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Cerebral palsy rehabilitation: comparison between italian child centred and canadian family centred healthcare models

Autori / Authors: C. Signorelli, L. Beccani, C. Gambarelli, L. Berzieri, A. Brianzi, R. Caudiero, S. Di Deco, C. Giovannetti, C. Govoni, C. Nardi, D. Pelizzola, C. Ruggieri, A. Ferrari

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Contatto autori / Corresponding author: Chiara SIGNORELLI, chiara.signorelli@alice.it

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Cerebral palsy rehabilitation: comparison between italian child centred and canadian family centred healthcare models

Chiara Signorelli[1], Laura Beccani[2], Carmen Gambarelli[3], Lara Berzieri[4], Arianna Brianzi[5], Raffaele Caudiero[6], Sara Di Deco[7], Claudia Giovannetti[6], Chiara Govoni[8], Claudia Nardi[6], Debora Pelizzola[7], Chiara Ruggieri[5], Adriano Ferrari[9]

[1] *University of Parma*

[2] *Rehabilitation Unit of Developmental Age Severe Disabilities. IRCCS "Arcispedale Santa Maria Nuova", Reggio Emilia*

[3] *Specialization School in Physical and Rehabilitative Medicine, University of Bologna*

[4] *Business Economics Department, University of Parma*

[5] *Degree course in physiotherapy. University of Parma.*

[6] *Degree course in physiotherapy. University of Ferrara*

[7] *Degree course in physiotherapy. University of Reggio Emilia*

[8] *Degree course in physiotherapy. University of Bologna*

[9] *Specialization School in Physical and Rehabilitative Medicine, University of Modena e Reggio Emilia*

Corresponding author: Chiara SIGNORELLI
chiara.signorelli@alice.it

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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, families have decision-making power in childcare, which includes rehabilitation treatments and socio-educational interventions. This family-centered 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, realizing setting modalities and measuring outcomes. This approach is child-centered, however with the participatory involvement of family.

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

Methods

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 the child, constantly involving the family in care programs, which we could coin "Child and Family Centre approach", would seem to be the key to a higher quality, efficacy and efficiency service.

Keywords

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

Introduction

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

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, attributed to non-progressive disturbances that occurred in the developing fetal or infant brain; the motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy and by secondary musculoskeletal problems (P. Rosenbaum et al., 2007).

Among the 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-centered service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centered 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-centered 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 (P. L. 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) (SIMFER & SINPIA, 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 center of services, according to the ICF-CY health model.

This model places child functioning at the center of treatment processes and considers family an environmental factor that can act as a facilitator or barrier, with a point of view strongly centered on the child.

According to Italian Recommendations, the family is always actively involved in childcare processes, but the 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 centered model to a family-centered one has its roots in changes in humanity perception developed over the 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 ICIDH, to ICIDH2, 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-centered model can be comparable to the family-centered one. Some CP parent associations have requested greater integration of family-centered model in Italian social-heath policies (ABC 2000).

In order to understand to what extent the family-centered therapy model is already present in the Italian health service, this study intends to compare the 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 centers through an organization that, unable to access every far-reaching citizen, requires that citizens go to a reference center, where they can find all the necessary services.

In Italy, we have the opposite situation: the relatively small but highly populated territory needs the capillarization of basic services through a network of local health services (AUSL) 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 specialized 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 an 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, datasets dealing with healthcare quality were compared to Ontario results collected by CanChild. It has to be pointed out that in Italy and in Canada the 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-centered approach. These tools are also used and validated to assess to what degree a service is deemed centered on families.

The results of these questionnaires describe to what extent health services are currently centered 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 previously 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 judgments 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 behaviors 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 behaviors of care providers in supplying specific information.
- COORDINATED AND COMPREHENSIVE CARE: this domain refers to 4 entries regarding those behaviors 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 behaviors, 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 pediatric care supplier self-assessing tool: it is made up of 27 questions inquiring about suppliers' specific behaviors during the previous year; value judgments 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-centered, while the MPOC-SP questionnaires are a valuable tool for assessing to what extent the service is coherent with the family-centered model from an expert's point of view.

STATISTICS METHODS: Average, standard deviation, 25th percentile, the 50th percentile (median) and 75th percentile were computed for all the MPOC-20 and MPOC-SP questionnaires domains. SPSS (Statistical Package for Social Sciences) program was used to analyze the data.

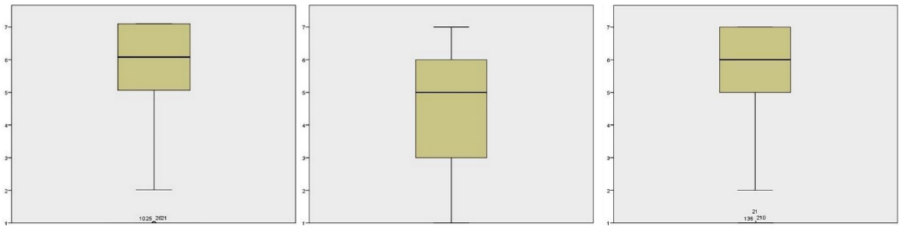
Results

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

PARENTS DATA ANALYSIS

Provincia	Frequenza	Percentuale (%)
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
Totale	219	100.00

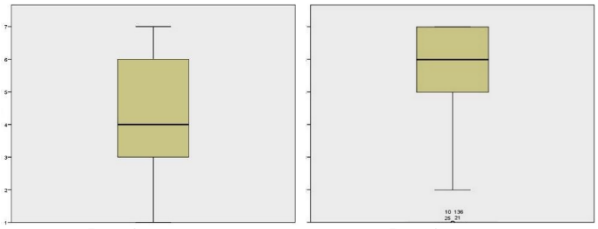
Table 1: Parents distribution per area.



Box-plot 1: abilitazione e collaborazione

Box-plot 2: fornire informazioni generali

Box-plot 3: fornire informazioni specifiche per il bambino



Box-plot 4: cure comprensive e coordinate

Box-plot 5: cure rispettose e di supporto

Figure 1: Box-plot 1-5: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care, respectful and supportive care.

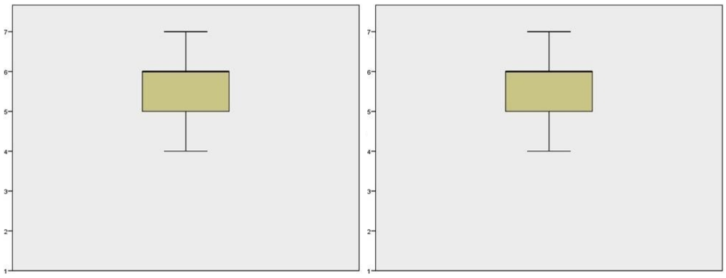
One-way indicators, such as average, median, standard deviation, and percentiles were distributed depending on the domain. Box-plots showed minimum and maximum value, first and third quartile and median for each domain.

PHYSIOTHERAPIST DATA ANALYSIS

Provincia	Frequenza	Percentuale (%)
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

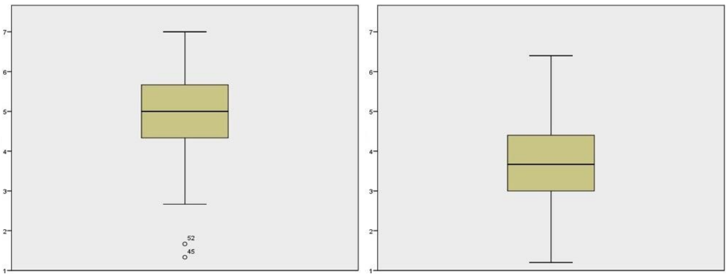
Table 2: Physical therapists distribution per area in Emilia Romagna.

The box-plot in figure 2 summarized domains of the physiotherapist questionnaire



Box-plot 6: dimostrazione della sensibilità interpersonale

Box-plot 7: fornire informazioni generali



Box-plot 8: comunicazione di specifiche informazioni sul bambino

Box-plot 9: trattare le persone con rispetto

Figure 2: box-plot 6-9, respectively showings interpersonal sensitivity, providing general information, communicating specific information about the child, treating people respectfully.

ITALIAN AND CANADIAN DATA COMPARISON

MPOC-20	MEDIA		DEV. STANDARD		MEDIANA	
	Emilia Romagna	Ontario	Emilia Romagna	Ontario	Emilia Romagna	Ontario
Abilitazione e collaborazione	5.63	5.11	1.52	1.55	6.00	5.33
Fornire informazioni generali	4.17	4.09	1.71	1.77	4.00	4.20
Fornire informazioni specifiche riguardanti il bambino	4.69	5.23	1.85	1.48	5.00	5.67
Cure comprensive e coordinate	5.73	5.25	1.40	1.39	6.00	5.42
Cure rispettose e di supporto	5.76	5.40	1.41	1.29	6.00	5.60

Tabella 3: MPOC-20 – Dati di Emilia Romagna ed Ontario a confronto

MPOC-SP	MEDIA		DEV. STANDARD		MEDIANA	
	Emilia Romagna	Ontario	Emilia Romagna	Ontario	Emilia Romagna	Ontario
Dimostrazione della sensibilità interpersonale	5.65	5.07	0.67	0.86	6.00	5.10
Fornire informazioni generali	3.74	4.68	1.26	1.30	3.60	4.80
Fornire informazioni specifiche riguardanti il bambino	4.93	5.50	1.20	1.10	5.00	5.67
Trattare le persone con rispetto	5.76	5.83	0.65	0.70	5.80	5.89

Tabella 4: MPOC-SP – Dati di Emilia Romagna ed Ontario a confronto.

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 the main values were within a range of 5 (first quartile) and 6 (third quartile). Similar values were revealed in the professional self-assessment concerning the 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 to the domain of "Showing Interpersonal Sensitivity": 5.76 in Emilia Romagna, 5.83 in Ontario.

Discussion

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.

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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 the main values were within a range of 5 (first quartile) and 6 (third quartile). Similar values were revealed in the professional self-assessment concerning the 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.

LIMITI DELLO STUDIO

- Il 20% dei questionari non sono stati inclusi; i questionari dei genitori e dei fisioterapisti di Modena come quelli dei fisioterapisti di Parma non sono stati considerati in questa analisi a causa di erronea compilazione.
- I dati sono stati raccolti per un lungo periodo

Questo studio è il primo in cui tesi di laurea in Fisioterapia provenienti da quattro diverse Università della stessa regione siano state compilate utilizzando uno strumento di ricerca su una vasta popolazione di famiglie di pazienti e professionisti nell'intento di migliorare la professionalità e la formazione dei fisioterapisti.

Conclusioni

I risultati dello studio ci permettono di affermare che i servizi territoriali di riabilitazione infantile dell'intera regione Emilia Romagna dove il bambino è posto al centro del progetto di cura e la famiglia è vista auspicabilmente come un facilitatore del progetto (visione ICF-CY) in un servizio di cure centrato sul bambino (CCS) ricevono livelli di soddisfazione simili a quelli dell' Ontario, dove le famiglie giocano un ruolo attivo nelle scelte terapeutiche e nell'eseguire il trattamento all'interno di un servizio fortemente centrato sulla famiglia (FCS).

In Italia all'interno dei servizi di riabilitazione infantile la responsabilità del progetto terapeutico è assunta dal medico riabilitatore (NPI o Fisiatra) che ha il compito di informare la famiglia e concordare con essa e gli operatori socio sanitari gli obiettivi riabilitativi, le modalità, le misure di esito attese e le tempistiche degli interventi attraverso la stesura di programmi terapeutici centrati sul benessere del bambino secondo il modello ICF-CY all'interno di un approccio che definiamo Child Centered.

Per migliorare il Servizio Sanitario Italiano e l'assistenza alle famiglie, dovrebbe essere incrementata la comunicazione tra famiglie e la condivisione di informazioni generali, sulla patologia e sulla terapia. Questi miglioramenti potrebbero aumentare la soddisfazione e la cooperazione tra gli operatori e i membri della famiglia nel programma terapeutico.

In un'ottica di miglioramento dei servizi sanitari l'attuale modello italiano applicato nella regione Emilia Romagna Child Centered, che pone al centro del servizio erogato il bambino e il suo benessere (ICF-CY), può positivamente integrare un approccio Family Centered volto all'analisi della qualità percepita dei servizi da parte delle famiglie così come in parte auspicato dal modello canadese.

In conclusione i dati non sostengono la validità assoluta di uno dei due approcci ma ci consentono di affermare che un modello integrato child and family centred potrebbe maggiormente rispondere alle esigenze dei servizi.

I dati dello studio sono stati condivisi con le strutture coinvolte, da questa condivisione sono nati dei percorsi di miglioramento aziendali (brochure informative per i genitori, fornire informazioni ai genitori relative a gruppi di supporto locale, revisione dei processi aziendali relativi alla compilazione e condivisione dei programmi riabilitativi, formazioni sul campo per gli operatori rivolte alle Medical Humanities).

Alla luce di questi interventi potrebbe essere utile riproporre a distanza di tempo lo studio, per verificare se i cambiamenti introdotti abbiamo modificato la qualità percepita dai genitori e dai fisioterapisti.

Riferimenti bibliografici

[1] A.B.C. (2000). Manifesto per la riabilitazione del bambino.

[2] Briar-Lawson, K., & Lawson, H. A. (2001). Family-centered Policies & Practices: International Implications. Columbia University Press.

[3] Janzen, W. (2001). Long-term care for older adults: The role of the family. Journal of Gerontological Nursing, 27(2), 36–43.

[4] King, G. A., King, S. M., & Rosenbaum, P. L. (1996). How mothers and fathers view professional caregiving for children with disabilities. Developmental Medicine & Child Neurology, 38(5), 397–407.

[5] King, S., Law, M., King, G., Kertoy, M., Hurley, P., & Rosenbaum, P. (2000). Children with disabilities in Ontario: A profile of children's services.

[6] King, S. M., Rosenbaum, P. L., & King, G. A. (1996). Parents 'perceptions of caregiving: development and validation of a measure of processes. Developmental Medicine & Child Neurology, 38(9), 757–772.

[7] King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: a review of the literature. In Seminars in pediatric neurology (Vol. 11, pp. 78–86). Elsevier.

[8] Leiter, V. (2004). Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. Social Science & Medicine, 58(4), 837–849. https://doi.org/10.1016/S0277-9536(03)00258-2

[9] O'Neil, M. E., Palisano, R. J., & Westcott, S. L. (2001). Relationship of therapists' attitudes, children's motor ability, and parenting stress to mothers' perceptions of therapists' behaviors during early intervention. Physical Therapy, 81(8), 1412–1424.

[10] Rosenbaum, P. L., King, S. M., & Cadman, D. T. (1992). Measuring processes of caregiving to physically disabled children and their families. I: Identifying relevant components of care. Developmental Medicine & Child Neurology, 34(2), 103–114.

[11] Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., ... Jacobsson, B. (2007). A report: the definition and classification of cerebral palsy April 2006. Developmental Medicine and Child Neurology. Supplement, 109, 8–14.

[12] SIMFER, & SINPIA. (2013). Raccomandazioni per la riabilitazione dei bambini affetti da Paralisi Cerebrale Infantile. Retrieved from <http://www.sinpia.eu/atom/allegato/1285.pdf>

[13] Woodside, J. M., Rosenbaum, P. L., King, S. M., & King, G. A. (2001). Family-centered service: developing and validating a self-assessment tool for pediatric service providers. Children's Health Care, 30(3), 237–252.