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Sharing Medical Decisions with the Child. An Exploratory Survey in Paediatric Primary Care.

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ABSTRACT

Objective: This paper presents an analysis of the shared decision-making between parents, children and physicians in paediatric primary care, taking into consideration that it is difficult but useful to promote the engagement of both the parents and the children in medical practice. Concordance between medical professionals and patients is a therapeutic strategy that is useful for achieving engagement between them, as they are the co-producers for the patients' health and are both responsible for their choices during the course of treatment.

Methods: The study involved observing and audio recording 185 medical visits that included children with a mean age of 8.16 years (± 2.41). Medical dialogues are described, with particular attention paid to the clinical conditions discussed, and the outcomes of the visits are reported. Shared decision-making is analyzed through the Observing PaTient Involvement in shared decisiON making (OPTION) tool, an observational grid composed of 12 items aimed at evaluating doctors' abilities to involve their patients in the decisions made concerning their therapeutic plans. The observations were carried out to obtain the paediatricians' dialogue with the parents and children.

Results: In all the dialogues, low levels of shared decision-making were detected. This type of communication allows for a fast and efficient execution of the visit, without the active involvement of the patients and with evident risks for their tendency to go to various health facilities.

Conclusions: Dialogue in the field of paediatric primary care seems to be influenced and characterized by unconditional forms of adherence to medical knowledge. Further exploration of this would be useful, along with the implementation of specific interventions aimed at promoting shared decision-making, to enhance the decision-making skills of mothers and children and to promote their engagement during the process of the medical care.

KEYWORDS

Paediatric primary care; communication in medicine; shared decision-making; patient engagement; doctor-patient relationship

Introduction

This paper presents an analysis of the shared decision-making processes in paediatric primary care. An exploration of these processes can make a useful contribution to

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promoting patient engagement in the medical care process (Graffigna et al., 2017), so that interventions can be truly aligned with the patient's needs and expectations and support an autonomous and proactive health management process (Graffigna & Barello, 2018).

Shared decision-making is a very controversial concept that involves patients being considered as co-producers of their own health and co-responsible for their choices (Bigi, 2016; Dicé et al., 2020a, 2020b). One of the main ways of getting patients engaged may be through achieving a *concordance*, a relational dynamic in which doctors and patients share in decisions about the care by taking their different perspectives into account (Atwool, 2006; Elwyn et al., 2016, 2017; Fiks et al., 2010; Freda & Dicé, 2017; Khair, 2014).

In the past, the field of medicine mainly operated to promote *compliance*, which refers to the agreement of patients to the proposed treatment for the management of their clinical conditions, considering this to be the basis for the success of the treatment process. Recently, many socio-cultural changes, including greater access to medical knowledge such as through the Internet and new services offering medical assistance, has led to reconsideration of the criteria for the doctor-patient relationship, readjusting its asymmetrical structures and reorganizing its dialogical and relational dispositions in favour of the *concordance* construct (Atwool, 2006; Elwyn et al., 2016, 2017; Khair, 2014; Lemmo et al., 2020; Martino et al., 2019a, 2019b). Another reason for this reconsideration is the need to consider the knowledge and competence of laypersons (De Luca Picione, 2020a, 2020b, 2020c; De Luca Picione et al., 2019; Freda et al., 2019; Quattropiani et al., 2018a, 2018b), to avoid misunderstandings or disagreements about therapeutic strategies, reduce the considerable risk for patients' tendency to go to various health facilities and increase the possibility of achieving successful treatments.

In spite of these assumptions, achieving a *concordance* is a very complex goal, because of widespread resistance among patients to participating in medical decisions about their physiological health and their tendencies to delegate these to their physicians (Elwyn et al., 2016). This difficulty is not without reason, since patients do not have the skills and experience that their physicians have and cannot necessarily understand their perspectives or the reasons behind their proposals, particularly because physicians have knowledge regarding the progression of diseases (Gerwing & Gulbrandsen, 2019; Kaldjian, 2017). A further complexity with regard to children is that there is a need to protect them from medical information that they can only partially understand and which might frighten them.

Because of these difficulties, shared decision-making cannot be considered as a prerequisite for the doctor-patient relationship, but rather as a *product* that presupposes the ability of both participants to propose their own needs and to consider the other's point of view (Dicé et al., 2017, 2018; Dicé, 2019). Shared decision-making can be considered to be an opportunity, a therapeutic strategy for medical practice that is aimed at structuring health care pathways that adapt to the patients' needs. However, sharing decisions does not mean that physicians should share all their medical knowledge with patients or request that they acquire this knowledge so that they can discuss it with them. They should provide patients with some decision-making tools to be able to move together into the margin of discretion required when making decisions about medical needs in people's daily lives. Therefore, shared decision-making could be considered as the result of an interactive process undertaken through the promotion of the specific relational skills of physicians along with the recognition of active participation by their patients (Elwyn et al., 2016).

In other studies, these topics were observed in relation to primary care, with physicians guiding patients in the daily management of their health (Dicé, 2019; Dicé et al., 2018, 2020a; Scandurra et al., 2020). Particularly in the paediatric field, this involves dual users (parents and children) and, more specifically, children in the course of their physiological development, including their growth within the contexts of their families and cultures (Esposito et al., 2017; Murray, 2015). Furthermore, in other papers (Dicé, 2019; Dicé et al., 2018, 2020b), the dialogue between paediatricians and their patients seemed largely aimed at listening to the concerns of parents, as they are considered to be the experts in speaking on behalf of children's health and very often resort to attitudes of a reassuring nature. Children often take more peripheral roles during the visits and rarely gain an understanding of the priorities of the medical care (e.g. making responses such as, "I do not want to take the pill because it's bitter!"). Children's worries are often expressed through crying, and their responses are not always considered for their informational value. Although engaging children in their medical care is very difficult to achieve, its value is often underestimated; it is necessary to get them involved in the medical care process to determine their needs and provide appropriate management (e.g. diets or suitable lifestyles). This paper continues this line of research by analysing the dialogue about decision-making in paediatric primary care in an innovative way, paying particular attention to the processes of shared decision-making between paediatricians and their patients, including the children, within the consultation room.

Materials and Methods

Context

The survey was conducted in eight primary paediatric practices in a town in Italy. The services offered by these practices, which are part of the National Health Service, are for children up to 14 years of age and include health budgets, screenings, medical examinations, treatment prescriptions, and, if necessary, consultations with specialists and laboratory tests.

Paediatric visits were observed by a clinical psychologist who was present for the entire time of each visit but did not intervene. The auditing of these visits took place an average of three days a week, on pre-determined days, in agreement with the paediatricians.

Participants

Data from 185 visits for paediatric primary care were collected, audio recorded and transcribed verbatim (approximate duration 12:43 min \pm 8), were carried out by 19 paediatricians (12 males, 7 females) and addressed these children (males with average age group of 8.16 ± 2.41 years and females between the ages of 8.22 ± 2.36 and 8.58 ± 2.46 years), who were accompanied by 173 mothers and 12 fathers.

Among the patients involved in the service, all the children who had reached at least school age (>5 years) were selected, as they were considered to be capable of participating in medical conversations. All the clinical conditions discussed during the visits were considered eligible, and all parents who agreed to participate were asked to sign an informed consent.

Tools

The Observing PaTient Involvement in shared decisiON making (OPTION) tool (Elwyn et al., 2003; Goss et al., 2007) was used to try to assess the doctors' abilities to involve their patients in decisions concerning the therapeutic plan. This tool involves a grid that focuses exclusively on the skills of health workers and consists of 12 items, each of which indicates a specific dialogic competence. These are described in Table 1.

The presence of this ability was evaluated through a Likert five-point scale (0–4), and the total score of each subject, relative to the mean scores of all items, could fluctuate between 0 (total absence of involvement) and 48 (maximum level of involvement). The attribution of the scores was carried out by two independent judges. They read the transcripts of all the visits and assigned, for each item, scores from 0 (absent behaviour) to 4 (excellent level).

Data analysis

To describe the context of this survey, a qualitative description of the dialogues was given in the results, with particular attention paid to the clinical condition discussed and the outcomes of the paediatric visits.

To describe the paediatric relationship, a triangular configuration was used, with the three participants positioned at the top. The analysis of the dialogic interaction was conducted separately along the sides of the relational triangle and was defined as the Dialogical Interaction Axes (DIA). The triangle is shown in the Figure 1.

For the analysis of the shared decision-making with regard to medical care, only axes concerning the relationship between the paediatrician and the parent and the paediatrician and the child were considered. The analysis process was conducted on the texts that had been transcribed verbatim of the visits that were observed and audio recorded. The means and standard deviations of the scores that related to the interactions along each of the axes were calculated, and the means of the total and individual items scores were presented. The OPTION Manual proposes the transformation of the scores from the 0–48 scale to a 0–100 scale but, for ease of reading the data, particularly the scores of individual items, the scores through the 0–48 scale were presented.

The reliability was assessed by measuring the Cronbach's alpha (α), considering the mean of the scores awarded by the two judges. The degree of agreement between

Table 1. Items of the OPTION tool.

ITEM 1	The clinician draws attention to an identified problem as one that requires a decision making process.
ITEM 2	The clinician states that there is more than one way to deal with the identified problem ("equipoise").
ITEM 3	The clinician assesses the patient's preferred approach to receiving information to assist decision making (e.g. discussion in consultations, read printed material, assess graphical data, use videotapes or other media).
ITEM 4	The clinician lists "options", which can include the choice of "no action".
ITEM 5	The clinician explains the pros and cons of options to the patient (taking "no action" is an option).
ITEM 6	The clinician explores the patient's expectations (or ideas) about how the problem(s) are to be managed.
ITEM 7	The clinician explores the patient's concerns (fears) about how problem(s) are to be managed.
ITEM 8	The clinician checks that the patient has understood the information.
ITEM 9	The clinician offers the patient explicit opportunities to ask questions during the decision making process.
ITEM 10	The clinician elicits the patient's preferred level of involvement in decision making.
ITEM 11	The clinician indicates the need for a decision making (or deferring) stage.
ITEM 12	The clinician indicates the need to review the decision (or deferment).

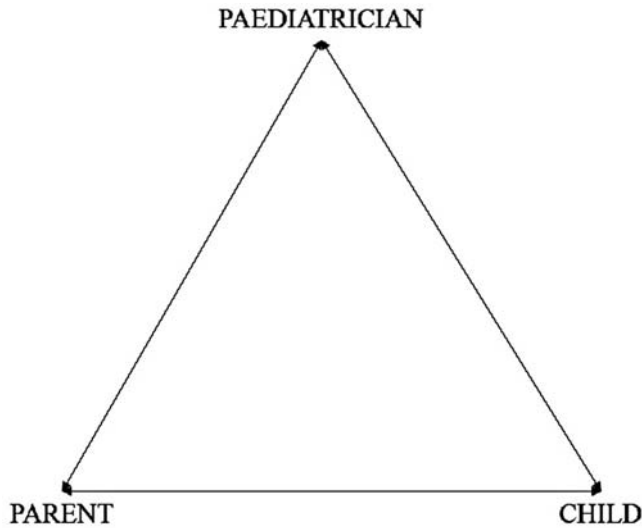


Figure 1. The relational triangle.

the two measurements was assessed using the concordance correlation coefficient (CCC) (Hinkle et al., 2003).

Finally, the correlation between the scores for the two axes (paediatrician–parent and paediatrician–child) was calculated. Given the strong asymmetry of the distributions, the Spearman ρ correlation coefficient was chosen (Hinkle et al., 2003), and statistical analyses were performed using SPSS 23.0 software.

Results

The clinical conditions discussed during the visits are shown below, in the [Figure 2](#). Most of the children visited the physicians for complete medical examinations or because of flu

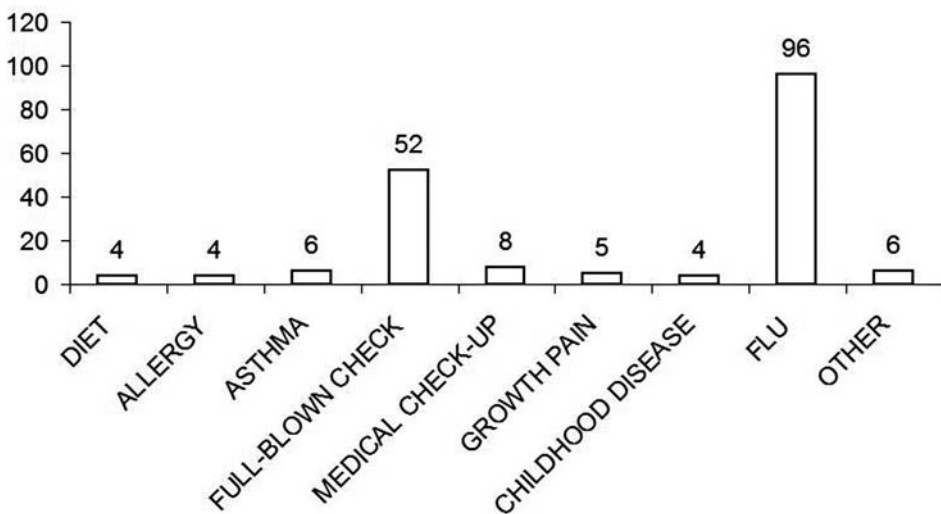


Figure 2. The clinical conditions discussed during the visits.

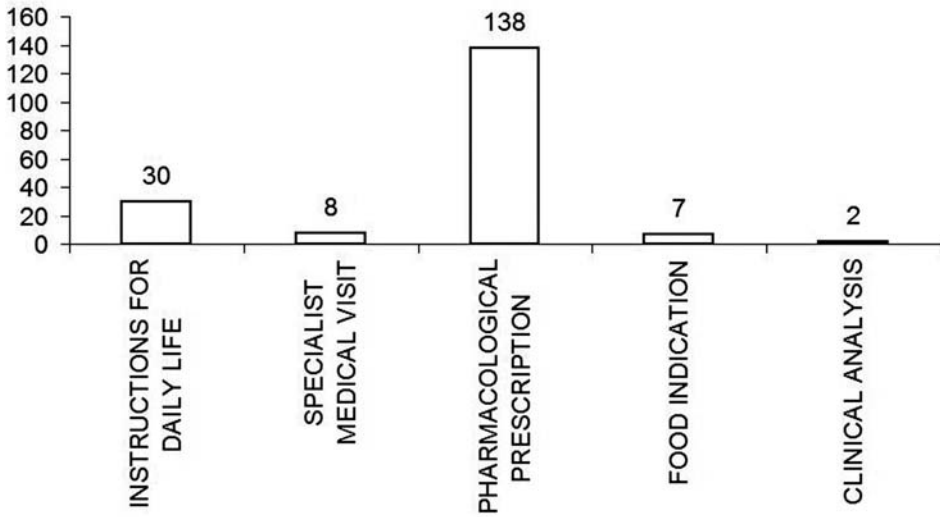


Figure 3. The outcomes of the visits.

Table 2. Means of OPTION's total scores.

MEAN (\pm ST.DEV)	DIA Paediatrician – Parent 4.56 (\pm 5.16)	DIA Paediatrician – Child 1.78 (\pm 4.17)

symptoms. The outcomes of the visits are shown below, in the graph in [Figure 3](#). Most of the visits ended with a pharmacological prescription or some indications for a healthy daily lifestyle.

With regard to the analysis of shared decision-making through the OPTION tool, the results of the two DIAs are shown below. [Table 2](#) depicts the total mean scores. For the DIA for the paediatrician–parent relationship, the value of .880 of Cronbach's α indicates a good internal consistency. The measurements of the two independent judges present a high agreement value of .827. Also, for the DIA for the paediatrician–child relationship, the values are very high: the measurements have an agreement value of .848 and a Cronbach's α of .910 (Hinkle et al., 2003).

For both interaction axes, the means of the total scores are very low, below the acceptable minimum of 24 (Elwyn et al., 2003). In most cases, in fact, the decisions discussed are very frequently based entirely on medical knowledge.

Some examples:

Example 1:

Paediatrician: Has the child had a meningococcal vaccination?

Mother: Do you think he should?

Paediatrician: Yes.

Mother: It's okay.

Example 2:

Child: I do not want to have jabs!

Paediatrician: I know, but the tablet is less effective.

Mother: You do as the doctor says.

The times in which it was possible to access a dialogic dimension involving a sharing of decision-making always involved choices relating to everyday situations that were already known and had been experienced by all the participants.

Example 3:

Mother: I had thought, a bit of aerosol?

Paediatrician: With what?

Mother: With anti-inflammatory?

Paediatrician: ... and the physiological solution. All right.

Example 4:

Paediatrician: You do not like pills? Do you prefer syrup? As you like.

Child: What is this?

Mother: The syrup, and these are pills.

Paediatrician: It's the same, what do you think?

Child: The syrup.

Table 3 depicts the means of the individual items. In both interaction axes, the scores averaged for each item are very low, below the acceptable minimum of 2 (Elwyn et al., 2003). However, it is important to emphasize that the highest means are in relation to the first item; that is, what may be explored if the paediatrician *draws attention to an identified problem as one that requires a decision-making process*. This is considered to be the first step in shared decision-making (Elwyn et al., 2003) (see Examples 5 and 6).

Table 3. Means of individuals items.

	DIA Paediatrician – Parent MEAN (±ST.DEV)	DIA Paediatrician – Child MEAN (±ST.DEV)
ITEM 1	.96(±1)	.36(±.72)
ITEM 2	.34(±.68)	.12(±.45)
ITEM 3	.05(±.24)	.16(±.62)
ITEM 4	.38(±.67)	.14(±.46)
ITEM 5	.49(±.87)	.20(±.59)
ITEM 6	.35(±.62)	.18(±.54)
ITEM 7	.18(±.51)	.09(±.35)
ITEM 8	.52(±.72)	.2(±.58)
ITEM 9	.76(±.63)	.17(±.45)
ITEM 10	.01(±.12)	.05(±.31)
ITEM 11	.23(±.62)	.06(±.33)
ITEM 12	.22(±.58)	.01(±.21)

Example 5:

Paediatrician: In addition to the mandatory ones, there are also optional vaccinations. In a manner of speaking, because they are necessary.

Mother: Oh, I understand.

Example 6:

Paediatrician: Look, the teeth brace must be used, it's best to do it as soon as possible.

Mother: He wanted to wait at least for the first communion ...

Paediatrician: But who looks at you in the mouth?

The value of the correlation between the scores for the two axes is equal to .398 and is considered acceptable ($>.30$) (Hinkle et al., 2003); therefore, the low level of shared decision-making along each axis implies the low level detected on the other axis.

Discussion

Most of the paediatric primary care visits that were analyzed involved periodic complete medical examinations or care relating to seasonal influenza and ended with a pharmacological prescription or some indications aimed at supporting the children in their daily growth. The results of the OPTION tool for both DIAs show that there are reduced levels of shared decision-making in paediatric primary care. Although, during the visits, the participants discussed mainly clinical conditions attributable to the physiological development of the children, the patients themselves did not seem to be able to participate in the decision-making processes. They appeared to be engaged only in dialogues characterized by fast communication exchanges, in which it was mainly the adults (paediatricians and parents) who participated. These dialogues indicate an absolute trust in the physicians, with a consequent tendency to delegate the decisions to them, even for the most ordinary choices relating to daily care (e.g. whether to wear wool or not and when to resume school activities after a flu). This positive attitude promotes the success of the medical intervention, but inevitably shows, in particular in the words of mothers, an important difficulty in recognizing their own decision-making skills concerning the care and management of their children's health conditions. However, the children seem to play extremely marginal roles in the decision-making processes. Even in cases where their ages would allow for their participation in the dialogue, they are mainly questioned only with regard to describing their symptoms or making minor decisions.

There were few opportunities to determine whether the decisions might be suitable for the family, if there were concerns about them, and if they could in fact be implemented (see Example 1, about vaccination). The possibility of devoting dialogic space to sharing decisions seems to be seen as considerably slowing down the health practice and, therefore, was immediately replaced with making quick decisions aimed at allowing time for the rest of the visit.

This trend cannot be interpreted as negligent or as a firm decision by physicians to avoid either in-depth dialogue with patients or shared decision-making, since it adheres to the patients' requests for medical services performed in a short time and

with great and undeniable efficiency. The role of paediatric primary care seems to be reduced within a dual function of medicine simply to fulfil a *prescriptive function* through the delivery of drugs aimed at eradicating physical illness along with a *pedagogical function* aimed at promoting best practices for the daily growth and management of children (Freda & Dicé, 2017; Freda et al., 2015). These two functions seem to be closely interrelated and very useful for the management of physiological clinical conditions regarding the growth of the children (e.g. seasonal flu, growth pains, food problems and sports). However, by focusing on these functions, doctors risk failing their patients when more complex choices are made regarding concerns that deviate from routine ones or that do not meet the real needs of the patients (see Example 6, where the child wanted to wait until after the first communion to wear the teeth braces). All this is indicative of a doctor-patient relationship that is characterized by reduced shared decision-making processes that would need to be promoted where they are deemed to be useful in contributing to the structuring of a concordance and, consequently, to an engagement process (Graffigna & Barello, 2018).

This study has an important limitation. It analyzed only visits that related to physiological medical conditions, for which decisions about daily management of care are necessary. It would be interesting to consider the differences with regard to visits about other more serious medical concerns as well (e.g. the diagnosis or treatment of severe, chronic diseases or conditions requiring surgery), for which critical decisions for the health of children are discussed.

It is essential to emphasize that a medical dialogue based on shared decision-making considerably complicates the work of physicians, because they have been specifically trained to acquire their patients' trust and reliance on their decision-making. Clearly, it would be difficult to overcome their resistance and show them the best way to resolve health problems in a quick, clear and simple way. Achieving this would surely prove helpful in avoiding the sometimes inexplicable tendency to go to various health facilities from health care or the tendency of patients to doctor shopping.

Sharing decisions is also fundamental for dialogues with children, even with the smallest ones, since their comfort with regard to the medical visits and their awareness that their needs have also been taken into account can determine their participation in the care and the ultimate success of the treatment. It is important that physicians address this aspect with regard to their younger patients, without delegating it to domestic dialogue. In fact, parents, as has already been highlighted, do not always have the technical skills necessary to give their children the information they may need and often respond to the daily refusals of medical treatment with hasty phrases such as, "You do as the doctor says", as reported in Example 2.

Precisely because the shared decision-making approach is complex, tiring and not always compatible with the hectic time pressures of the medical teams, it seemed useful to implement specific projects involving research into psychological interventions that are aimed at promoting this decision-making (Dicé et al., 2018; Freda & Dicé, 2017; Freda et al., 2015). In these interventions, it would indeed be necessary to promote the recognition in operational practice of widespread decision-making competence among all the participants, including the most peripheral ones (i.e. the children) (Freda & Dicé, 2017; Freda et al., 2015), favouring the development of a *concordance* (Khair, 2014). In this way, it could be possible to enhance the patients' decisional skills to

contribute to care strategies, promoting their centralization, their active roles and their engagement when visiting their doctors (Graffigna et al., 2017). Working in this way could enhance the relationship so that it could be organized according to the needs of each participant and therefore become a space for dialogical meeting for all those present, resulting in the integration of desires and points of view (Atwool, 2006; Elwyn et al., 2016).

Disclosure Statement

No potential conflict of interest was reported by the author(s).

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