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CEREBRAL PALSY REHABILITATION: COMPARISON BETWEEN ITALIAN CHILD CENTRED AND CANADIAN FAMILY CENTRED HEALTHCARE MODELS.

KEY WORDS:

Cerebral Palsy, Family Centred Service, Children Rehabilitation, Perception of Care, MPOC-20, MPOC-SP.

ABSTRACT

Background

Among disabling pathologies, that affect children from birth, Cerebral Palsy (CP) is the most important for frequency and multiplicity of associated disorders.

Care of CP requires a long and complex rehabilitation process that involves healthcare services, educational facilities and social agencies, but above all family members (SCPE 2000).

In Canada, family has decision-making power in childcare, which includes rehabilitation treatments and socio-educational interventions. This family-centred approach presupposes a shared responsibility between caregivers and family in planning and applying child rehabilitation therapies.

In Italy, "Recommendations for cerebral palsy rehabilitation" provide for a drafting of an Individual Rehabilitation Plan (PRI), according to the ICF-CY model. Designing the therapeutic project (PRI) is the physician's responsibility, who subsequently involves the family in reaching objectives, timing interventions, realising setting modalities and measuring outcomes. This approach is child-centred, however with the participatory involvement of family.

The aim of this study is to compare perception of Italian and Canadian families regarding these two different healthcare models in CP rehabilitation.

Method

Data from 219 MPOC-20 and 75 MPOC-SP questionnaires were collected from child healthcare services in Emilia Romagna Region and compared to Ontario province data published by CanChild.

Results

By comparing MPOC-20 and MPOC-SP results obtained in Emilia Romagna and Ontario, we found that average values of various domains reveal few differences. The only domain showing lower results for Emilia Romagna concerned child-specific information supply (Emilia Romagna average is 4.69, Ontario is 5.23). On the contrary, for all the remaining domains, Emilia Romagna had higher averages.

Considering physiotherapist questionnaires, we found higher satisfaction levels regarding treatment in Ontario. The greatest difference related to the "Providing General Information" domain: parental perception; Emilia Romagna average was 3.74, while Ontario's average was 4.68. For the domain "Showing Interpersonal Sensitivity", satisfaction was high for both countries: 5.76 in Emilia Romagna, 5.83 in Ontario.

Discussion

Communication regarding general aspects, pathology and treatment information must be improved in Emilia Romagna in order to increase satisfaction and cooperation between families and healthcare professionals.

Conclusions

The study results allow us to conclude that Italian and Canadian family satisfaction of healthcare quality is quite similar, and that the Italian model of CP rehabilitation, with a few slight modifications, could be judged competitive. An organizational model focused on child, constantly involving family in care programs, which we could coin "Child-and-Family-Centred approach", would seem to be the key to a higher quality, efficacy and efficiency service.

INTRODUCTION

Family is the main environment for development of child adaptive functions (Briar-Lawson & Lawson, 2001) (Leiter, 2004) (Janzen, 2001). Collaboration between family and healthcare services is essential for realization of care pathways.

Among common therapeutic projects between parents and professionals for children suffering from chronic diseases such as cerebral palsy (CP), the FAMILY-CENTRED APPROACH has been in use both in USA and Canada for two decades and has recently been proposed in Italy (S. M. King, Rosenbaum, & King, 1996; O'Neil, Palisano, & Westcott, 2001). The CanChild Centre for Childhood Disability Research, promoter of this model, defines it as follows:

Family-centred service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognizes that each family is unique; that the family is the constant in the child's life; and that they are the experts on child's abilities and needs. The family works together with service providers to make informed decisions about services and supports the child and family receive. In family-centred service, strengths and needs of all family members are considered (G. A. King, King, & Rosenbaum, 1996).

This definition states the three Family-Centred Care (FCC) fundamental principles:

- 1) Parents know their children better than anyone else and always want the best for them;
- 2) Each Family is unique and possesses distinctive features;
- 3) Children perform better if surrounded by a supporting family and community environment.

These principles support parental participation in decision-making, cooperation, respect, acceptance of family choices, help, interest in individual characteristics, delivery of personalized and flexible services, information sharing and consent (G. A. King et al., 1996). Indeed, in the FCC model, the family has the decision-making power over all therapeutic processes, including various rehabilitation treatments and socio-educational interventions (Rosenbaum, King, & Cadman, 1992).

CP Italian Recommendations for child rehabilitation (commissioned by Health Ministry and co-written by SIMFER and SINPIA society scientific experts in 2002 and updated in 2006 and 2013) aim at promoting the best quality of life for CP children and their families. This aim can be achieved through therapeutic programs related to rehabilitation, care and education that place the needs of the child at the centre of services, according to the ICF-CY health model. This model places child functioning at the centre of treatment processes and considers family an environmental factor that can act as a facilitator or barrier, with a point of view strongly centred on child. According to Italian Recommendations, the family is always actively involved in childcare processes, but responsibility of rehabilitation project must be assumed directly by the physician. The family contributes to the rehabilitation program by applying at home what the CP child has learned during physiotherapy. The Rehabilitation service must interact with families, provide and encourage their education and participation, **support relational processes with their CP child, assist in their role as facilitators, or re-orient them if they can represent a barrier to child recovery.**

The need to **evolve from a health-service centred model** to a family-centred one has its roots in changes in humanity perception developed over last century. Among these changes, there has been

the greater attention on child and disabled people rights and a shift from pathogenesis and impairment to a cultural approach oriented on contextualized individual functioning (from ICDH, to ICDH2, to ICF).

Canadian research findings are supported by their extensive experience (S. King, Teplicky, King, & Rosenbaum, 2004) and by several large population sample studies, using specific tools (Questionnaire MPOC-20). Recent literature reveals that the FCC approach, although widely supported in its theoretical principles, is difficultly applicable.

In Italy, there is a lack of data supporting the theory that the current child-centred model can be comparable to the family-centred one. Some CP parent associations have requested greater integration of family-centred model in Italian social-health policies (ABC 2000).

In order to understand to what extent the family-centred therapy model is already present in the Italian health service, this study intends to compare Italian and Canadian perception of healthcare quality using Canadian parameters.

MPOC questionnaires were created within a specific context, the Canadian one, which presents similarities but also profound differences with respect to the Italian one: both have a public health system of universalistic nature, financed through general taxation, but facing a very different geographical area; the extent of Canada compared to Italy is equal to a ratio of 9:1.

This has influenced a different vision of health models. In fact, Canadian health services must cover a large geographical area, therefore the health authority has chosen to concentrate services within cities. These offer comprehensive treatment centres through an organization that, unable to access every far-reaching citizen, requires that citizens go to a reference centre, where they can find all the necessary services.

In Italy, we have an opposite situation: the relatively small but highly populated territory has necessitated a capillarization of basic services through a network of local health services (AUSL) and citizens are referred to general hospitals only for specific or severe needs.

The purpose of this study is to evaluate whether:

- it would be useful for Italian health institutions to adopt the Canadian rehabilitation model, in which services help families make informed and conscious decisions in all care processes
- the Italian model, where the rehabilitation team is solely responsible for the re-education

process, can satisfy the requests of Italian families, assessed through MPOC Canadian Questionnaire.

MATERIALS AND METHODS

This study is part of a regional project sponsored by the specialised unit for disabled children rehabilitation of IRCCS Santa Maria Nuova Hospital (Reggio Emilia). The following cities of the Emilia Romagna Region took part in this project: Bologna, Imola, Ravenna, Forlì, Cesena, Rimini, Ferrara, Modena, Reggio Emilia, Parma and Piacenza.

This cross-sectional study consists of analysis of data relative to the perception of healthcare quality of CP children in Emilia Romagna, supplied by both parents and physiotherapists. Data were anonymously collected from 2010 to 2013 by means of 11 Physiotherapy graduation theses of the four Universities present in Emilia Romagna. In each thesis, data dealing with healthcare quality were compared to Ontario results collected by CanChild. It has to be pointed out that, in Italy as well as in Canada, criteria for selecting population samples, tools and data collecting procedures were identical (S. King et al., 2000)

Each thesis considered the following aspects:

- In order to evaluate the perception of care quality, Rosenbaum's questionnaires, created in 1996, were used: MPOC-20 for parents (S. King et al., 2004) and MPOC-SP for physiotherapists (Woodside, Rosenbaum, King, & King, 2001), validated in Italian language by CanChild and downloadable from their web site (www.canchild.ca).

Questionnaires areas of interest reflect the main characteristics of a family-centred approach. These tools are also used and validated to assess to what degree a service is deemed centred on families. The results of these questionnaires describe to what extent health services are currently centred on families, both from parent and physiotherapist points of view.

STUDY SAMPLE

For this research, all the physiotherapists employed in the local services of child rehabilitation of the specialized units of Child and Adolescent Neuropsychiatry or of Rehabilitation Medicine (UONPIA and UOMR) of the Emilia Romagna region have been involved. They had to treat at least one CP child a year before the study, or at the time of the study. All parents whose CP children were treated in the year preceding the study or at the time of the study, meeting the inclusion criteria, were also

involved.

Inclusion and exclusion criteria

The criteria adopted for inclusion in the study were the following:

- Physiotherapists who completed the MPOC-SP questionnaire must belong to UONPIA or UOMR participating in the study; must have treated at least one CP child in the previous year or at the time of the study.
- The family members (mother and father) who fill out the MPOC-20 questionnaire must be parents of a CP child aged 0-18 years, under the care of the previous mentioned services, and possess a good command of the Italian language.

To standardize this study for each province, physiotherapists employed in the services were contacted in order to present and explain the project, request their collaboration, clarify the methods for administering the questionnaire and provide a list of families who could meet the inclusion criteria. Parents were invited to participate in this study through a written letter from the collector service (ASMN RE) and informed by their physiotherapist about how to complete the MPOC-20 questionnaire, specifying that the questionnaire would be anonymous, filled out at home, inserted in a sealed white envelope (provided by the collector service) and placed in a special container outside the door of their rehabilitation centre. Physiotherapists employed in the service completed the MPOC-SP questionnaire anonymously, inserted it in a sealed white envelope previously provided by the collector service and placed in the same container.

THE QUESTIONNAIRES

The MPOC-20 questionnaire helps parents to assess the quality of care. It is made up of 20 questions, which can be grouped into five domains. Value judgements are expressed on a 1-7 scale: 1 meaning “not at all”, 7 meaning “to a very great extent”. Zero is excluded from the value range, as it would mean the impossibility to judge (not applicable).

- **ENABLING AND PARTNERSHIP:** this domain refers to 3 entries regarding behaviours actively involving parents, dealing mainly with decision-making and obtaining information, opinions and concerns.

- PROVIDING GENERAL INFORMATION: this domain refers to 5 entries regarding how parents perceive general information supplied by Healthcare services (for instance: information about services).
- PROVIDING SPECIFIC INFORMATION ABOUT THE CHILD: 3 entries concerning behaviours of care providers in supplying specific information.
- COORDINATED AND COMPREHENSIVE CARE: this domain refers to 4 entries regarding those behaviours dealing with child and family needs from a holistic point of view and delivery of a complete and continuous service over time and within the relative environment.
- RESPECTFUL AND SUPPORTIVE CARE: this domain refers to 5 entries concerning behaviours, which determine if parents are being treated respectfully, both as human beings and as experts of their child.

The above domains correspond to the different situations that parents undergo when dealing with their child's therapy process and are strictly related to parent satisfaction relative to delivered health services. Parents fill out the questionnaire autonomously.

MPOC-SP is a paediatric care supplier self-assessing tool: it is made up of 27 questions inquiring about suppliers' specific behaviours during the previous year; value judgements are expressed on a 1-7 scale; 0 is excluded from the value range as it would mean impossibility to judge (not applicable). Similarly to MPOC-20, there are four question domains:

- 10 entries for SHOWING INTERPERSONAL SENSITIVITY;
- 5 entries for PROVIDING GENERAL INFORMATION;
- 3 entries for COMMUNICATING SPECIFIC INFORMATION ABOUT THE CHILD;
- 9 entries for TREATING PEOPLE RESPECTFULLY.

Results revealed by the MPOC-20 questionnaires underline to what degree the service is currently family-centred, while the MPOC-SP questionnaires are a valuable tool for assessing to what extent the service is coherent with the family-centred model from an expert's point of view.

Statistics Methods:

- Average computing standard deviation, 25th percentile, 50th percentile (median) and 75th

percentile for all the MPOC-20 and MPOC-SP questionnaires domains.

- The SPSS (Statistical Package for Social Sciences) program for analysing the data.

RESULTS

The questionnaires were submitted to subjects who met inclusion criteria: 97 questionnaires were filled out by physiotherapists and 257 by families. However only 75 questionnaires out of 97 by physiotherapists and 219 out of 257 by parents were filled out correctly and analysed.

60 missing questionnaires (22 MPOC-SP and 38 MPOC-20) were excluded due to incomplete data collection or non-participation.

Parent data analysis

Analysed population: 219 units

Area	Frequency	Percentage
Bologna	23	10.5%
Cesena	9	4.1%
Ferrara	13	5.9%
Forlì	36	16.4%
Imola	4	1.8%
Parma	25	11.4%
Piacenza	36	16.4%
Ravenna	23	10.5%
Reggio Emilia	17	7.8%
Rimini	33	15.1%
Tot.	219	100.00%

Table 1: Parent distribution per area

One-way indicators, such as average, median, standard deviation and percentiles were distributed depending on domain.

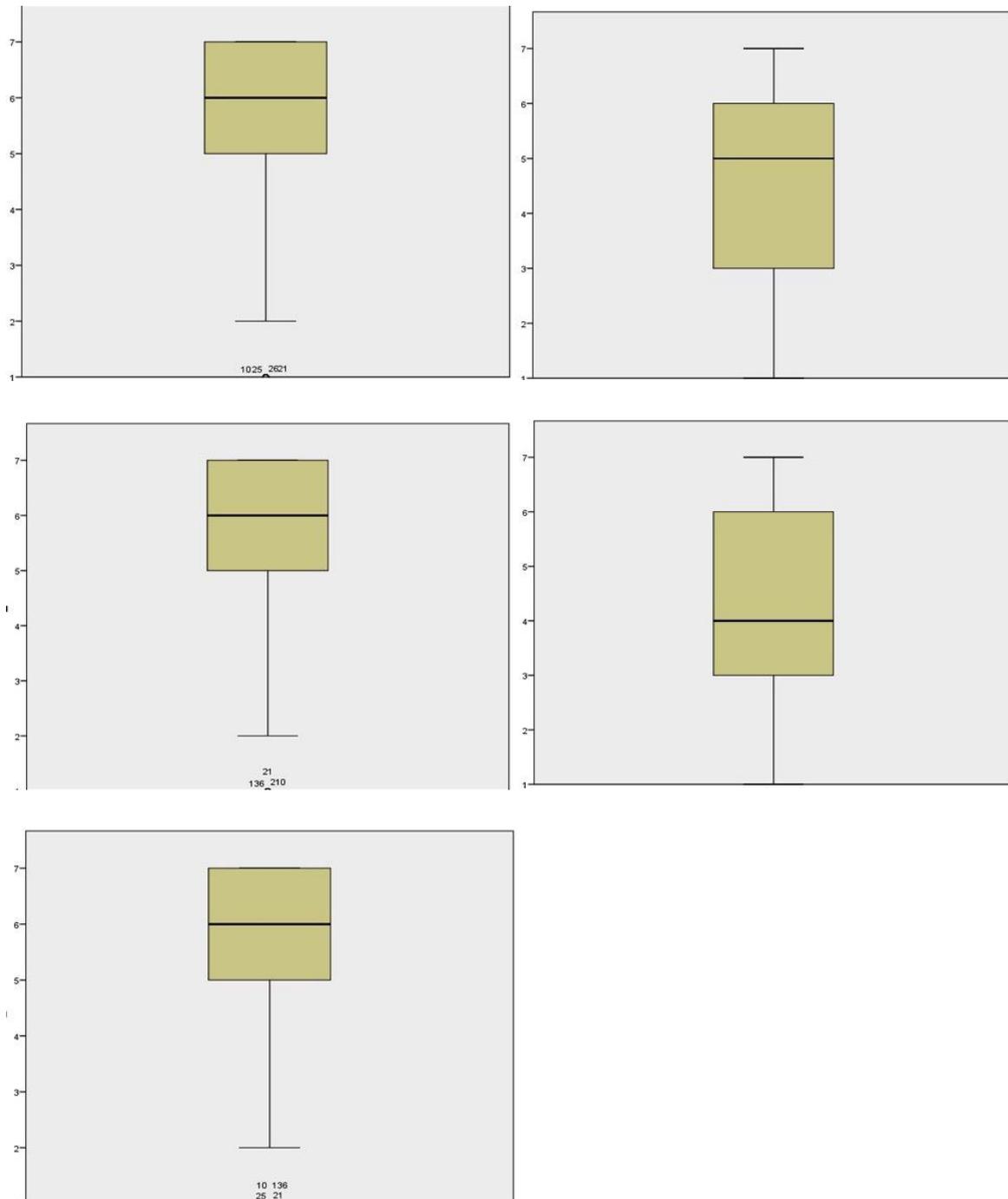


Figure 1-5: Box-plot 1: enabling and partnership. Box-plot 2: providing general information. Box-plot 3: providing specific information about the child. Box-plot 4: coordinated and comprehensive care. Box-plot 5: Respectful and supportive care.

Box-plots showed minimum and maximum value, first and third quartile and median for each domain.

Physiotherapist data analysis

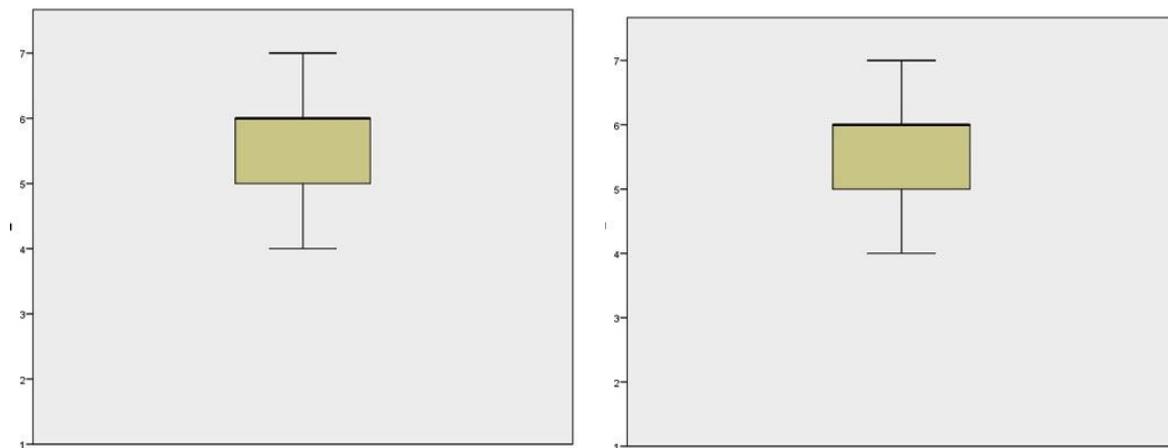
Final sample analysis consisted of 75 units.

Physiotherapists in Emilia Romagna:

Area	Frequency	Percentage
Bologna	9	12.0%
Cesena	5	6.7%
Ferrara	8	10.7%
Forlì	8	10.7%
Imola	3	4.0%
Piacenza	11	14.7%
Ravenna	10	13.3%
Reggio Emilia	13	17.3%
Rimini	8	10.7%
Tot.	75	100%

Table 2: Physical therapists distribution per area.

The following box plot summarised domains of the physiotherapist questionnaire



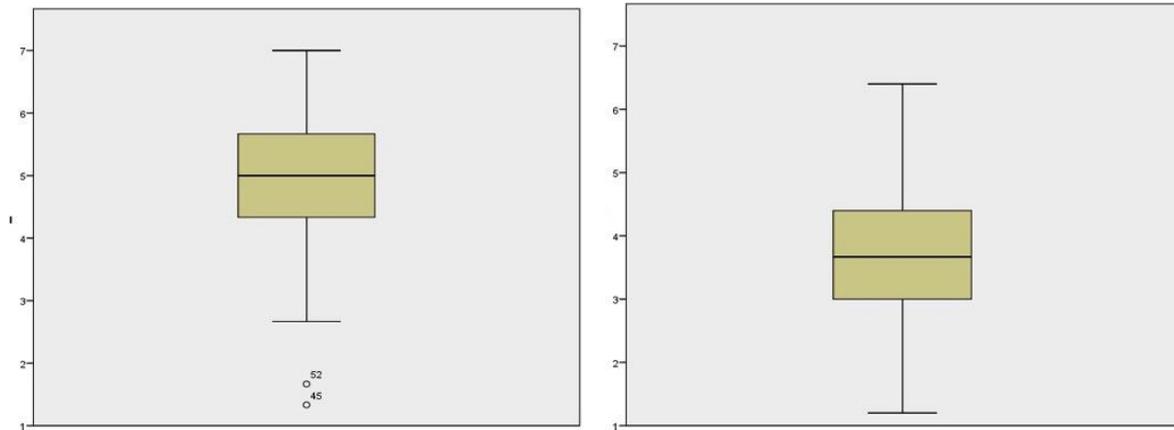


Figure 6-9: Box-plot 6: showing interpersonal sensitivity. Box-plot 7: providing general information. Box-plot 8: communicating specific information about the child. Box-plot 9: treating people respectfully

Italian and Canadian data comparison

MPOC-20

MPOC-20 DATA: EMILIA ROMAGNA VS ONTARIO	AVERAGE	STANDARD DEVIATION	MEDIAN
ENABLING AND PARTNERSHIP			
EMILIA ROMAGNA	5.63	1.52	6.00
ONTARIO	5.11	1.55	5.33
PROVIDING GENERAL INFORMATION			
EMILIA ROMAGNA	4.17	1.71	4.00
ONTARIO	4.09	1.77	4.20
PROVIDING SPECIFIC INFORMATION ABOUT THE CHILD			
EMILIA ROMAGNA	4.69	1.85	5.00
ONTARIO	5.23	1.48	5.67
CORDINATED AND COMPREHENSIVE CARE			
EMILIA ROMAGNA	5.73	1.40	6.00
ONTARIO	5.25	1.39	5.42
RESPECTFUL AND SUPPORTIVE CARE			
EMILIA ROMAGNA	5.76	1.41	6.00
ONTARIO	5.40	1.29	5.60

Table 3: Emilia Romagna and Canada MPOC-20: average, standard deviation and median value

MPOC-SP

MPOC-SP DATA: EMILIA ROMAGNA VS ONTARIO	AVERAGE	STANDARD DEVIATION	MEDIAN
SHOWING INTERPERSONAL SENSITIVITY			
EMILIA ROMAGNA	5.65	0.67	6.00
ONTARIO	5.07	0.86	5.10
PROVIDING GENERAL INFORMATION			
EMILIA ROMAGNA	3.74	1.26	3.60
ONTARIO	4.68	1.30	4.80
COMMUNICATING SPECIFIC INFORMATION ABOUT THE CHILD			
EMILIA ROMAGNA	4.93	1.20	5.00
ONTARIO	5.50	1.10	5.67
TREATING PEOPLE RESPECTFULLY			
EMILIA ROMAGNA	5.76	0.65	5.80
ONTARIO	5.83	0.70	5.89

Table 4: Emilia Romagna and Canada MPOC-SP: average, standard deviation and median value

Parent data

According to parent box plot analysis, the domains receiving higher consent in Emilia Romagna were:

- “Enabling and Partnership” (box 1);
- “Coordinated and Comprehensive Care for Child and Family” (box 4);
- “Respectful and Supportive Care” (box 5).

The median of these three domains was 6, thus the satisfaction value was very high and expressed within a limited range (5 to 7); the first quartile value corresponded to 5, the maximum value was 7, which also corresponded to the third quartile, while the minimum value was 2.

The “Providing general information” domain (box 2) displayed non-homogeneous judgment results: the median was 4, the first quartile was 3, the third quartile was 6, the maximum value was 7 and the minimum was 1. 50% of parent main values were within a range from 3 to 6.

Regarding the “Providing Specific Information about the Child” domain (box 3), the median had a fair value of 5, but 50% of parent main values were within a range from 3 (first quartile) to 6 (third quartile); the minimum value was 1 and the maximum 7.

Physiotherapist data

According to physiotherapist box plot analysis, the domains receiving the highest consent in Emilia

Romagna were:

- “Showing interpersonal sensitivity” (box 6)
- Treating People Respectfully (box 9)

The satisfaction value was high as the median was 6 in both cases and 50% of main values were within a range of 5 (first quartile) and 6 (third quartile). Similar values were revealed in the professional self-assessment concerning respectful treatment of families. Indeed, the value range was between 5 and 6. The values decreased if compared to “Providing General Information” and “Communicating Specific Information about the Child” domains.

For the “Communicating Specific Information about the Child” domain (box 8), the median was 5, while 50% of main values laid in the range from 4.3 to 5.6, with 3.6 as median average.

MPOC-20: COMPARING EMILIA ROMAGNA AND ONTARIO

By comparing MPOC-20 results obtained in Emilia Romagna and Ontario, it can be seen that the average values of the various domains displayed very few differences. The domain showing the worst results was related to “Child-specific Information Supply” (Emilia Romagna average was 4.69, Ontario was 5.23). On the contrary, Emilia Romagna obtained higher average values relative to Ontario for the remaining domains.

MPOC-SP: COMPARING EMILIA ROMAGNA AND ONTARIO

If we considered physiotherapist questionnaires, on the contrary, we found a higher level of satisfaction regarding treatments in Ontario. The greatest difference was found in the “Providing General Information” domain: parent perception; Emilia Romagna average was 3.74, while in Ontario the average was 4.68. For both countries, satisfaction level was high and similar for the domain of “Showing Interpersonal Sensitivity”: 5.76 in Emilia Romagna, 5.83 in Ontario.

DISCUSSION

Parent data

Results indicated that parents were satisfied with treatments their child received from Child Rehabilitation Health Services. The domains concerning parent satisfaction were as follows:

- The possibility of participating in the choice of interventions, especially therapeutic ones (Enabling and Partnership);
- The presence of a multidisciplinary team, suitable for identifying therapeutic options and objectives and whose members play clearly defined roles (Coordinated and Comprehensive Care for the Child and Family);
- The team of respectful and polite professionals: whose conduct is coherent towards both children and families, supporting parent role (Respectful and Supportive Care).

The “Providing General Information” domain showed parents who were satisfied with the information provided through different modalities, but also revealed parents who were by no means satisfied. This discrepancy could be interpreted as a need to provide greater information on the evolution of palsy, possible therapeutic approaches and scientific advances concerning CP treatment.

Moreover, from a detailed analysis of the abovementioned domain, as suggested in the FCC questionnaire manual (threshold: 33%), the most crucial items were:

- The possibility of providing families with written information about child pathologies (n. 19);
- The possibility of providing families with information about parent associations (n. 20).

The “Providing Specific Information about the Child” domain also displayed non-homogeneous values. Some parents were satisfied with provided information, while others were not. Again, parents expressed a certain dissatisfaction towards child-specific information supply, although the level of this dissatisfaction was not as high as in the previous cited domain.

It is evident therefore, that parents felt there was a lack of written information concerning their child’s therapeutic programs. It should be pointed out the Italian Health services usually do not issue detailed written documentation concerning therapeutic goals, rehabilitation projects and reeducation program components. This documentation is usually present in the clinical case history and produced during more specific examinations, or when parents explicitly ask for it.

Physiotherapist data

Regarding the “Showing Interpersonal Sensitivity” domain, 10 questions asked physiotherapists to reflect upon their modalities when dealing with parents, concerning supplied information,

recognition of fears, support and assistance. The high values for this domain meant that physiotherapists felt they were adequately sensitive to these needs.

The “Providing General Information” domain median showed that services were judged inadequate or hardly sufficient, since it fluctuated between a 3.0 and 4.5 range. This evaluation revealed that physiotherapists did not feel confident or adequate in providing general information to families.

A statistical correlation between parent and physiotherapist questionnaire was not possible since the questions were numerically diverse and differently formulated. This study could only establish a strong affinity between judgments expressed by parents and physiotherapists regarding the lack of shared written information.

RESEARCH LIMITS

- Unfortunately, some data were lost: almost 20% of questionnaires were not returned and the parental and physiotherapists questionnaires of Modena as well as the physiotherapist ones of Parma were not considered in this analysis, due to data inconsistencies.
- The data were collected over a long period.
- This study was the first time that graduation theses in Physiotherapy from the four Universities of the Region were compiled and utilized as a research tool on a vast population of patient families and professionals, with the aim of improving physiotherapist behavior and training.

CONCLUSIONS

Study results allow us to conclude that child rehabilitation services of Emilia-Romagna region, where the child is placed at the centre of the care project and the family is a facilitator (ICF-CY vision) in a child-centred care Service (CCS), perceive satisfaction levels similar to those of Ontario, where families play an active role in therapeutic choices and in performing treatment within services strongly centred around the family (FCS).

In Italy, physicians (child neuropsychiatrist or physiatrist) are responsible for the therapeutic project (PRI). It is then their task to inform families and reach an agreement with them and health workers concerning rehabilitation objectives, modalities, outcome measures and intervention timing.

This is achieved through the drafting of therapeutic programs oriented around the wellbeing of the child according to the ICF-CY model in a “child-centred” approach.

To improve Italian Healthcare Services and better assist families, communication about general information on pathology and therapy should be enhanced. These improvements could increase satisfaction and cooperation between practitioners and family members in treatment programs.

To improve health services, the current Italian model applied in child-care centres of Emilia Romagna region, which places children and their well-being at the centre (ICF-CY), can positively integrate a Family Centred approach to analyze the perceived quality of services by families, as proposed by the Canadian model.

In conclusion, the data do not support the absolute validity of either approach, but allow us to state that an integrated child-and-family-centred model could better respond to the needs of child services.

The data of the study were shared with the participating facilities. From this, specific programs were created to improve services (brochures, information to parents about local support groups, review of procedures related to the compilation and sharing of rehabilitation programs, field training for professionals on Medical Humanities).

In the light of these interventions, it would be useful to re-propose this study after some time, in order to assess if the proposed improvements have modified the quality perceived by parents and physiotherapists.

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