

## Making decisions on health care for children / adolescents with complex chronic conditions: a review of the literature

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**Abstract** *The profile of pediatric care has gone through changes in Brazil and in the world. This process becomes more visible in surveys that deal with hospital admission or specialized outpatient care data. This fact leads us to the idea that it is in such spaces that these children and subjects who care for them are more visible and negotiate decisions. We aim to perform a state of the art literature review on decision making discussions and definitions, analyzing the current research in light of the theoretical Mol perspectives on the actors' logics of chronic diseases care; And the perspective of care goods exchanges in the dialogue between Martins and Moreira, triggering the Theory of Gift. The synthesis of the literature shows that decision making may be understood as a care planning process in which family, patients and health professionals are involved, and is linked to the family-centered care model. In terms of difficulties, we point out the prevalence of a dynamic that favors a criticizable choice because of the risks of inequality, such as the lack of discussion on the options and the actuation of the family mostly in times of difficult decisions.*

**Key words** *Decision making, Chronic disease, Child, Adolescent*

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## Introduction

Pediatrics is undergoing changes where the increase in childhood chronic diseases impacts on hospital care. Hospitalizations due to complex chronic health conditions (CCHC) in Brazil represented, in 2013, 21% of the total of 56 thousand pediatric beds<sup>1</sup>. In 2008, 47.6% of the pediatric hospitalizations of hospitals in the city of Rio de Janeiro (RJ) were due to chronic diseases<sup>2</sup>. In 2006, in a specialized pediatric outpatient clinic of a reference hospital in Rio de Janeiro, 56.3% of children and adolescents were dependent on two to four different types of technology<sup>3</sup>. In the same hospital, in 2015, 87.2% of hospitalizations of pediatrics were CCHC, due to congenital malformations and chromosomal abnormalities<sup>4</sup>. Such research indicates an alert for change in the epidemiological profile of pediatric care, with the presence of CCHC and a multiplicity of demands and decisions to be made.

The CCHC delineates a group of children living with dependency on specialized health care, rehabilitation needs, multiple systems commitment, and the need for life-sustaining technologies<sup>5-7</sup>.

Recognizing the needs of these children means planning their attention and facing barriers to access to rehabilitation services and technologies to support feeding and breathing functions. This includes considering the multiplicity of actors and interests involved in their care, removing them from invisibility.

Our aim is to systematize a definition of decision-making (DM) in the conduct of care provided to children with chronic health conditions in a universe of negotiation between families and professionals of various formations and specialties, how it is given and what aspects it integrates, and the difficulties that go through the decisions. The DM is understood by us as a process involving patients, their families and health professionals, involving a flow of information exchange, followed by the decision and implementation of the care<sup>8-10</sup>.

This discussion can contribute to a greater visibility of the needs of these children, preventing possible vulnerabilities in the care process that is intense, permeated by many interpretations, which generates overload for their families, and unfolds in the difficulties faced by the professionals involved in the work with them.

The following questions have guided the analysis of the literature: 1) What are the characteristics of DM related to the care given to chil-

dren with chronic conditions? 2) What are the main actors and debates involved in the academic production of DM in attention to this group of children? 3) What are the roles assigned to the actors involved in DM and what are their main difficulties?

## Methodology

We conducted a literature review, understood as an exploratory study of the production of knowledge about a subject or theme<sup>11,12</sup>. The survey was carried out in April 2016, in Pubmed and Lilacs databases using the descriptors following Decs parameters<sup>13</sup>, listed on Chart 1.

We have counted on the support of a librarian adjusting the search terms. We considered publications with access to abstracts, in Spanish, English or Portuguese; we excluded those referring to chronic diseases in young adults and adults, as well as those related to medical DM on the diagnosis of a particular chronic condition or its differential diagnosis. Thus, the review was related to the care process of children with chronic conditions and not those related to diagnosis and/or differential diagnosis of chronic diseases. We selected articles that highlight the subjects involved with this DM and not the diseases, their etiology and differential clinic. As for the time limit, we set the year 2000 as the milestone of a new century, in which WHO<sup>14</sup> recognizes the need for new guidelines for chronic disease care.

Inspired by Moreira *et al.*<sup>12</sup> and Gomes *et al.*<sup>11</sup> the analysis of the collection took place in two analytical movements: (a) a description of the set of articles, considering the following variables: date and country of publication, methodological design, origins, profile of children and their diagnoses, participants and objectives of the article; (b) adaptation of the thematic content analysis proposed by Bardin<sup>15</sup> with an exhaustive and critical reading of all the articles, identification of the themes and the meanings attributed to them in the different texts and grouping of thematic nuclei that synthesized the production<sup>11,12</sup>. This material was interpreted in the light of two theoretical perspectives that evoke dimensions transversal to the health care field: Anne Marie Mol<sup>8,16</sup> with her analysis of the two logics that are designed from the actors and their networks in regard to attention to chronic diseases, the logic of choice and the logic of care; and the perspective of the exchange of care goods and healing goods in the dialogue between Moreira<sup>17</sup> and Martins<sup>18</sup>,

**Chart 1.** Descriptors utilized in research<sup>13</sup>.

Descriptors	Doença crônica ("chronic disease")	Tomada de decisões ("decision making")	criança, pré-escolar, adolescente, lactente, recém- nascido (child OR "preschool child" OR adolescent OR infant OR "newborn infant")
<b>Definitions</b>	Diseases that present one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological change, require special patient training for rehabilitation, a long period of supervision, observation or care can be expected.	The process of conducting a selective intellectual judgment when presented with several complex alternatives consisting of several variables, that generally leads to the definition of a way of acting Synonyms: Joint, shared decision-making. Indexing Annotation Portuguese: is different from "Clinical decision making", defined as the process of formulating a diagnosis based on medical-clinical history and physical or mental exams and/or the choice of an appropriate intervention. or an idea.	Considering the existence of a fragmentation by age group, the Decs delimits 5 bands: newborn, from zero to one month of life; infant, from 1 to 23 months of age; pre-school, between 2 and 5 years of age; child between 6 and 12 years; adolescent, from 13 to 18 years of age.

both triggering the Theory of the Gift proposed by Mauss.

## Results

Initially we selected 286 articles, whose abstracts have been read. After applying the exclusion criteria, we collected 69 articles, read in their entirety. Of these, the following have been excluded: those whose research designs did not have a clear description of the methodology used; those based on personal opinions; the texts that referred to an unpublished research project; those who did not deal with the practical process of DM as the theoretical essays; and those who addressed research involving adults with chronic diseases along with children. There remained 33 articles that constituted the analytical *corpus*. Chart 2 classifies the data from the 33 articles.

In the analyzed texts, the inclusion of children/adolescents as participants in their own care highlights the current trends regarding their consideration as subjects of fact and law<sup>19</sup>. Research is shifting from being "in-children" research to "with-children" research, with recognition of them as promoter of social transformation in relationships of mutual influence with adults and other children<sup>20</sup>.

It has been observed, in the articles, that the diagnoses have been either grouped into larger sets (such as children with CCHC, terminal, with special health needs) or were more specific (such as children with inflammatory bowel disease, diabetes, cystic fibrosis, asthma). Yet, in some surveys, these diagnoses have not been specified. Using the descriptor "chronic disease", we identified all the articles that group similarities with regards to the needs, evolution, prevalence, and that are recognized as chronic course. Methodologically, even using the descriptor "chronic disease", it is important to emphasize that this concept does not clarify the diversity of the health needs of these children<sup>6,7,12,21</sup>.

Most of the studies have used qualitative designs. This makes us consider that there are many issues related to DM that can not be answered by the quantitative methods, the need to deepen relationships and experiences, the singularities of getting sick, the production of care and the search for health<sup>22</sup>. The fact that the authors are very close to the care clinic can be a stimulus for reflexivity and propositions about this field in the DM approach. This should be due to the need of incorporating user-focused care models, considering the environment of human relations and the meetings as a possibility of production of health and autonomy<sup>23,24</sup>.

Chart 2. Description of the data found in the articles.

Research participants	Disease	Method	Year	Country	Domain	Goal
Pais e prof e saúde	IBD and JIA	Quali	2015	USA	Med 26	Understanding parents' DM process for chronic disease management
	IBD and JIA	Quali	2014	USA	Med 27	Understand how decisions are made about treatment of chronic diseases
	CHISPEN	Quali	2013	USA	Med 29	Describe factors that influence parental/medical partnerships in exchange for information and SDM when CHISPEN are referred to subspecialists
Prof Saúde	IBD and JIA	Survey	2016	USA	Med 28	To examine the use of SDM by pediatricians and their perception of facilitators and barriers to SDM with parents and patients in the beginning of treatment
	CCHC	Survey	2014	USA	Med 48	Identify existing challenges and potential strategies to provide complex care training for future pediatricians
	Chronic disease	Quali	2013	Australia	Nur 50	Explore nurse's perception of parental empowerment in chronic disease
	Chronic disease	Lit rev	2009	USA	Psyc 52	Analyzing and synthesizing research on the behavior of pediatricians in the management of chronic disease and its relation with treatment adherence
	Those who brought death	Quanti	2003	Arg	Med 30	Describing the modalities of death and factors involved in procedural DM that limit the maintenance of life.
	Those who brought death	Quanti	2001	Brazil	Med 44	Determining the prevalence of different ways of dying and identifying therapeutic limits in patients of a pediatric ICU
	Diabetes, asthma, eczema, epilepsy, O2 dependence, ventilation and nutritional, cardiac and metabolic supports	Quanti	2000	UK	Nur 31	Exploring the role and use of nur competencies in relation to the physical and psycho-social needs of children and examining how these skills are used in DM in relation to the care of children and their families with chronic illness in the community
	ALL, asthma, DM (Diabetes Mellitus), CF, obesity	Quanti	2015	USA	Med and Nur 47	Understanding the nature of the child's participation in the management of the care of his or her illness.
	CCHC	Quali	2013	USA	Med 49	Identifying prevailing issues discussed in the pediatric palliative care consultation of patients with CCHC care by pediatric generalists
	JIA	Quali	2007	UK	Antrop 42	Exploring the experience of everyday life and dealing with the illness of children that live with JIA.
Prof saúde, adolescentes e seus pais	Diabetes M1	Quali	2006	UK	Sociol 57	Investigating children's opinions about their diabetes, their participation in the management
	Of their care, their daily likes and dislikes, achievements and problems	Quali	2009	Israel	Med, ci soc 32	Estudar formas como decisões de tratamento são alcançadas na prática, durante encontros em que gastro pediatras comunicam más notícias e seus reflexos para pacientes, familiares e relação médico paciente
	DII	Quali	2009	Israel	Med, soc, sci 32	Studying how treatment decisions are reached in practice during encounters in which gastro pediatricians communicate bad news and their reflexes to the patients, family and patient-physician relationship
Pais e Crianças	CF, Diabetes M and asthma	Quanti	2012	USA	Psyc 33	Developing an instrument to measure DM involvement in the management of health condition in children and adolescents with CF, Diabetes M and asthma.

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Chart 2. Description of the data found in the articles.

Research participants	Disease	Method	Year	Country	Domain	Goal
Pais e adolescentes	Asthma, DM type 1 or CF	Quali	2009	USA	Psyc 34	Exploring collaborative DM concept from the perspective of children and their parents and generating items for new measure of SDM parent-child report
	JIA/Crohn	Quali	2016	USA	Med 36	Comparing factors considered by the parents with those considered by the adolescents in DM regarding treatments of chronic diseases.
Crianças	CF, JIA, DII, sickle cell anemia	Survey	2008	USA	Med 35	Describing the preferences for decision-making for the treatment of adolescents with chronic diseases and their parents, and on what measures they agree.
	Haemorrhagic Disorder	Quali	2012	Can	Nur 51	Analyzing how children understand family-centered care and their inherent role in this approach
Adolescentes	Crohn and JIA	Quali	2013	USA	Med 37	Understanding the roles and preferences of adolescents in DM for chronic diseases
	Cancer	Lit rev	2011	USA	Multiprof 38	Summarizing available literature on decision-making aspects of fertility preservation among adolescent cancer patients and recommending strategies for their participation.
	Healthy and sickle cell anemia, HIV, cancer, asthma	Survey	2004	USA	Psyc 43	Exploring whether there are differences between adolescents with chronic diseases and healthy with regard to their attitudes about end-of-life issues
	Chronic disease	Lit rev	2014	Brazil	Collective health 12	Analyzing the production of knowledge about chronic diseases in children/ adolescents, aiming to contribute to the systematization of care principles for these subjects.
Pais	Healthy and asthma, Diabetes M	Quali	2003	EUA	Enf 54	Descrever compreensão de crianças dos adolescentes sobre pesquisas e fatores socioculturais que as influenciam a envolverem-se e a continuarem a participar de pesquisas clínicas
	epilepsy or eczema	Quanti	2010	UK	Nur 56	Determining whether the point of view of children with a chronic disease in relation to clinical trials was different from that of healthy children
Pais	Diabetes M and hematologic oncotic disease	Quali	2003	USA	Nur 54	Describing the understanding of children and adolescents about research and sociocultural factors that influence them to become involved and to continue to participate in clinical research
	CHISPEN	Quali	2015	Italy	Med 45	Exploring experiences and perceptions of parents in information, management and relational continuity of care for CHISPEN after discharge
	Thalassaemia	Quali	2015	Tail	Nur 55	Designing, implementing and evaluating a Family Empowerment Program guided by the disease belief Model.
	CHISPEN	Survey	2015	USA	Nur, Med, Psyc 39	Analyzing whether the way parents report SDM varies with type of need (physical, mental or both) and whether home medical care attenuates these differences
	Chronic	Survey	2014	USA	Med 46	Exploring experience of parents and caregivers their knowledge and preferences regarding early directives for children with chronic diseases
	Life risk	Quali	2013	USA	Med 40	Identifying and illustrating common heuristics used by parents of children with life-threatening illnesses while confronting and making medical decisions

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Chart 2. Description of the data found in the articles.

Research participants	Disease	Method	Year	Country	Domain	Goal
	Cancer	Quali	2011	USA	Nur 41	Analyzing how parents who do not live together make treatment decisions for their children with Cancer
	Diabetes M, asthma, epilepsy, CRF, Cancer and illnesses that limit life	Quanti quali	2005	USA, Ch Scot	Nur 53	Examining, culturally cross-examined, the experience of parents caring for children with chronic diseases both in terms of the impact on family life as well as the nature of the support received from the health services in Hong Kong and Scotland

Legend: IBD: inflammatory bowel disease; IIA: juvenile idiopathic arthritis; CHISPEN: children with special needs; CCHC: complex chronic health conditions; ALL: acute lymphocytic leukemia; DM: diabetes mellitus; CF: cystic fibrosis; HIV: infection from Human Immunodeficiency Virus; CRF: chronic renal failure; Quali: qualitative; Quant: quantitative; Lit rev: Literature review; USA: United States of America; Arg: Argentina; UK: United Kingdom; Can: Canada; Ch: China; Scot: Scotland; Med: medicine; Nur: nursery; psyc: psychology; Antrop: anthropology; Sociol: sociology; soc sci: social sciences; Multiprof: multiprofessional;

Seventeen articles have been published in the last 5 years. Such an interest may reflect concern about innovations in the relations of care and utilization of life supporting technologies. The different ways of constructing the disease and the diseased body articulating materials, techniques, knowledge and practices, makes the reflection on biopower contemporary<sup>5</sup>. The knowledge about available technologies, the possibility of assuring households a participation in the choice of which technologies to use and the clarified risk authorization requirements in the interventions also qualifies this scenario. What used to be unquestionable now begins to be seen within a context of choices that involves the demands on shared decisions among caregivers, including sick children and adolescents.

The country with most published articles was the USA, predominating studies focusing on medicine. The fact that most publications originate in northern countries may be a reflection of the interface between technological development and the epidemiological transition of these countries which occurred before than the happenings, for example, in Brazil. The United States, for example, drives Family-Centered Care (FCC) as the innovation, a philosophy that is based in a shared DM as one of its key principles<sup>25</sup>. Born in the second half of the twentieth century, the FCC concept coincides with the awareness of the importance of uniting psychosocial and child development needs and the role of families in promoting their well-being and health. In 1992, the FCC Institute was founded to foster partnerships among people with chronic diseases, their families and health professionals, and to promote leadership in the practice of FCC in all settings. Ever since then, the FCC combines several levels of prestige and starts to base research, in alliance with renowned organizations in order to generate scientific evidence. The American Academy of Pediatrics (AAP) has several FCC principles embodied in its policy statements and manuals<sup>25</sup>.

Almost half of the studies had as one of the objectives the analysis of decisions about the care given to children with chronic diseases<sup>26-41</sup>. Those who would not refer to the decisions in the objectives, brought this subject in the results and discussions, which could point to a finding linked to the object of study, that is, a discovery worthy of discussion.

From the analysis of thematic content, we identified four main themes related to DM: DM as a process<sup>12,26-28,30,32-38,40-44</sup>; DM as an aspect within the health planning<sup>29,30,43-46</sup>; DM as a compo-

ment of FCC<sup>12,27,28,31-39,47-56</sup>; DM as a result from other sharings<sup>27,28,40-42,56,57</sup>.

Although we found only one article problematizing DM as a process<sup>26</sup>, we consider relevant the consideration of this as a theme, since many papers start from the assumption that DM is a process, however, without the problematization of this assumption<sup>12,27,28,30,32-38,40-44</sup>.

## Discussion

In light of Mol's contributions<sup>8,16</sup>, we discuss the DM processes mentioned in the articles. The logical processes that govern health care could, on the side of choice, generate a linear decision-making process, and it is up to the health professional to transmit information to the patient, who, in turn, based on his values, will make his choice, and then the professional will perform. In this linearity the decisions are difficult, but confined to crucial moments and the choice results from the solution of a mathematical sentence between fixed variables that are named as pros and cons to the decision.

On the other hand, Mol describes the logic of care, which goes far beyond this orderly sequence of information, values, decisions and applications, where the decision-making process does not follow a linearity and facts and values intertwine. In this case, the variables to be considered are not fixed and therefore, it is impossible to make a balance between pros and cons, and even after decided, what has been decided may not work. Those involved in decision making are the ones to try, observe, adapt, try again. The CCHC demand this continuous DM process, which will extend throughout the days of a child's lifespan. Problems keep emerging and, as they are treated, new problems and solutions appear; far beyond implementing technology and care, it is worth experimenting them<sup>8,16</sup>. This cycle makes us reflect that there is no rational calculation, orienting ends, means and results in an alleged flow of causality. We have but something that evokes a technical craft, based on the necessary dialogue between actors positioned differently in the clinical scene, with diverse interests, affections and references, who have in common the task of offering comfort and qualified care. The body of professionals - diverse in their multidisciplinary knowledge and functions - and family members are involved and mobilized around this task, but with different roles, interests and investments. Dialoguing with Latour<sup>58</sup>, we also highlight the

importance of the connections between human and non-human actors. In health care of children with complex chronic diseases these connections include management and access to the technological apparatus, mediations and changes that it produces in the bodies and in the subjectivity of DM processes. It is important to note that these processes on the side of the family and the child require numerous adaptations, and even a relation of attribution towards the technology of salvation or rescue of life. Moreover, the limit between the body of children with CCHC and the needs of living with a whole body altered, mediated investments and generated overload and gender inequities in the maternal component<sup>5</sup>.

The synthesis of a DM definition from the selected collection has put us in challenge. This because the concern with the definition of this category does not appear directly in the articles. The term is sometimes used in an obvious way, as if it did not have to be defined, contrasted in its elements. Even if the category is not defined, we could gather in the course of the articles elements that offer us ideas about which logic prevails in the use of the term. In the light of Mol, the logic of choice prevails, where the physician, holder of scientific technical knowledge, will inform the sick person of what will best serve to "train" them for care, preparing them to use the information and operate in the reality. Such a utilitarian logic generates a dangerous disincentive of the professional in this process. However, in complex care, the need for a proximity between the health team and the family prevails as common in the time line. This closeness can generate a virtuous circle of exchanges of care goods<sup>17,18</sup>, from the confrontation with the uncertainties, with the realization that what was "taught" inside the hospital - and was submitted to a technical framework of safety and control - is lost or is resignified upon arrival at home, for example with a "tracheostomized" child, "gastrostomized", or "ventilated", who needs someone to interpret their signs of discomfort and malaise. We did not find any article addressing the need for renegotiation of decisions, which is present in Mol's logic of care<sup>8,16</sup>.

Regarding the second theme, DM has been regarded as an aspect of the care plan<sup>29,30,43-46</sup>. The planning of care for children with chronic conditions can go towards the market-based care model or the "care-producing" model. At one side, market-based assistance and the production of procedures prioritize the use of equipment and the logic of freely informed choice under Mol<sup>16</sup>. At the other side, the "care-producing" models fo-

cus on the sick person and their needs, being the basis for the development of therapeutic projects (TP)<sup>23</sup>. For the crafting of this model, we believe that the dialogue promoted by Mauss' Theory of Gift is valid<sup>17,18</sup>. In the gift<sup>17,18,59</sup>, reciprocity implies concern for the other, in the establishment of affective and ethical values in exchange for giving, which are trust, mutual understanding, and a "bond of souls"<sup>59</sup>.

In the "careproducer" assistance models, diseases are addressed as a social and symbolic total fact, endowed with signs and meanings<sup>17</sup>, circulating goods of healing and care, redemption of reciprocity, welcoming and bond of trust, so dear to the process of building self-care and autonomy. As for the "producers of procedure" assistance models<sup>23</sup>, there is an inversion of reciprocity, and the first concern is the satisfaction of self-interest.

Articles that considered DM as an aspect of the care plan, referred to the decisions regarding both care transition<sup>45</sup> as related to the end of life<sup>30,43,44,46</sup>. While we understand that care planning should encompass all aspects of DM, from "easy" to "most difficult", we were able to see more concern about "difficult" decisions - those taken in end-of-life situations. Difficult DMs for people with chronic illnesses are more often non-electively in an intensive or hospital setting, with a lot of technology and little time to be taken, while less urgent situations can facilitate the sharing of DM, once that patients have more time to redeem and process information<sup>60</sup>. This explains why end-of-life decisions are often taken solitarily by physician caregivers<sup>61</sup>. This way, end-of-life decisions, more difficult, cause more health professionals to worry, which is why they are looking for ways to share them.

Still related to the care planning, an article<sup>29</sup> addresses the number of subspecialties involved in the TP and feels that the large number of stakeholders involved in DM hampers the process and is a problem to be managed. Ideally, the therapeutic project would integrate the various professionals responsible for care, with multi-centered actions in the health problems of people, with the production of a resolution capacity, since the "caregiver field" is common to all and the "specialized knowledge center" belongs to each professional who participates in the care<sup>23</sup>. However, the multiprofessional presence in care does not guarantee a shared and non-instrumental DM, for there is a risk of intervention fragmentation, which characterizes a divided care planning, not centered on the user<sup>23</sup>.

With regard to the large number of studies that consider DM a component of the Family-Centered Care philosophy (FCC)<sup>12,27,28,31-39,47-56</sup>, we problematize which borders, between constructing alliances for the care that promote supports, health, exchanges of virtuous care goods<sup>17</sup>, between kin and professionals, valuing the logic of care<sup>16</sup> and the dangerous tendency to hold the family accountable - albeit unintentionally - for care, for example by increasing gender inequities and therapeutic "pilgrimages"<sup>19</sup>.

With will to innovate in the planning, distribution and evaluation of health care, the FCC, which is part of DM, is based on a mutual partnership between people with chronic diseases, their families and health professionals. FCC recognizes the importance of the family in the person's life<sup>25</sup>, though we make a critical reflection on the possibility of FCC generating or increasing inequities. We found articles dedicated to assessing participation, as well as the perspectives of children, adolescents and their families in making decisions, and several factors that they take into account in DM<sup>12,33-39,47,51</sup>. However, those have not bothered to criticize the limits of FCC - where the shared DM theme prevails. The shared DM lies between the polar paternalistic (prescriptive) and informed attitudes, in which the sick person makes a decision based on the information passed by the physician<sup>9,10</sup>. In the shared model of DM, present in the FCC, the physician passes the technical information to the patients, who in turn will express their beliefs, fears, experiences, with a view to a consensus on which better treatment, and the physician should support the patient in his choice<sup>9,10</sup>. However, it should be emphasized that the type of model prevailing in clinical practice depends on broader conceptions regarding the patient-physician relationship, consistent with the current culture about the belief of the patient's autonomy and which are the tasks and responsibilities of the physicians<sup>9,10</sup>. Models applied to DM within the clinical practice have their limits. As theoretical models, they are frameworks that often may not correspond to reality. In the caregiving relationship there are many actors - symbolic, human and nonhuman - that in the same decision-making process can contour several models. Issues ranging from the scarce range of options to be chosen until deliberation of this choice through greater clarity than professional / patient "negotiation" deserve greater attention<sup>10</sup>. Wirtz et al.<sup>10</sup> problematizing SDM, points out that the sharing of decisions does not mean sharing options, leaving the choice of options to the doctor.

Based on this discussion of DM models, the big question worth basing on Mol is the “choice” category. Category evokes ideas about freedom, independence, consent based on information, which deserve a critical reflection. To what extent is this choice freed from influence? Within the logic of scientific knowledge, the choice can be considered as an action that places itself before a collection of facts that are linked by the pretension of generating evidences and certainties. Professionals crave for these facts and add certainty to them. And in the case of the relationship with the laity the task is to offer information by externalizing relevant facts in order to determine the value of several possible courses of action. In this context a value-free logic prevails, where the choice is made in a territory where doctors, nurses and patients stand as neutral actors. The only values that are relevant refer to measures, according to Mol. The logic of care is defined by the fact that the decisions that associate humans and non-humans, i.e. people and technologies, are not linear, and not a simple implementation of knowledge and technologies. Instead, experiences with them. This category of experience evokes meanings, values, interpretations and, above all, use. Another important clue is that the idea of care is not restricted only to the doctor, but to the whole health team.

Whether for Wirtz there is a difference between “decisions” and “choice of options”, on the options there exists also asymmetry between physician and patient in the clinical scene. Shared decisions are offered, but the management of these reside in the power of reasserting the “best option”. And which would be the best? Such a discussion tunes in with Mol’s reflections, which emphasizes that in the logic of choice a good decision depends on adequately balancing the advantages and disadvantages of various courses of action. Such a “balance” model combines with accounting, where medical interventions are more difficult to quantify than sums of money. It is as if the meaning of making a decision corresponds to the act of making a calculation between pros and cons. In the logic of caring, according to Mol, this is different. ‘Balance’ is important, once more, but not as a matter of adding, subtracting advantages and disadvantages. After all, addition and subtraction require a fixed number of variables, but in the logic of caring no variables are fixed. The sought “balance”, then, is something that needs to be established, in an active way. Instead of the image of the counter balance, the best image which is synthesized is of

the balancing body of an artist who walks on the wire.

Other aspects that emerge are: parent empowerment<sup>31,50,55</sup>; DM over children and adolescents whether or not they participate in clinical trials<sup>54,56</sup>; evaluation of DM as an indicator of the quality of health services from the perspective of parents<sup>53</sup>. In FCC, communication processes - which as an ideal type should enable an action constituted both by transmission of information from the health professional, and by their hearing out the person with chronic illness, valuing their culture, experience and social reality - are one of the key principles<sup>25</sup>. In this process, the participation of children/adolescents and their families in health care support groups is taken under consideration. Another key principle is the collaboration between health professionals, children/adolescents and family members that occurs at all levels of care: in planning, developing and evaluating programs, in vocational education, in policy development, in participation in health care and at all levels of the research design. FCC empowerment values support in a process in which the children/adolescents and their families gain confidence to make decisions about their health care.

The practice of DM within the context of FCC appears as a skill that needs to be taught to doctors, either because it is unknown (for young doctors)<sup>48</sup> or contradictory (for pediatricians who know its importance but have difficulty in its execution)<sup>27,28,32,49,52</sup>, or still because it is found that subjects from different cultures have different perspectives regarding their participation in DM<sup>53</sup>. In a Bourdieusian analysis of the social organization of pediatric hospitals, resources of parents and health professionals are not equitably distributed, and their *habitus* differ hierarchically<sup>62</sup>. Thus, limits arise on the ability of parents and health professionals to work collaboratively as partners as a team in the field of pediatric medicine. The increase in the symbolic/cultural capital of the parents can be seen as a solution to improve the practices of doctors and nurses in communication and decision making, improving the practice of FCC.<sup>62</sup>

Finally, there is the understanding of TD as a result of sharing not only between the actors involved, but of other sharings<sup>27,28,40-42,56,57</sup>, where environment, senses and experiences also influence decisions. The disease, embodied in a subject, comes loaded with a series of meanings, which integrate the meanings on the side of the patient, which does not summarize the illness

only in physical suffering, incapacity, disability, but the possibility of not being worthy anymore of love and respect. According to Canesqui<sup>63</sup>, this interpretation of the cultural dimensions of organic phenomena will be based on concepts, symbols and structures internalized by the subjects, taking into account the social group to which they belong. Carapineiro<sup>64</sup> derives from the (un)definition of health the variability of the meaning of disease. It is in sharing meanings with their group that individuals will make decisions about their health. In addressing the experiences of chronic illness, Mol<sup>8</sup> points out that living with diabetes does not boil down to insulin, but encompasses a whole production of the realness from actions. The experience of living with a certain disease occurs in the significance of the illness processes and the decisions made around it.

The essential values maintained by the family interfere in the decision-making processes, for example, evaluations about their comfort and the consequences of the decision taken over time. These decisions address complex processes that encompass both objective, management, interpretation and synthesis, as well as subjective, senses and experiences of sickening<sup>65</sup>. It is important to provide information, respect and support to parents to allow them to live with their decisions for a lifetime<sup>60</sup>.

It should be pointed out, as the limits of this study, that due to the fact that databases were used within few journals from the areas of anthropology and sociology indexed, this review was intended to look at articles related to DM that are closer to the field of health care than in the studies related to an anthropological partner analysis of the same. This way we suggest the need for research raising the bibliography of DM in the socio-anthropological field, accessing other databases as a future proposal. Another limitation concerns the lack of a single descriptor that facilitates the comparison between the articles and their search. We urgently consider the need to create a descriptor in the Decs that identifies children with chronic diseases according to their health care needs, in the case of complex care. For this reason, the interim summary for Decision-Making that we present must be understood within the framework of the dialogue between the generic and more encompassing category that defines studies for the care of children with chronic diseases, and the specificity of this new group of small actors born under the sign of complexity and chronicity: children with complex chronic conditions that we recognize here in their existence.

## Conclusion

Based on the undertaken review, we conclude that the main actors involved in DM of pediatric chronic diseases were children/adolescents and their parents, but also health professionals (mainly doctors and nurses). This DM is characterized by a process that, the more complex the health situation, with more dependence on technology, the greater the investment in therapeutic plans, where the management of instability in the presence of the chronic condition is part of the set of actions. Thus, it would be more appropriate to devise the expression "Decision-Making Processes", considering they occur mainly in the interstice of relations, being influenced by the act of sharing events amongst all actors involved. This Shared DM Process, included in the predominant FCC model, composes therapeutic planning for children with chronic diseases and prioritizes extreme, end-of-life decisions. Moreover, every choice for care is at the same time the source and mouth of senses and experiences and is also influenced by and at the same time influences the environment in which those involved in the care are inserted.

We take as a proposition the difference between "decisions" and "choice of options" and between "care" and "choice". Talking about options means to generate expectation of freedom between equals deciding, which masks the asymmetry and hierarchy between doctors, family and children. The illusion that they can share decisions erases the fact that their management is in the power of reasserting the "best option". Searching for Mol's model of care logic in opposition to the logic of choice, to discuss DM, we point out that the logic of choice is accounting, based on asymmetry and hierarchy. While in the logic of care, the "balance", represented by the decision made, is something that needs to be actively established. Therefore, this DM is a dynamics where deciding means being able to reevaluate decisions made based on the logic of solidarity, empathy and gift between actors differently situated.

As roles and challenges of the actors, we highlight the risk of holding the family accountable only in moments of difficult decisions. Just as in believing family can freely "choose" from a set of information offered. In pediatric care based on multiprofessionality, the challenge lies in integrating technical and lay knowledge, placing child and family needs at the center of decisions. In the case of a health care line for children with

CCHC, it is important to recognize that it should be discussed with itineraries that are experienced as therapeutic “pilgrimages” to access the right to health. In this complexity scenario, the technological apparatus becomes an actor that arises new investments and interests, placing the technology in relation, as symbols that mediate and influence the decisions, having therefore agency. In this context, technology can be considered as one more participant in DM processes.

There exist inherent barriers to culture focused on biomedicine and the market and these need to be reviewed. We believe that the increase

of the symbolic capital of the patient, the use of the logic of care in DM and the humanization of care, may be a path for this reflection. However, the change in DM processes depends on being careful not to fall into the hegemonic system’s intelligence, where masked models of new ones arise. Shared DM, for example, may come in the form of techniques to induce the patient to make decisions according to the will of the system. Hence the question is well in keeping with the logic of choice: to offer options as if they were free from dilemmas, changes, negotiations and values.

### **Collaborations**

HGC Fernandez was responsible for the review and analysis of the literature, writing, critical review and approval of the final version of the article to be published. MCN Moreira participated in the methodological design, literature analysis, writing, critical review and approval of the final version of the article to be published. R Gomes participated in the critical review and approval of the final version of the article to be published.

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