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ORIGINAL RESEARCH

Family-Centered practice in a Brazilian rehabilitation network service



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Abstract

Background: Family-centered practice (FCP) is widely accepted as a best practice in pediatric rehabilitation. However, its implementation in Brazil is incipient, and systematic documentation of the extent to which it has been achieved is not available.

Objectives: To determine parents' and service providers' perceptions of family-centeredness and specific areas in need of improvement in four rehabilitation hospitals.

Methods: A total of 107 caregivers and 89 service providers responded to the Measure of Processes of Care-20 (MPOC-20) and the Measure of Processes of Care for Service providers (MPOC-SP), respectively. The MPOC questionnaires evaluate FCP from the point of view of parents and rehabilitation professionals. Domain scores within each questionnaire were compared with Kruskal–Wallis and Mann–Whitney tests. MPOC items with low scores (from 1–4 out of 7 by 33% or more of respondents) were considered to indicate weaknesses in service delivery.

Results: Median MPOC-20 scores varied from 5.2 (4.7, 5.8) (Providing General Information) to 7.0 (6.0, 7.0) (Enabling and Partnership). The Providing General Information scores were significantly lower than those of other domains ($p < 0.003$). The MPOC-SP scores varied from 4.8 (4.0, 5.8) (Providing General Information) to 6.1 (5.8, 6.6) (Treating People Respectfully). Scores for Treating People Respectfully were significantly higher ($p < 0.0001$) and Providing General Information scores significantly lower ($p < 0.0001$) than those of the other domains. Most items with high percentages of low scores were from the domain Providing General Information.

Conclusion: Except for Providing General Information, the results indicated that services implement FCP "to a fairly great extent," comparing favorably to international data. Provision of information can be improved.

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Introduction

Family-centered practice (FCP) is widely accepted as a best practice in pediatric rehabilitation.^{1–3} FCP is organized around three core principles: (1) respect for children and their families, (2) appreciation of the family's impact on the child's well-being, and (3) collaboration between families and service providers.⁴ In FCP, families and service providers collaborate to identify goals and priorities, plan and implement services, and evaluate outcomes.^{5–8} FCP can improve service efficiency to promote health and quality of life.^{1,7,9}

Several authors have strongly argued for FCP in community rehabilitation services offered by the Brazilian public health system^{10,11} and in hospital-based pediatric care.^{12,13} Current scientific knowledge supports the implementation of therapies that are family-centered.¹⁴ However, in practice, implementation of FCP is in very incipient stages.^{11,12,15} The most important barriers to FCP relate to institutional policies and infrastructure, professional training, and culture. Decades-long pioneering efforts to overcome these barriers have been taking place at the publicly funded SARAH Network of Rehabilitation Hospitals.^{16,17} Currently, however, systematic documentation of the extent to which FCP has been achieved is not available.

Implementation of FCP requires systematic service evaluations¹⁸ with valid and reliable measurement tools.^{19,20} Staff education and training initiatives in FCP can only be effective when associated with systematic evaluation that allows for the detection of problems to change methods and ensure effective implementation.^{18–20} Two standardized instruments to evaluate FCP have been adapted for use in Brazil: the Shields and Tanner Questionnaires,²¹ which are adequate for children receiving hospital-based health care, and the Measures of Processes of Care (MPOC), which were specifically designed for rehabilitation services. The MPOC-20 evaluates the perceptions of parents about the central tenets of FCP in the care their children receive.^{22–24} The MPOC-SP is a complementary tool that evaluates central aspects of FCP from the point of view of service providers.¹⁸ Together, the two instruments give a comprehensive and realistic indication of FCP. The MPOC questionnaires have been translated into and adapted for more than 14 languages^{23,24} with extensive documentation of reliability and validity.^{18,19,23–25} The Brazilian versions have been shown to have generally adequate psychometric properties.²⁵ Service evaluation with the two questionnaires can generate internationally comparable data.⁶

The primary aim of this study was to determine parents' and service providers' perceptions of the extent to which rehabilitation services for children with chronic health or developmental problems are family-centered, as measured by the MPOC-20 and the MPOC-SP. The secondary aim was to identify service areas that many parents or service providers consider to be poorly delivered and thus determine specific areas in need of improvement. Finally, we aimed to compare our results to internationally published data.

Methods

Participants

One hundred and seven caregivers of patients with physical disabilities under 12 years of age (the age limit defined in the original MPOC validation study)²³ were asked to participate in this study. Their children had been receiving treatment for at least one year (outpatient or inpatient) in one of the hospitals of the SARAH Network in Rio de Janeiro/RJ, Belo Horizonte/MG, Salvador/BA, or São Luís/MA. Eighty-nine service providers working on children's rehabilitation teams for at least a year at the same four hospitals were also invited to participate. Service providers included physical therapists, pediatricians, occupational therapists, pedagogues, nurses, physical educators, speech therapists, psychologists, social workers, and dietitians. This study was approved by the Research Ethics Committee of the Universidade Federal de Minas Gerais, Belo Horizonte, Brazil (CAAE: 74097417.7.1001.5149).

Instruments

The Brazilian MPOC-20²⁵ is a questionnaire with 20 questions divided into five domains corresponding to key aspects of FCP: Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care for Child and Family, and Respectful and Supportive Care.^{18,23,24} The internal consistency (Cronbach's alpha) for each domain varies from 0.61 to 0.91, while the test-retest reliability (intraclass correlation coefficient) varies from 0.44 to 0.83. The domains Enabling and Partnership and Coordinated and Comprehensive Care have the lowest internal consistency (0.61 and 0.66) and reliability (0.44 and 0.49). All questions start with the expression "In the past year, to what extent do the people who work with your child. . .," followed by, for example, "...help you to feel competent as a parent" or "...provide you with written information about what your child is doing in therapy." Responses vary from 0 to 7 in a Likert-type scale: 7 = To a very great extent, 6 = To a great extent, 5 = To a fairly great extent, 4 = To a moderate extent, 3 = To a small extent, 2 = To a very small extent, and 1 = Not at all. Option zero (0) refers to "not applicable."²² Item scores (0 excluded) are averaged to generate the final score of each domain.²² High domain scores indicate that caregivers perceive frequent family-centered behaviors.²⁶

The Brazilian MPOC-SP²⁵ is a self-administered questionnaire designed to measure the professional's reported implementation of FCP. The MPOC-SP has 27 questions divided into four domains: Showing Interpersonal Sensitivity, Treating People Respectfully, Communicating Specific Information about the Child, and Providing General Information.^{18,23} The internal consistency varies from 0.52 to 0.83 and the test-retest reliability varies from 0.83 to 0.90. All the MPOC-SP questions begin with the expression "In the past year, to what extent did you. . .," followed by, for example, "...take the time to establish rapport with

parents and children?" or "...discuss expectations for each child with other service providers, to ensure consistency of thoughts and action?" The response options are the same as in the MPOC-20. Each domain has its own average score (0 excluded). Higher scores reflect a greater focus on the patient and family.²⁷

Procedures

The first author invited parents and service providers to answer the questionnaires, either by self-administration with anonymity (all service providers) or by oral interview (as chosen by 90 of the 110 parents). The first author conducted all interviews. A few parents in Rio de Janeiro ($n = 2$) and Salvador ($n = 1$) declined to participate. All participants signed the informed consent form. The time taken to complete the questionnaires was around 15 min for professionals and 30–50 min for parents.

Data analysis

Domain scores were the primary variables analyzed in this study. The Shapiro–Wilk test was used to test for normality of the distribution of domain scores.²⁸ As the test indicated non-normal distributions, medians and interquartile ranges were used to describe domain scores for each questionnaire.²³ The Kruskal–Wallis test was used to compare scores across the domains of each questionnaire. Mann–Whitney tests with Bonferroni corrections were used to check for pairwise differences between domains.²³ The level of significance was set at 0.05.

To identify weaknesses in service delivery, we checked for items that received scores varying from 1–4 ("not at all" to "to a moderate extent") from at least 33% of respondents.²⁹ To compare our results to international data, we also computed aggregated mean ratings and 95% confidence intervals (CIs) from a recent meta-analysis of studies that used the MPOC-20⁶ and from 15 other studies^{18,26,27,30–40} that used the MPOC-SP. The Statistical Package for Social Sciences version 18.0 (2011) was used for all analyses.

Results

Participant characteristics for each hospital unit are available in Table 1. Table 2 shows medians and interquartile ranges for each domain score of the MPOC-SP and the MPOC-20 for each participating hospital and for the complete sample of participants. Table 3 shows the overall domain scores for the MPOC-SP and the MPOC-20.

Domain scores for the MPOC-20 varied from 5.20 (Providing General Information) to 7.00 (Enabling and Partnership). The difference between the five domains was significant ($p < 0.0001$). Mann–Whitney tests with Bonferroni corrections for multiple comparisons were applied, so all effects are reported at a 0.005 ($p = 0.05/10$) level of significance. Providing General Information scores were significantly lower than those of all other domains ($p < 0.003$). Enabling and Partnership scores were significantly higher than Providing Specific Information and Providing General Information scores ($p < 0.001$) but not significantly different from

Coordinated and Comprehensive Care and Respectful and Supportive Care scores ($p > 0.501$).

Domain scores for the MPOC-SP varied from 4.80 (Providing General Information) to 6.11 (Treating People Respectfully). The difference between the four domains was significant ($p < 0.0001$). Mann–Whitney tests with Bonferroni corrections were applied, so all effects are reported at a 0.0083 ($p = 0.05/6$) level of significance. Providing General Information scores were significantly lower than those of all other domains ($p < 0.0001$). Treating People Respectfully scores were significantly higher than those of all other domains ($p < 0.0001$).

Table 4 shows all questions scored from 1–4 by at least 33% of respondents. For the MPOC-SP and for the MPOC-20, most of the questions were in the domain Providing General Information. Table 5 shows our results compared to international data computed from previously published studies.^{6,18,26,27,30–40} All MPOC-20 and MPOC-SP median domain ratings were above the upper limit of the 95% CI for aggregate means of the reviewed studies.

Discussion

This study determined the extent to which rehabilitation services for children across four hospitals of the SARAH Network in Brazil are family-centered, according to parents' and service providers' perceptions, as measured by the MPOC-20 and the MPOC-SP. To the best of our knowledge, this is the first study using MPOC measures in Brazilian rehabilitation services. Only a few other studies have used the two MPOC measures simultaneously,^{32,34,40} and they report findings that are similar to ours. Our results show two complementary perspectives on the rehabilitation process that allow for planning improvements to the rehabilitation program.

The first perspective into FCP comes from parents of children in rehabilitation. Our results indicate that parents rated FCP as having been provided "to a fairly great extent" (score 5) in Providing General Information and Providing Specific Information, "to a great extent" (score 6) in Respectful and Supportive Care and Coordination and Comprehensive Care, and "to a very great extent" (score 7) in Enabling and Partnership. Scores for the last two domains, however, must be interpreted cautiously. Both Coordinated and Comprehensive Care and Enabling and Partnership had low internal consistency and test-retest repeatability in the original validation study of the Brazilian Portuguese version of the MPOC-20.²⁵ Therefore, specific practices related to the two domains must be carefully investigated in follow-up studies in the SARAH Network.

Enabling and Partnership addresses the participatory aspects of FCP. To ensure the participation of families, services must be tailored to individual family needs and must engage the family in identifying goals and priorities, planning and implementing services, and evaluating child and family outcomes.⁹ During the MPOC interviews, many respondents spontaneously pointed out that having their opinions heard by service providers was essential for achieving good service quality. The fact that parents felt the need to point that out might itself indicate how infrequently it actually happens. Some professionals

Table 1 Characteristics of MPOC-20 and MPOC-SP respondents.

Tutors		Mean $\pm$ SD, range or frequency (%)
Age (years)		35.7 $\pm$ 5.6, 19 to 71
Sex	Male	7 (6.5%)
	Female	100 (93.4%)
Family Relationship	Mother	92 (85.9%)
	Father	6 (5.6%)
	Other	9 (8.4%)
Education	Higher Education or above	17 (15.8%)
	High School Complete	55 (51.4%)
	High School Incomplete	8 (7.4%)
	Elementary School Complete	13 (12.1%)
	Elementary School Incomplete	12 (11.2%)
Family income	Less than 1 minimum wage	48 (44.8%)
	1 to 2 minimum wages	31 (28.9%)
	Above 2 minimum wages	28 (26.1%)
Socioeconomic status (Brazil-ABEP criteria)	A	3 (2.8%)
	B	28 (26.1%)
	C	57 (53.2%)
	D/E	19 (17.7%)
Child age (years)		6.7 $\pm$ 2.1, 1 to 12
Child sex	Female	42 (39.2%)
	Male	65 (60.7%)
Child diagnosis	Cerebral Palsy	49 (45.7%)
	Myelomeningocele	27 (21.4%)
	Club-foot	7 (6.5%)
	Congenital Zika Syndrome	7 (6.5%)
	Other	17 (15.8%)
Service Providers		
Age (years)		41.7 $\pm$ 8.4, 32 to 58
Sex	Male	12 (13%)
	Female	80 (86.9%)
Profession	Physical Therapist	24 (26%)
	Medical Doctor	20 (21.7%)
	Nurse	10 (10.8%)
	Psychologist	9 (9.7%)
	Others	29 (31.5%)
Time in service		12.1 $\pm$ 5.6, 1 to 30
Educational degree	Graduate	32 (34.7%)
	Specialist	44 (47.8%)
	Master	13 (14.1%)
	Doctorate	2 (2.1%)
	Post-Doctorate	1 (1%)
Socioeconomic status (Brazil-ABEP criteria)	A	46 (50%)
	B1	29 (31.5%)
	B2	17 (18.4%)

ABEP: Associação Brasileira de Empresas de Pesquisa (Brazilian Association of Research Companies).

in the four SARAH hospitals included in this study are using standardized tools such as the Canadian Occupational Performance Measure⁴¹ and Goal Attainment Scaling⁴² to collaborate with parents in defining rehabilitation goals, but this practice has not yet been standardized throughout the network.

Coordinated and Comprehensive Care behaviors are also difficult to operationalize in multi-professional settings, and service coordination is a challenge in successful FCP.²⁰ Pre-

vious studies have shown that staff turnover may negatively affect the continuity of care.^{30,31} Major concerns of families and clinicians in past studies related to the need to ensure that at least one team member had a stable, long-term relationship with the family and the need to work towards consistency between service providers. At the SARAH hospitals, rehabilitation professionals work in multidisciplinary teams in shared spaces and have frequent team meetings to discuss patient cases. Parents are also frequently con-

Table 2 Scores for the MPOC-20 domains and the four MPOC-SP domains at each hospital.

	Belo Horizonte	Rio de Janeiro	Salvador	São Luís
MPOC-20	Median (Q1, Q3)			
	n = 85	n = 10	n = 6	n = 7
Respectful and Supportive Care	6.8 (6.2, 7.0)	7.0 (6.5, 7.0)	7.0 (6.4, 7.0)	6.8 (6.6, 7.0)
Enabling and Partnership	6.5 (5.0, 7.0)	7.0 (4.0, 7.0)	7.0 (1.0, 7.0)	4.0 (1.0, 7.0)
Co-ordination & Comprehensive Care	6.7 (6.2, 7.0)	7.0 (6.6, 7.0)	7.0 (6.6, 7.0)	7.0 (6.5, 7.0)
Providing Specific Information	5.8 (5.0, 7.0)	5.5 (4.7, 7.0)	5.0 (2.5, 7.0)	7.0 (3.0, 7.0)
Providing General Information	5.2 (4.4, 6.2)	4.8 (4.3, 5.5)	5.5 (4.9, 6.2)	4.0 (3.4, 5.8)
MPOC-SP	n = 39	n = 18	n = 21	n = 15
Showing Interpersonal Sensitivity	5.8 (5.3, 6.1)	5.7 (5.2, 6.1)	6.1 (5.7, 6.5)	5.3 (4.8, 6.1)
Treating People Respectfully	6.0 (6.0, 7.0)	6.0 (5.0, 7.0)	7.0 (6.0, 7.0)	6.0 (5.0, 7.0)
Communicating Specific Information	5.8 (4.9, 6.3)	5.7 (5.0, 6.7)	5.7 (4.8, 6.5)	5.3 (4.3, 6.3)
Providing General Information	5.0 (4.0, 6.0)	5.0 (4.0, 6.0)	5.0 (5.0, 6.0)	5.0 (4.0, 5.0)

Table 3 Scores for the five MPOC-20 domains and the four MPOC-SP domains.

Domain	Median (Q1, Q3)
Parents – MPOC-20	
Respectful and Supportive Care	6.8 (6.2, 7.0)
Enabling and Partnership	7.0 (6.0, 7.0)
Co-ordination and Comprehensive Care	6.7 (6.2, 7.0)
Providing Specific Information	5.7 (5.0, 7.0)
Providing General Information	5.2 (4.7, 5.8)
Service Providers – MPOC-SP	
Showing Interpersonal Sensitivity	5.8 (5.2, 6.2)
Treating People Respectfully	6.1 (5.8, 6.6)
Communicating Specific Information	5.7 (4.7, 6.3)
Providing General Information	4.8 (4.0, 5.8)

tacted to discuss the development of their children. These practices can enhance the coordination of care.

The second perspective into FCP comes from service providers at the same hospitals of the SARAH Network, representing “the other side of the mirror.”³² The MPOC-SP is a self-reflection and self-assessment tool for service providers regarding FCP implementation. In our study, service providers rated FCP as having been provided to “a moderate extent” (score 4) in the domain Providing General Information, to “a fairly great extent” (score 5) in the domains Showing Interpersonal Sensitivity and Communicating Specific Information, and “to a great extent” (score 6) in Treating People Respectfully.

Just as Respectful and Supportive Care was rated high among parents, service providers rated Treating People Respectfully with the highest score. This is consistent with findings of the latest literature review.²⁴ In contrast, both groups rated Providing General Information with the lowest scores (5.2 and 4.8 for parents and service providers, respectively), as is commonly reported in the literature.¹⁹ The aggregated mean score for this domain was only 4 (“to a moderate extent”) in a recent meta-analysis of MPOC-20 studies.⁶

Table 4 Items identified as areas for improvement (scored ≤ 4 by more than 33% of parents or service providers).

Question/ Domain	%1-4
MPOC – 20	
2 ...provide you with information about what your child is doing in therapy /PGI	35.5%
19 ...have information available to you in various forms, such as a booklet, kit, video, etc./PGI	37.3%
20 ...provide advice on how to get information or to contact other parents (e.g. Organizations’ parent resource library)/PGI	44.8%
MPOC – SP	
15 ...provide parents with written information about their child’s condition progress or treatment /PSI	36.7%
25 ...provide advice on how to get information or to contact other parents (e.g. through a community’s resource library, support groups or the internet)/PGI	40.8%

PGI: Providing General Information, PSI: Providing Specific Information
 %1-4: Percentage of respondents who answered 1 to 4 out of 7 on that question.

In our study, most questions showing areas in need of improvement (questions 2, 19, and 20 of the MPOC-20 and question 25 of the MPOC-SP) come from the domain Providing General Information (Table 4), in line with several other studies.^{20,30,34} For these questions and for question 15 from Communicating Specific Information about the Child in the MPOC-SP, 33% or more of respondents gave ratings of 4 (“to a moderate extent”) or less. Together with the overall median scores, these results confirm previous findings indicating that Provision of General Information is an area of service where FCP is quite challenging.

The literature indicates that both service providers and families consider provision of information about where to get into contact with other families in the same situation and about the child’s condition, therapies, and progression to be usually poorly executed.^{20,30,34} Information kits have been reported as strategies to improve service quality.⁴⁰ Provision of information can empower families to make decisions

Table 5 Summary of results for reviewed studies.

	Number of studies	Aggregated Mean	Standard Error	95% CI
MPOC- 20*				
Respectful and Supportive Care	13	5.5	0.02	(5.2, 5.8)
Enabling and Partnership	12	5.2	0.22	(4.8, 5.6)
Coordination and Comprehensive Care	11	5.3	0.03	(5.0, 5.6)
Providing Specific Information	12	5.0	0.03	(4.8, 5.4)
Providing General Information	13	4.1	0.21	(3.7, 4.5)
MPOC – SP†				
Showing Interpersonal Sensitivity	15	4.8	0.02	(4.8, 4.9)
Treating People Respectfully	15	5.7	0.02	(5.7, 5.8)
Communicating Specific Information	15	5.1	0.03	(5.0, 5.1)
Providing General Information	14	4.0	0.03	(4.0, 4.1)

* Data available in Almasri et al ⁶.† Data calculated from 15 studies^{18,26,27,30,31,32,33,34,35,36,37,38,39,40}.

about their children and alleviate the stress that arises from uncertainty.³⁰

Together, the MPOC-20 and the MPOC-SP were useful in comprehensively and systematically identifying FCP at four SARAH Network hospitals. Except for Providing General information on the MPOC-SP, all median domain scores were above 5. These results show that the SARAH Network hospitals generally implement FCP “to a fairly great extent,” as a result of decades-long institutional policy.^{16,17} Our results compare very favorably with international data. A recent meta-analysis synthesized results of studies including MPOC-20 scores of 2582 parents of children with physical disabilities in 10 countries: the USA, Canada, Norway, Australia, China, Slovenia, the Netherlands, Japan, Iceland, and Finland.⁶ All our median domain ratings were above the upper limit of the 95% CI for aggregate means in the meta-analysis, indicating generally more positive perceptions. The MPOC-SP scores were also generally higher (Table 5) than those reported in 15 studies^{6,18,26,27,30–40} with 1935 service providers in nine countries: Australia, Canada, China, Finland, Iceland, Italy, Netherlands, Singapore, and the USA. This study has also identified specific areas that need improvement, and the results can be used to plan service innovations.

FCP is intended to actively engage families in the decision-making process about rehabilitation in partnership with service providers. In our experience, the use of the MPOC-20 and the MPOC-SP serves to highlight good areas of practice while challenging staff to reflect on aspects of their practice that they may have not considered before. The two tools served to heighten all parties’ awareness of the FCP ideal. Widespread discussion of results within rehabilitation services can further promote FCP culture and improve services provided to families. Future mixed-methods and qualitative studies that expand on MPOC ratings should be conducted to investigate how parents and service providers experience relational and participatory processes in Brazilian rehabilitation services.

It is important to consider the limitations of this study. The first is the possibility that the relatively high scores may have been influenced by the desire of some participants to provide pleasing responses as they were being interviewed. This may have led to an overestimation of positive service

aspects. However, the high convergence of responses from parents and service providers supports the general validity of results. Families and service providers agreed on the areas of service that were in need of improvement with respect to FCP principles. This study also did not assess factors that may influence the parents’ perceptions of service delivery, such as self-reported health, depression, and anxiety and their children’s levels of functioning.^{29,41,43} Finally, the results of this study may not be representative of practices in other Brazilian rehabilitation services.

Conclusion

The results indicated that services in the SARAH network implement FCP “to a fairly great extent”, except for Providing General Information, comparing favorably to international data. Evaluation with the MPOC-20 and MPOC-SP allowed for the identification of priorities for future improvements in service provision.

Conflicts of interest

This study assessed the extent to which family-centered care is implemented at four hospitals of the Sarah Network of Rehabilitation Hospitals. The first author was employed by the Sarah Network of Rehabilitation Hospitals at the time the study was conducted.

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