be observed for every decision, avoiding the judgment about the set of decisions that one must take during a life span <sup>31</sup>.

The existence of a diagnosis of mental illness or disability does not indicate, a priori, the inability of people to communicate, understand and make choices regarding actions that affect their health or life <sup>24</sup>.

The Ministry of Health (MoH), aiming at improving human relations, specifically between professional and patient, has developed and is implementing the National Program for Humanization of Hospital Care. In this context, the humanization is seen as a redefinition of human relations, meaning that users have the right to know and make decisions about diagnoses and interventions to be carried out <sup>32</sup>. Thus, there is a need to broaden the application of the concept of humanization to attend the PSN, which can display its capacity for a committed decision, due to the condition of vulnerability.

The family of the PNE has a unique role in the decision-making, assistance with treatment and as a source of social support for the PSN. For Tiengo <sup>33</sup>, the family provides development for greater opportunities of autonomy, given that within it there is a differentiation of its members, including the special ones. However, the family may present difficulties to pursue its constructive role and thus be a strengthening agent of heteronomy. There is a need for orientation and intervention focused on specific problems faced by the family of the PSN.

Another important point showed that for most professionals PSN does not participate in decision making regarding the work or treatment to be performed. The evidence reported two aspects: the decision is in the hands of the team and the child does not decide.

For Port and Garrafa <sup>34</sup> *it is only through recognition of differences and diverse needs of the social subjects that we can achieve equality*. Therefore, they bring the perspective of equity or of the *recognition of different needs, for subjects also different to achieve the same goals*. It is understood

that the differences are part of a plural society and therefore should be kept, and we cannot accept inequalities when seeking to develop the individual and collective potential <sup>35</sup>.

The bioethical reflection helps consolidate actions to strengthen dignity. In this sense, the professional has an important role in the construction of autonomy, especially those who have it in a limited or reduced way, or in contexts in which heteronomy can not be avoided, as in the case of children and adolescents. It is known that autonomy is built throughout the life of the individual, that it is initially subjected to the standards of the family, showing a heteronomous condition. However, the moral values acquired allow that decisions pass to rely on independent choices and in judging what is best for one, reaching, therefore, autonomy. Children and teenagers are under construction to achieve autonomy. However, this situation is exacerbated when there is an impairment of the ability of the individual, as in the case of PSN. It can be seen therefore that this construction is not fully achieved by all.

The reduced autonomy refers to a person who is controlled by another or that lacks the ability to decide based on parameters such as personal desire <sup>15</sup>.

Action by parents and professionals is based on the argument that they have competence and authority to impose their will on the PSN, and thus determine the behavior that they should have, evidencing his condition of heteronomy <sup>13</sup>. Bernardes, Maior, Spezia and Araujo <sup>22</sup> show the potential risk that the PSN has to have their autonomy restricted if the deficiency is confused with the inability to make decisions. The existence of a disability does not invariably determine the ability to make choices or that reasoning about actions is impaired.

All professionals stated that the PSN attention is differentiated. An important aspect identified referred to the maintenance of equal procedures regardless of the patient, but dependent on the level of understanding. For a professional, her work depends on the requirements of each patient, which may demonstrate a lack of uniformity in the various types of care offered by the institution, which shows some level of accommodation in professional practices.

Another point addressed in the interviews was the specific scientific knowledge, corroborated by Silva, Panhoca and Blachman, who consider the need that university education be directed to aspects such as understanding and caring for human beings and their social and historical context. Moreover, work and study teams consisting of professionals from different professional areas should be valued, to promote comprehensive and multifaceted training on the health-disease processes <sup>5</sup>.

For Schramm <sup>29</sup>, the limited training on ethical issues in the training of health professionals hampers their application in practice. Furthermore, some practitioners may believe that the technical knowledge they possess enables them to decide for others, especially when faced with conflict situations encountered in professional practice <sup>30</sup>.

Professionals also reported that there is greater participation in the care of those people who do not have special needs compared to the PSN. This demonstrates the difficulty for both the exercise of autonomy by PSN as for the promotion of it by the professional.

Regarding the involvement of a third person in decisions related to PSN, most professionals do not feel discomfort. However, most respondents cited situations of conflict or divergence of opinion against the participation of that third person in decision making about PSN treatment. Most of the conflicts experienced are related to aspects linked to the professional, highlighting the personal aspects and the fear of the unknown. Continuous training could be a strategy to avoid this difficulty mentioned by the professionals in the study.

The existential situation of the PSN is configured as vulnerability. The bioethical reflection in face of this situation brought bioethics of protection as a possible refuge for the individual that has no conditions for a dignified life with quality <sup>36, 37, 38</sup>.

In that sense, it was observed that some of the points raised by the professionals are associated with problems, impositions, or limitations of the institution itself, and not specifically of the relationship of the professional with PSN.

Points such as large number of people awaiting care, number of absences as a parameter for the continuity of treatment, infrastructure, among others, indicate the responsibility of the institution in the attention of PSN.

The site for the study was chosen because of its multiprofessional fetures: it is public and the clientele is focused on the objective of the study. It should be noted, however, that the completion of data collection in only one institution was presented as a limitation, because the reports were restricted to serving the professional profile of the institution.

### **Final considerations**

Faced with these results, it was found that the relationship between health professional and child or adolescent with special needs presents itself permeated by the decision-making situations faced by professionals. Even if the possibility of interaction/communication with the PSN is perceived, it is still difficult that they participate in decisions about what affects their lives.

It appears that although the PSN has limited autonomy or heteronomy in face of

his limitations, the dignity of the individual cannot be ignored - which, even if he is unable make decisions, should be respected in their individuality, taking into account their differences, but not with inequality. From the acceptance of difference as a condition of human existence, it is necessary to pursue equity and protection in order to achieve what is best for every citizen, because of their unique differences.

Considering the relevance of these aspects, it is essential to carry out debates on measures for protection and promotion of independence, even if limited for people who present a condition of vulnerability. Continuous professional training and focused not only on aspects of technical knowledge, but for human relationships, valuing the others' welfare, is a necessary measure. This reflection should exceed the limits of academia and be applied to healthcare practice, in order to promote dignity, regardless of its special condition, addressing staff training, and establishing public policies for health assistance, in line with the Convention on the Rights of Persons with Disabilities, which states the need to ensure the quality of available services to people. In order to achieve this goal, training activities and definition of ethical issues should be conducted for public and private health sectors in order to guarantee human rights and the dignity of persons with disabilities.

## Resumen

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### Estudio sobre la heteronimia en la asistencia en salud a los niños y adolescentes con necesidades especiales

El objetivo del estudio fue comprender, a la luz del concepto bioético de la heteronimia, la relación entre el profesional de la salud y los niños o adolescentes con necesidades especiales, en relación a la toma de decisiones enfrentada por profesionales en la atención a pacientes con diferentes niveles de discapacidad. Participaron diez profesionales que atienden a esos pacientes en el servicio público especializado, por medio de entrevista semi-estructurada, lo que permitió investigar seis ejes temáticos: discusión acerca del trabajo; comunicación entre profesionales y pacientes; participación de la persona con necesidades especiales (PNE) en la decisión; diferencias en la atención; dificultades notadas por el profesional; y participación de terceros. La mayor parte de los profesionales entiende que la PNE debe participar en la discusión acerca de la intervención, pero no en la toma de decisiones en relación a la intervención. Se han referido situaciones de conflicto por la participación de otras personas en la relación profesional-PNE. Se concluyó que hay necesidad de protección a la PNE y de acciones de capacitación profesional.

**Palabras-clave:** Bioética. Personas con deficiencia. Autonomía personal.

## Resumo

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O estudo objetivou compreender, à luz do conceito bioético da heteronomia, a relação entre profissional de saúde e criança ou adolescente com necessidades especiais, no que diz respeito aos processos de tomada de decisão enfrentados por profissionais na atenção a pacientes com diferentes níveis de deficiência. Participaram dez profissionais que atendem essa clientela em serviço público especializado, por meio de entrevista semiestruturada, permitindo a investigação de seis eixos temáticos: discussão do trabalho; comunicação entre profissional e paciente; participação da pessoa com necessidades especiais (PNE) na decisão; diferenças no atendimento; dificuldades percebidas pelo profissional; e participação de terceiros. A maior parte dos profissionais entende que a PNE deve participar na discussão sobre a intervenção, contudo esta não participa da tomada de decisão quanto à intervenção. Foram referidas situações de conflito diante da participação de outra pessoa na relação profissional-PNE. Concluiu-se que há necessidade de proteção da PNE e de ações de capacitação profissional.

**Palavras-chave:** Bioética. Pessoas com deficiência. Autonomia pessoal.

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Received: 11.18.10

Approved: 3.22.11

Final approval: 3.24.11

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### **Authors' participation in the work**

Alessandra Freitas prepared the study and carried out data collection, as well as their analysis and writing. Eliane Seidl participated in data analysis and she has a guiding role in the study.